The Life Course Metrics Project

As MCH programs begin to develop new programming guided by a life course framework, measures are needed to determine the success of their approaches. In response to the need for standardized metrics for the life course approach, AMCHP launched a project designed to identify and promote a set of indicators that can be used to measure progress using the life course approach to improve maternal and child health. This project was funded with support from the W.K. Kellogg Foundation.

Using an RFA process, AMCHP selected seven state teams, Florida, Iowa, Louisiana, Massachusetts, Michigan, Nebraska and North Carolina, to propose, screen, select and develop potential life course indicators across four domains: Capacity, Outcomes, Services, and Risk. The first round of indicators, proposed both by the teams and members of the public included 413 indicators for consideration. The teams distilled the 413 proposed indicators down to 104 indicators that were written up according to three data and five life course criteria for final selection.

In June of 2013, state teams selected 59 indicators for the final set. The indicators were put out for public comment in July 2013, and the final set was released in the Fall of 2013.

Life Course Indicator: Adverse Childhood Experiences Among Adults

Basic Indicator Information

Name of indicator: Adverse Childhood Experiences Among Adults (LC-01)

Brief description: Prevalence of adverse childhood experiences

Indicator category: Childhood Experiences

Indicator domain: Risk/Outcome

Numerator: Number of adults ages 18 and over responding to the Behavioral Risk Factor Surveillance System (BRFSS) survey who report that they experienced three or more adverse childhood experiences (ACE)

Denominator: Number of adults ages 18 and over

Potential modifiers: Age, race/ethnicity, gender, education level, income level

Data source: Behavioral Risk Factor Surveillance System (BRFSS)

Notes on calculation: The BRFSS ACE module consists of 11 questions within eight categories of ACEs (verbal abuse, physical abuse, sexual abuse, household mental illness, household substance abuse, domestic violence, parental separation/divorce, and incarcerated family members). Respondents are told that the 11 questions referred to the time before they were aged 18 years. The questions in the ACE module are listed below, headed by the eight categories of ACEs.

1) Verbal abuse: "How often did your parent or adults in your home ever swear at you, insult you, or put you down?"

2) Physical abuse: "How often did your parents or an adult in your home ever hit, beat, kick, or physically hurt you in any way? Do not include spanking."

3) Sexual abuse:
   a) "How often did anyone at least five years older than you or an adult, ever touch you sexually?"
   b) "How often did anyone at least five years older than
Life Course Indicator: Adverse Childhood Experiences Among Adults (LC-01)

you or an adult try to make you touch them sexually?"
  c) "How often did anyone at least five years older than you or an adult, force you to have sex?"
4) Household Mental Illness: "Did you live with anyone who was depressed, mentally ill, or suicidal?"
5) Household Substance Abuse:
   a) "Did you live with anyone who was a problem drinker or alcoholic?"
   b) "Did you live with anyone who used illegal street drugs or who abused prescription medications?"
6) Domestic Violence: "How often did your parents or adults in your home ever slap, hit, kick, punch or beat each other up?"
7) Parental Separation/Divorce: "Were your parents separated or divorced?"
8) Incarcerated Family Members: "Did you live with anyone who served time or was sentenced to serve time in a prison, jail, or other correctional facility?"

This indicator is comprised of the aggregate results from multiple ACE questions. The numerator is the number of adults who experienced at least three ACEs out of the 11 questions. For questions that assess "how often" an adverse event was witnessed or experienced, a response of “once” or “more than once” is considered an experience of that adverse event. For all other questions, a response of “yes” is considered an experience of that adverse event. The numerator is calculated as the sum of adverse events experienced. The denominator is the total number of adults. Analysts attempting to generate a multi-state estimate of ACES should limit the analysis dataset to include only those states who used the ACES module in that year in order to obtain an appropriate denominator. Analysts who use the raw datasets should apply the appropriate survey weights to generate the final estimates.

Similar measures in other indicator sets: None

Life Course Criteria

Introduction
Adverse childhood experiences (ACEs) are experiences of emotional, physical, or sexual abuse, and household dysfunction during childhood. The short- and long-term outcomes of these childhood exposures include a multitude of health and social problems. Childhood maltreatment – a component of ACEs – has been linked to a variety of changes in the structure and function of the brain and stress–responsive neurobiological systems. Epidemiological studies have documented the impact of childhood maltreatment on health and emotional well-being (Anda et al 2006).

Overall, the prevalence of adults reporting adverse childhood experiences is a life course measure because the indicator captures past childhood experiences that may have influenced the life course trajectory and have lasting impact on current health and social outcomes. The impact of ACEs (i.e. prevalence of or lack of) over the life span has been well established within the life course science literature. This research reveals that if ACEs are pervasive, they can negatively impact the life trajectory of the individuals experiencing them and increase the potential for inter-generational familial adversity. In addition, the lack of ACEs and increased prevalence of protective factors can decrease inter-generational familial adversity, reducing the potential for harm for the individual and his or her children. (Forrest 2004; Kelly-Irving 2013; Richardson 2013).

Implications for equity
ACEs include psychological, physical, or sexual abuse (witness or victim); living with household members who were substance abusers, mentally ill or suicidal or ever incarcerated, and living in a household with poor economic resources, with parents who got divorced or separated after the child was born, or childhood exposure to racial or ethnic discrimination. Exposures to these events are experienced differently across population subgroups, including gender and race/ethnicity. For example, while men and women report similar prevalence of some ACEs, women report more than twice as many experiences with sexual abuse as men (17.2 percent for women, 6.7 percent for men) and report a higher prevalence of living with a mentally ill or substance-abusing household or family member. Women are more likely to report five or more ACEs (10.3 percent) compared to men (6.9 percent). The prevalence of experiencing individual ACE categories and the number of ACEs reported differ by race/ethnicity: for example, Black, non-Hispanic respondents reported the highest prevalence of having a household member in prison (12.9 percent) or parents being separated or
divorced (37.9 percent) compared to other race/ethnicity categories; whereas Hispanic respondents indicated the highest prevalence of sexual abuse (14.8 percent) or having a substance-abusing household member (33.4 percent). By number of ACEs reported, Black, non-Hispanic respondents indicated the highest prevalence of experiencing 1 ACE, however the category that comprises “Other, non-Hispanic” – Asian, Native Hawaiian/Pacific Islander, American Indian/Alaska Native, and multiracial – had the highest prevalence of 5 or more ACEs. Finally, prevalence of ACES reported by adults differs by educational attainment, with respondents with less than a high school education having a greater prevalence of five or more ACEs when compared to those who have graduated high school or have more than a high school education (14.9 percent compared to 8.7 percent and 7.7 percent) (CDC 2010). ACEs related to incarceration and racial or ethnic discrimination are most intrinsically linked to inequity as both are markers of larger issues of institutionalized racism and are highly clustered within specific geographic areas and population groups (Lynch and Sabol 2004; Pettit and Western 2004).

As a composite, the ACEs indicator has implications for many social and psychosocial equity-related measures. Examples of social conditions that are captured in the ACES indicator include limitations in educational attainment/occupational opportunities, reductions in income/socioeconomic status, and increased risk of food insecurity. Adults who grew up in families with adverse experiences are at increased risk for cognitive and social development problems that may result in learning difficulties and barriers to higher education (Felitti et al 1998; Perry 1998; Anda et al 2006). Lower education levels may translate into fewer job opportunities and a reduced income potential in adulthood (Bremmer 2003). Children raised in certain types of adverse family environments may also be more vulnerable to food insecurity as a result of parental substance abuse, physical/emotional abuse, or neglect (Anda 2004).

Examples of psychosocial measures that are captured in the ACEs indicator include depression, hopelessness, and aggression/hostility. Research suggests that individuals who had adverse experiences in childhood are more vulnerable to social/developmental problems (poor self-control, aggression, violence, and social isolation) (Dong et al 2004; Evans et al 2008). Additionally, they may be more likely to have alcohol, tobacco, substance abuse disorders or mental health disorders such as depression, suicidal thoughts/attempt, borderline personality disorder, or post-traumatic-stress disorder (Van Der Kolk et al 1991; Chapman et al 2004; Dube et al 2001; Varese et al 2012).

The basic framework for examining and understanding the impact of any ACE or collection of ACEs across the trajectory of an individual’s life span has multiple inherent implications for equity. As Braveman and Barclay (2009) summarize, the life course approach “is particularly relevant to understanding and addressing health disparities, because the social and physical contextual factors underlie socioeconomic and racial/ethnic disparities in health.”

**Public health impact**

The public health impact of ACEs can be framed in two ways: the relationship of individual health trajectories on larger public health spending and the overall impact of risk and protective factors throughout the life course and their influences on intergenerational outcomes.

ACEs put individuals at risk for a wide variety of chronic mental, physical and emotional health problems in adulthood. Additionally, ACEs have been associated with an increased propensity to engage in health risk behaviors, including risky sexual behavior, alcohol, drug, and tobacco use, that are associated with chronic disease and injury (Goodwin 2004; CDC 2013; Anda 2007). Overall, in relation to individual’s experiences of ACEs and larger public health impacts, if the number of children experiencing multiple adverse circumstances was reduced, one might expect to see a substantial reduction in mortality and prevalence rates for these key indicators of risk and chronic disease. Additionally, a reduction in overall health costs would be expected as individuals experiencing ACEs are more likely to incur higher health care costs as a result of riskier behavior and a higher rate of physical and mental health issues (Bremner 2003; Walker et al 1999).

A measure called the population attributable fraction (PAF) can be used to quantify the reduction in population disease or mortality if exposure to a risk factor were reduced or eliminated. A specific analysis conducted in the state of Maine of the PAF of a person with four or more ACEs having a subsequent poor adult mental, physical or emotional health outcome demonstrated PAFs of seven -58 percent. For example, severe obesity in adulthood had a PAF of seven percent while attempted suicide had a PAF of 58 percent. The authors of this report noted these ACEs are therefore resulting in millions of dollars in costs for individuals and health systems--$863 million for severe obesity and $29.5 million for attempted suicides (Forsttad and Rains, 2011).
When framing impact beyond specific health outcomes, linking ACEs to the broader life course approach is important. The life course approach focuses on exposures and experiences, including both risk and protective factors, that occur during critical periods of development, such as childhood, and their impact on the future for the individual, the family unit, the community, and the larger society. The impact of ACEs over the life span has been well established within the life course science literature. This research reveals that ACEs are pervasive, can negatively impact the life trajectory of the individuals experiencing them, and increase the potential for inter-generational familial adversity (Forrest and Riley 2004; Kelly-Irving et al 2013). On the other hand, protective factors can decrease inter-generational familial adversity (Bremmer 2003; Richardson et al 2013).

**Leverage or realign resources**

Traditionally, MCH programs have tended to focus on physical and developmental health outcomes as they pertain to the pregnant mother and her fetus, infant, or child. Collecting and using data on ACEs opens up opportunities for data-driven approaches to improving pediatric and adult primary care; one possible mechanism would be to enhance screening to identify risk for poor mental and physical health outcomes in childhood and beyond. The inclusion of ACEs in public health data analyses expands the sphere of MCH services to include collaborations with mental/behavioral health services, child abuse/neglect programs, and law enforcement; home visiting programs are already modeling this type of partnership to provide services to young families. Additionally, the assessment of ACEs risks within the MCH community can benefit other public health promotion and disease prevention programs including chronic disease and communicable/sexually transmitted disease (Fine and Kotelchuck 2010; Shonkoff et al 2009; Foege 1998).

Protective factors (e.g., child’s positive relationship with a caring adult, easy temperament of the child, health insurance coverage for the child) can be more important than risk factors because they mitigate the negative effects of risk factors such as ACEs (Werner and Smith 1992). Leveraging or realigning resources to provide supports for positive factors would complement the traditional risk-based approaches of medicine and health. Public health and other partners could work together to support policy and program interventions that contribute to or enhance protective factors such as helping parents and family members understand how to support easy temperament in children, establishing family friendly work policies (i.e. paid maternity and paternity leaves) and working to provide health insurance coverage for all children.

**Predict an individual’s health and wellness and/or that of their offspring**

The level of exposure to ACEs correlates to an association with adult risk behavior, poor health status and disease. The number of categories of adverse childhood experiences shows a graded relationship to the presence of adult diseases (Felitti 1998).This graded relationship has been documented throughout a significant body of research (Dube et al 2003; Danese et al 2009; Hillis et al 2001; Williamson et al 2002; Ford et al 2011; Chapman et al 2013). Specifically, individuals reporting ACEs, especially multiple ACEs, have greater risks of developing:

- Chronic diseases (autoimmune, COPD, chronic headaches, ischemic heart disease, liver disease, and lung cancer)
- Poor reproductive health outcomes and risky sexual behaviors (fetal death, promiscuity, sexual risk behaviors, sexually transmitted diseases, teen pregnancy, and unintended pregnancy)
- Health risk behaviors (alcohol abuse, drug abuse, obesity, smoking)
- Poor mental health (memory disturbances, depression, hallucinations, suicidal tendencies, work absenteeism, sleep disturbances)

As a result, individuals having ACEs are at increased risk of premature mortality, compared with individuals who did not have ACEs (Brown et al 2009). Additionally, research reveals that ACEs often do not occur in a vacuum – they are comorbid conditions that often occur simultaneously (e.g. a single parent that is mentally ill becomes an alcoholic and physically abuses their child) (Dong et al; Chartier 2010; Edwards 2003). This in turn underscores the individual and population impact of ACEs not just on the victim, but also on the family (including the perpetrator) and the community.

**Data Criteria**

**Data availability**

The Behavioral Risk Factor Surveillance System (BRFSS) is the world’s largest, on-going telephone health survey system, tracking health conditions and risk behaviors in the United States yearly since 1984. Currently, data are collected
monthly in all 50 states, the District of Columbia, Puerto Rico, the U.S. Virgin Islands, and Guam for adults 18 years and older. CDC provides state and national level prevalence data on their web site.

The CDC develops approximately 80 BRFSS questions each year. Some of these are core questions asked each year, and some are rotating core questions asked every other year. There are also CDC supported modules that address specific topics that states can use on an optional basis. States can also develop additional questions to supplement the core questions (CDC 2008). Modules used by states are noted on the CDC website.

Local level estimates for BRFSS data can be obtained using the Selected Metropolitan/Micropolitan Area Risk Trends (SMART) data. Local areas are metropolitan or micropolitan statistical areas (MMSAs) as defined by the Office of Management and Budget. SMART data is currently available for data going back to 2002 for MMSAs with 500 or more respondents.

The ACE questions are currently available as an optional CDC module. As a result, the collection of ACE data is not part of the required set of questions that must be collected by all states on a routine basis (CDC 2010). The data are relatively timely; the 2012 BRFSS data were released in July 2013, indicating an approximate six month delay in data availability for the preceding year.

Data quality
Numerous studies have compared estimates of chronic conditions and behaviors obtained from BRFSS to other national surveys including the National Health Interview Survey and the National Health and Nutrition Examination Survey; while there are some differences, findings on overall health status and certain chronic conditions tended to be similar despite declining response rates for BRFSS.

Since some questions on the BRFSS address sensitive health conditions and behaviors, there is intermittent missing data throughout the dataset. However, refusal to answer generally accounts for a small proportion of responses for most data elements. The notable exception is income, where refusals accounted for more than 23 percent of the data in one state in 2010; the median percent missing across BRFSS for income in 2010 was 14 percent.

Quality control computer programs are used to check the raw data for values out of range. CDC performs quality checks for core questions, and each state has its own protocol for checking state-specific questions. Interviewers are monitored during the annual questionnaire pilot period and intermittently during the data collection period to determine whether any interviewer bias exists and to correct any bias that might be found. On an ongoing basis, 10 percent of interview calls are verified.

Prior to 2011, the sampling for BRFSS represented only adults living in a private residence with a landline telephone, but starting in 2011, the sample also included data from respondents living in cell phone-only households. Weighted response rates are presented by state. For 2011, the median weighted response rate for the combined cell phone and landline was 49.7 percent.

The survey adjusts for non-response to reduce the known differences between respondents and non-respondents. Although participants interviewed may not represent a state in terms of age, sex and race distribution, it is believed that weighting the data corrects for this potential bias. As with other health surveys, estimates are based on self-report data and they may over- or underestimate the actual prevalence of a particular risk factor in the population. Despite some oversampling in states by geography, the annual sample size is too small to compute precise estimates at the county level. The child prevalence data are reliant on proxy report from the adult respondent to the BRFSS and may be subject to misclassification related to this method.

The ACE questions were adapted from large, validated survey instruments measuring the frequency of adverse childhood experiences. The BRFSS ACE module was initially tested in five states (Arkansas, Louisiana, New Mexico, Tennessee, and Washington).

Studies specific to the quality of data from the ACE module are not available. Factors that might impact the quality of the BRFSS and/or ACE data include:
1) The BRFSS data are weighted to account for non-response. However, low response rates overall may impact the reliability of the estimates. BRFSS response rates vary by state and by demographic groups.

2) Some respondents may quit the BRFSS survey before the ACE module can be asked, thereby reducing the number of respondents eligible for the ACE module.

3) Respondents may refuse to respond to one or more questions included in the ACE module because they may feel uncomfortable responding to the sensitive, personal nature of the questions and/or the relationship of the ACE questions to a health survey. As a result, the ACE module may have lower response rates than other sections of the BRFSS, which increases the risk for response bias.

4) The sensitive, personal nature of the ACE questions may result in "social desirability bias." Respondents may feel uncomfortable revealing negative childhood experiences to a stranger over the phone. This tendency may vary by race/ethnicity, gender, or age.

5) ACE prevalence might be underestimated because BRFSS excludes persons in institutions and hospitals, who might be disproportionately vulnerable to ACEs.

6) The ACE questions require that the respondent recall a variety of events that occurred in childhood. Some respondents may have forgotten some adverse events that occurred in childhood or the events may have occurred before an age that they were cognitively able to remember them.

**Simplicity of indicator**

As described above, the BRFSS ACE Module is optional, so not all states will have data for this indicator. The Notes On Calculation section describes the process for calculating the indicator from the 11 ACE questions. Given that this indicator is a composite measure of 11 questions that comprise the concept of 'adverse childhood experiences,' its level of difficulty to calculate is moderate. However, the concept of ACE and its implications for health and development are not difficult to explain.

**References**


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The Life Course Metrics Project

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In June of 2013, state teams selected 59 indicators for the final set. The indicators were put out for public comment in July 2013, and the final set was released in the Fall of 2013.

Basic Indicator Information

Name of indicator: Prevalence of Adverse Childhood Experiences among Children (LC-2)

Brief description: Prevalence of adverse childhood experiences among children

Indicator category: Childhood Experiences

Indicator domain: Risk/Outcome

Numerator: Weighted number of children whose parents responded to the NSCH that their children were exposed to adverse childhood experiences (nine questions related to ACEs)

Denominator: Total number of children

Potential modifiers: Child’s gender, age group, race and ethnicity, special health care needs status, family structure, household income, insurance type, and insurance status

Data source: National Survey of Children’s Health (NSCH)

Notes on calculation: This indicator should be calculated from ACE1, ACE3, ACE4, ACE5, ACE6, ACE7, ACE8, ACE9, and ACE10 on the NSCH.

1. (ACE1) Since [CHILD’S NAME] was born, how often has it been very hard to get by on your family’s income – hard to cover the basics like food or housing? Would you say very often, somewhat often, often, rarely, or never?
2. (ACE3) Did [CHILD’S NAME] ever live with a parent or guardian who got divorced or separated after [CHILD’S NAME] was born?
3. (ACE4) Did [CHILD’S NAME] ever live with a parent or guardian who died?
4. (ACE5) Did [CHILD’S NAME] ever live with a parent or guardian who served time in jail or prison after [CHILD’S NAME] was born?
5. (ACE6) Did [CHILD’S NAME] ever see or hear any parents or adults in (his/her) home slap, hit, kick, punch, or beat each other up?
6. (ACE7) Was [CHILD’S NAME] ever the victim of violence or witness any violence in (his/her) neighborhood?
7. (ACE8) Did [CHILD’S NAME] ever live with anyone who was mentally ill or suicidal, or severely depressed for more than a couple of weeks?
8. (ACE9) Did [CHILD’S NAME] ever live with anyone who had a problem with alcohol or drugs?
9. (ACE10) Was [CHILD’S NAME] ever treated or judged unfairly because of (his/her) race or ethnic group? (National Survey for Children’s Health 2011/2012)

For questions that assess how often an experience occurred (ACE1), the response of ‘somewhat often’ or ‘very often’ is coded as an adverse family experience. The other questions are dichotomous ‘Yes/No’ response options. Using the Data Resource Center methodology, this indicator should be grouped to generate three categories: a) zero adverse experiences, b) one adverse experience and c) two or more adverse experiences. Analysts who use the raw datasets should apply the appropriate survey weights to generate the final estimates.

Similar measures in other indicator sets: Maternal, Infant, and Early Childhood Home Visiting (MIECHV) Benchmark Area Reduction in Crime or Domestic Violence: Screening for domestic violence

Life Course Criteria

Introduction
Adverse childhood experiences (ACEs) are childhood experiences of emotional, physical, or sexual abuse, and household dysfunction. The short- and long-term outcomes of these childhood exposures include a multitude of health and social problems. Childhood maltreatment has been linked to a variety of changes in brain structure and function and stress–responsive neurobiological systems. Epidemiological studies have documented the impact of childhood maltreatment on health and emotional well-being (Anda et al 2006).

Overall, the prevalence of adverse childhood experiences among children is a life course measure because the indicator reflects current childhood experiences that impact health and have the potential to predict future individual and intergenerational health and social outcomes.

Implications for equity
Adverse childhood experiences (ACEs) include psychological, physical, or sexual abuse (witness or victim); living with household members who were substance abusers, mentally ill, suicidal or ever incarcerated; living in a household with poor economic resources, or with parents who got divorced or separated after the child was born; or child exposed to racial or ethnic discrimination. Inherent in this definition of ACEs are reflections of inequity as exposure to any of these events is experienced differently across different populations. ACEs related to incarceration and racial or ethnic discrimination are most intrinsically linked to inequity, as both are markers of larger institutionalized racism and are highly clustered within specific geographic and racial or ethnic populations (Lynch and Sabol 2004; Pettit and Western 2004).

As a composite, the ACEs indicator has implications for many social and psychosocial equity-related measures. Examples of social conditions that the ACEs indicator reflects include limitations in educational attainment/occupational opportunities, reductions in income/socioeconomic status, and increased risk of food insecurity. Children growing up in families with adverse experiences are at increased risk for cognitive and social development problems that may result in learning difficulties and barriers to higher education (Felitti et al 1998; Perry 1998; Anda et al 2006). Lower education levels may translate into fewer job opportunities and a reduced income potential into adulthood (Bremmer 2003). Children raised in certain types of adverse family environments may also be more vulnerable to food insecurity as a result of parental substance abuse, physical/emotional abuse, or neglect (Anda 2004).

Examples of psychosocial measures that ACEs indicators might reflect and influence include depression, hopelessness, and aggression/hostility. Research suggests that individuals who had adverse experiences in childhood are more vulnerable to social/developmental problems (poor self-control, aggression, violence, social isolation) (Dong et al 2004; Evans et al 2008). Additionally, they may be more likely to have social/emotional development problems, alcohol, tobacco, or substance abuse disorders, or mental health disorders (such as depression, suicidal thoughts/attempts, borderline personality disorder, post-traumatic-stress disorder) (Van Der Kolk et al 1991; Chapman et al 2004; Dube et al 2001; Varese et al 2012).
In addition, the basic framework for examining and understanding the impact of any ACE or collection of ACEs across the lifetime trajectory of an individual is also exemplary of the life course perspective and therefore has multiple inherent implications for equity. As Braveman and Barclay summarize, “[T]he life course perspective focuses on understanding how early-life experiences can shape health across an entire lifetime and potentially across generations; it systematically directs attention to the role of context, including social and physical content along with biological factors, over time. This approach is particularly relevant to understanding and addressing health disparities, because the social and physical contextual factors underlie socioeconomic and racial/ethnic disparities in health.”

**Public health impact**

The public health impact of ACEs can be framed in two ways: the relationship of individual health trajectories on larger public health spending and the overall impact of risk and protective factors throughout the life course and their influences on intergenerational outcomes.

Analysis reveals that ACEs put individuals at risk for a wide variety of chronic mental, physical and emotional health problems in adulthood. Additionally, ACEs have been associated with an increased propensity to engage in health risk behaviors that are associated with chronic disease and injury, including risky sexual behavior, alcohol, drug, and tobacco use, and a greater likelihood of being overweight/obese (Goodwin 2004; CDC 2013; Anda 2007). Overall, in relation to individual’s experiences of ACEs and larger public health impacts, if the number of children experiencing multiple adverse circumstances was reduced, one might expect to see a substantial reduction in mortality and prevalence rates for these key public health risk and chronic disease indicators. Additionally, a reduction in overall health costs would be expected, as individuals experiencing ACEs are more likely to incur higher health care costs as a result of riskier behavior and a higher rate of physical and mental health issues (Bremner 2003; Walker et al 1999).

A measure called the population attributable fraction (PAF) can be used to quantify the reduction in population disease or mortality if exposure to a risk factor were reduced or eliminated. A specific analysis conducted in the state of Maine of the PAF of a person with four or more ACEs having subsequent poor adult mental, physical or emotional health outcomes demonstrated PAFs of seven to 58 percent. For example, severe obesity in adulthood had a PAF of seven percent while an attempted suicide has a PAF of 58 percent. The authors of this report noted these ACEs are therefore resulting in millions of dollars of costs for individuals and health systems: $863 million for severe obesity and $29.5 million for attempted suicides (Forstadt and Rains, 2011).

When framing impact beyond specific health outcomes, linking ACEs to the broader life course theory is important. Life course theory focuses on exposures and experiences, including both risk factors and protective factors, that occur during critical periods of development, such as childhood, and their impact on the future for the individual, the family unit, the community, and the larger society. The impact of ACEs throughout the life cycle has been well established within the life course science literature. This research reveals that ACEs are pervasive, can negatively impact the life trajectory of the individuals experiencing them, and increase the potential for inter-generational familial adversity (Forrest and Riley 2004; Kelly-Irving et al 2013). On the other hand, protective factors can decrease inter-generational familial adversity (Bremner 2003; Richardson et al 2013). This type of mitigation can influence not only the individual but his or her children as well.

**Leverage or realign resources**

Traditionally, MCH programs have tended to focus on physical and developmental health outcomes as they pertain to the pregnant mother and her fetus, infant, or child. ACEs information provide opportunities for data-driven approaches to improving both pediatric and adult primary care through risk screening individuals for poor mental and physical health outcomes in childhood and beyond. The inclusion of ACEs in public health data analyses and assessments expands the sphere of MCH services to include collaborations with mental/behavioral health services, child abuse/neglect programs, and law enforcement. Additionally, the assessment of ACEs risks within the MCH community could also be of use for other public health promotion and disease prevention programs including chronic disease and communicable/sexually transmitted disease (Fine and Kotelchuck 2010; Shonkoff et al 2009; Foege 1998).

Protective factors (e.g., child’s positive relationship with a caring adult, easy temperament of the child, health insurance coverage for the child) can be more important than risk factors as they mitigate the negative effects of risk factors such as ACEs (Werner and Smith 1992). More attention could be paid to leveraging or realigning resources to provide supports for positive factors. Public health and other partners could work together to support policy and program interventions that

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*Life Course Indicator: Prevalence of Adverse Childhood Experiences among Children (LC-2)*

3
contribute to or enhance protective factors, such as helping parents and family members understand how to support easy temperament in children, establishing family-friendly work policies to allow parents time to parent (i.e. paid maternity and paternity leaves) and working to provide health insurance coverage for all children.

**Predict an individual’s health and wellness and/or that of their offspring**

The level of exposure to ACEs correlates to an association with adult risk behavior, poor health status and disease. The number of categories of adverse childhood experiences shows a graded relationship to the presence of adult diseases (Felitti 1998).

This graded relationship has been documented throughout a significant body of research (Dube et al 2003; Danese et al 2009; Hillis et al 2001; Williamson et al 2002; Ford et al 2011; Chapman et al 2013). Specifically, individuals reporting ACEs, especially multiple ACEs, have greater risks of developing:

- Chronic diseases (autoimmune, COPD, chronic headaches, ischemic heart disease, liver disease, and lung cancer)
- Poor reproductive health outcomes and risky sexual behaviors (fetal death, promiscuity, sexual risk behaviors, sexually transmitted diseases, teen pregnancy, and unintended pregnancy)
- Health risk behaviors (alcohol abuse, drug abuse, obesity, smoking)
- Poor mental health (memory disturbances, depression, hallucinations, suicidal tendencies, work absenteeism, sleep disturbances)

As a result, individuals having ACEs are at increased risk of premature mortality, compared with individuals who did not have ACEs (Brown et al 2009). Additionally, research reveals that ACEs often do not occur in a vacuum – they are comorbid conditions that often occur simultaneously (e.g. a single parent that is mentally ill becomes an alcoholic and physically abuses their child) (Dong et al 2004; Chartier 2010; Edwards 2003).

**Data Criteria**

**Data availability**

The National Survey of Children’s Health (NSCH), sponsored by the Maternal and Child Health Bureau of the Health Resources and Services Administration, examines the physical and emotional health of children ages zero to 17 years of age. The survey is administered using the State and Local Area Integrated Telephone Survey (SLAITS) methodology, and it is sampled and conducted in such a way that state-level estimates can be obtained for the 50 states, the District of Columbia, and the Virgin Islands. The survey has been designed to emphasize factors that may relate to the well-being of children, including medical homes, family interactions, parental health, school and after-school experiences, and safe neighborhoods. The Maternal and Child Health Bureau leads the development of the NSCH and NS-CSHCN survey and indicators, in collaboration with the National Center for Health Statistics (NCHS) and a national technical expert panel. The expert panel includes representatives from other federal agencies, state Title V leaders, family organizations, and child health researchers, and experts in all fields related to the surveys (adolescent health, family and neighborhoods, early childhood and development, etc.). The most recent data set, the 2011-2012 NSCH, encompasses a sample size of more than 95,000 children with approximately 1,800 interviews completed in each of the 50 states and the District of Columbia.

MCH programs can readily gain immediate access to the data through datasets released by the National Center for Health Statistics, and on the MCHB-sponsored National Data Resource Center for Child and Adolescent Health website (childhealthdata.org). Data from the 2011/2012 NSCH were made available in early 2013. The survey questionnaire and raw dataset are available for download on the Centers for Disease Control and Prevention NCHS website in SAS format. The Data Resource Center (DRC) website provides data nationwide, for all 50 states and the District of Columbia. Additionally, both the raw datasets and the website allow users to stratify measures by sociodemographic groups, including but not limited to age, sex, race/ethnicity, primary household language, household income, and special health care needs. Cleaned, state-specific datasets with new variables that include national and state indicators are available at no cost in SAS and SPSS formats. For information on how to order state-specific sets, contact cahmi@ohsu.edu. Local data is not searchable. The NSCH is not administered annually. Over the past decade, the NSCH has been administered four times.
The ACE module is a new series of questions included for the first time beginning with the 2011-12 survey. Presumably, these questions will be included in subsequent NSCH questionnaires; however, there is no documentation to this effect. 

cdc.gov/nchs/slaits/nsch.htm
http://www.childhealthdata.org/learn/NSCH

Data quality
The main limitation of the NSCH is that the information provided is from parent recollection of screenings received and the perception of the child’s health and development over the past year. The survey methodology does not provide an opportunity for confirmation with medical records or physical measurements. The NSCH is weighted to represent the national population of non-institutionalized children age zero to 17 years. According to the survey documentation, missing data for income were relatively high for 2011-2012 data, and a study of nonresponse patterns indicated that excluding records with missing income could impact the representativeness of the remaining data; therefore, a data file with imputed values for income is provided to be used with the datasets.

The NSCH documentation presents both response rates and completion rates. For 2011-2012 data, the combined national response rate for both landline and cell phone samples was 23 percent. The completion rate, which is calculated as the proportion of households known to include children that completed all sections up to and including Section Six (for children less than six years of age) or Section Seven (for children six to 17 years of age), was 54.1 percent for the landline sample and 41.2 percent for the cell-phone sample.

Qualitative testing of the entire 2007 National Survey of Children’s Health was conducted by the National Center for Health Statistics. They conducted cognitive interviews with the 2007 NSCH Computer-Assisted Telephone Interview (CATI) to make sure the entire survey instrument was functioning properly. N=640 interviews were completed over three days in December 2006. The questionnaire was then revised and finalized based on feedback from participants in these interviews.

Previously validated questions and scales are used when available. All aspects of the survey are subjected to extensive literature and expert review. Respondents’ cognitive understanding of the survey questions is assessed during the pretest phase and revisions made as required. All final data components are verified by NCHS and DRC/CAHMI staff prior to public release. Face validity is conducted in comparing results with prior years of the survey and/or results from other implementations of items.

No specific reliability results are available for this measure; however, several of the ACE questions included in the NSCH were adapted from a large, validated survey instrument (the Behavioral Risk Factor Surveillance System ACEs Module) measuring the frequency of adverse childhood experiences. Additional ACEs questions were added based on recommendations from the Technical Expert Panel and a period of public comment.

Factors that might impact the quality of the NSCH and/or ACE data include:

1. Respondents may feel uncomfortable responding to the sensitive, personal nature of the ACE questions. As a result, the ACE questions may have lower response rates than other questions on the NSCH, which increases the risk for response bias.

2. The sensitive, personal nature of the ACE questions on poverty, and incarceration, mental illness, drug, alcohol use/abuse, and physical violence taking place in the child’s household or neighborhood may lead to a “social desirability bias”. Respondents may feel uncomfortable disclosing their child’s experiences related to these topics to a stranger over the phone. This tendency may vary by demographic characteristics.

3. Responses to some of the ACE questions may be inaccurate because it is based on parental report of their child’s experiences. Parents may be unwilling to reveal experiences that reflect poorly on their parenting skills, or their own mental health or substance abuse issues. Similarly, while the questions do not ask directly about parental violence towards the child, parents who abuse their children may not want to reveal this due to fear of reprisal. In other cases, parents may not even be aware of their child’s exposure to adverse experiences —such as their child’s feelings and/or frequency of experiencing racial/ethnic bias.

Poor overall survey response rates for the NSCH overall can also impact the quality of the ACE estimates. In 2007, the NSCH survey response rate was 46.7 percent (Shonkoff 2009). For 2011-2012 data, the combined national response rate
for both landline and cell phone samples was 23 percent. The completion rate, which is calculated as the proportion of households known to include children that completed all sections up to and including Section Six (for children less than six years of age) or Section Seven (for children six to 17 years of age), was 54.1 percent for the landline sample and 41.2 percent for the cell-phone sample. A study published in 2012 examined non-response bias in the 2007 NSCH and found that even when nonresponse-adjusted survey weights were used, the interviewed population was more likely to live in areas associated with higher levels of home ownership, lower home values, and greater proportions of non-Hispanic white persons when compared with the non-responding population (Skalland 2012). As a result, estimates derived from the NSCH may not be reflective of the overall population.

**Simplicity of indicator**

There are a total of nine ACE questions (ACE1; ACE3; ACE4; ACE5; ACE6; ACE7; ACE8; ACE9; ACE10) included on the 2011-12 NSCH:

Results of all nine of the main ACE questions can be summed and scored. Most studies utilize a summative integer count across the different categories of ACEs to categorize responses into high, medium, and low levels of adverse experiences. The Data Resource Center uses the following methodology to generate percentages for experience of a) zero adverse experiences, b) one adverse experience and c) two or more adverse experiences: For question one, which assess how often an experience occurred, the response of 'somewhat often' or 'very often' is coded as an adverse family experience. The other questions are dichotomous 'Yes/No' response options.

The indicator is available pre-calculated for all 50 states and the District of Columbia, so for state and national level estimates no calculation is required. The Data Resource Center provides code for commonly used statistical programs, easing the complexity of performing the calculation from the raw data. The main complexity with this indicator may be with explaining the concept of ACEs to those who are unfamiliar.

**References**


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Life Course Indicator: Substantiated Child Maltreatment

The Life Course Metrics Project

As MCH programs begin to develop new programming guided by a life course framework, measures are needed to determine the success of their approaches. In response to the need for standardized metrics for the life course approach, AMCHP launched a project designed to identify and promote a set of indicators that can be used to measure progress using the life course approach to improve maternal and child health. This project was funded with support from the W.K. Kellogg Foundation.

Using an RFA process, AMCHP selected seven state teams, Florida, Iowa, Louisiana, Massachusetts, Michigan, Nebraska and North Carolina, to propose, screen, select and develop potential life course indicators across four domains: Capacity, Outcomes, Services, and Risk. The first round of indicators, proposed both by the teams and members of the public included 413 indicators for consideration. The teams distilled the 413 proposed indicators down to 104 indicators that were written up according to three data and five life course criteria for final selection.

In June of 2013, state teams selected 59 indicators for the final set. The indicators were put out for public comment in July 2013, and the final set was released in the Fall of 2013.

Basic Indicator Information

Name of indicator: Substantiated Child Maltreatment (LC-03)

Brief description: Substantiated child maltreatment including experience of physical abuse, neglect or deprivation of necessities, medical neglect, sexual abuse, psychological or emotional maltreatment

Indicator category: Childhood Experiences

Indicator domain: Risk/Outcome

Numerator: Number of children (under age 17 years) with reports of maltreatment types that include physical abuse, neglect or deprivation of necessities, medical neglect, sexual abuse, psychological or emotional maltreatment and the report is considered substantiated

Denominator: Number of children under 17 years of age in the state

Potential modifiers: Age of child, race, ethnicity

Data source: National Child Abuse and Neglect Data System (NCANDS)

Notes on calculation: The numerator is comprised of the number of children with reports of maltreatment types that correspond to the following codes: ChMal1, ChMal2, ChMal3, ChMal4 with value of anything other than 6 (no alleged maltreatment) AND Mal1Lev, Mal2Lev, Mal3Lev, Mal4Lev with value of 1, 2, 3, or 4 (substantiated, indicated or reason to suspect, alternative response victim, alternative response non-victim). The data source can be found at: ndacan.cornell.edu/ndacan/Datasets/Abstracts/DatasetAbstract_NCA NDS_Child_File.html

Similar measures in other indicator sets: HP 2020 Focus area IVP-38; MIECHV Benchmark Area Prevention of Child Injuries, Child Abuse, Neglect, or Maltreatment, and Reduction of Emergency Department Visits: Reported substantiated maltreatment (substantiated/ indicated/ alternative response victim) for children in the MIECHV program.
**Life Course Criteria**

**Introduction**
Maltreatment is defined by the Administration for Children & Families (ACF) National Child Abuse and Neglect Data System (NCANDS) as an act or failure to act by a parent, caretaker, or other person as defined under State law which results in physical abuse, neglect, medical neglect, sexual abuse, emotional abuse, or an act or failure to act that presents an imminent risk of serious harm to a child (ACF NCANDS). The short- and long-term outcomes of these childhood exposures include a multitude of health and social problems. Maltreatment in childhood has been linked to a variety of changes in brain structure and function and stress-responsive neurobiological systems (Brenner 2003). Epidemiological studies have documented the impact of maltreatment on health and emotional well-being (Anda et al 2006).

Overall, the prevalence of substantiated child maltreatment is a life course measure because it captures experiences during sensitive periods of development that can impact health and social outcomes across the life span. The impact of maltreatment throughout the life cycle has been well established within the life course science literature. Research on the impacts of experiencing multiple forms of child maltreatment is addressed by the Adverse Childhood Experiences (ACEs) study and demonstrates that if pervasive, they negatively impact the life trajectory of the individuals experiencing them, and increase the potential for inter-generational familial adversity. In addition, an absence of ACEs and increased prevalence of protective factors can decrease inter-generational familial adversity, reducing the potential for harm for the individual and his or her children (Forrest 2004; Kelly-Irving 2013; Richardson 2013). It is difficult to study the effects of child maltreatment removed from other adverse childhood experiences as child maltreatment is more likely to occur in families affected by poverty, domestic violence, substance abuse, incarceration, and mental health problems (Chatier 2010). However, a significant predictive relationship between child abuse and poor adult health outcomes exists even when controlling for other ACEs, suggesting child maltreatment has an influence on poor health and development independent from other ACEs (Chatier 2010). This influence on health outcomes highlights a need for intervention and prevention strategies designed specifically for child maltreatment. An assortment of programs and interventions, particularly those with a home visiting component, have proven effective in reducing child maltreatment and improving health outcomes for families at risk for child maltreatment (Avellar 2013). Evidence on effectiveness of intervention programs for child maltreatment suggests an opportunity for improvement of this indicator.

**Implications for equity**
Community level factors related to variation in rates of officially reported child maltreatment have been documented, including structural determinants of community social organization, economic and family resources, residential instability, household and age structure and geographic proximity of neighborhoods to concentrated poverty. Children at the highest risk of maltreatment live in neighborhoods characterized by poverty, excessive numbers of children per adult resident, population turnover, and concentration of female-headed households (Coulton 1995). On the family level, children living in single parent homes have a rate of child abuse twice the rate of child abuse in two parent households (Goldman, 2003).

At a very high level, there are differences in the characteristics of victims by age and race/ethnicity. Data reported by ACF show that young children are more likely to be victims of child maltreatment with the highest rate (14.3 per 1,000) among children three and younger (Child Trends Data Bank, 2011). Among racial/ethnic groups, non-Hispanic Black, American Indian or Alaska Native children and children of multiple race groups had higher rates of maltreatment compared with Hispanic, Pacific Islander, White, and Asian children (Child Trends Data Bank, 2011). Children with disabilities are more likely to be victims of maltreatment than children without disabilities. National data on maltreatment among children with disabilities is lacking, however, research shows a significantly higher incidence of maltreatment among children with disabilities compared to children without disabilities (Children’s Bureau, 2012).

Experiences of maltreatment have implications for many social and psychosocial equity-related measures. Examples of social conditions where child abuse and neglect may co-occur are limitations in educational attainment/occupational opportunities, reductions in income/socioeconomic status, and increased risk of food insecurity. Adults who grew up in families with adverse experiences are at increased risk for cognitive and social development problems which may result in learning difficulties and barriers to higher education (Felitti et al 1998; Perry 1998; Anda et al 2006). Lower education levels may translate into fewer job opportunities and a reduced income potential into adulthood (Bremmer 2003).
Public health impact
Experience of child maltreatment puts individuals at risk for a wide variety of chronic mental, physical and emotional health problems in adulthood. Additionally, maltreatment has been associated with an increased propensity to engage in health risk behaviors that are associated with chronic disease and injury, including risky sexual behavior, alcohol, drug, and tobacco use, and a greater likelihood of being overweight/obese (Goodwin 2004; CDC 2013; Anda 2007). Overall, in relation to individual’s experiences of ACEs and larger public health impacts, if the number of children experiencing multiple adverse circumstances was reduced, one might expect to see a reduction in mortality and prevalence rates for these key public health risk and chronic disease indicators. Additionally, individuals who have experienced ACEs are more likely to incur higher adult health care costs and medical visits (Walker et al 1999). Reducing individuals exposed to child maltreatment could conceivably reduce overall health care costs.

Beyond the individual level impacts and costs, there are also large costs associated with maintaining the social systems which respond to child maltreatment, including child welfare systems, judicial systems, law enforcement, special education programs, and health care and mental health systems that are needed to respond to and to treat victims of child neglect and their families. Direct costs of child abuse and neglect include those associated with maintaining a child welfare system to investigate and respond to allegations of child abuse and neglect, as well as expenditures by the judicial, law enforcement, health, and mental health systems. A 2012 report by Prevent Child Abuse America estimates these costs at $33 billion per year. Indirect costs represent the long-term economic consequences of child abuse and neglect. These include costs associated with juvenile and adult criminal activity, mental illness, substance abuse, and domestic violence. They can also include loss of productivity due to unemployment and underemployment, the cost of special education services, and increased use of the health care system. Prevent Child Abuse America estimated these indirect costs at more than $46.9 billion per year. Combining the direct and indirect costs of child abuse and neglect, the cost to society of the 1.2 million maltreated children in years 2005-2006 adjusted to 2012 dollars sums to $80,260,411,087. The total yearly cost of each abused or neglected child in the United States is $63,871 (Gelles 2012).

Leverage or realign resources
Traditionally, MCH programs have tended to focus on physical and developmental health outcomes as they pertain to the pregnant mother and her fetus, infant, or child. Child maltreatment data provide opportunities for data-driven approaches to improving both pediatric and adult primary care. The mechanism for this is through screening individuals for risk factors for poor mental and physical health outcomes in childhood and beyond. The inclusion of child maltreatment reporting in public health analyses and assessments expands the sphere of MCH services to include collaborations with child welfare agencies, mental/behavioral health services, child abuse/neglect programs, and law enforcement. Additionally, the assessment of maltreatment risks within the MCH community could also be of use for other public health promotion and disease prevention programs including chronic disease and communicable/sexually transmitted disease (Fine and Kotelchuck 2010; Shonkoff et al 2009; Foege 1998).

Certain child-, caregiver-, family-, and community-level factors increase the risk of child maltreatment, which presents an opportunity to engage other public health services in reduction and prevention efforts. Parents or caregivers that possess inadequate parenting knowledge and skills, experience high stress, or suffer from substance abuse or depression are at higher risk for child maltreatment (Bethea 2010). Family level poverty, unemployment, or social isolation as well as community level violence, housing instability, and community-level poverty are all associated with an increased risk of child maltreatment (Bethea 2010). Public health services focusing on interventions such as improving health care accessibility and affordability, improving treatment for alcohol and drug abuse, increasing the availability of affordable child care, increasing family planning and parental support services are all potential partners that can be engaged to achieve reductions in risk factors for child maltreatment (Bethea 2010).

In 2010, the Patient Protection and Affordable Care Act authorized the Maternal Infant and Early Childhood Home Visiting (MIECHV) program which provides $1.5 billion in funds over five years for evidence-based home visiting programs (Avellar 2013). Families in maternal, infant, or early childhood home visiting programs participate in home visits with a trained professional who can provide information, support, training, or referrals to overcome barriers to services. Home visiting personnel can identify existing resources available through other programs and departments and refer families to these services including services that will aid in child maltreatment prevention. A review of home visiting programs found five of six programs reviewed resulted in reductions in child maltreatment as measured through substantiated abuse records, encounters with health providers for injuries or poisonings, or self-reported parenting behaviors (Avellar 2013).
Protective factors (e.g., child’s positive relationship with a caring adult, easy temperament of the child, health insurance coverage for the child) can be more important than risk factors as they mitigate the negative effects of maltreatment risk factors (Werner and Smith 1992). More attention could be paid to leveraging or realigning resources to provide supports for positive factors. Public health and other partners could work together to support policy and program interventions that contribute to or enhance protective factors such as helping parents and family members understand how to support easy temperament in children. Establishing family friendly work policies, such as paid maternity and paternity leave, flexible schedules, paid sick leave, and infant at work policies all have the potential to improve outcomes for families including reduction of postpartum depression, promotion of breastfeeding, increasing parent-infant bonding, and reducing sick days used to care for a sick child.

Predict an individual’s health and wellness and/or that of their offspring

The level of exposure to child maltreatment correlates to an association with adult risk behavior, poor health status and disease. The number of categories of maltreatment experiences shows a graded relationship to the presence of adult diseases (Felitti 1998). This graded relationship has been documented throughout a significant body of research (Dube et al 2003; Danese et al 2009; Hillis et al 2001; Williamson et al 2002; Ford et al 2011; Chapman et al 2013). Specifically, individuals reporting multiple maltreatment exposures, have greater risks of experiencing:

- Chronic diseases (autoimmune, COPD, chronic headaches, ischemic heart disease, liver disease, and lung cancer)
- Poor reproductive health outcomes and risky sexual behaviors (fetal death, promiscuity, sexual risk behaviors, sexually transmitted diseases, teen pregnancy, and unintended pregnancy)
- Health risk behaviors (alcohol abuse, drug abuse, obesity, smoking)
- Poor mental health (memory disturbances, depression, hallucinations, suicidal tendencies, work absenteeism, sleep disturbances)
- Homelessness

As a result, individuals who have experienced child maltreatment are at increased risk of premature mortality (Brown et al 2009). Additionally, multiple maltreatment experiences often do not occur in a vacuum – they are comorbid conditions that often occur simultaneously (e.g. a single parent with mental illness who also suffers from substance abuse and physically abuses their child) (Dong et al 2004; Chartier 2010; Edwards 2003).

Child maltreatment also affects intergenerational health; a number of studies have demonstrated that a history of maltreatment in childhood and adolescence increases the likelihood of perpetrating child maltreatment; victims of maltreatment during adolescence were almost five and a half times more likely to engage in maltreating behavior than those who were never maltreated (Thornberry 2013). The risk of offspring child maltreatment is strongest when child maltreatment of the parent started in childhood and persisted into adolescence (Thornberry 2013). The association between maltreatment in childhood and perpetration of child maltreatment may be mediated through mental health problems, social isolation, and social information patterns such as hostile attributions and aggressive responses which are all predicted by physical abuse and predictive of physical abuse (Berlin 2011).

Data Criteria

Data availability

Each state has its own definitions of child abuse and neglect that are based on standards set by federal law. Federal legislation provides a foundation for states by identifying a set of acts or behaviors that define child abuse and neglect. The Child Abuse Prevention and Treatment Act (CAPTA), (42 U.S.C. §5101), as amended by the CAPTA Reauthorization Act of 2010, retained the existing definition of child abuse and neglect as, at a minimum:

Any recent act or failure to act on the part of a parent or caretaker which results in death, serious physical or emotional harm, sexual abuse or exploitation; or an act or failure to act, which presents an imminent risk of serious harm (U.S. Department of Health and Human Services 2013).

The 1988 CAPTA amendments directed the U.S. Department of Health and Human Services (HHS) to establish a national data collection and analysis program. The Children’s Bureau in the Administration on Children, Youth and Families, Administration for Children and Families, HHS, collects and analyzes the data, which is now the National Child Abuse and
Neglect Data System (NCANDS), a federally sponsored effort that collects and analyzes annual data on child abuse and neglect. The data are submitted voluntarily by the States, the District of Columbia, and the Commonwealth of Puerto Rico. The first report from NCANDS was based on data for 1990; and the most recent report available is for Federal fiscal year 2011. The 2011 national statistics were based case-level data received from 49 states, the District of Columbia, and the Commonwealth of Puerto Rico; aggregate data were received from one state.

NCANDS collects case-level data on all children who received a Child Protective Services (CPS) agency response in the form of an investigation response or an alternative response. States that are unable to provide case-level data submit aggregated counts of key indicators. Case-level data include information about the characteristics of screened-in referrals (reports) of abuse and neglect that are made to CPS agencies, the children involved, the types of maltreatment they suffered, the dispositions of the CPS responses, the risk factors of the child and the caregivers, the services that are provided, and the perpetrators (U.S. Department of Health and Human Services 2012). NCANDS is a continuous data collection activity with an annual acquisition cycle, with reports released annually approximately 18 months after the close of the collection year.

Data quality
Most states recognize four major types of maltreatment: neglect, physical abuse, psychological maltreatment, and sexual abuse. Although any of the forms of child maltreatment may be found separately, they can occur in combination. Because NCANDS relies on official reports, state variation in reporting laws (for example, states use different definitions of abuse and neglect), evidentiary standards used by child protective services agencies to verify a report of maltreatment, and the number of investigators that a state deploys to influence the process that leads to a disposition of the report (Wulczyn 2009).

Fallon and colleagues described the quality of NCANDS data, beyond challenges with state variation: “Data are evaluated and validated through both qualitative analysis of items for compatibility and a set of rules used to assess data consistency and evaluate data ranges for accuracy, missingness, and cross-submission reliability. Information collected includes report sources, demographics of the children and the perpetrators, maltreatment types, dispositions of the assessment or investigation, worker and supervisor IDs, risk factors, and services and placements that result from the investigation. In addition, an ID linkage is provided to case-level data on children who are included in data submissions to the federal Adoption and Foster Care Analysis and Reporting System (AFCARS). Data in the Agency File are aggregated and include information regarding children and family funding sources, screened-out referrals, CPS workforce, and additional information on child victims and child fatalities” (Fallon et al 2010). Therefore, the data are of sufficient quality to inform a life course approach to health.

Simplicity of indicator
Due to differences between states in the definitions of abuse and neglect, standards used to verify a report of maltreatment and the number of investigators employed, data may not be comparable between states. Analysts are encouraged to explore the definitions and standards used in their state to provide context for these data. Please refer to the Notes on Calculation section for a detailed explanation of the variables from the NCANDS system; the numerator is comprised of information from two variables, which increases the calculation complexity. Despite these challenges and the multiple components of child maltreatment, the concept is simple to explain.

References


This publication was supported by a grant from the W.K. Kellogg Foundation. Its contents are solely the responsibility of the author and do not necessarily represent the official views of the W.K. Kellogg Foundation.

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**Life Course Indicator: Breastfeeding Support - Baby Friendly Hospitals**

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**Basic Indicator Information**

**Name of indicator:** Breastfeeding Support – Baby Friendly Hospitals (LC-4)

**Brief description:** Proportion of births occurring in baby friendly hospitals

**Indicator category:** Community Health Policy

**Indicator domain:** Service/Capacity

**Numerator:** Number of births at Baby-Friendly designated hospitals for a given year

**Denominator:** Number of births in State for a given year

**Potential modifiers:** Race/ethnicity, socioeconomic status, geography, density of Baby-Friendly Hospitals in a given state, available funding for a state/hospital to pursue the designation, location/size of baby-friendly hospital, rate at which Baby-Friendly USA can move through process to award designation

**Data source:** Annual Centers for Disease Control and Prevention (CDC) Breastfeeding Report Card

**Notes on calculation:** As an alternative to Baby-Friendly designation, this indicator can be examined as the proportion of births occurring in facilities who provide recommended care for lactating mother and their babies. This can be determined by state-specific metrics, or by looking at facilities who have implemented the ten steps for successful breastfeeding. To calculate an indicator based on the ten steps for successful breastfeeding, the analyst would need to design a way to obtain information on the progress each hospital in a given geographic area has made on the ten steps; there is currently no standard source for this information other than the Baby-Friendly Hospital designation. The CDC Maternity Practices in Nutrition and Care (mPINC) Survey generates a score for each facility and state to indicate their performance regarding implementation of practices that support breastfeeding. The mPINC score ranges from zero to 100, with higher scores indicating more supportive maternity care

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**The Life Course Metrics Project**

As MCH programs begin to develop new programming guided by a life course framework, measures are needed to determine the success of their approaches. In response to the need for standardized metrics for the life course approach, AMCHP launched a project designed to identify and promote a set of indicators that can be used to measure progress using the life course approach to improve maternal and child health. This project was funded with support from the [W.K. Kellogg Foundation](https://www.wkkellogg.org).

Using an RFA process, AMCHP selected seven state teams, Florida, Iowa, Louisiana, Massachusetts, Michigan, Nebraska and North Carolina, to propose, screen, select and develop potential life course indicators across four domains: Capacity, Outcomes, Services, and Risk. The first round of indicators, proposed both by the teams and members of the public included 413 indicators for consideration. The teams distilled the 413 proposed indicators down to 104 indicators that were written up according to three data and five life course criteria for final selection.

In June of 2013, state teams selected 59 indicators for the final set. The indicators were put out for public comment in July 2013, and the final set was released in the Fall of 2013.
Breastfeeding impacts women and infants in the immediate postpartum period and infancy and confers lifelong benefits to both. It is consistent with the life course model which states that early exposures during a critical or sensitive period during childhood influence adult health outcomes. Breastfeeding can also reduce cumulative exposures to health risks over time for both the mother and infant. The Baby-Friendly hospital designation is designed to recognize facilities that offer an optimal level of care for lactation based on the WHO/UNICEF Ten Steps to Successful Breastfeeding for Hospitals. While it is a proprietary designation, today it remains one of the few standardized methods for assessing breastfeeding support in birth facilities. Maternity practices in hospitals and birth centers can influence breastfeeding behaviors during a period critical to successful establishment of lactation, in turn influencing initiation and duration of breastfeeding that can have lifelong implications for the health of the mother and the infant.

Implications for equity

Baby-Friendly hospital policies reduce health disparities within an institution because all infants are born into similar environments that promote breastfeeding. However, there is the potential for inequity if the adoption of the Baby-Friendly designation is not uniform and low-income or diverse populations do not have similar access to Baby-Friendly hospital care as other populations. Because of the financial costs associated with the Baby-Friendly designation, including the fees related to the designation pathway, education/training requirements, and the requirement for institutions to purchase infant formula, there is the potential for the adoption of the Baby-Friendly designation to vary between resource-rich and resource-poor institutions. However, it is not uncommon for decision makers to overestimate the actual costs associated with the process, and after designation is achieved, the financial implications of the designation appear to be minimal. A recent study demonstrated that the cost differences between Baby-Friendly and non-Baby-Friendly for a typical acute care hospital were not statistically significant (DelliFraine et al., 2011). Literature demonstrates that among Baby-Friendly institutions, breastfeeding rates do not vary based on race/ethnicity/poverty as they do in the general population (Merewood et al, 2005).

Compared with white infants, breastfeeding initiation and continuation rates for Black infants are approximately 50 percent lower. Although the reason for this is not yet fully understood, the need to return to work earlier and lack of social support for Black women desiring to breastfeed are thought to be contributing factors to lower breastfeeding initiation and duration rates compared with White women (CDC 2007). Women living in the southeast area of the U.S. are also less likely to breastfeed to any extent (DHHS 2011). However, breastfeeding can improve food security as it is usually readily available, low cost, and requires no preparation to provide an infant feeding (Bai 2009, Guttman 2000, Neifert 1988). Breastfeeding may also reduce financial strain as families can save $1,200-1,500 in the cost of non-specialty formula during the first year of a baby's life (Ball 1999). Breastfeeding improves infant health and has been shown to decrease direct and indirect insurance claims cost and lost days from work due to caring for a sick infant (USBC 2002). According to one review of the benefits of breastfeeding, cost savings for decreased cases of ear and respiratory infections, gastroenteritis, and necrotizing enterocolitis would have equaled an estimated $3.6 billion annually in direct and indirect health care costs (Weimer 2001).

Additionally, the relationship of breastfeeding rates to lower income is demonstrated in the studies done by the U.S. Department of Agriculture (USDA) Supplemental Nutrition Program for Women, Infants, and Children (WIC). This study found that sociodemographic factors such as WIC participation, for which eligibility is based on income, and maternal education, are inversely related with the likelihood to have ever breastfed and similarly up to six and twelve months.

Only a small percentage of women have access to Baby-Friendly designated hospitals in the US. Currently there are only 166 birthing hospitals/centers in 41 states and the District of Columbia that are designated as Baby-Friendly. Because of the limited number, access to these hospitals/centers is based on the woman’s residence. Therefore, only 6.9 percent of births occur in hospitals/centers demonstrating they provide the recommended, evidence-based care for lactating mothers.
and babies through Baby-Friendly designation (Baby-Friendly USA 2013). Implementing the standards for Baby-Friendly designation in hospitals across the U.S., especially in those areas where breastfeeding rates are lowest, has the potential to put babies and mothers on a healthier trajectory and close ongoing disparities in breastfeeding rates.

Public health impact
The potential life-long implications of breastfeeding through the recommended milestones for both mothers and their infants make indicators associated with improvements in breastfeeding outcomes a natural component of life course measurement and equity. The 2011 Surgeon General’s Call to Action recommends the acceleration of maternity institution designations as Baby-Friendly because of the improved breastfeeding rates associated with the Baby-Friendly Hospital Initiative (BFHI). Data from the Promotion of Breastfeeding Intervention Trial (PROBIT) demonstrated links between BFHI and longer breastfeeding duration at 12 months (19.7 percent vs. 11.4 percent, p < .001) and exclusivity at three months (43.3 percent vs. 6.4 percent, p < .001) (Martens 2012). Maternity practices in hospitals and birth centers can influence breastfeeding behaviors during a period critical to successful establishment of lactation. Abundant literature, including a Cochrane review, document that institutional changes in maternity care practices to make them more supportive of breastfeeding increase initiation and continuation of breastfeeding (CDC 2009).

The risks of not breastfeeding include increased incidence of many common childhood infections as well as chronic pediatric conditions such as obesity, asthma and certain cancers (Stuebe 2009). Not breastfeeding is also associated with an increased risk of disease for women, including breast and ovarian cancer and type II diabetes (Stuebe 2009).

Infants who are exclusively breastfed or breastfed to any extent experience significantly fewer infections and diseases than formula-fed infants. Longer and more exclusive breastfeeding is also associated with better health outcomes. A 2010 Pediatrics study demonstrated that the United States incurs $13 billion in excess costs annually and suffers over 900 preventable deaths per year because breastfeeding rates fall far below medical recommendations (Bartick and Reinhold 2010).

Economic effects of breastfeeding can be experienced by families, insurers, employers, schools, and society as a whole through increased health care costs, missed work and school, cost of formula for families and society, among others. It is estimated that the United States could save $10.5 billion per year in additional health care costs associated with breastfeeding (DHHS 2011).

Healthy People 2020, has included initiation, continuation, and exclusivity as national breastfeeding priorities. Under the health objectives for Perinatal Care, MICH–24: Increase the proportion of live births that occur in facilities that provide recommended care for lactating mothers and their babies. The baseline is 2.9 percent and target is 8.1 percent (HP 2020, 2013).

Leverage or realign resources
This indicator presents opportunities for leveraging and realigning resources in sectors such as health care, employers, accrediting organizations, childcare facilities, and government programs (WIC, State perinatal programs). Breastfeeding success while in the birthing hospital/center is critical in determining the duration of breastfeeding following discharge. By not having the support needed during the early postpartum period, the rates for successful breastfeeding are decreased and therefore affect the lifelong health outcome for the child (DiGirolamo 2008). Hospitals are recognizing that achieving Baby-Friendly designation indicates they are following a set of evidence-based practices that promote, protect and support breastfeeding. The Joint Commission, the organization that accredits and certifies U.S. hospitals, added exclusive breast milk feeding in the hospital as a new quality of care measure in the Perinatal Care Core Measure Set in 2010 (Joint Commission 2013).

Securing Baby-Friendly designation requires both traditional and non-traditional partnerships at the institutional level, from obstetric, pediatric and nursing professionals to the marketing, purchasing, IT, compliance and quality improvement departments. Marketing teams are engaged to promote the improved hospital experience associated with the Baby-Friendly environment as well as to set expectations for parents for upcoming hospital stays. Purchasing departments become involved due to the required shift from receiving free formula from companies to purchasing it. IT departments are engaged with requirement changes to MIS systems in order to comply with the required data collection associated with the Baby-Friendly designation. Compliance teams may become involved as some of the Baby-Friendly requirements are
well aligned with hospital directives around conflict of interest. Lastly, the quality improvement teams typically engage with the processes behind achievement of each of the ten Baby-Friendly steps. There is some interest in investigating Medicaid pay for performance initiatives related to the implementation of Baby-Friendly policies based on the evidence that maternity practices that facilitate successful breastfeeding positively impact the incidence of newborn readmission, costly infection, and morbidities later in childhood. Community-based health care providers and organizations are also tied into successful efforts to secure and support the Baby-Friendly designation, as prenatal breastfeeding education by physicians and post-discharge community-based breastfeeding support must be in place in order for a facility to achieve Baby-Friendly status.

Breastfeeding is considered to have many health benefits including obesity prevention; promoting, protecting and supporting breastfeeding is very much a focus among health care professionals, insurers, communities, government groups, employers, hospitals, and others, including but not limited to:

- The worldwide Baby-Friendly Hospital Initiative launched in 1991 by World Health Organization (WHO) and United Nations Children’s Fund (UNICEF) (WHO 2013)
- The CDC, The CDC Guide to Breastfeeding Interventions (Shealy 2005)
- National Initiative for Children’s Healthcare Quality (NICHQ), Best Fed Beginnings (NICHQ 2013)
- American Academy of Pediatrics (AAP 2012)
- Academy of Breastfeeding Medicine – Protocols (ABM 2007)
- WIC: Breastfeeding Peer Counseling Program (USDA 2013)
- US Surgeon General – Call to Action to Support Breastfeeding 2011 (DHHS 2011)
- Baby-Friendly USA (Baby-Friendly USA 2013)

The Patient Protection and Affordable Care Act (ACA) women's preventive services include "breastfeeding support, supplies, and counseling” without copayment (HRSA 2013). Employers have a responsibility to provide support to breastfeeding employees since studies show that employed breastfeeding women have lower breastfeeding initiation and shorter duration rates than those who are not employed while breastfeeding (DHHS 2011). On Mar. 23, 2010, the break time for nursing mothers requirement included in the ACA was signed into law. The law requires “employers to provide a nursing mother reasonable break time to express breast milk after the birth of her child.” The law also requires that employers provide “a place, other than a bathroom, that is shielded from view and free from intrusion from coworkers and the public, which may be used by an employee to express breast milk.” The duration of this requirement applies to breastfeeding employees up to the time the child is 12 months of age and applies to employers with 50 or more employees (DOL 2013).

Also under the ACA, women’s preventive services are covered by health plans without cost sharing. Included in these services are "comprehensive lactation support and counseling, by a trained provider during pregnancy and/or in the postpartum period, and costs for renting breastfeeding equipment” (HRSA 2013).

Another far-reaching program that supports breastfeeding women and families is the WIC program. The number of women, infants, and children receiving WIC benefits in 2011 was nearly nine million per month (USDA About WIC 2013). Since 1996, the USDA Food and Nutrition System has allocated a minimum expenditure for breastfeeding promotion and support activities equal to $21 multiplied by the number of pregnant and breastfeeding women in the WIC Program, based on the average of the last three months for which USDA has final data. State agencies must spend a specified amount of the total funding for breastfeeding promotion and support. Efforts to increase and support the number of women breastfeeding have also included enhanced food packages for women breastfeeding up to 12 months and the implementation of the Peer Counseling Program (USDA WIC Benefits and Services 2013).

Predict an individual’s health and wellness and/or that of their offspring
Breastfeeding falls under the “timing” component of the MCH Life Course Model as it is a behavior that can affect one’s health trajectory during a critical or sensitive period. Research studies have documented known risks of not breastfeeding for an individual child including an increase in the incidence of several diseases and conditions, including ear infections, gastrointestinal infection/diarrhea, respiratory infection, necrotizing enterocolitis, SIDS, allergic disease, asthma, celiac disease, obesity, diabetes, and childhood leukemia and lymphoma (lp 2007, DHHS 2011). As children progress into adolescence, they are more likely to be overweight or obese, develop type II diabetes, and experience other chronic
Breastfeeding also impacts women’s health. Women who do not breastfeed are at higher risk for breast cancer, ovarian cancer, cardiovascular diseases and type II diabetes. In women with a cumulative duration of breastfeeding more than 12 months there is a 28 percent decrease in the incidence of breast cancer and ovarian cancer and a four percent to 12 percent decreased risk of type II diabetes for each year of breastfeeding (AAP 2012). The longitudinal Nurses’ Health Study noted an inverse relationship between the cumulative lifetime duration of breastfeeding and the development of rheumatoid arthritis. If cumulative duration of breastfeeding exceeded 12 months, the relative risk of rheumatoid arthritis was 0.8 (95 percent CI: 0.8–1.0), and if it was longer than 24 months, the relative risk of rheumatoid arthritis was 0.5 (95 percent CI: 0.3–0.8) (Karlson, 2004). Further, women who breastfeed experience a more rapid return to pre-pregnancy weight and a decreased risk of bleeding postpartum.

The table below from the 2011 Surgeon General’s call to action highlights the impact of not breastfeeding on infant and maternal morbidity:

Additionally, research has shown that the rate of abuse and neglect was significantly increased for mothers who did not breastfeed as opposed to those who did (OR: 2.6; 95 percent CI: 1.7–3.9) (Strathearn 2009). Data from the Women’s Health Initiative has demonstrated an association between cumulative lactation experience and the incidence of adult cardiovascular diseases (AAP, 2012). Women with a cumulative lactation history of 12 to 23 months had a significant reduction in hypertension (OR: 0.89; 95 percent CI: 0.84–0.93), hyperlipidemia (OR: 0.81; 95 percent CI: 0.76–0.87), cardiovascular diseases (OR: 0.90; 95 percent CI: 0.85–0.96), and diabetes (OR: 0.74; 95 percent CI: 0.65–0.84) (AAP, 2012). In conclusion, breastfeeding has implications for the health of both the mother and the child across their lifespan. Baby-Friendly hospitals improve breastfeeding rates, and therefore the proportion of births that occur at Baby-Friendly hospitals is an important life course indicator.

### Data Criteria

#### Data availability

Data on the percent of live births occurring at Baby-Friendly facilities are available each August from CDC for the United States and by state for all 50 states and the District of Columbia.
The numerator, the number of births occurring in Baby-Friendly facilities (which through Baby-Friendly designation means they provide lactation support services), is calculated and published by Baby-Friendly USA (Baby-Friendly USA 2013). Data may also be obtained for the numerator from state vital records birth certificate data and assessed against the Baby-Friendly Hospital Directory at www.babyfriendlyusa.org, which is updated more regularly (as hospitals achieve designation, they are placed in the directory). The denominator, number of live births in all birthing facilities, can be obtained from the National Vital Statistics report (Hamilton 2012).

Baby-Friendly USA calculates the percent of births occurring at a Baby-Friendly facility. The assumption is that CDC will be able to access the state-level data to put on their annual Breastfeeding Report Card, which will be readily available to the public. The 2013 Breastfeeding Report Card reported data on live births from 2011, indicating a two year lag from this data source. Accessing this data source does not require special permission.

**Data quality**
Data quality appears to be good. The list of currently designated hospitals on the Baby-Friendly Hospital Directory is updated regularly, usually once a hospital is awarded Baby-Friendly status according to Baby-Friendly USA staff. Hospitals cannot be mischaracterized given the rigor required to be designated as a Baby Friendly hospital. Although there is no set schedule for updates or awards, the list of designated hospitals is updated in a timely enough manner to calculate percentages based on state vital records and the National Vital Statistics data. Data are reported consistently across states.

Data in the National Vital Statistics report is based on 100 percent of the births from the state vital statistics offices reported on an annual basis. In a 2007 study, Reichman and Schwartz-Soicher reported that birth certificates are a valuable resource for tracking and analyzing infant health at the state and national levels. Although a comprehensive validation study of birth certificate data has never been conducted at the national level, researchers have conducted a number of validation studies from different states and years that indicate that birth certificates have highly accurate reporting of birth weight, demographic characteristics, and most methods of delivery (Reichman and Schwartz-Soicher, 2007).

**Simplicity of indicator**
There is a low level of complexity in calculating this indicator since it is a basic percentage calculation. The numerator is a number that is commonly recorded in all birthing facilities and reported to state vital statistics. Baby-Friendly USA is accurate in identifying those hospitals that are designated and obtaining annual statistics.

Although the steps in achieving Baby-Friendly status can be complicated, the notion of certification for hospitals that provide an optimal level of care for lactation is accessible and conceptually simple to understand. The Baby-Friendly designation is designed to recognize facilities that offer an optimal level of care for lactation based on the WHO/UNICEF Ten Steps to Successful Breastfeeding for Hospitals. Baby-Friendly USA maintains the guidelines and the minimum standard criteria on their website. The guidelines and evaluation criteria for hospital/birthing center implementation include ten steps predicated on eight principles (Baby-Friendly USA, 2013).

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Life Course Indicator: Breastfeeding Support - Baby Friendly Hospitals (LC-4)


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Life Course Indicator: Fluoridation

The Life Course Metrics Project

As MCH programs begin to develop new programming guided by a life course framework, measures are needed to determine the success of their approaches. In response to the need for standardized metrics for the life course approach, AMCHP launched a project designed to identify and promote a set of indicators that can be used to measure progress using the life course approach to improve maternal and child health. This project was funded with support from the W.K. Kellogg Foundation.

Using an RFA process, AMCHP selected seven state teams, Florida, Iowa, Louisiana, Massachusetts, Michigan, Nebraska and North Carolina, to propose, screen, select and develop potential life course indicators across four domains: Capacity, Outcomes, Services, and Risk. The first round of indicators, proposed both by the teams and members of the public included 413 indicators for consideration. The teams distilled the 413 proposed indicators down to 104 indicators that were written up according to three data and five life course criteria for final selection.

In June of 2013, state teams selected 59 indicators for the final set. The indicators were put out for public comment in July 2013, and the final set was released in the Fall of 2013.

Basic Indicator Information

Name of indicator: Fluoridation (LC-05)

Brief description: Proportion of population served by community water systems that received optimally fluoridated water, defined as a fluoride concentration of 0.7-1.2 ppm, depending on the average maximum daily air temperature in the area.

Indicator category: Community Health Policy

Indicator domain: Service/Capacity

Numerator: Population on community water systems that received optimally fluoridated drinking water in a calendar year.

Denominator: Population on community water systems in a calendar year

Potential modifiers: Respective community water supply regulators

Data source: Water Fluoridation Reporting System (WFRS)

Notes on calculation: WFRS is an authenticated (password-protected) application requiring approved users to enter a passcode to access the application. Employees of state oral health and drinking water programs can be granted permission to use the WFRS database. For those who do not have access to WFRS, some states share fluoridation data from WFRS and the fluoridation status of their state via other Centers for Disease Control and Prevention (CDC) data applications that have a public access component. There are three additional sources of state-level data, including CDC’s My Water’s Fluoride data system, Oral Health Maps and reports from the National Oral Health Surveillance System. More information can be found under the Data Availability section.

Similar measures in other indicator sets: HP 2020 focus area OH-13; Chronic Disease Indicator; National Oral Health Surveillance System Indicator
Life Course Criteria

Introduction
The CDC has recognized water fluoridation as one of ten great public health achievements of the 20th century (CDC 1999). Optimally fluoridating a community’s water supply has been shown to effectively reduce dental caries, a common oral disease that disproportionately affects racial minorities and low-income groups. The importance of water fluoridation as an intervention to prevent oral health conditions lies in both its proven and historical effectiveness and its ability to reach all individuals in a population, including the most vulnerable populations. Through these avenues, increasing the proportion of the population served by an optimally fluoridated water supply has the ability to improve health disparities, public health, and individual health throughout the life course.

Implications for equity
Dental caries is the most common chronic disease for children, affecting 25 percent of children ages 6-11 years and 59 percent of children ages 12-19 years (CDC 2013). Children from lower income families and racial and ethnic minority groups are disproportionately affected by oral disease. Hispanic and non-Hispanic black children have a significantly higher prevalence of untreated dental caries than non-Hispanic white children. Children ages 3-5 years and 6-9 years living below 100 percent of the federal poverty level have higher rates of untreated dental caries than children of the same age group living above 100 percent of the federal poverty level (Dye 2012). Disparities persist into adulthood, where tooth retention varies by race, ethnicity, and poverty level (Dye 2012). Effective prevention measures, such as community water fluoridation and dental sealant programs, exist to avoid these dental problems. However, dental sealant interventions may not be reaching the most vulnerable populations, as prevalence of dental sealants also varies by poverty status and race (Dye 2012). Community water fluoridation helps to decrease dental disease disparities by providing prevention benefits to all residents of a community regardless of race, sex, age or socio-economic status. Riley et al. (1999) found in an ecologic study done in England that water fluoridation reduced dental caries more in materially deprived areas than in affluent areas and concluded that the introduction of water fluoridation could substantially reduce inequalities in dental health. In 2010, 73 percent of the United States had access to an optimally fluoridated water supply. Access to fluoridated water has a wide, varied range across the United States and is dependent on state and community residence (CDC 2012).

Public health impact
Frieden (2010) describes the impact of different public health interventions using a five-tiered pyramid. Water fluoridation comes under the second tier, which includes interventions that change the environmental context to make individuals’ default decisions healthy. An important characteristic of this group is that individuals would have to go to significant effort not to benefit from the intervention. In the case of water fluoridation, there is a reduction in tooth decay, which improves individuals’ health and which is difficult to avoid because it is part of the public drinking water supply. It also provides economic benefits by reducing health care spending and productivity losses. It has been estimated that about every $1 invested in community water fluoridation saves approximately $38 in averted costs (CDC 2013). Savings are generated through avoidance of dental expenditures such as complex and expensive restorative and emergency dental treatment.

Water fluoridation is of the ten top achievements in public health according to the CDC (1999). CDC (1999) reports that studies in the mid-eighties showed mean DMFS (decayed, missing, and filled surfaces of permanent teeth) scores of children in fluoridated communities were 18 percent less than those in non-fluoridated communities, and in adolescents, there was a mean reduction of 26 percent. Armfield (2010) compared the caries prevalence in two areas of Australia, one with negligible fluoride and one with optimal fluoride. After controlling for child age, place of residence and socioeconomic status, he found that permanent caries experience was 28.7 percent higher in deciduous teeth and 31.6 percent higher in permanent teeth in non-fluoridated communities compared with fluoridated communities. Due to the diffusion of fluoridated water through bottling and processing of food and beverages using optimally fluoridated water, there has been a decline of caries prevalence even in non-fluoridated communities. Given these findings, an increase in the proportion of community water systems that receive optimally fluoridated drinking water could not only result in a decrease in tooth decay and improved oral health, but also offer significant cost savings in health expenditures to the community.

Leverage or realign resources
Maupone and colleagues (2007) compared dental treatment expenses and costs of patients belonging to an HMO in areas with and without water fluoridation. They found that community water fluoridation was associated with lower restorative costs in patients less than 18 years old and in those greater than 58 years of age. Water fluoridation is a cost effective intervention, as the cost of community water fluoridation is less than restorative dental care. Griffin and colleagues looked at the annual cost per person of community water fluoridation and compared to the cost of averted dental disease and loss of productivity and found significant cost savings. In light of high health care costs, such findings could make water fluoridation more attractive to public and private payers of dental health care costs, and offers a simple public health message for advocacy by payers and health professionals.

The American Dental Association (ADA) has supported fluoridation of community water supplies for the purpose of preventing tooth decay since 1950. In combination with the Association of State and Territorial Dental Directors (ASTDD) and the CDC, the ADA recognizes communities, states, and organizations that have worked to implement or maintain water fluoridation with merit awards. The ADA website, ADA.org, contains information on recent fluoridation issues, evidence-based fluoridation recommendations, and a list of other water fluoridation internet resources.

Implementing water supply fluoridation programs may require decisions on multiple state or local levels (Office of Surgeon General 2000). City councils and state and local governments typically need to be engaged when attempting to implement water supply fluoridation. Information regarding current federal and state policies regarding fluoridation can be accessed using the Fluoride Legislative User Information Database (FLUID). The database contains information on all 50 states, District of Columbia, Puerto Rico, and the U.S. Virgin Islands (FLUID 2013) and is accessible at fluidlaw.org.

**Predict an individual’s health and wellness and/or that of their offspring**

Although water fluoridation is a community-level intervention, it has implications for individual health. Individuals without access to fluoridated water are more likely to have dental caries, loss of productivity, and costs associated with dental disease. The prevention of dental caries is linked to improved general health, as the pain and infections caused by untreated tooth decay can eventually lead to problems with eating, nutrition, sleeping, social interactions, speaking and learning. Poor oral health may have implications for other health outcomes including cardiovascular disease and preterm birth, which also impact individual health throughout the life course (Dasanayake et al., 2008; Montebugnoli et al., 2004; and Pitiphat et al., 2008). Increasing the proportion of the population drinking from a fluoridated water supply should decrease the number of individuals experiencing dental caries and the related oral and general health issues.

**Data Criteria**

**Data availability**

The Water Fluoridation Reporting System (WFRS) ([https://nccd.cdc.gov/DOH_WFRS/default/Login.aspx](https://nccd.cdc.gov/DOH_WFRS/default/Login.aspx)) is an online tool that helps states manage the quality of their water fluoridation programs. The WFRS was developed by CDC in partnership with the Association of State and Territorial Dental Directors (ASTDD). The most current data available is from 2010. The tool is only accessible by state water fluoridation program officials. WFRS information is the basis for national surveillance reports that describe the percentage of the U.S. population on community water systems that receive optimally fluoridated drinking water. Optimally fluoridated water is defined as a fluoride concentration of 0.7-1.2 ppm, depending on the average maximum daily air temperature in the area. The WFRS website provides the total population served by public water systems, the total population served by fluoridated water systems and the proportion of the population of people on public water systems that receive fluoridated water.

WFRS is an authenticated (password-protected) application requiring approved users to enter a passcode to access the application. Employees of state oral health and drinking water programs can be granted permission to use the WFRS database. For those who do not have access to WFRS, some states share fluoridation data from WFRS and the fluoridation status of their state via other CDC data applications that have a public access component. Although the WFRS database contains information for all states and the District of Columbia, only 36 states have allowed access to their water fluoridation information on the public website.

The CDC’s My Water’s Fluoride data system allows public access to participating states’ basic community water system information, including the number of people served by the system and the fluoride level. My Water’s Fluoride data system is accessible here: [http://apps.nccd.cdc.gov/MWF/index.asp](http://apps.nccd.cdc.gov/MWF/index.asp).
Water fluoridation information from WFRS is also displayed in Oral Health Maps, a Web-based Geographic Information System interactive-mapping application that shows the percentage of people receiving fluoridated water at the state and county levels. Oral Health Maps can be accessed here: http://apps.nccd.cdc.gov/gisdoh/default.aspx.

CDC also prepares periodic reports of populations served by fluoridated water systems by state and for the United States. These reports are published in the National Oral Health Surveillance System (NOHSS) and provide the percentage of people served by public water systems who received fluoridated water on the national level and state level. Data is available for all states, and the most recent report contains data from 2006. These reports can be accessed here: http://www.cdc.gov/nohss/FSMain.htm

WFRS data was obtained by questionnaires sent to the directors of dental programs in all 50 states, the District of Columbia and to U.S. associated jurisdictions including American Samoa, Guam, the Commonwealth of Northern Mariana Islands, the Commonwealth of Puerto Rico, the Federated States of Micronesia (2002 only), the Republic of Palau and the U.S. Virgin Islands.

Data quality
The water fluoridation reporting system (WFRS), started in 2000, is built on an existing database maintained by the Drinking Water Program of the Environmental Protection Agency. States update their own information directly and regularly (some as frequently as daily and as seldom as yearly). The Division of Oral Health (DOH) of the CDC completes ongoing and annual assessments to enhance the quality of data in the system.

The methodology behind the calculation of the percentage of a state’s population that receives public water supplies and also receives fluoride is discussed in a CDC publication which can be accessed at http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5727a1.htm. In March 2007, CDC asked state dental directors and drinking water administrators to validate their state data reported via WFRS for 2006. Estimates of the population served by community water systems were based on the number of households served and the number of persons in each household. Some states supplemented population data in WFRS with population data from the EPA Safe Drinking Water Information System (SDWIS), which can differ slightly from WFRS.

The percentage of the population served by community water systems who received optimally fluoridated water was calculated by dividing the population served by community water systems with optimal fluoride levels by the total population served by community water systems. For eight states and DC, the reported 2006 total community water system population estimates exceeded mid-year intercensal state population estimates due to the application of a standard persons-per-household factor to the number of households served. For these eight states and DC, state community water system population estimates were set equal to the intercensal state population estimates, and estimates of the population receiving optimally fluoridated water were reduced by a factor equal to the state's intercensal population estimate divided by the initially reported total state community water system population. National community water system population estimates were calculated by adding the state community water system population estimates after this reduction.

Simplicity of indicator
The proportion of the population served by community water systems that received optimally fluoridated water is simple to calculate using the CDC WFRS data. The estimates for each state’s population on community water systems and population on optimally fluoridated community water system drinking water are available on the CDC WFRS website. The indicator is simple to explain.

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Life Course Indicator: Concentrated Disadvantage

Basic Indicator Information

Name of indicator: Concentrated Disadvantage (LC-6)

Brief description: Proportion of households located in census tracts with a high level of concentrated disadvantage, calculated using five census variables

Indicator category: Community Well-being

Indicator domain: Risk/Outcome

Numerator: Number of households with children less than 18 years of age located in census tracts of high concentrated disadvantage

Denominator: Total number of households with children less than 18 years of age

Potential modifiers: age, race, ethnicity, gender, geographic location

Data source: American Community Survey (ACS)

Notes on calculation: Concentrated disadvantage is calculated from five Census variables: 1) Percent of individuals below the poverty line, 2) Percent of individuals on public assistance, 3) Percent female-headed households, 4) Percent unemployed, 5) Percent less than age 18. The percentages of each individual indicator are z-score transformed. A Z-score transformation is achieved by subtracting the mean of the distribution from the variable value and dividing the difference by the standard deviation of the distribution. $Z = (score - mean)/standard\ deviation$. The resulting value should be averaged into an overall index of concentrated disadvantage or deprivation (6, 9).

Once the index is calculated for all census tracts, the analyst will need to apply a cutoff to determine which census tracts are considered to have “high concentrated disadvantage” and then calculate the number of households in that tract. While there are many options presented in the literature for how to determine what constitutes “high” disadvantage or deprivation, we present a methodology here to start with and that can be used to perform

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As MCH programs begin to develop new programming guided by a life course framework, measures are needed to determine the success of their approaches. In response to the need for standardized metrics for the life course approach, AMCHP launched a project designed to identify and promote a set of indicators that can be used to measure progress using the life course approach to improve maternal and child health. This project was funded with support from the W.K. Kellogg Foundation.

Using an RFA process, AMCHP selected seven state teams, Florida, Iowa, Louisiana, Massachusetts, Michigan, Nebraska and North Carolina, to propose, screen, select and develop potential life course indicators across four domains: Capacity, Outcomes, Services, and Risk. The first round of indicators, proposed both by the teams and members of the public included 413 indicators for consideration. The teams distilled the 413 proposed indicators down to 104 indicators that were written up according to three data and five life course criteria for final selection.

In June of 2013, state teams selected 59 indicators for the final set. The indicators were put out for public comment in July 2013, and the final set was released in the Fall of 2013.
comparisons across jurisdictions. To that end, areas of “high concentrated disadvantage” are defined as those census tracts whose averaged z-scores fall within the 75th percentile of values. The indicator's purpose or use determines 1) the desired level of geography for establishing the 75th percentile of values and 2) the geographic unit for the numerator and denominator. If the purpose is to compare this indicator across states to identify states with higher and lower values, the 75th percentile of the averaged z-score for census tracts needs to be established at a national level. For a comparison across counties, the percentile could also be established at a state level. A simple comparison of a jurisdiction or jurisdictions over time is more complicated because the indicator needs to be able to change in a meaningful fashion over time. We recommend 1) the absolute value of the averaged z-score of the 75th percentile for the first time period be held constant over time, and 2) the absolute values of the statistical parameters (means and standard deviations) used to calculate the z-scores for each of the components for the first time period also be held constant. The indicator itself is simply the number of households with children living in a census tract above the 75 percentile in that jurisdiction divided by the total number of households in the same jurisdiction.

This indicator relies on the American Community Survey (ACS) to produce census-tract level estimates. The ACS provides yearly estimates for all states, as well as all cities, counties, metropolitan areas, and population groups of 65,000 people or more. For smaller areas, such as census tracts, multiple survey years are combined to obtain reliable estimates: three survey years in areas with 20,000 to 65,000 people, and five survey years in areas with fewer than 20,000 people.

Similar measures in other indicator sets: None

Life Course Criteria

Introduction

Concentrated disadvantage, poverty, and socioeconomic position are all very similar markers, but concentrated disadvantage may be the most relevant indicator for life course. Poverty or socioeconomic position, which includes income, education, and employment, by themselves do not capture the synergistic effects of economic and social factors that cluster geographically and create truly disadvantaged neighborhoods (11).

The components of concentrated disadvantage include poverty, use of public assistance, female-headed households, unemployment, and density of children. Each of these factors was shown by Sampson (1997) to be highly associated with the others and together constitute a proxy of a community at an economic disadvantage (19). In other words, single-parent households and those with children are differentially found in neighborhoods with high concentrations of poverty, unemployment, and use of public assistance (19). Communities with concentrated disadvantage have less mutual trust and willingness among community members to intervene for the common good, which is sometimes referred to as collective efficacy or social capital. Since collective efficacy is a critical way that neighborhoods inhibit the perpetration of violence, individuals, particularly children, who live and grow in disadvantaged neighborhoods are therefore more likely to experience violence just because of where they live.

Implications for equity

The relationship between concentrated disadvantage and various forms of equity has been long known, particularly among children. African American children who lived in severely disadvantaged communities had decreased verbal ability (skill with understanding and using words and language) equivalent to missing a year of schooling when compared with peers who live in less disadvantaged neighborhoods (2). Concentrated poverty also contributes to increased rates of high school drop-out, teen pregnancy, and adolescent delinquency (3,4). Finch (2010) identifies concentrated disadvantage as being associated with decreased overall health (8). More specifically, adverse health outcomes relating to childbearing such as infant mortality rate, low birth weight, and child maltreatment increase among communities with concentrated disadvantage (3,4). Mental health has similarly been linked to concentrated disadvantage, as girls who grew up in communities with high levels of poverty have decreased mental health and increased risk-taking behaviors (10). High poverty neighborhoods are also more likely to lack affordable access to healthy foods and spaces for recreation, resulting in less social capital.

Public health impact
While the association between health and wealth is well established, the direction between the two factors is less so. Literature suggests that the relationship is bidirectional, with health affecting a person’s or community’s wealth and their wealth also affecting their overall health. It is safe to say, however, that there is an inverse relationship, where reduction of poverty is associated with an increase in health. In addition, as concentrated disadvantage has been shown to be related to reduced educational attainment, future earnings potential is also affected, which continues to deleteriously affect health in these communities.

A positive and sustained change in this indicator would be a decrease in the number of census tracts that meet the initial definition of high concentrated disadvantage and therefore a lower proportion of households exposed to concentrated disadvantage. A positive change in this indicator should result in communities that have improved social capital or collective efficacy. Improved social capital would mean there are more neighborhood-level supports for families, resulting in more opportunities to participate fully as individuals within their communities and ultimately, improved health status.

**Leverage or realign resources**

Bollens (1997) identifies concentrated disadvantage as a result of institutional discrimination and individual prejudice, arguing that segregation concentrates poverty, particularly among metropolitan inner-cities (1). Quillian (2012) identifies three different types of segregation that affect concentrated disadvantage; racial segregation, poverty-status segregation within race, and segregation from high- and middle-income members of other racial groups (5).

In addressing concentrated poverty, Bollens (1997) references the importance of public policy-makers, regional and city planners, and lawmakers at various levels (particularly at the regional level). Concentrated poverty can be addressed in two primary ways: via enrichment, or in-place, and integration, or mobility interventions. Enrichment consists largely of improvement of living and economic conditions through community development and revitalization programs. Integration interventions, conversely, refer to moving concentrations of poor people to other areas, often suburbs, with better economic and social structures. The mobility method of intervention is effective to some degree; moving an individual out of a high-poverty area to a low poverty area does result in some improved outcomes, such as improved mental health, indicating that the effect of poverty on an individual is not necessarily permanent (17). However, as a strategy to build healthy communities, enrichment through place-based initiatives is preferable to the removal of resources and families from an already disadvantaged area and perpetuating the concentration of disadvantage. The Best Babies Zone Initiative ([http://www.bestbabieszone.org/](http://www.bestbabieszone.org/)) is a place-based multi-sector approach to reducing infant mortality and racial disparities in birth outcomes that works through mobilizing communities to address the social determinants of health in four critical sectors: economics, education, health, and community. The approach aims to strengthen environments that support healthier outcomes and works within a very small zone, sometimes just a few blocks of a neighborhood, where change is needed and resources can be aligned to have a measureable impact.

Within a community, concentrated disadvantage can indicate reduced access to health care, social services, resources, skills, work, education, technology, nutrition, and safety. Addressing these issues of access would cross into every other sector of life. Starting at the most basic level, education is one of the strongest predictors of access to resources for good health and has to be addressed early in the life course. There are many policies that could improve access to better nutrition, physical activity, safety, resources, health care, technology, health care, and social services. Changing the experience of concentrated disadvantage through a strategy like enrichment requires a multi-pronged approach in where activities to improve health work in concert with activities to stimulate the economy, improve educational opportunity, and access to affordable housing.

**Predict an individual’s health and wellness and/or that of their offspring**

The driving force in concentrated disadvantage revolves around experiences of concentrated poverty. Particularly when experienced early in life, poverty is a solid indicator of an individual’s health. In addition, exposure during adolescence raises an individual’s risk for teen pregnancy, which in turn raises the risk for adverse birth outcomes. It is clear that concentrated disadvantage affects an individual’s future mortality and affects health outcomes for their offspring as well. It is clear that experiencing poverty, particularly during important and transitive phases in the life course, will have an adverse impact on future health. This impact likely exists even if the effect is minimized by later life course events or removing the individual from a highly disadvantaged community.

**Data Criteria**

*Life Course Indicator: Concentrated Disadvantage (LC-6)*
**Data availability**

ACS is an ongoing nationwide survey that collects and provides annually data on demographic, social, economic and housing in the United States. The survey is administered by the U.S. Census Bureau, and it replaced the decennial census long form starting in 2010. The ACS is sampled each year, resulting in three million addresses selected and approximately two million final interviews. However, the sample drawn is substantially smaller than the one used for the previous Census long form; as a result, data must be pooled across years in order to provide reliable estimates for some geographic units. ACS data are released the year following the year in which they were collected, making the estimates extremely timely.

**Data quality**

Since the ACS is a sampled survey, there are questions about response rates and the statistical precision of the estimates. The Census Bureau takes steps to minimize the error associated with non-sampling error (reporting, coding, sampling frame, survey questionnaires, non-response and interviewer bias) through the use of trained interviewers and careful review of all questionnaire design, sampling, and analytic steps. In addition, the Census Bureau began releasing margin of error data for ACS estimates starting in 2006; these estimates allow data users to calculate 90 percent confidence limits for all point estimates released from the ACS.

To account for the complex sampling design, the ACS employs an equally complex weighting scheme. The weighting process is well-documented in the survey methodology handbook, accessible on the web. Response rates for the ACS are calculated for housing units and group quarters (person). From 2000 to 2011, the housing unit response rates were high and ranged from a low of 93.1 percent in 2004 to a high of 98 percent in 2009. Between 2006 and 2011, the group quarter response rate were even higher and ranged from a low of 97.4 percent in 2006 to a high of 98 percent in 2008 and 2009.

The data quality is excellent. Sensitivity, specificity, predictive value positive and reliability will vary depending on the outcome.

**Simplicity of indicator**

No linkages are required to calculate this indicator; all of the core elements are publicly available from the Census data. This indicator is somewhat complex to calculate because once the percentages are obtained for each of the five elements, they must be z-score transformed by the analyst. This indicator is designed to be calculated using household data at the county level and can be aggregated up to the state level, which adds analytic steps and levels of complexity to the indicator.

Perhaps the most complex aspect of concentrated disadvantage is the interpretation. The indicator scale, as originally conceptualized by Sampson and colleagues (1997) included a sixth element, percentage of black residents. During the public comment period, concerns were raised that this element was mismatched with the other five, which are primarily economic indicators. In communications with Sampson about this issue, he agreed that there is nothing inherent in racial composition that is disadvantageous. The inclusion of percent black was designed as a proxy to get at the confounding of segregation and poverty in the United States, which he noted is socially produced and maintained (Massey and Denton). Sampson’s work originated in Chicago neighborhoods, and the concentrated disadvantage scale was an attempt to quantify the exposure of segregated African American neighborhoods to poverty and other forms of disadvantage (Sampson 2013 personal communication). Ultimately, the sixth element was excluded, with Sampson’s guidance that careful interpretation is necessary. It may be useful to compare concentrated disadvantage with another life course indicator, the dissimilarity index, which is a measure of racial residential segregation.

**References**


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Life Course Indicator: Homelessness

Basic Indicator Information

Name of indicator: Homelessness (LC-07A/B)

Brief description:
 a. Prevalence of homelessness among individuals
 b. Prevalence of homelessness among families.

Indicator category: Community Well-being

Indicator domain: Risk/Outcome

Numerator:
 a. Number of individuals experiencing homelessness in a given county
 b. Number of families experiencing homelessness in a given county

Denominator:
 a. Total county population
 b. Total # families at county level

Potential modifiers: Race, ethnicity, sex, age, geographic location

Data source: U.S. Department of Housing and Urban Development, Annual Homeless Assessment Report to Congress

Notes on calculation: The Annual Homeless Assessment Report (AHAR) to Congress can be accessed here: hudhdx.info/PublicReports.aspx. Families are defined as any household that includes at least one adult over 18 years old and one child who is younger than 18 years old. All other persons, including those in multi-person households consisting of only adults or only children, are reported as single individuals. At the state level, calculate by county, or roll into a summary indicator that is the rate of homelessness per population in the state. Alternatively, the analyst could choose a cutoff value for the rate and at the state level, report the percent of counties with at least X percent of individuals (or families) that are experiencing homelessness.

Similar measures in other indicator sets: None
Life Course Criteria

Introduction
According to the 2013 Annual Homeless Assessment Report to Congress, on a single night in January 2013, 610,042 people were experiencing homelessness of which 394,698 were in sheltered locations and 213,344 were in unsheltered locations such as under bridges or in cars (18). Homelessness affects both individuals and families. During the point-in-time count in January of 2013, there were 70,960 homeless families accounting for 36 percent of homeless people (18). Homelessness can be a short-term, transitional or episodic problem for some or a long-term, chronic issue for others. Of the 610,042 people who were homeless on a single night in January 2013, almost 18 percent (109,132) were chronically homeless, which is defined as homeless for more than one year or four or more episodes of homelessness over a three-year span (18).

A number of factors contribute to risk of homelessness including extreme poverty, lack of affordable housing, single parenthood, domestic violence, and lack of social support (30). Specific life events and potentially critical periods have a great impact on an individual’s risk for homelessness. Adverse childhood experiences (ACEs), substance abuse, and mental illness all have strong associations with homelessness (10,11). ACEs and risk factors for homelessness appear to be cumulative; increasing numbers of risk factors translates to greater risk of becoming homeless and increasing challenges to successfully maintain stable housing (31, 32). There are well-established health risks associated with homelessness and an excess of mortality among the homeless population compared to the non-homeless population (28). Children who experience homelessness have seriously compromised life trajectories and are at a disadvantage compared to both the general U.S. population and poor children (29).

Implications for equity
Established factors place certain populations at risk for homelessness more so than others. ACEs are strongly associated with homelessness in adulthood and adolescence (10, 11). Exposure to family dysfunction, early socioeconomic disadvantage, academic underachievement, and separation from caregiver have all been independently associated with homelessness later in life (11). In addition to early life events, current socioeconomic issues, mental illness, and substance abuse also have been independently associated with an increased risk of homelessness (11). Conversely, having adequate family support, good coping skills, recent employment, and an absence of an arrest history or substance abuse treatment history were found to be associated with a shorter duration of homelessness (16). People experiencing chronic homelessness have a life course trajectory that has been altered by an accumulation of risk factors without the balance of supportive factors to allow them to find and maintain stable housing (10). Incarceration is a particularly important factor in chronic or recurrent homelessness as it can lead to initial loss of housing and criminal history can create ineligibility for public housing (17). A study of recurrent and chronic homelessness found incarceration to be a characteristic present in 63.6 percent of people with recurrent homeless episodes and 75.8 percent of people in a state of chronic homelessness (17). Drug and alcohol use disorders are also associated with recurrent homelessness when linked with a history of arrest and antisocial personality disorder (17). These findings are indicative of the multiple, complex factors that contribute to chronic homelessness (17).

According to the 2013 Annual Homeless Assessment Report to Congress (AHAR), nearly 25 percent of homeless people are children under the age of 18, while nearly two-thirds of homeless people were adults over the age of 25 (18). Families who are homeless are more likely to be headed by young females while individuals who are homeless are more likely to be middle to late middle aged men (19). People who experience homelessness as individuals instead of as a family are more likely to be on the street as opposed to a shelter and more likely to have disabling conditions (19). Homelessness also has geographic trends with the majority of homelessness concentrated in urban cities (19). More than half of the homeless population is concentrated in five states (California 22 percent, New York 13 percent, Florida 8 percent, Texas 5 percent, and Massachusetts 3 percent) while 24 other states combined accounted for less than 11 percent of U.S. homelessness (18).

Homeless populations tend to be spatially clustered. In a study comparing pre-homeless environments to homeless environments, the investigators found that after becoming homeless, people tend to cluster in areas of higher poverty, unemployment, higher rent to income ratios, and lower median income compared to their locations prior to becoming homeless (7). This likely occurs, at least in part, due to the fact that the majority of shelters and homeless services are
located in these areas. Still, the spatial clustering of homeless populations in areas of high poverty could provide additional barriers to finding stable housing and employment (7).

**Public health impact**

Much of the research on the factors that distinguish the homeless population focuses on factors that lead to and cause long-term homelessness, such as mental health and substance abuse. Decreasing homelessness, therefore, may not necessarily impact substance use though it is possible that, decreasing substance use could decrease homelessness. There are several interventions to address homelessness that measure public health outcomes. One systematic review of interventions to improve the health of the homeless found that case management, particularly when linked with other services, led to a decrease in the number of hospitalizations for psychiatric disorders and an increase in the amount of outpatient contact for those in the intervention group (8). Case management was also generally found to be successful in decreasing substance use (8). The review also found that monetary incentives increased medication adherence of homeless people with latent tuberculosis infections (8). The interventions studied were heterogeneous, however, the majority focused on case management and coordinating homeless services (8). Presumably some of these participants were helped to find stable housing, however to better understand the impact of homelessness on health outcomes, studies that provided housing to a randomized group of participants would provide stronger evidence.

A systematic review by Fitzpatrick-Lewis and colleagues found that homeless people with substance use disorders or concurrent disorders who were provided housing reported a decrease in substance use, fewer relapses, and less utilization of health care resources (15). They also found interventions that provided abstinent dependent housing were more effective than non-abstinent dependent housing or no housing at supporting housing status, substance abstinence, and better psychiatric outcomes (15). It should be noted that in both systematic reviews, the highest quality studies rated only “fair to good.” These studies are often difficult to implement and need more evidence-based examples.

Homelessness and incarceration have a direct relationship in that incarceration is a risk factor for homelessness but homelessness is also a risk factor for incarceration (20). People who are homeless have an increased likelihood for incarceration due to property crimes and non-violent crimes related to untreated mental illness (20, 28). In the United States, 15.3 percent of the adult population in jails was homeless within the year prior to their incarceration, which is 7.5 to 11.3 times the estimate of homelessness among the general U.S. population (20).

The “hunger-obesity paradox” describes concurrent hunger and obesity in an individual. The highest rates of obesity currently exist in people of low-income and socioeconomic status (21). This trend continues in the homeless population where a study comparing a homeless population to the National Health and Nutrition Examination Survey (NHANES) data found homeless adult obesity prevalence to be as high as 30 percent and homeless women to be more likely to be obese than non-homeless women (21). Homelessness may contribute to the U.S. obesity epidemic through homeless adults choosing cheap, energy-dense, low-nutrient foods in order to avoid hunger with limited resources or physiological changes occurring to help the body conserve energy when diets are not consistently adequate (21).

A challenging aspect to understanding homelessness is understanding and quantifying the effects of providing stable housing for the homeless population. Two systematic reviews of randomized control trial interventions in this population provide some evidence that decreasing homelessness has positive health outcomes with respect to mental illness management and substance abuse (8,15). These interventions are difficult and expensive to implement and because the homeless population is so heterogeneous, the same intervention is not guaranteed to work from one population to the next (8,15).

**Leverage or realign resources**

Affordable housing is a crucial step to decreasing homelessness. The Department of Housing and Urban Development (HUD) as well as state and local governing bodies are logical partners for establishing access to housing among homeless populations. A number of programs are already in existence including subsidized housing and a housing voucher program. HUD provides funding opportunities to nonprofits and State and local governments to create quick re-housing programs for homeless individuals and families through the Continuum of Care (CoC) Program (22). CoC planning committees at the local level employ a community-based approach to re-housing homeless populations and take the specific needs of local homeless populations into account (22). Although these programs are a step in the right direction, a survey of 27 major cities found the number one cause of homelessness was still lack of affordable housing.
The extent of homelessness in the United States indicates the need for affordable housing program expansion. Education, counseling, life skills training, and case management are all additional program areas that could help to reduce homelessness (27).

In addition to addressing affordable housing, other causes of homelessness must be addressed to prevent the reoccurrence of homelessness. Mental illness and substance abuse are strongly associated with homelessness and unless these problems are addressed it is unlikely that homelessness will substantially decrease. Integrating multiple systems of services would provide more streamlined and comprehensive care to homeless clients (6). In the case of a homeless person with substance abuse problems, the substance abuse can be addressed by the medical system and the patient’s discharge plan could then be coordinated with programs to find the patient stable housing. Opportunity exists with the passing of the Affordable Care Act in 2012 for prevention of homelessness in people with mental illness through improved managed care as a result of health homes, accountable care organizations, health care team development, and co-location of services (24). ACEs are thought to be the beginning of an accumulation of adversity that may lead to homelessness in many people (10). Preventing and addressing family instability and negative events during childhood may prevent future homelessness and further accumulation of risk factors among these children. Home visiting models, including Child First and Nurse-Family Partnership, may contribute to prevention of homelessness through supporting families and preventing ACEs. Child First is an evidence-based model funded by the Robert Wood Johnson Foundation in Connecticut for preventing adverse events in childhood through home visiting and community services (25). Nurse-Family Partnership, which links high-risk new moms with home visiting nurses who provide support to help improve outcomes for the moms and their babies (26).

Childhood homelessness is associated with mental health problems, school failure, and developmental delay (12). The school system represents a partner that could aid in evaluating students for these issues (12). This would require a system of surveillance and evaluation to be put in place by the school systems and may require additional funding and trained staff to implement new policies.

Predict an individual’s health and wellness and/or that of their offspring

Much of the research on the health effects of homelessness is on diseases that lead to homelessness, not the result of homelessness on an individual’s health. Diseases common among the homeless population include: substance use, mental illness, traumatic brain injury, and infectious diseases (1-4). Rates of chronic and acute health issues are high among homeless populations and conditions requiring long-term treatment such as tuberculosis, HIV/AIDS, diabetes, hypertension, and mental illnesses are more difficult to treat in people who lack housing (33). Homeless populations have excess mortality compared to non-homeless populations (6). The mortality rate for people experiencing chronic homelessness is four to nine times higher than that of the general population (28). Common causes of death among homeless people are drug overdose, cancer, and heart disease (6). Drug overdose is by far the most common cause of death among homeless people under the age of 45, indicating that people who are drug users experiencing homelessness are at an increased risk of adverse health outcomes compared to those with housing (6). In addition to an increase in mortality, homeless populations are at an increased risk for numerous infectious diseases, particularly HIV, tuberculosis, and hepatitis C virus (HCV) (2). Other common infections among the homeless include: respiratory infections, skin infections (scabies, pediculosis, tinea, and impetigo), foot problems (ulcers, cellulitis, erysipelas, and gas gangrene), and infectious common to intravenous drug users (HCV, HIV, and hepatitis B) (4).

The health effects of homelessness in families, particularly children, have been studied as well. It is challenging to disentangle the effects of living in poverty and the effects of homelessness since children who are homeless almost always also experience living in poverty. The higher prevalence for obesity in homeless populations could be antecedent to homelessness and an effect of eating fast food and experiencing food insecurity (12-14). Asthma and iron deficient anemia are also increased in homeless children but these findings may be artifacts of living in poverty prior to experiencing homelessness (12). However, studies that compare homeless children with those living in low-income areas have found that homeless children have more mental health problems and experience more developmental delays than children with housing living in low-income areas(14). Homeless children have more serious medical problems than low-income non-homeless children including delay of immunizations, high lead levels, acute illnesses, chronic conditions, and hospital admissions (12). Homelessness among children creates a higher risk for hunger and poor nutrition, lack of health
Life Course Indicator: Homelessness (LC-07A/B)

care, health problems, developmental delays, psychological problems, and academic underachievement (29). The impact of these issues can be devastating to the current well-being and future life of a child (29).

**Data Criteria**

**Data availability**
The data for this indicator (both parts A and B) are available by county or state through the HUD website by calendar year. These reports on sheltered homeless persons are based on local data submitted to the 2007 and 2008 Annual Homeless Assessment Report (AHAR). The AHAR is a report to the U.S. Congress on the extent and nature of homelessness in America, prepared by HUD. It provides nationwide estimates of homelessness, including information about the demographic characteristics of homeless persons, service use patterns, and the capacity to house homeless persons. The reports are based primarily on Homeless Management Information Systems (HMIS) data about homeless persons who used emergency shelters or transitional housing programs. The data are collected in four categories: Persons in Families in Emergency Shelters, Individuals in Emergency Shelters, Persons in Families in Transitional Housing, and Individuals in Transitional Housing. As specified in the Notes on Calculation, families are defined as any household that includes at least one adult over 18 years old and one child who is younger than 18 years old. All other persons, including those in multi-person households consisting of only adults or only children, are reported as single individuals.

These reports do not include or purport to extrapolate about persons that are served by “victim service providers” including rape crisis centers, battered women’s shelters, domestic violence transitional housing programs, and other programs whose primary missions is to provide services to victims of domestic violence, dating violence, sexual assault or stalking. These reports also do not include those who were living in places not meant for human habitation, such as on the street, in hotels or motels, or in doubled-up living situations, unless these persons also used emergency shelter or transitional housing. Reports can only be generated if a community participated in the 2007 and/or 2008 AHAR (5).

Continuums of Care (CoC) are regional or local planning bodies that coordinate housing and services funding for homeless families and individuals. They are in all 50 states and are responsible for the tracking and management of homeless communities in their area. CoC provide point-in-time counts to ascertain the total number of homeless people (sheltered and unsheltered) on a single night in January of each year to HUD. CoC also provides housing inventory reports to HUD each year on the number of homeless assistance programs and beds in their community (9).

**Data quality**
The data are obtained from the Homeless Data Exchange. The HDX is an on-line tool where CoC can submit data to the HUD; CoC is comprised of regional or local planning bodies that coordinate housing and services funding for homeless families and individuals. The data are collected and maintained in the HMIS, and the reports are generated through HMIS.

All data are based on unduplicated counts, such that each person is counted only once, regardless of how many different programs the person used. Data on length of stay represent the cumulative length of stay for each person within a particular category. For communities that have all emergency shelter, transitional housing and permanent supportive housing providers using HMIS, the total counts reflect the numbers that those providers reported for the 12 month reporting period. For communities where not all emergency shelter, transitional housing and permanent supportive housing providers are using HMIS, this report provides estimates of the homeless individuals and persons in families in emergency shelter, transitional housing and permanent supportive housing programs. The estimate is an “extrapolated count” and is based on the assumption that beds located in programs that do not participate in HMIS are occupied at the same rate and with the same amount of overlap as beds located in HMIS-participating programs.

Data were only included in the national AHAR if HMIS participation rates for a particular category exceeded 50 percent of total beds. The extent to which extrapolated data are representative of the entire community depends on the validity of the assumption that non-participating programs are similar to participating programs. Some programs may target specific sub-populations (such as veterans or women), and their inclusion or exclusion may skew the overall values in particular questions.

**Simplicity of indicator**

These indicators are relatively simple to calculate across geographic regions, once the data has been obtained. Data can be obtained by generating reports through the HUD or DOE websites but this must be done county by county in a given state for HUD data which makes the indicator somewhat time-consuming to produce.

The indicator components are fairly easy to communicate and to understand but may have different meanings and are indicative of potentially different problems and populations (e.g., individual homelessness due to severe mental illness versus family homelessness due to economic instability), and consequently, different methods of prevention.

References


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Life Course Indicator: Homelessness (LC-07A/B)
The Life Course Metrics Project

As MCH programs begin to develop new programming guided by a life course framework, measures are needed to determine the success of their approaches. In response to the need for standardized metrics for the life course approach, AMCHP launched a project designed to identify and promote a set of indicators that can be used to measure progress using the life course approach to improve maternal and child health. This project was funded with support from the W.K. Kellogg Foundation.

Using an RFA process, AMCHP selected seven state teams, Florida, Iowa, Louisiana, Massachusetts, Michigan, Nebraska and North Carolina, to propose, screen, select and develop potential life course indicators across four domains: Capacity, Outcomes, Services, and Risk. The first round of indicators, proposed both by the teams and members of the public included 413 indicators for consideration. The teams distilled the 413 proposed indicators down to 104 indicators that were written up according to three data and five life course criteria for final selection.

In June of 2013, state teams selected 59 indicators for the final set. The indicators were put out for public comment in July 2013, and the final set was released in the Fall of 2013.

Basic Indicator Information

Name of indicator: Homicide rate (LC-08)

Brief description: Homicide rate

Indicator category: Community well-being

Indicator domain: Risk/Outcome

Numerator: Total homicide-related deaths

Denominator: Total population

Potential modifiers: Race, ethnicity, sex, age, socioeconomic status, geographic region

Data source: National Vital Statistics System (NVSS) records

Notes on calculation: Multiply by 100,000 for rate

Similar measures in other indicator sets: HP 2020 Focus area IVP-29
Life Course Criteria

Introduction
Growing evidence suggests the social environment has an impact on health. Research on this relationship is focused on aspects of support and cohesion within the social environment. These concepts are often discussed as ‘social capital’ across populations. Social capital is the collection of features of social organization – such as civic participation, norms of reciprocity, and trust in others – that help facilitate cooperation for mutual benefit. In an attempt to clarify social capital and to assess its importance to social policy, Forrest and Kearns (2001) identify eight domains of social capital. Social capital, they argue, is composed of the following: empowerment; participation; associational activity and common purposes; supporting networks and reciprocity; collective norms and values; trust; safety; and belonging. Homicide has implications for all of the domains of social capital (22).

Homicide is related to community well-being and wider social conditions such as poverty and low education, racial composition, and the disruption of family structure. Homicide events influence larger, community-level aspects of social capital (i.e. trust, safety, belonging) and impact life course trajectories, turning points, and transitions, for victims, perpetrators, and their families (1). Homicide rate is an important life course indicator for both individual level health effects and overall social capital within and across populations.

Implications for equity
Homicide is deeply rooted in equity issues. Tcherni (2011) has examined how homicide and social conditions are intertwined. Research suggests there are three major structural factors related to homicide: poverty and low education, racial composition, and the disruption of the family structure (1).

Poverty and low-education are often highly connected (1). Poverty stricken neighborhoods often lack social control and cohesion (1). Lack of social control and cohesion can lead to community disorganization which corresponds with a higher tolerance for disorder (1). Conflict in impoverished areas is more likely to be resolved through physical means than verbal communication, and poverty leads to higher incidences of conflict in relationships (1). Youth raised in poverty are typically exposed to higher incidences of interpersonal conflict and also experience harsher, inconsistent discipline and less supervision than youth raised in non-impoverished areas (1).

Another social factor correlated with homicide is disruption of family structure. Single parent homes lack economic resources, time and energy to be involved in building community, which serves as a protective factor against homicide (1). Additionally, separated women tend to have elevated levels of interpersonal violence between previous partners (17). Unstable household arrangements have adverse effects on children and play a crucial role in adolescent delinquency, which is also related to homicide rates.

Racial composition of a neighborhood also is related to homicide rate. Among young males 15-34 years of age, African-American men are 12 times more likely than White men to be victims of homicide and Hispanic men are four times more likely as White men to be victims of homicide (23). Homicide rates are higher in neighborhoods that have higher concentrations of African-Americans and Hispanics, however, large portions of these rates are attributable to neighborhood and social characteristics (23). A study of 10 major U.S. cities found two measures of social disadvantage, percent of households headed by a female and lower levels of educational attainment, explained a large portion of higher homicide rates in neighborhoods with high concentrations of African-Americans or Hispanics (23). These data support the Social Disorganization theory, which states higher homicide rates in neighborhoods with high concentrations of African-Americans and Hispanics are attributable to the social conditions of that neighborhood (24). Additionally, neighborhoods with low social capital are unable to maintain a safe environment because the community lacks shared common values and informal social controls (25).

Beyond descriptive differences across populations, homicide rate is a larger measure of inequity of wider social conditions and structural factors. There is evidence that homicide rate affects social capital, just as social capital affects homicide rate. High rates of violent crime promote fear in a community leading to constraints on social interaction, withdrawal from community life, and disorder within the neighborhood (25, 26, 27). Homicide rate also is strongly spatially clustered. Lowering homicide rates will not only contribute to health equity, but also broader social equity across communities.
Public health impact

Violence, in itself, is a major contributor to premature death, injury, and disability, and highly influences quality of life (12). The consequences of violence for victims and those exposed to it are severe, including serious physical injuries, post-traumatic stress disorder (PTSD), depression, anxiety, substance abuse, and other long-term health problems associated with the bio-psychosocial effects of such exposure (15). Many urban youth experience trauma and may have PTSD from exposure to violence. One study found that more than 75 percent of urban elementary school children living in high-violence neighborhoods had been exposed to community violence and other studies have shown that 35 percent of urban youth exposed to community violence develop PTSD (16). The negative effects of exposure to homicide and violence also may manifest themselves as violence and criminal behavior, particularly among adolescents and young adults who were exposed as children (19). This reaction to violence creates a self-perpetuating cycle in communities most affected by homicide and violence. Homicide also influences other aspects of public health. For example, violence (or perceived violence) influences physical activity rates, particularly because if a community is perceived as violent or unsafe, members of the community are less likely to be physically active outdoors (20). The public health implications of changing the rates of homicide in the United States are far-reaching, from improved mental health outcomes to higher social cohesion, and resulting in improved social capital, and reduced mortality and morbidity.

Leverage or realign resources

Historically, homicide has not been considered a public health issue. Until recently, the focus on prevention of homicide and violence were outside the scope of public health, and instead belonged to other jurisdictions, such as city and state municipalities, justice systems, and law enforcement. Given that the factors influencing ongoing violent victimization are varied and include a number of health and social issues, the aforementioned entities would serve as potential collaborators for public health advocates aiming to reduce homicide rates. Neighborhood associations and schools in high-risk areas also may be ideal places to leverage community support and advocacy.

Recently, programs like Chicago’s Cease-Fire have been tackling homicide from a multifaceted approach by including public health program design with interventions, clergy and community mobilization, educational campaigns, and involvement of police and prosecution. Cease-Fire has formed partnerships with businesses, churches, community organizations, police, schools, and other human service agencies. This program has been successful at reducing homicide crime and has been used as a program model for other cities (13). Further, given that high rates of homicide and violence are associated with increased community tolerance for social disorder, public health leaders can collaborate with community members to build social capital from within, working to improve feelings of community control and investment by improving advocacy skills and voter registration rates.

Homicide is the second leading cause of death for youth between the ages of 15-24, creating a need for youth engagement in violence prevention (28). The Centers for Disease Control and Prevention (CDC) funds six National Centers of Excellence in Youth Violence Prevention that implement comprehensive strategies that engage the community to reduce youth violence (28). Youth Empowerment Solutions (YES) is one such strategy developed at the University of Michigan by the Michigan Youth Violence Prevention Center academic-community partnership (28). The project goals are to "provide youth with opportunities for meaningful involvement in preventing youth violence and creating community change, enhance neighborhood organizations ability to engage youth in their activities, and change the social and physical environment to reduce and prevent violence (28)." Evaluation of the program has shown YES participants had better conflict resolution skills and were less likely to be victims of neighborhood crime (29). A school-based intervention, Second Step, was developed at Virginia Commonwealth University to reduce impulsive and aggressive behaviors and increase protective factors and social-emotional competence (28). The Second Step curriculum uses discussion, teacher modeling, coaching skills, and role playing to focus on building skills surrounding empathy, impulse control and problem solving and anger management (28). Evaluations of the program have shown reductions in physical aggression in the classroom (30). These programs and others designed by National Centers of Excellence in Youth Violence Prevention serve as models for youth violence prevention interventions.

Predict an individual’s health and wellness and/or that of their offspring

As described by Settersten (2003), trajectories in life course chart the course of an individual’s experiences over time (11). Therefore, it is important to identify opportune moments related to homicide in order to find ideal times / ages / circumstances at which to intervene and prevent the perpetration of this kind of crime. Settersten (2003) also highlights turning points as significant events that mark when a trajectory takes a certain form or direction (11). Prior exposure to
violence, prior perpetration of crimes, and maltreatment during childhood (18) are important risk factors for subsequent violent activity and these may serve as useful turning points or opportunities to affect individuals’ trajectories. This is exemplified in how homicide reflects psychosocial conditions. Brezina (2009) states that youth who anticipate early death and hopelessness are more likely to take risks and engage in reckless behaviors (21). Sharkey et al found homicides occurring near the home of preschoolers have negative effects on their attention levels, impulse control, and preacademic skills, possibly due to increases in parental stress (32).

In 2012, 12,765 people were victims of homicide (33). An estimated seven to 10 close relatives, in addition to the victim’s neighbors, friends and coworkers, are left to deal with the consequences of each homicide (34). Relatives of people who have been lost to sudden and violent deaths experience a wide range of mental health problems including PTSD, alcohol and drug abuse/dependence, suicidal thoughts, major depressive disorder and prolonged grief disorder (35). Symptoms can persist for years after the death has occurred (35).

Poverty/low education, neighborhood factors, and family structure may influence homicide rates (1). Public health professionals, as well as strong collaborations with other disciplines, may be able to change trajectories in the life course by intervening through increased social control and cohesion, conflict resolution skill building, family mediation including appropriate and consistent parental discipline. These factors could influence critical and transitional periods throughout a child’s life, particularly as the child moves toward adolescence and young adulthood where homicide has the highest potential of affecting a person’s life. Homicide also can influence life course trajectories for children of homicide victims. Children who are exposed to violence may experience higher rates of PTSD, depression, anxiety and substance abuse (15).

Data Criteria

Data availability
Information on U.S. mortality, including homicide, is collected by state registries and provided to the National Center for Health Statistics (NCHS) National Vital Statistics System (NVSS). NVSS is an intergovernmental sharing of data whose relationships, standards, and procedures form the mechanism by which NCHS collects and disseminates the nation's official vital statistics. Vital event data are collected and maintained by the jurisdictions that have legal responsibility for registering vital events; these entities provide the data via contracts to NCHS. Vital events include births, deaths, marriages, divorces and fetal deaths. In the United States, legal authority for the registration of these events resides individually with the 50 states, two cities (Washington, DC, and New York City), and five territories (Puerto Rico, the Virgin Islands, Guam, American Samoa and the Commonwealth of the Northern Mariana Islands).

Vital Statistics data are available online in downloadable public use files, through pre-built tables in VitalStats, and through the ad-hoc query system CDC WONDER (Wide-ranging Online Data for Epidemiologic Research). Death certificate data is available by underlying cause of death (detailed mortality) for 1999-2010, and CDC WONDER includes this data at the county level as well.

Data quality
Standard forms for the collection of the data and model procedures for the uniform registration of the events are developed and recommended for state use through cooperative activities of the states and NCHS. As reported in the NCHS publication U.S. Vital Statistics System, Major Activities and Developments, 1950-1995, efforts to improve the quality and usefulness of vital statistics data are ongoing. NCHS uses techniques such as testing for completeness and accuracy of data, querying incomplete or inconsistent entries on records, updating classifications, improving timeliness and usefulness of data, and keeping pace with evolving technology and changing needs for data. Work with state partners to improve the timeliness of vital event reporting is ongoing, and NCHS is working closely with National Association of Public Health Statistics and Information Systems and the Social Security Administration to modernize the processes through which vital statistics are produced in the United States, including implementation of the 2003 revised certificates.

However, the death reporting systems will vary state by state. Medical examiners and coroners determine the cause and mode of death in each county. A study conducted by the Oklahoma statewide Medical Examiner and Vital Statistics Office surveillance systems that compared reporting on violent injury death methods (including homicide) in the state of Oklahoma found that sensitivity rates were higher in the Medical Examiner system for homicides (99.2 percent versus
90.7 percent). Positive predictive value rates were higher in the Vital Statistics system (99.1 percent versus 95.0 percent)(2). Other studies have demonstrated the usefulness of mortality rates through Medical Examiner and Surveillance Systems (4-10). The National Violent Death Reporting System (NVDRS) is a surveillance system that pulls together data on violent deaths including information about homicides from a variety of sources, including death certificates, coroner/medical examiner reports, law enforcement reports and crime laboratories (36). These data may be useful in determining opportunities for prevention because they include more information on why an event may have occurred, however NVDRS data are only available for the 32 states that currently participate (36).

**Simplicity of indicator**

The level of complexity in calculating and explaining this indicator is low. The numerator and denominator are simple as they are both calculated by state-level data. Data weighting, indexing or adjustments are not required as they are actual counts not sample counts and the statistical formula is straightforward. Homicide is a standard definition according to the law on all vital records. The indicator is straightforward and easy to communicate to the public and partners.

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Life Course Indicator: Household Food Insecurity

The Life Course Metrics Project

As MCH programs begin to develop new programming guided by a life course framework, measures are needed to determine the success of their approaches. In response to the need for standardized metrics for the life course approach, AMCHP launched a project designed to identify and promote a set of indicators that can be used to measure progress using the life course approach to improve maternal and child health. This project was funded with support from the W.K. Kellogg Foundation.

Using an RFA process, AMCHP selected seven state teams, Florida, Iowa, Louisiana, Massachusetts, Michigan, Nebraska and North Carolina, to propose, screen, select and develop potential life course indicators across four domains: Capacity, Outcomes, Services, and Risk. The first round of indicators, proposed both by the teams and members of the public included 413 indicators for consideration. The teams distilled the 413 proposed indicators down to 104 indicators that were written up according to three data and five life course criteria for final selection.

In June of 2013, state teams selected 59 indicators for the final set. The indicators were put out for public comment in July 2013, and the final set was released in the Fall of 2013.

Basic Indicator Information

Name of indicator: Household Food Insecurity (LC-09)

Brief description: Household Food Insecurity

Indicator category: Community Well-being

Indicator domain: Risk/Outcome

Numerator: Number of households experiencing food insecurity (household reports being unable to afford balanced meals, having to cut the size of meals because of too little money for food, or being hungry because of too little money for food.)

Denominator: Number of households

Potential modifiers: Adjunctive eligibility in TANF and Medicaid, race/ethnicity, age, education, income, geography, and rural/urban residence

Data source: United States Department of Agriculture (USDA) Economic Research Service (ERS)

Notes on calculation: Food insecurity is a status assigned by USDA based on the responses to a series of questions: household reports being unable to afford balanced meals, having to cut the size of meals because of too little money for food, or being hungry because of too little money for food. The estimate is available pre-calculated from http://www.ers.usda.gov/.

Similar measures in other indicator sets: Healthy People 2020 focus area NWS-13
**Life Course Criteria**

**Introduction**
According to the World Health Organization food security exists when “when all people at all times have access to sufficient, safe, nutritious food to maintain a healthy and active life.” It is common for specific measures of food security to be defined as including both physical and economic access to food that meets individuals’ dietary needs as well as their food preferences (WHO 2012).

Therefore, household food insecurity is when the conditions of food security are not met and members within a household report being unable to afford balanced meals, having to cut the size of meals because of too little money for food, or being hungry because of too little money for food. In 2011, 14.9 percent (17.9 million) of U.S. households were food insecure. Of these, 5.7 percent (6.8 million households) had very low food security. Nationally, 10 percent of households with children (3.9 million) experienced episodes of food insecurity during the past year. (Coleman-Jensen, 2012)

Growing up or living in food secure environments is a key component of ensuring good nutrition within and across populations. Poor nutrition has a large impact on overall health. Lifetime exposure to poor nutrition can increase the risk of negative adult and intergenerational health outcomes (Sell et al 2010). Research indicates that a lifetime of exposure to poor nutrition affects brain development, contributes to child mortality and is associated with chronic diseases including diabetes, heart disease and other chronic conditions (Bryce et al 2005) (Darnton-Hill, 2004).

Household food insecurity is an important life course indicator for both individual level health effects and overall community well-being. Community-level social capital (i.e. civic participation, norms of reciprocity, and trust) is significantly associated with decreased odds of experiencing hunger. In addition, social capital, particularly in terms of reciprocity among neighbors, contributes to household food security. Households may have similarly limited financial or food resources, but households with higher levels of social capital are less likely to experience hunger. (Martin et al 2004)

**Implications for equity**
As both a measure of individual and community well-being, household food insecurity has implications for social equity. Different populations experience different rates of household food insecurity. When examining national data on household food insecurity, certain populations have been disproportionately affected by increased food insecurity since the economic recession of 2008, including women living alone, Black and Hispanic households and households living below 185 percent of the federal poverty level (FPL). For households with incomes near or below the FPL, households headed by single parents, and Black and Hispanic households, rates of food insecurity were substantially higher than the national average. (Coleman-Jensen, 2012) Further, households that are below 185 percent FPL are 34 percent more likely to experience food insecurity than those who are above the 185 percent of FPL (Coleman-Jensen, 2012). Food insecurity is strongly linked to not having money to purchase food or resources available to attain food within one’s community; although food spending is an indirect indicator of food consumption, when household food spending drops below a minimum level because of resource constraints, food insecurity can manifest in disrupted eating patterns and reduced food intake (Coleman-Jensen, Nord, Andrews & Carlson, 2011). Most food-secure households spent 24 percent more for food than food-insecure households of comparable size and composition (Coleman-Jensen, Nord, Andrews & Carlson, 2012).

Such disparities are also reflected on the community level. Food insecurity was more prevalent in large cities and rural areas compared with suburban areas and within communities surrounding large cities. Very low food security is more prevalent in households located in principal cities of metropolitan areas (Coleman-Jensen, 2012).

**Public health impact**
In 2011, more than 50 million people in the United States experienced food insecurity. Ensuring food security in U.S. households is a critical public health issue. Lack of access to adequate and nutritious food is associated with many negative health outcomes that span across a lifetime and influence future generations. Poor nutrition affects the individual both physically and mentally; poor nutrition resulting from food insecurity was linked to experience of behavioral problems in preschoolers (Sell et al 2010). Infants born to mothers with inadequate nutrition before and during their pregnancy may experience developmental delays, congenital anomalies, low birth weight, and other health issues. Children who experience food insecurity are at increased risk for behavioral and social issues, chronic health conditions, and impaired academic development. (Bryce et al 2005) (Darnton-Hill et al 2004)
Good nutrition is the basic building block of human capital. Within communities, improving nutrition contributes to increased productivity, economic development, and reduced poverty; as disease and mortality are reduced, the community benefits from improved physical work capacity, cognitive development, school performance, and the overall better of its members health. Borrowing research and conceptual frameworks from international development, there is much evidence that nutrition and economic development have a two-way relationship. Improved economic development contributes to improved nutrition (albeit at a very modest pace), but more importantly, improved nutrition drives stronger economic growth (WHO 2006).

In response to food insecurity among low-income families, USDA supports the Supplemental Nutrition Assistance Program (SNAP), which offers nutrition assistance to households with a gross income less than 130 percent FPL. Evaluation and return on investment data from this program illustrates the broader public health impact of intervention on household food insecurity. SNAP leverages resources that reach beyond improving household nutrition to strengthening the economy by providing fiscal resources to local communities, thereby improving family economic self-sufficiency. For example, SNAP has a powerful anti-poverty impact that is not reflected in the Nation’s official poverty statistics. If SNAP benefits were included in the official measure of income and poverty, the Census Bureau indicates that SNAP would lift 3.9 million Americans, including 1.7 million children, out of poverty. Further, with the deep recession in 2009 and the benefit increase with the Recovery Act, the estimated number of people lifted out of poverty rose to 4.5 million. Over the past 10 years, the number of households with earned income receiving SNAP has increased from 27 percent to 30 percent. In addition to assistance to individual families, SNAP provides a fiscal boost to the economy during economic recessions by putting critical dollars back into local economies. Every $1 of SNAP benefits generates up to $1.80 in economic activity, which translates into an estimated 18,000 jobs created or maintained for every $1 billion increase in SNAP benefits (Ziliak, 2011). SNAP is a critical component of efforts to reduce food insecurity.

**Leverage or realign resources**

This indicator has the potential to leverage or realign resources as multiple potential partners, including many non-traditional public health partners, have a vested interest in food security and amelioration of household food insecurity within the United States. Because of the impact of poor nutrition on growth and development, children are a main focus of food security efforts, creating a natural area of partnership with MCH programs. In addition, there are three major national food and nutrition assistance programs in the United States administered by USDA Food and Nutrition Assistance service: SNAP, the Special Supplemental Program for Women, Infants, and Children (WIC), and the National School Lunch Program.

New or strengthened partnerships with the following organizations could realign resources and maximize impact on reducing food insecurity:

- Social or human service agencies or other community services organizations can work on promotion, advocacy or education around SNAP benefits across populations and other antipoverty work.
- Economic and community development agencies and urban planners, as well as obesity and chronic disease prevention partners can work on policy, systems, and environmental change work related to food access.
- WIC programs can work towards increasing nutrition access and food security during the perinatal period.
- Education and school health programs can work on continued promotion, advocacy and education around the National School Lunch Program.

Other community-based food security programs may provide opportunities for partnership, for example, food pantries, food banks, and emergency kitchens. The food provided by emergency kitchens and food pantries comes mostly from local sources, distributed by volunteers. Food pantries, in 2000, distributed 239 million pounds of food per month, and emergency kitchens served a total of 479,000 meals on an average day. Many are operated by faith-based or community-based organizations (ERS 2005). Food banks through the non-profit group, Feeding America, feed 37 million people a year (Feeding America, 2013). Funding is acquired through donations from corporations, foundations and individuals to obtain food from local manufacturers, retailers, farmers and government sources and distribute it to local sites.

According to the National Resource Defense Council (NRDC), almost 40 percent of edible food in the United States goes to waste; it is estimated that an additional 25 million people could be fed if food waste were reduced by 15 percent (NRDC 2013). In an effort to reduce some of this waste, some restaurant groups participate in “food rescue” programs that
distribute unserved food that is still safe to eat to community agencies and organizations across the country. Programs such as these could avert the estimated costs of food waste that include $750 million in waste disposal and 33 million tons of landfill waste annually. Increasing food security for U.S. households through these types of programs engages the restaurant industry in a health and social issue and can have a consequent positive impact on the environment.

In addition to expanded opportunities and partnerships, improved nutrition will lead to expanded productivity, economic development, and poverty reduction. As human capital and community well-being increase, additional resources may be realigned as a part of broader community development.

*Predict an individual’s health and wellness and/or that of their offspring*

Food access and its effects on nutrition have multiple individual and intergenerational impacts for health. Experiencing food insecurity has impacts for both physical and mental health. Food insecurity is associated with a range of chronic illnesses such as hypertension, hyperlipidemia, and various cardiovascular risk factors (Seligman 2009). Food insecure adults have an increased risk of developing diabetes (Seligman 2007).

Although food insecurity is harmful to any individual, it can be particularly devastating among children due to their increased vulnerability and the potential for long-term consequences (Kushel, 2006). Food insecurity is associated with adverse outcomes in young children. In households where there is food insecurity, children display a higher rate of fair/poor health status and illness leading to hospitalizations which in turn, contributes to higher health care costs. The psychological health of children is affected when living in homes where food insecurity is prevalent, due to feelings of deprivation, increased stress, and depression created within the family (Cook, 2004). Research has also found that academic development is impaired in young, school-age children when they grow up in an environment of food insecurity. Their reading and math skills develop more slowly than in other children when entering kindergarten. They also may experience behavior problems including fighting, hyperactivity, anxiety, mood swings, and bullying (Feeding America Child Development 2013).

Food access and nutrition is also important during the perinatal period. Because of the lack of proper nutrients needed in pregnancy, a woman may be at risk for long-term physical health problems beyond pregnancy as well as depression and other mental health issues (Tarasuk 2011, Heflin 2005). In addition, infants may experience developmental delays, low birth weight, and other health issues if their mother did not have access to proper nutrition while pregnant.

In addition to specific health conditions, food insecurity is associated with incomes below the federal poverty level, decreased access to health care, and a higher incidence of visits to emergency departments and hospitalizations. Those lacking food security may prioritize meeting basic needs over preventive health care, and obtaining food for their families over medications for themselves. Medical care may be delayed which can further predispose individuals to a greater need for acute care (Coleman-Jensen et al 2011).

**Data Criteria**

*Data availability*

The USDA monitors the extent and severity of food insecurity through a nationally representative survey conducted by the United States Department of Agriculture (USDA) Economic Research Service (ERS) as a supplement to the U.S. Census Bureau Current Population Survey (CPS). This survey has been conducted annually since 1995. Reports from this survey include household food security, food expenditures and use of food and nutritional assistance programs. USDA ERS sponsors the annual survey and then compiles and analyzes the results.

Data for rates of food insecurity and very low food insecurity are readily available by state, including all 50 states and the District of Columbia. Data are combined over a three year period (2009 – 2011) and averaged in order to be more reliable (Coleman-Jensen, 2012)

MCH programs in all 50 states and the District of Columbia can gain access to the data through datasets released annually by the USDA Economic Research Report on the USDA website, http://www.ers.usda.gov/. The data is easy to access and interpret, presented in a variety of ways including 16 Tables in the *Household Food Security in the United States in 2011: Statistical Supplement/ap-058*, and available annually to the entire United States by state, including the
District of Columbia (ERS 2005). Data on food insecurity in the United States in 2012 were published in September 2013, indicated a less than one year lag in disseminating the data.

**Data quality**
The Census Bureau quality standards apply to all products released, including the CPS and the ERS. The Census Bureau makes every effort to ensure the data are accurate and reliable. The Office of Management and Budget (OMB) released Standards and Guidelines for Statistical Surveys with requirements for federal statistical agencies in 2006 (OMB 2006). In 2012, the U.S. Census Bureau reissued their statistical quality standards in 2012, which complement the 2006 OMB standards ensuring data quality (USCB 2012).

The food security statistics reported by ERS are based on survey measures developed by the U.S. Food Security Measurement Project, an on-going collaboration among federal agencies, academic researchers, and private, commercial and nonprofit organizations that was established in response to the National Nutrition Monitoring and Related Research Act of 1990 (NNMRR). The ERS survey consists of 18 questions exploring food security experienced within the previous 12 months. Following the enactment of the National Nutrition Monitoring and Related Research Act, a questionnaire was developed and field tested with the first analysis of the data produced in 1995. From 2003 to 2006 an expert panel convened by the Committee on National Statistics (CNSTAT) of the National Academies conducted a review of the survey and measurement methods. CNSTAT recommended that USDA continue to monitor food insecurity, affirmed the appropriateness of the current methodology, and suggested refinements.

The standardized questionnaires and methods for analyzing data developed by The Food Security Project are used by several national surveys including the National Health and Nutrition Examination Survey (NHANES), National Center for Education Statistics’ Early Childhood Longitudinal Study – Kindergarten Cohort (ECLS-K), National Center for Education Statistics’ Early Childhood Longitudinal Study – Birth Cohort (ECLS-B), National Health Interview Survey (NHIS) and Survey of Income and Program Participation (SIPP).

The annual survey covers a representative sample of the U.S civilian non-institutionalized population of 119 million households, with 43,770 households participating in the survey in 2011. These data have contributed to a growing number of regional, state and local studies that use the standardized data and analysis (ERS 2013).

**Simplicity of indicator**
Calculating this indicator is straightforward, comparable across all states, and simple to explain. The food security survey asks one adult respondent in each household a series of questions about experiences and behaviors that indicate food insecurity such as being able to afford balanced meals, cutting the size of meals because of too little money for food, or being hungry because of too little money for food. The food security status is assigned based on the number of food-insecure conditions reported.

The survey also collects information on whether a household participated in a federal food and nutrition assistance program such as Supplemental Nutrition Assistance Program (SNAP) or WIC nutrition services. Prevalence of food insecurity is reported at the state level and analyzed by multiple characteristics including family composition, race/ethnicity, household income, rural/urban residence, and participation in federal food and nutrition programs among other characteristics.

**References**


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In June of 2013, state teams selected 59 indicators for the final set. The indicators were put out for public comment in July 2013, and the final set was released in the Fall of 2013.

Basic Indicator Information

Name of indicator: Poverty (LC-10)

Brief description: Percent of population living under the Federal Poverty Level

Indicator category: Community Well-being

Indicator domain: Risk/Outcome

Numerator: Number of families below the Federal Poverty Line or FPL (determined by U.S. Thresholds)

Denominator: Total number of families

Potential modifiers: age, sex, race, ethnicity, geographic location. If age, sex, race and ethnicity are examined as moderators, data users should limit analysis to the number of individuals living below the FPL, as opposed to the number of families or households, as these units are less amenable to sub-group analyses.

Data source: American Community Survey (ACS)

Notes on calculation: Families are defined as any household that includes at least one adult over 18 years old and one child who is younger than 18 years old. All other persons, including those in multi-person households consisting of only adults or only children, are reported as single individuals.

Similar measures in other indicator sets: HP 2020 Focus area SDOH-3; MIECHV Benchmark Area Improvements in Family Economic Self-Sufficiency: Household income (including earnings, cash benefits, and in-kind and non-cash benefits); Chronic Disease Indicator; United Health Rankings Core Measure
Life Course Criteria

Introduction
Poverty is associated with health deficits over the life course, particularly when the individual was exposed to high levels of concentrated disadvantage early in life. Poverty is widely regarded as a driver of increased morbidity and mortality in the United States, and the relationship between poverty and reduced health is likely cyclical. Concentrated disadvantage, poverty, and socioeconomic position (SEP) are all very similar markers. While poverty is consistently linked to a host of health outcomes, it may not fully capture the synergistic composite of social factors that mark spatial disadvantage, or the qualitatively distinct aspect of growing up in truly disadvantaged neighborhoods (8). This narrative focuses on poverty and SEP given their overlapping and often inseparable conceptual foundation and serves as a complement to the narrative for the concentrated disadvantage life course indicator.

Poverty is consistent with life course science because it has significant effects both at “critical periods” of development (infancy and parental socioeconomic position, for example) and throughout life through cumulative burden. Across the entire life course, poverty is associated with cognitive function, depression, health behaviors, and diabetes risks. Poverty also is transmitted across generations. Children growing up in impoverished homes are more likely to lack resources and opportunities that promote resilience to the adverse impact of the stressors of poverty throughout the life span.

Implications for equity
Poverty, or being poor, is defined as living in conditions that are both below the conditions of the average citizen and deemed as socially unacceptable (1). The gap between rich and poor (or income inequality) has remained wide, and this gap may be increasing in certain areas (7). The federal poverty guideline for a family of four in the 48 contiguous states and D.C. was $22,050 in 2010 and $22,350 in 2011. There are clear disparities in poverty across racial and ethnic groups. In 2010, 27.4 percent of blacks and 26.6 percent of Hispanics were poor, compared to 9.9 percent of non-Hispanic whites and 12.1 percent of Asians (4). Poverty rates are highest for families headed by single women, particularly if they are black or Hispanic. In 2010, 31.6 percent of households headed by single women were poor, while 15.8 percent of households headed by single men and 6.2 percent of married-couple households lived in poverty (4).

There are clear disparities in poverty across racial and ethnic groups. In 2010, 19.9 percent of foreign-born residents lived in poverty, compared to 14.4 percent of residents born in the United States. Foreign-born, non-citizens had an even higher incidence of poverty, at a rate of 26.7 percent. Children represent a disproportionate share of the poor in the United States; they are 24 percent of the total population, but 36 percent of the poor population. In 2010, 16.4 million children, or 22.0 percent, were poor (4). The poverty rate for children also varies substantially by race and Hispanic origin, similar to adult disparities.

SEP, including poverty, is seen as a common social stratification, and its implications for equity are numerous. On a social level, the levels of prestige across SEP are inversely associated with mortality. On a psychosocial level, SEP is inversely associated with adverse behaviors such as drug use across all ages and bullying in children. On an environmental level, exposures to asthma triggers, hazardous waste, lead particulates, and air pollution are all more common in areas with greater poverty. With respect to health disparities, SEP has implications in HIV diagnosis rates, cardiovascular disease (CVD) risks, body mass index (BMI), cancer diagnoses and treatments, general practitioner and follow-up visits, physical activity, diet, and diabetes incidence. A complex relationship exists between health, gender and racial discrimination, and SEP; nonetheless improvements in poverty status may have major health benefits. Evidence has shown that moving an individual out of a high-poverty area to a low poverty area does result in some improved outcomes, such as improved mental health, indicating that the effect of poverty on an individual is not necessarily permanent (17).

Public health impact
Socioeconomic factors such as poverty have been proven to act cumulatively over a lifetime to impact health (3). While the association between health and wealth is well-established, the direction between the two factors is less so. Literature suggests that the relationship is bidirectional. Poverty has a tremendous impact on health, not only through material resources, e.g., access to care and healthy food, but through its psychological and psychosocial impact on health and behavior of individuals and their communities. Poverty also has been shown to be related to reduced educational
attainment, meaning future earnings potential also is affected, which continues to deleteriously affect health and the health of communities as a whole.

High concentrations of poverty also have been shown to have increased high school drop-out rates, high rates of teen pregnancy, and higher rates of adolescent delinquency \(9, 10\). More specifically, birth and early childhood outcomes, such as infant mortality, low birth weight, and child maltreatment have all been shown to increase among communities with poverty and concentrated disadvantage \(9, 10\). Mental health has similarly been linked to poverty and concentrated disadvantage, as girls who grew up in communities with high levels of poverty have decreased mental health and show increased risk-taking behaviors \(14\). These areas also show increased proliferation of food deserts, decreased social capital, and less recreational space. In older ages, the linkage between poverty and concentrated disadvantage and health is less clear, however evidence shows that higher levels of poverty result in lower self-rated health \(15, 16\).

SEP is as much a health stratifier as a social one, and changes in SEP would greatly impact public health \(13\). On an individual level, the impact of low SEP starts at the molecular level with inflammatory markers of chronic disease and moves into oral health, mental health, health behaviors like dietary patterns and early screenings, and chronic disease like diabetes, BMI, CVD, and cancer incidences. On a neighborhood level, low SEP is associated with differences in a range of outcomes and risk factors, from less frequent cancer screenings and physical activity, and more violence/victimization, to arthritis, depression and poor mental health, and overall morbidity and mortality. From a public health program perspective, educational attainment may affect receptivity to health interventions and messages, which in turn influence the ability to make healthy choices and practice healthy behaviors \(20\).

A positive and sustained change in this indicator, or a reduction in the percent of families living in the most extreme poverty (less than 100 percent of the FPL), would indicate that more families have access to basic resources (e.g. stable housing, food) to meet physiological needs and allow for their own satisfaction of self-actualization (among other human needs) to participate more fully as individuals within their communities. This is a critical component of not only improving the health status of the impoverished population but also educational attainment of individuals and the strength and well-being of the community in which they live.

**Leverage or realign resources**

Bollen (1997) identifies poverty and concentrated disadvantage as results of institutional discrimination (“institutional practices that create and reinforce oppressive systems of race relations whereby people and institutions engaging in discrimination adversely restrict, by judgment and action, the lives of those against whom they discriminate” \(Krieger 2003\)) and individual prejudice, arguing that segregation concentrates poverty, particularly among metropolitan inner-cities\(2\). In addressing concentrated poverty, he references the importance of public policy-makers, regional and city planners, and lawmakers at various levels (particularly at the regional level). Concentrated poverty can be addressed in two primary ways: via enrichment (or in-place), and integration (or mobility interventions). Enrichment consists largely of improvement of living and economic conditions through community development and revitalization programs, as well as educational improvements. Integration interventions, conversely, refer to moving concentrations of poor people to other areas, often suburbs, with better economic and social structures. Quilian (2012) similarly finds that there are three different types of segregation that affect concentrated disadvantage: racial segregation, poverty-status segregation within race, and segregation from high- and middle-income members of other racial groups \(11\). To slow the cyclical relationship between poverty, education, and health and address poverty and segregation requires the purposeful engagement and leadership of key stakeholders to change the economic systems of their communities. Already mentioned are policymakers and regional and city planners, especially with regard to zoning; related entities could include housing agencies, local businesses, social services, and programs for job training, mental health and substance abuse, and re-entry for previously incarcerated individuals.

Monitoring and reporting on poverty, its relationship to community well-being, and its relation to MCH outcomes will provide not only the opportunity to create new, non-traditional partnerships but will perhaps paint a clearer picture of MCH disparities within and across states in the United States. With the growing momentum for the life course approach, poverty is emerging as a root cause for health inequities and is raising the alarm for social and economic justice.

**Predict an individual’s health and wellness and/or that of their offspring**

Poverty, especially when experienced at early ages, has been shown to be a reliable indicator of individual health. It sets a trajectory of exposure to heightened intra- and inter-personal physical, emotional, and mental stress, poor health...

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*Life Course Indicator: Poverty (LC-10)*
behaviors, and unequal access to myriad services and supports that accumulate over time. When interacting with other socioeconomic and community factors, the cumulative impact greatly contributes to inequities both inside and outside of health. These inequities emerge as early as childhood and adolescence, in the form of lower school attainment or dropout, risk-taking behaviors, and delinquency. Individuals exposed to poverty experience higher CVD risks, tobacco use, and alcohol consumption as young adults. The increased exposure to risk factors and decreased exposure to protective factors contributes to poorer maternal health and birth outcomes, and this increased risk for poorer health of offspring, coupled with the likelihood that offspring will be born into poverty, further perpetuates the cycle. For example, children growing up in impoverished households are more likely to be exposed to physical hazards (e.g., air pollution, lead, violence, poor nutrition) as well as psychosocial hazards (e.g., unhealthy role models and norms, family conflict) (5). This association with health remains consistent over the life span. A mother’s SEP is associated with breastfeeding intention, maternal diet, and early childhood nutrition.

Later in life, individuals exposed to poverty in childhood have lower self-rated health and higher risks for CVD, and further, the association with poverty and mental health carry over into both adult SEP and health. As an adult, the later in life SEP changes for the worse, the more extreme the health effects. Poverty and SEP have associations with everything from spontaneous abortion and depression to diabetes and early morbidity and mortality. It is clear that experiencing poverty, particularly during critical and sensitive periods of the life course, will have an adverse impact on future health. This impact likely exists even if the effect is minimized by later life course events or removing the individual from a highly disadvantaged community.

Data Criteria

Data availability

The American Community Survey (ACS) is an ongoing nationwide survey that collects and provides annual data on demographic, social, economic, and housing characteristics in the United States. The survey is administered by the U.S. Census Bureau, and it replaced the decennial census long form starting in 2010. The ACS is sampled each year, resulting in three million addresses selected and approximately two million final interviews. However, the sample drawn is substantially smaller than the one used for the previous Census long form; as a result, data must be pooled across years in order to provide reliable estimates for some geographic units. The ACS provides yearly estimates for all states, as well as all cities, counties, metropolitan areas, and population groups of 65,000 people or more. For smaller areas, multiple survey years are combined to obtain reliable estimates: three survey years in areas with 20,000 to 65,000 people, and five survey years in areas with fewer than 20,000 people. ACS data are released the year following the year in which they were collected, making the estimates extremely timely.

FactFinder provides tables by year, state and county, or data can be downloaded from an FTP (file transfer protocol) site. Data are available for all 51 jurisdictions (50 states and DC). Data also are available at county and in some cases sub-county levels (may require combining several years of data, especially for rural areas).

Data quality

Since the ACS is a sampled survey, there is uncertainty in the estimates. The Census Bureau takes steps to minimize the error associated with non-sampling error (reporting, coding, sampling frame, survey questionnaires, non-response, and interviewer bias) through the use of trained interviewers and careful review of all questionnaire design, sampling, and analytic steps. In addition, the Census Bureau began releasing margin of error data for ACS estimates starting in 2006; these estimates allow data users to calculate 90 percent confidence limits for all point estimates released from the ACS.

To account for the complex sampling design, the ACS employs an equally complex weighting scheme. The weighting process is well-documented in the survey methodology handbook, accessible on the web. Response rates for the ACS are calculated for housing units and group quarters (person). From 2000 to 2011, the housing unit response rate ranged from a low of 93.1 percent in 2004 to a high of 98 percent in 2009. Between 2006 and 2011, the group quarter response rate ranged from a low of 97.4 percent in 2006 to a high of 98 percent in 2008 and 2009.

The data quality is excellent. Sensitivity, specificity, predictive value positive and reliability will vary depending on the outcome. The challenge in calculating the percent of families living in poverty emerges in the calculation of poverty status. The Census Bureau does not take into account geographic variation in cost of living, nor some significant expenses such...
as child care costs when assessing poverty status (18). It is for this reason that the indicator must be contextualized with the cost of living for the area under investigation.

**Simplicity of indicator**

This indicator is fairly easy to calculate because it is calculated by the U.S. Census. It does not require linkage on the part of the data user. Poverty thresholds are determined by household family size and age of members and do not change geographically. Thresholds are updated annually to account for inflation.

Poverty as an indicator can be calculated by accounting for total family income compared to the appropriate threshold for each family. If the family income is less than or equal to the poverty level, their income is considered as less than the threshold. However, if total family income is greater than the threshold, it does not constitute poverty.

\[
\text{Poverty} = \frac{\text{income}}{\text{(threshold income)}} \times 100.
\]

Then, if poverty ≤100, that family is 100 percent under the FPL.

This indicator is simple to explain. Its connection to health may be more difficult to communicate, however it can be achieved through the focal point of access. The most significant implication of poverty is access: health care, social services, resources, skills, work, education, technology, nutrition, and safety are all impacted by poverty status (19).

**References**


Life Course Indicator: Small for Gestational Age

The Life Course Metrics Project

As MCH programs begin to develop new programming guided by a life course framework, measures are needed to determine the success of their approaches. In response to the need for standardized metrics for the life course approach, AMCHP launched a project designed to identify and promote a set of indicators that can be used to measure progress using the life course approach to improve maternal and child health. This project was funded with support from the W.K. Kellogg Foundation.

Using an RFA process, AMCHP selected seven state teams, Florida, Iowa, Louisiana, Massachusetts, Michigan, Nebraska and North Carolina, to propose, screen, select and develop potential life course indicators across four domains: Capacity, Outcomes, Services, and Risk. The first round of indicators, proposed both by the teams and members of the public included 413 indicators for consideration. The teams distilled the 413 proposed indicators down to 104 indicators that were written up according to three data and five life course criteria for final selection.

In June of 2013, state teams selected 59 indicators for the final set. The indicators were put out for public comment in July 2013, and the final set was released in the Fall of 2013.

Basic Indicator Information

Name of indicator: Small for Gestational Age (LC-11)

Brief description: Proportion of singleton live-born infants whose birth weight is at or below the 10th percentile for a given gestational age

Indicator category: Community Well-being

Indicator domain: Risk/Outcome

Numerator: Singleton live-born infants whose birth weight is at or below the 10th percentile for a given gestational age

Denominator: Total number of singleton live births

Potential modifiers: Race/ethnicity, age, educational attainment, income, rural vs. urban

Data source: National Vital Statistics System (NVSS) Records

Notes on calculation: Small for Gestational Age (SGA) was defined as sex-specific birth weight <10th percentile at each week of gestation as measured using the last menstrual period. The 10th percentile cut points of birth weight was derived from the 1990 live births in the United States as a baseline (i.e. internal reference norms). This indicator should be calculated using the methodology from Oken, E., Kleinman, K. P., Rich-Edwards, J., & Gillman, M. W. (2003). A nearly continuous measure of birth weight for gestational age using a United States national reference. BMC pediatrics, 3(1), 6.

Similar measures in other indicator sets: None
Introduction
SGA is defined as an infant smaller in size than normal after taking gender and gestational age into account. The standard criteria for SGA are birth weight below the 10th percentile for a given gestational age. The measurement of SGA compares infant birth weight with a national distribution of live births so that weights are relative to infants of the same gestational age. If an infant is not small at birth due to genetic factors, SGA is a measure of intrauterine growth restriction. The two components of SGA are gestational age and birth weight; an infant can be preterm but an appropriate weight for that gestational age, and therefore not SGA. Conversely, an infant can be born at less than 2500 grams at any gestational age and not necessarily considered SGA; SGA criteria include the combination of low birth weight for gestational age. The proportion of infants born low birth weight in the United States has been increasing since 1990 but has remained relatively constant in recent years. In 1990, 7.0 percent of live births were low birth weight and between 2004 and 2010, percentages ranged from 8.1 percent to 8.3 percent (Future of children, 2013). SGA is reflective of life course science in that birth weight is influenced by maternal health and social factors prior to pregnancy, and has implications for the health of the infant through childhood and into adulthood. Infants with birth weight below the 10th percentile have likely been severely growth restricted and are at an increased risk for infant morbidity and mortality, permanent deficits in growth and neurocognitive development in childhood, and at an increased risk for development of adult chronic disease.

Implications for equity
Disparities in experience of SGA exist among various racial and ethnic groups in the United States (Collins et al, 1997, Schempf, Kaufman & Messer, 2011). In 2008-2010, African American mothers had almost twice the rate of low birth weight infants (13.6 percent) compared to that of White (7.2 percent) and Hispanic (7.0 percent) mothers (March of Dimes, 2013). A study performed in North Carolina found that African American women were twice as likely to deliver a term SGA infant compared with non-Hispanic White women. Disparities remained even after controlling for individual socioeconomic factors and neighborhood characteristics (Schempf et al, 2011). Another study found college educated African American women were three times as likely to deliver a SGA infant than college educated White women (Collins et al, 1997).

As socioeconomic disadvantage increases, so does the risk for SGA. Beard et al (2009) found nearly half of the increased risk for SGA in socioeconomically disadvantaged women was accounted for by maternal smoking and delayed entry into antenatal care, however, a strong relationship between socioeconomic disadvantage and SGA remained after controlling for both of these covariates as well as race. Other research has found markers of socioeconomic disadvantage influence SGA outcomes. Parents who did not complete high school or equivalent have an increased risk of delivering a low birth weight infant. Parents without a high school diploma or equivalent are often unable to find adequate employment resulting in low income and socioeconomic status (The Future of Children, 2013). Moreover, many low-income parents experience food insecurity due to their lower wages compared to middle and upper-income families. Lack of adequate nutrition during pregnancy is a risk factor for SGA. Therefore, birth weight of infants is influenced, in part, by the social gradient of health whereby lower income families experience a higher prevalence of poor health outcomes. Environmental toxins present in the home and at work also have an influence of whether a mother will give birth to a low birth weight infant (CDC, 2012).

Young mothers (less than age 18) and older mothers (greater than age 35) also are at higher risk for delivering a SGA baby (Kozuki et al, 2013, Odibo et al, 2006, Fraser and Ward, 1995). Inadequate prenatal care and sociodemographic risk factors do not entirely explain the association between teen birth and SGA, which may be partially driven by biologic immaturity (Fraser and Ward, 1995). In addition to social and economic challenges teenagers face after giving birth (Ellenbein and Felice, 2003), SGA-related health outcomes can further affect health over the life course of the mother and child. After the age of 35, a dose response relationship exists with age and SGA, justifying indication for ultrasound screening in older mothers (Odibo et al, 2006).

Public health impact
Birth weight is often used as a measure of current and future population-level health due to the high correlation between birth weight and infant morbidity and mortality and adult chronic disease, mental health, and socioeconomic status (Margerison-Zilko, 2014). SGA is a contributor to low birth weight costs in the United States, which total $5.4 billion per year. Many low birth weight infants often need lengthy stays in neonatal intensive care units and require re-
hospitalizations and special education services, all of which add an additional cost of $500 million per year (Lewit, 1995; Environmental Protection Agency).

SGA is associated with the development of costly, prevalent chronic disease in adulthood including coronary heart disease, stroke, hypertension and type II diabetes (Salam, Honeycutt, & Thompson, 2001). Research also found possible links between SGA and future development of osteoporosis and depression (Salam et al, 2001). The increased risk for these diseases may be long-term effects of abnormal nutrient supply to the fetus (Salam et al, 2001). Where future projections show 40.5 percent of the U.S. population will have some form of cardiovascular disease by 2030 (Heidenreich et al, 2011) and type II diabetes prevalence will increase by 165 percent by 2050 (Boyle et al, 2001), reducing risk factors for these diseases is of high public health concern.

Leverage or realign resources
Medicaid is a key partner in lowering SGA rates. Medicaid covers 40 percent of all births in the United States and the added costs of low birth weight complications are in the millions (NCSL, 2011). In Wisconsin, the average estimated cost of health care for babies with a very low birth weight is $61,902 compared to $7,260 for a baby born at normal weight (NCSL, 2011). The Colorado Prenatal Plus program provides pregnant Medicaid-eligible women with comprehensive services and an evaluation of the program showed an estimated $2.9 million in Medicaid savings (ASTHO, 2012). In Virginia, the Partners in Pregnancy program provides a “medical home” intervention to pregnant women enrolled in Medicaid and has achieved a medical cost savings of $2,287 for each mother and newborn enrolled in the program (NCSL, 2011).

Many existing interventions target upstream or potential contributors of SGA, including tobacco use during pregnancy, drug and alcohol use during pregnancy, inadequate weight gain during pregnancy, prenatal case management, and support during pregnancy. Significant reductions in low birth weight have been observed in smoking cessation interventions; however, inconclusive or equivocal findings have been reported for nutrition education interventions aimed at improving maternal weight gain during pregnancy, prenatal case management programs, and alcohol and illicit drug use programs (Murray, 2009; da Silva, n.d.). The Collaborative Improvement & Innovation Network (CoIIN) to Reduce Infant Mortality is a public-private partnership between the Health Resources and Services Administration Maternal and Child Health Bureau and state Title V MCH programs to reduce infant mortality and improve birth outcomes (HRSA n.d.). In addition to learning from one another and national experts, sharing best practices and lessons learned, and tracking progress toward shared benchmarks, participants are encouraged to engage stakeholders outside of their usual MCH and public health partnerships to implement strategies that will ultimately improve birth outcomes. Strategies currently used by the states participating in CoIIN that could reduce SGA include promoting smoking cessation, expanding access to interconception care (between pregnancies) through Medicaid, and addressing the social determinants of health. While infant mortality was not selected as a life course indicator, SGA was because of the risk of mortality for severely growth-restricted infants. Legislators could support continual and new allocation of funds to programs or initiatives that focus on improving the health of maternal and child populations within their communities.

Partnering with organizations and initiatives to reduce maternal smoking before and during pregnancy should improve rates of SGA. The Patient Protection and Affordable Care Act requires Medicaid to cover counseling and pharmacotherapy for tobacco cessation for pregnant women (Adams et al, 2013). Coverage of these interventions significantly reduces smoking rates among women (Adams et al, 2013). In clinical practice, physicians are an important partner to engage to employ evidence-based interventions such as the “5 A’s” model recommended by the Agency for Healthcare Research and Quality. The intervention advises clinicians to ask pregnant women about tobacco use, advise them to quit, assess their willingness to attempt to quit, assist them in quitting and arrange follow-up regarding their smoking status (AHRQ, 2012).

Early intervention (EI) services, including early childhood development, family support services and pediatric follow-up to reduce developmental and behavioral problems in low birth weight infants, was studied in the Infant Health and Development Program (IHDP) in the 1980s. Results showed EI was an important strategy to improve developmental and health outcomes in low birth weight infants (Mallik & Spiker, 2004). High-quality group care for low birth weight infants starting at 12 months of age enhanced cognitive development and reduced behavioral problems (Mallik & Spiker, 2004).
Social services and the education sector also have a stake in improving SGA. Low birth weight infants are twice as likely as normal-weight babies to be placed in foster care and to be maltreated during their early years of life (Lee, 2009) thereby potentially placing added burdens on social services. The Healthy Families New York (HFNY) prenatal home-visitation program focuses on social support, health education, and access to services. Among participants randomized to the HFNY program during years 2000 to 2002 (n=236), 5.1 percent delivered a low birth weight baby in 2007 compared to 9.8 percent in the control group (Lee, 2009). Infants born low birth weight or SGA have an increased risk of receiving costly special education services (Lewit, 1995; Environmental Protection Agency) and thus may have some influence on realigning resources in the education sector. Targeting prevention of teen pregnancy in the education sector may reduce rates of SGA births due to the association between young maternal age and SGA.

Predict an individual’s health and wellness and/or that of their offspring

SGA is an indicator that can predict individual health outcomes at each stage of the life course and in future generations. In infancy, intrauterine growth restriction, a main driving cause behind SGA, is associated with a wide range of infant morbidities including metabolic, thermal, and hematological problems. Infants born with weight between the third and 10th percentile are at a higher risk for mortality than infants born with weights in the 25th-50th percentile (Grisaru-Granovsky et al, 2012). Higher infant mortality rates have been found in both term and preterm SGA infants (Grisaru-Granovsky et al, 2012). Additionally, low birth weight infants are at increased risk of health problems, developmental delays, physical disabilities, and maltreatment, which influence health status throughout their life, school success and employability later in life (Lee 2009).

In childhood, birth weight is a predictor of developmental delays and cognitive problems resulting in lower IQ test scores, lower educational attainment and adulthood lower incomes compared to normal birth weight infants (Promising Practices Network, 2013; CDC 2012). Studies focused primarily on birth weight have demonstrated that a mother who was born low birth weight is more likely to have a child born low birth weight (Emanuel 1986). According to David J. Barker, MD in his research on the fetal origins of disease, birth weight is a predictor of poor life course trajectories such as chronic health conditions (hypertension, coronary artery disease and diabetes), depression and suicide ideation (Barker et al 1993). Further, low birth weight is a multi-generational issue. Mothers who were born low birth weight are more likely to give birth to a low birth weight infant independent of factors such as receipt of adequate prenatal care, thereby continuing this cycle into future generations (Coutinho et al 1997, Collins et al 2003). Poor maternal health increases the risk of delivering a low birth weight baby, creating intergenerational health issues. Maternal asthma, diabetes, and high blood pressure are all associated with increased risk of low birth weight (Hayes et al, 2014). Obese mothers have a higher risk of having a baby small for gestational age with greater chance of needing intensive care after birth (Radulescu et al, 2013).

Mothers of low birth weight infants may fall into a mental state of depression due to the burden of intensive caring for their infant (Poehlmann et al, 2009). Burdens such as financial hardships, food insecurity, and health complications concerning their infant weigh down the mother mentally increasing the risk of maternal morbidity (e.g. increase risk of smoking and consuming alcohol to alleviate pain) (Feeding America, 2013).

Data Criteria

Data availability

The National Vital Statistics System is an intergovernmental sharing of data whose relationships, standards, and procedures form the mechanism by which the National Center for Health Statistics (NCHS) collects and disseminates the nation's official vital statistics. Vital event data are collected and maintained by the jurisdictions that have legal responsibility for registering vital events; these entities provide the data via contracts to NCHS. Vital events include births, deaths, marriages, divorces and fetal deaths. In the United States, legal authority for the registration of these events resides individually with the 50 states, two cities (Washington, DC and New York City), and five territories (Puerto Rico, the Virgin Islands, Guam, American Samoa and the Commonwealth of the Northern Mariana Islands). Vital Statistics data are available online in downloadable public use files, through pre-built tables in VitalStats, and through the ad-hoc query system CDC WONDER (Wide-ranging Online Data for Epidemiologic Research). Birth certificate data is available in WONDER for 1995-2010, and death certificate data by underlying cause of death (detailed mortality) is available for 1999-2010.
Birth weight data are readily available for all U.S. states, Washington, DC, counties, and other jurisdictions (e.g. major metropolitan areas) through the Vital Statistics birth records. The data sets do not require linkage for calculation. The numerator is calculated as the number of infants with a sex-specific birth weight below the 10th percentile for each week of gestation and is retrieved from the birth certificate. Date of last menstrual period (LMP) has been collected on the birth certificate since 1968, with minor revisions to the instructions for birth attendants in calculating LMP in the years since its implementation. The 1989 revision of the birth certificate included a new field – clinical estimate of gestation or delivery – to facilitate discussions. The complexity of calculation of SGA is moderate to complex. The complexity comes in comparing the birth weight percentile to determine whether an infant is below the 10th percentile. SGA is better known among maternal and child health professionals than among other public health audiences or wider stakeholder groups and will require explanation of the way SGA is determined; the evidence to support how SGA can negatively impact the infant’s life course and family members is summarized above to facilitate these discussions.

Data quality

Standard forms for the collection of the data and model procedures for the uniform registration of the events are developed and recommended for state use through cooperative activities of the states and NCHS. As reported in the NCHS publication U.S. Vital Statistics System, Major Activities and Developments, 1950-1995, efforts to improve the quality and usefulness of vital statistics data are ongoing. NCHS uses techniques such as testing for completeness and accuracy of data, querying incomplete or inconsistent entries on records, updating classifications, improving timeliness and usefulness of data, and keeping pace with evolving technology and changing needs for data. Work with state partners to improve the timeliness of vital event reporting is ongoing, and NCHS is working closely with National Association of Public Health Statistics and Information Systems and the Social Security Administration to modernize the processes through which vital statistics are produced in the United States, including implementation of the 2003 revised certificates.


The number of infants born SGA is collected from birth certificate data and is considered to be an accurate measure of what is contained in the medical record. Reliability can be determined by comparing various methods of measurements to see if the results contain similar values via equivalence assessments. Buescher et al (1993) compared birth certificates and medical records of 395 cases in 42 North Carolina hospitals. The birth weight, Apgar score, and delivery methods had 91.9 percent to 100 percent agreement (Northam & Knapp, 2006).

Simplicity of indicator

The complexity of calculation of SGA is moderate to complex. The complexity comes in comparing the birth weight for age of infants born in a given jurisdiction to the reference percentiles to determine whether an infant is below the 10th percentile. SGA is better known among maternal and child health professionals than among other public health audiences or wider stakeholder groups and will require explanation of the way SGA is determined; the evidence to support how SGA can negatively impact the infant's life course and family members is summarized above to facilitate these discussions.
References


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Life Course Indicator: Small for Gestational Age (LC-11)
Life Course Indicator: Bullying

The Life Course Metrics Project

As MCH programs begin to develop new programming guided by a life course framework, measures are needed to determine the success of their approaches. In response to the need for standardized metrics for the life course approach, AMCHP launched a project designed to identify and promote a set of indicators that can be used to measure progress using the life course approach to improve maternal and child health. This project was funded with support from the W.K. Kellogg Foundation.

Using an RFA process, AMCHP selected seven state teams, Florida, Iowa, Louisiana, Massachusetts, Michigan, Nebraska and North Carolina, to propose, screen, select and develop potential life course indicators across four domains: Capacity, Outcomes, Services, and Risk. The first round of indicators, proposed both by the teams and members of the public included 413 indicators for consideration. The teams distilled the 413 proposed indicators down to 104 indicators that were written up according to three data and five life course criteria for final selection.

In June of 2013, state teams selected 59 indicators for the final set. The indicators were put out for public comment in July 2013, and the final set was released in the Fall of 2013.

Basic Indicator Information

Name of indicator: Bullying (LC-12)

Brief description: Percent of 9-12th graders who reported being bullied on school property or electronically bullied.

Indicator category: Discrimination and Segregation

Indicator domain: Risk/Outcome

Numerator: Number of 9th through 12th grade students (12-17 years) who reported having been bullied on school property or electronically during the past 12 months.

Denominator: 9th through 12th grade student population (12-17 years)

Potential modifiers: Sex, race/ethnicity, grade level, self-reported academics/grades in school

Data source: Youth Risk Behavior Surveillance System (YRBSS)

Notes on calculation: Numerator is derived from the responses to two questions: During the past 12 months, have you ever been bullied on school property? During the past 12 months, have you ever been electronically bullied? (Count being bullied through e-mail, chat rooms, instant messaging, websites or texting.) Respondents who answer yes to either question are included in the numerator. Analysts who use the raw datasets should apply the appropriate survey weights to generate the final estimates.

Similar measures in other indicator sets: Healthy People 2020 focus area IVP-35.
Life Course Indicator: Bullying (LC-12)

**Introduction**
Existing literature supports that bullying on school property and electronically can impact an individual's health and wellness throughout the life course. There are several disparities within the prevalence of this indicator, and bullying can have substantial health-related, psychosocial, and economic impacts. Adolescence also is a critical time of physical and mental development where bullying and associated risk factors have potential to negatively impact the life course trajectory. Schools are key social contexts in which important health and developmental processes unfold for adolescents, and an opportune environment to intervene to prevent bullying and reduce adverse health outcomes in the population.

While childhood is a critical stage in development, there is a lack of standardized data to assess bullying nationwide. Tools such as the National Survey of Children's Health rely on parent reports to measure child involvement in bullying. Children and youth often do not report bullying to adults; therefore self-reported measures, such as those assessed through the Youth Risk Behavior Surveillance System (YRBSS), are more likely to reflect true rates and experiences of bullying. It is for this reason that this indicator and its supporting narrative focus on the 9th-12th grade population.

Furthermore, this narrative acknowledges that bullying has significant associations and implications for both the victim and the perpetrator – to date, the public health field lacks a nationwide, standardized measure of bullying perpetration, and therefore this indicator is limited to bullying victimization. This indicator is a reliable measure of prevalence of bullying among the nation's adolescent population. Improvements in this indicator have potential to greatly improve the health of the adolescent population, both current and throughout life.

**Implications for equity**

Bullying is prevalent among school-age youth, with risk factors among groups that have implications for disparities and inequity in certain environments.

Based on 2011 National YRBSS data, female students (22.0 percent) were more likely than male students (18.2 percent) to have been bullied on school property during the past 12 months [3]. The data also show females are more likely than males to be electronically bullied. Other studies have found males to experience higher rates of bullying, or no disparity [4-6]. This suggests a gender disparity with this indicator that may be dependent on environment and context, which can have implications for public health approaches to prevent bullying. In addition, the association between bullying and psychosocial health varies between males and females, thus interventions should take these differences into account to increase effectiveness.

2011 National YRBSS data also suggest that White students were more likely to have been bullied on school property or electronically during the past 12 months when compared to both Black and Hispanic students [3]. However, it is unclear how many youth are bullied based on their race or ethnicity. Some evidence suggests that Black or Hispanic youth who are bullied fare worse academically, but further research is needed to understand the implications race and ethnicity have on bullying and health equity.

Risk for bullying victimization is higher among lesbian, gay, bisexual, or transgender (LGBT) youth and those perceived as LGBT than heterosexual youth [7]. Often, bullying among students involves the use of homophobic teasing and slurs [8]. LGBT youth struggle with rejection from parents, peers and teachers, as well as societal homophobia. This can put them at greater risk for depression, which compounded with frequent bullying, can lead to increased risk of self-injury or suicide. Indeed, rates of suicide attempts in LGBT youth are between two to seven times higher than their heterosexual peers [9]. Additionally, LGBT students often do not receive much protection or support from school policies or administration [7]. These factors contribute to disparities in bullying victimization among this population.

Disparities also exist for youth with special health care needs (YSHCN), who are particularly vulnerable to bullying victimization. Students with disabilities are subject to more bullying than peers without disabilities, and the bullying is often a direct result of the disability [10]. Youth with disabilities also may have significant social skills challenges, either as a core trait of their disability or as a result of social isolation due to segregated environments or peer rejection. While all youth victims of bullying face negative emotional, educational and physical outcomes from bullying, students with disabilities are disproportionately impacted by the bullying.

Other studies have found that victims of bullying are more likely to be from low income families, not have a happy home life, have frequent arguments with their parents, and feel like leaving home [6,11].
Public health impact

Bullying is a significant problem in our society that can have short and long-term psychological and health implications. In 2011, 20.1 percent of 9th through 12th grade students within the United States reported that they were bullied on school property and 16.2 percent reported they had been electronically bullied at some point during the past 12 months [3].

Evidence indicates bullying victims and perpetrators to have higher levels of depression, self-harm behavior, engagement in risky behaviors and suicidal ideation and suicide attempts. Suicide is the third leading cause of death of adolescents aged 15-19 years [12]; therefore bullying as a risk factor is a particular concern for public health. Youth involved in bullying also report lower levels of academic achievement and school attachment [13], and are more likely to report physical health problems, such as abdominal pains [14], and develop other common health programs, such as obesity [15].

Long-term health outcomes associated with bullying also have implications for public health. Individuals bullied as youth are more likely to develop generalized anxiety disorder, panic disorder, depression and suicidality as adults [16]. Further, research has shown those who bully as youth are more likely to have low job status at 18 years old, and use drugs, alcohol and cigarettes [17-18].

Reducing bullying within our schools and electronically should have a direct impact on the prevalence of these adverse health outcomes within the adolescent population, and potential to reduce the number of conditions that impact health as adults. Reducing the prevalence and impact of mental health conditions that are often lifelong and debilitating also should result in a reduction in health care costs. Public health policies and interventions that focus on reducing risk factors of bullying and promoting protective factors and resilience have the potential to lead to improved mental health outcomes, academic achievement, and reduce mortality in the adolescent populations.

Leverage or realign resources

While bullying is not a new issue for youth, the awareness of the harmful effects of bullying and understanding of the risk factors is relatively new. The Task Force on Community Preventive Services conducted a systematic review and found strong evidence that universal, school-based programs decrease rates of violence among school children [23]. These programs were delivered to all children in a particular grade or school, regardless of prior violence or risk of violence, and effects of the program were found at all grade levels. The Task Force on Community Preventive Services has recommended the implementation of universal, school-based programs to prevent violent behavior, including bullying.

Expanded bullying education programs for students and staff are needed in order to address this public health issue. Continued research also will contribute to a better understanding and recognition of bullying risk factors, in order to develop effective interventions. Further school funding is needed for the implementation of programs that educate students and staff on bullying and the severe impacts it can have on other students. These programs also should identify support mechanisms for students who are currently being bullied.

Health care providers often do not screen for emotional distress or provide services to address bullying [19]. There is an opportunity to expand health care services, and also make inroads with multiple settings – schools, communities, homes, etc. – in order to provide comprehensive, coordinated approaches to bullying prevention and reach more youth at risk. Bullying prevention also can be addressed through general youth violence prevention efforts and efforts to promote mental health and well-being among youth and families in clinical and nonclinical settings. Additionally, school anti-bullying policies are an important step to preventing bullying. Policies that include specific protections for at-risk groups (i.e. LGBT) can reduce bullying and also have protective effects for the mental health of students in those populations [7].

The potential to leverage and realign resources to impact bullying is great as efforts to reduce youth violence and promote mental health address many of the same factors to improve the mental and physical health of young people.

Predict an individual’s health and wellness and/or that of their offspring

Being bullied on school property or electronically over time can affect the life course trajectory of children and adolescents as well as their long-term health.

Adolescence is a pivotal point in development that involves complex endocrine, neural, and social changes that can make adolescents very susceptible to psychological, physical, and emotional challenges, as well as risky behavior [20-21]. The
link between bullying and a multitude of adverse psychosocial health outcomes indicates that intervening during this critical time can have a positive impact on an individual’s life course.

Bullying victims have shown increased internalizing behaviors (such as depression, anxiety, withdrawal, and avoidance), negative attitudes towards self, and lower social skills. Those who bully have shown higher externalizing behaviors (such as defiant or disruptive behaviors), academic challenges and negative self-cognitions [22]. Public health and other professionals may be able to positively affect the life course of adolescents through integrated approaches that aim to stop and prevent risk factors associated with bullying, as well as increase coping skills, family and school social support and supportive school environments. Such approaches can help ensure youth have skills and support to navigate the circumstances and complexities later in life and transition to young adulthood successfully.

Data Criteria

Data availability
The prevalence of having been bullied on school property or electronically during the past 12 months is calculated every two years based on data collected through the YRBSS. The YRBSS monitors priority health-risk behaviors and the prevalence of obesity and asthma among youth and young adults. The YRBSS includes a national school-based survey conducted by the Centers for Disease Control and Prevention (CDC), state, territorial, and local education and health agencies and tribal governments. YRBSS monitors six categories of priority health-risk behaviors among youth and young adults, including behaviors that contribute to unintentional injuries and violence; sexual behaviors that contribute to unintended pregnancy and sexually transmitted diseases, including HIV infection; alcohol and other drug use; tobacco use; unhealthy dietary behaviors; and inadequate physical activity. In addition, YRBSS monitors the prevalence of obesity and asthma.

The YRBSS is administered every other year (odd years), generally in the spring semester in schools via a pencil and paper mode. The YRBSS survey contains no skip patterns. In the even-numbered years, CDC leads a process of examining and revising the questionnaire, using both expert opinion and votes from the YRBSS coordinators in states. The final result is a standard questionnaire that can be modified by states to meet their needs, but modifications must be within certain parameters.: 1) the modified questionnaire must contain at least two-thirds of the original standard questionnaire, 2) questions that are added are limited to 8 mutually exclusive response options, 3) the questionnaire may not have skip patterns or fill in the blanks, and 4) the questionnaire may not exceed 99 questions, and the state must retain the height and weight questions. The 2011 YRBSS included a national school-based survey conducted by CDC and 47 state surveys, six territory surveys, two tribal government surveys, and 22 local surveys conducted among students in grades 9-12 during October 2010-February 2012. Data collected by CDC represent both public and private schools with students in grades 9 through 12; data collected by states, territories, tribes, and localities represents primarily public school students.

The YRBSS question related to this measure is part of the standard high school YRBSS questionnaire. These data are collected every two years at the national level and within approximately 90 percent of all states. Territorial, tribal, and local surveys also are conducted on a non-routine basis. The data for each jurisdiction (nation, state, territory, tribe, and local) are weighted by CDC so that the prevalence estimates based on these data are representative of the 9th through 12th grade student populations (12-17 years) within each jurisdiction. Jurisdiction-specific YRBSS prevalence estimates (overall and by potential modifiers) can be found on the Youth Online data exploration system (http://apps.nccd.cdc.gov/youthonline). These prevalence estimates also can be obtained by visiting state-specific YRBSS websites. For those who would like to analyze the data on their own, national YRBSS datasets and documentation files can be downloaded from the YRBSS Data Files & Methods website (http://www.cdc.gov/healthyyouth/yrbs/data/index.htm). Those interested in getting access to state, territory, tribe, or local survey data are required to submit the YRBSS Data Request Form (http://www.cdc.gov/healthyyouth/yrbs/requestdata.htm). YRBSS data collected within one calendar year are usually available to the public by the middle of the next calendar year.

Data quality
From the available YRBSS documentation, the 2011 national YRBSS school response rate was 81 percent; the student response rate was 87 percent; and the overall response rate was 71 percent. Comparisons between estimates for states and districts from the national data collection effort and the surveys collected by states, territories, tribes, and localities...
can be found on the CDC YRBSS website. Each jurisdiction reached a minimum site response rate of 60 percent and therefore had weighted data for that year. Weighted data allows a jurisdiction to make statements from the data that generalize to all high school students in that jurisdiction.

Studies by CDC and others indicate that data about risk behaviors can be gathered as credibly from adolescents as from adults. YRBSS performs internal reliability checks to help identify the small percentage of students who falsify their answers. To obtain truthful answers, students must perceive the survey as important and know procedures have been developed to protect their privacy and allow for anonymous participation.

A test-retest study of the 1999 version of the questionnaire [1] found that 47 percent of items had at least “substantial” reliability, with kappa statistics of agreement of 61 percent or greater, and 93 percent of items had at least “moderate” reliability, with kappas of 41 percent or greater. The study found no differences in reliability by gender, grade, or race/ethnicity. The study found that items related to tobacco use, alcohol and other drug use, and sexual behavior had the highest reliability. By comparison, items asking about dietary behaviors, physical activity, and other health-related topics were less reliable. A study of mode and setting using the YRBSS questions [2] determined that students were more likely to report risk behaviors when they took the survey at school compared with taking the survey at home.

YRBSS prevalence estimates are based on self-reported responses from a random sample of the 9th through 12th grade student population (12-17 years) and thus are subject to some reporting bias that may lead to underreporting or overreporting for some behaviors. Furthermore, the YRBSS only captures information from the youth population that attends school, and therefore, is not 100 percent representative of this age group. CDC uses the most currently available demographic estimates for their weighting procedures. While no validity studies have been conducted on YRBSS questions, the YRBSS bullying on school property indicator is at least of substantial reliability.

**Simplicity of indicator**
The level of complexity in calculating and explaining the bullying on school property or electronically indicator is low. This indicator is based on two YRBSS questions with simple “Yes” or “No” response options. The numerator and denominator are simple and the meaning of this indicator can be easily explained to professionals and the public. This measure does not require the linkage of datasets. CDC calculates and provides the weighting variables necessary for the proper analysis of this indicator. The data analyses for all YRBSS indicators require the use of statistical software programs that can analyze data from complex sample designs (e.g., SUDAAN, SAS, SPSS, STATA, and R).

**References**


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Life Course Indicator: Experiences of Race-Based Discrimination or Racism among Women

The Life Course Metrics Project

As MCH programs begin to develop new programming guided by a life course framework, measures are needed to determine the success of their approaches. In response to the need for standardized metrics for the life course approach, AMCHP launched a project designed to identify and promote a set of indicators that can be used to measure progress using the life course approach to improve maternal and child health. This project was funded with support from the W.K. Kellogg Foundation.

Using an RFA process, AMCHP selected seven state teams, Florida, Iowa, Louisiana, Massachusetts, Michigan, Nebraska and North Carolina, to propose, screen, select and develop potential life course indicators across four domains: Capacity, Outcomes, Services, and Risk. The first round of indicators, proposed both by the teams and members of the public included 413 indicators for consideration. The teams distilled the 413 proposed indicators down to 104 indicators that were written up according to three data and five life course criteria for final selection.

In June of 2013, state teams selected 59 indicators for the final set. The indicators were put out for public comment in July 2013, and the final set was released in the Fall of 2013.

Basic Indicator Information

Name of indicator: Experiences of Race-Based Discrimination or Racism among Women (LC-13)

Brief description: Percent of women who experienced discrimination right before or during pregnancy.

Indicator category: Discrimination and Segregation

Indicator domain: Risk/Outcome

Numerator: Number of women who answer Yes to the question “During the 12 months before your new baby was born, did you feel emotionally upset (for example, angry, sad or frustrated) as a result of how you were treated based on your race?”

Denominator: Total number of women who recently had a live birth

Potential modifiers: race, ethnicity, sex, age, SES, geographic location

Data source: Pregnancy Risk Assessment Monitoring System (PRAMS)

Notes on calculation: Analysts who use the raw datasets should apply the appropriate survey weights to generate the final estimates.

Similar measures in other indicator sets: None
Life Course Criteria

Introduction
In their seminal paper on the life course perspective, Lu and Halfon posit that a portion of the racial and ethnic disparities in birth outcomes in the United States are attributable to the experience of discrimination on the basis of race (Lu and Halfon 2003). This assertion is bolstered by studies that have demonstrated associations between maternal perception of exposure to discrimination during pregnancy and giving birth to a very low birth weight infant, among low income African American women (Collins et al 2000) and experiences of discrimination during prenatal care among African American women with limited incomes (Salm Ward et al 2012). A review of studies demonstrated associations between perceptions of discrimination and poor birth outcomes, including preterm birth, low birth weight, and very low birth weight (Giurgescu 2011). There is evidence that race-based discrimination impacts not only a woman’s health and her birth outcomes, but also impacts birth outcomes across generations. Studies focused primarily on birth weight have demonstrated that a mother who was born low birth weight is more likely to have a child born low birth weight (Emmanuel 1986). The Barker hypothesis demonstrated how the fetal environment (including the experience of stress by the mother during pregnancy) impacts the health of that adult, including coronary artery disease and hypertension risk (Barker et al 1993). Further, the impact of maternal weight on the weight of her offspring is independent of factors such as receipt of adequate prenatal care (Coutinho et al 1997, Collins et al 2003).

Finally, the concept of “weathering,” or early health deterioration among African American women, as introduced and explored by Geronimus (1992 and 1996), explicitly points to the cumulative nature of the impact of discrimination on the health of African American women; “This hypothesis suggests that maternal age be reexamined as being not only a developmental indicator but also a reflection of the ways in which social inequality, racial discrimination, or race bias in exposures to psychosocial or environmental hazards may, on a population level, affect differentially the health of black vs. white women who will become mothers, not only in absolute terms, but also interactively with each other and cumulatively as women age” (Geronimus 1996).

For the purposes of this discussion, the phrases “perceived discrimination” and “experience of discrimination” will be treated as having the same meaning, which is to say that a person is reporting their lived experiences with discrimination; no self-report health survey is able to assess the intent of those inflicting the discrimination.

Implications for equity
A key factor in exploring issues of discrimination is to use a clear definition of racism. Krieger defines racism as, “Institutional and individual practices that create and reinforce oppressive systems of race relations whereby people and institutions engaging in discrimination adversely restrict, by judgment and action, the lives of those against whom they discriminate” (Krieger 2003). This definition is useful because it calls out actions of the individual as well as the policies that contribute to system level institutionalized racism. A further examination of the levels of racism put forth by Jones describes three levels, which include the above-described institutionalized and personally mediated racism, and introduces a third level, internalized racism, which she defines as, “Acceptance by members of the stigmatized races of negative messages about their own abilities and intrinsic worth (Jones 2000).” All three levels of racism contribute to poor health outcomes.

There are many socioeconomic factors that impact the health of women in the United States, including education, income, and health insurance status (Ross et al 2012, Jones et al 2002). There is evidence that women of all racial/ethnic groups have worse health outcomes than their male counterparts (Read and Gorman 2006). Further, women of color have worse health outcomes than their white counterparts (Read and Gorman 2006). All of this information points to a need to focus particularly on the experiences of women as they seek and receive health services.

Pregnancy is a critical and sensitive period in the life course of a woman; her life experiences prior to and during pregnancy have the potential to directly impact the health of her children and her children’s children, as well as the overall health and well-being of her family. Despite decades of work to reduce disparities in birth outcomes, two- and three-fold differences in infant mortality, low birth weight, preterm birth, and other health outcomes persist. As proposed by Lu and Halfon (2003), if the persistent disparity in outcomes is at least in part attributable to the impact of racism experienced by African Americans over generations, it is essential to monitor women’s experiences of discrimination immediately before and during pregnancy, as well as the experiences of discrimination when receiving health care for all adults and the
experiences of racism reported by children. These three life course indicators provide the field of MCH and our partners with a powerful picture of the pervasiveness of experiences of racism, which is the first step in being able to design strategies to reverse racism and restore equity.

Racism in health care can occur at the physician-patient level and at the health care system level including institutionalized racism. As outlined in the Institute of Medicine Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care, racial and ethnic disparities are consistently present across a wide array of diseases, and the quality of health care services received varies by race and ethnicity, with African Americans and Hispanic/Latino Americans receiving poorer quality care than white Americans (Smedley et al 2002). Schulman et al found that the race and sex of the patient affected physician’s decisions about recommending cardiac catheterization even after adjusting for symptoms, clinical characteristics, and physician estimates of the probability of coronary disease; black females were least likely to be referred for cardiac catheterization compared with white males (Schulman et al 1999).

At least one factor that underlies the issue of discrimination in health care is what some call a legacy of racism in health care in the United States that has contributed to distrust in the health care system. The Tuskegee Syphilis Study, in which researchers from the government (the U.S. Public Health Service) withheld treatment from 400 black men with syphilis in Alabama, has been well described. Kennedy et al explore the historical context that contributes to distrust of the health care system, which includes experiences with slavery and segregation, feelings of being used as experimental guinea pigs, and belief of being treated differently from white patients (Kennedy et al 2007). Part of achieving equity is not just to provide equal access to health care, but to ensure that the access is equitable, meaning that it meets the needs of the person receiving it.

An analysis of North Carolina PRAMS data from 2006-2008 found that 16 percent of African American mothers reported emotional upset due to perceived racism compared with only eight percent of white mothers (NC PRAMS fact sheet 2011). Oregon PRAMS conducted a similar analysis with some notable differences. There is very little racial/ethnic diversity in the Oregon population, and therefore, the PRAMS question assesses whether women felt they had ever been treated differently by health care providers during prenatal care, labor, or delivery because of their race, culture, ability to speak or understand English, age, insurance status, neighborhood in which they lived, religious beliefs, sexual orientation or lifestyle, marital status, or desire to have an out-of-hospital birth (DeMarco et al 2008). Nearly one in five Oregon mothers reported discrimination during prenatal care, labor, or delivery, and the most common perceived discrimination was on the basis of age or insurance status. This study illustrates that perceived discrimination, while primarily focused on race, can be related to many other social and economic characteristics; when a woman has more than one of these characteristics (low income, young age, minority race/ethnicity), her chances of experiencing some sort of discrimination may increase.

**Public health impact**

The consequences of experiencing discrimination in health care settings are multifaceted. The sections above addressed the biological consequences for a woman, her family, and potentially for generations, as transmitted through accumulated stress and poor birth outcomes. However, if racism is reduced or eliminated, there are immediate consequences beyond the long-term outcomes, including a potential reduction in the dissatisfaction with the care received (Bird et al 2004), an increase in the likelihood that a woman will continue to seek care (Blanchard and Lurie 2004), and an increase in seeking and receiving preventive health services (Trivedi and Ayanian 2006). In addition to care satisfaction and care seeking behavior, reducing racism may result in improvement in health behaviors and outcomes; for example, studies have found that women who experience racism also are more likely to contract HIV (Newman et al 2008), to smoke (Purnell et al 2012) and be depressed (Ertel et al 2012).

**Leverage or realign resources**

Many public health agencies have begun to implement principles of cultural competence. Betancourt et al defined a framework for cultural competence that addresses barriers to appropriate care at the organizational (leadership/workforce), structural (processes of care), and clinical (provider-patient encounter) levels (Betancourt et al 2003). Experiences of racism occur at all levels of patient interaction, from receptionist to surgeon, and therefore work to ensure culturally and linguistically appropriate care must extend beyond just the provider-patient relationship. All members of facility or practice staff should be included in training and implementation of cultural competence. Health care systems
also can reach out to community services that work to eliminate racism and engage in new partnerships to develop programs for their institution.

Efforts to address the experiences of discrimination in health care and health research have utilized the concepts of “undoing racism” and community-based participatory research (CBPR) to begin the conversations around racism and begin to establish trust (PISAB 2013, Yonas et al 2006). It should be noted that efforts to “un-do” racism and achieve equity require more than a short-term training and will include an authentic partnership between care providers, public health, and communities, including community leaders, to make strides toward improving experiences of care and equity in health care in the long term.

Predict an individual’s health and wellness and/or that of their offspring

Previously discussed in the context of health equity are the impacts and effects of race-based discrimination on a woman’s health and her birth outcomes, the cumulative nature of the impact of discrimination, and the concept of “weathering.” An exploratory study utilizing focus groups of African American women found that women experienced racism throughout the life course, that childhood experiences of racism seemed to have enduring effects, and that women experienced racism directly, through the experiences of their children, and in all three forms outlined above (interpersonal, institutional and internalized) (Nuru-Jeter et al 2009).

In a study of the perceptions of racism among African American mothers participating in a pre-paid health plan, mothers were most concerned about their children being subject to institutionalized racism, such as being harmed or harassed by the police or getting stopped in a predominantly white neighborhood, and respondents who reported high levels of perceived racism also reported greater concern for their children (Vines and Baird 2009).

The experience of racism in health care is further compounded by experience of racism in other areas of life including residential segregation, which also is a life course indicator. According to Williams & Collins (2001), segregation is a main source of racial and ethnic differences in socioeconomic status (SES) by determining equitable access to education and employment opportunities, as well as environmental conditions that may impact health (e.g., health care access, healthy food or physical activity environments), all of which have implications for racial and ethnic differences in health.

Data Criteria

Data availability

PRAMS was initiated in 1987 and is an ongoing population-based surveillance system designed to identify and monitor selected maternal experiences and behaviors that occur before and during pregnancy and during the child’s early infancy. Forty states and New York City currently participate in PRAMS, representing approximately 78 percent of all U.S. live births. Six other states previously participated. The CDC maintains a combined dataset with information from all participating PRAMS states, which represents approximately 87 percent of all live births in the United States. CPONDER is a Web-based query system created to access data collected through PRAMS surveys.

The length of time between an event and entry into the sampling frame is typically two to six months. Because PRAMS data are weighted to the final birth file, there is a data availability lag between the close of a calendar year and access to the final PRAMS dataset. As of July 2013, the most current year of data available in CPONDER was 2008. Although the 40 states and one city that participate in PRAMS have access to their own state data, only states where the minimum response rate has been met are included in CPONDER. For 2000-2006, this required response rate was 70 percent, and for 2007-08 it was 65 percent. The required response rate may limit the availability of a “national” estimate through CPONDER, but states with PRAMS are encouraged to use their own data whenever possible. The PRAMS survey consists of core questions that all states must include and standard, pilot-tested questions that states may choose to add. In addition, PRAMS allows states to design and add their own questions, and the state is responsible for completing question testing before the question can be included.

Although the question associated with this indicator is part of the standard list of questions that states can add to their PRAMS surveys, this indicator is not available for all states. This question was asked in Phase Five of the survey (2004-2008) for: North Carolina, New York City, Tennessee, Washington and Wisconsin; in Phase Six of the survey (2009-2011)
by: Michigan, North Carolina, Tennessee, and Wisconsin. Currently, there are nine sites using this question in Phase 7 of PRAMS (2012- present): Wisconsin, Ohio, Virginia, Louisiana, Minnesota, North Carolina, Utah, New York City and Iowa.

**Data quality**

PRAMS is a mixed-mode surveillance system that combines mail and telephone surveillance. Each year’s sample is weighted to represent all births that meet the inclusion criteria before reporting. Unlike many health surveys, the PRAMS project has a wealth of information from the birth certificate on those who do not respond by either mode of contact, and therefore weighting can be effective at minimizing differences between respondents and non-respondents.

Since the PRAMS survey is completed retrospectively by a woman two to six months after her birth outcome, some bias may occur due to self-reporting and recall. PRAMS is sampled from live births only, so the data do not include information on other pregnancy outcomes such as abortions, miscarriages, or stillbirths; the data do include responses from women who have experienced an infant death. PRAMS is sampled among singleton, twin, and triplet births, and therefore it is not representative of higher order births.

This measure is unique in its availability because no other data source captures this information specifically for women who have had a live birth. However, this is a single question that attempts to measure a very complex construct, and there have been no studies to date that have validated the information collected.

**Simplicity of indicator**

This indicator is relatively simple to calculate across geographic regions, where available, once the data has been downloaded and available. The indicator is simple to explain and use.

**References**


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The Life Course Metrics Project

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Using an RFA process, AMCHP selected seven state teams, Florida, Iowa, Louisiana, Massachusetts, Michigan, Nebraska and North Carolina, to propose, screen, select and develop potential life course indicators across four domains: Capacity, Outcomes, Services, and Risk. The first round of indicators, proposed both by the teams and members of the public included 413 indicators for consideration. The teams distilled the 413 proposed indicators down to 104 indicators that were written up according to three data and five life course criteria for final selection.

In June of 2013, state teams selected 59 indicators for the final set. The indicators were put out for public comment in July 2013, and the final set was released in the Fall of 2013.

Basic Indicator Information

Name of indicator: Perceived Experiences of Discrimination Among Children (LC-14)

Brief description: Percent of children who experienced discrimination in the past year (parent report)

Indicator category: Discrimination and Segregation

Indicator domain: Risk/Outcome

Numerator: Number of children age zero to 17 years who (somewhat or very) often experience racial discrimination in the past year, as reported by their parent

Denominator: Total number of children zero to 17

Potential modifiers: Race, ethnicity, sex, age, SES, Geographic location

Data source: NSCH Survey of Children’s Health (NSCH)

Notes on calculation: This indicator should be calculated from the responses to the screener question “Was [child's name] ever treated or judged unfairly because of [his/her] race or ethnic group?” (Section Nine: Parental Health, ACE10) and the follow-up question, “During the past year, how often was [child’s name] treated or judged unfairly? Would you say very often, somewhat often, rarely, or never?” (Section Nine: Parental Health, ACE11). The numerator includes those who responded “Yes” to the screener question and “very often” or “somewhat often” to the follow-up question. The denominator is obtained from those who answered “No” to the screener question and those who answered “Yes” to the screener question but responded “rarely” or “never” to the follow-up question. Analysts may wish to create a composite variable using the sample code:

```r
Discrimination=.;
if ACE10=0 or (ACE10=1 and (ACE11 in (3,4))) then Discrimination=0;
```
Analysts who use the raw datasets should apply the appropriate survey weights to generate the final estimates.

Similar measures in other indicator sets: None

Life Course Criteria

Introduction
As a life course indicator, a child’s perceived experience of racial discrimination is critical to understanding the impact of racism across the life span and across generations, why disparities in health outcomes persist and what can be done to reverse these trends. For the purposes of this discussion, the phrases “perceived discrimination” and “experience of discrimination” will be treated as having the same meaning, which is to say that a person is reporting their lived experiences with discrimination; no self-report health survey is able to assess the intent of those inflicting the discrimination.

A key factor in exploring issues of discrimination is to use a clear definition of racism. Krieger defines racism as, “institutional and individual practices that create and reinforce oppressive systems of race relations whereby people and institutions engaging in discrimination adversely restrict, by judgment and action, the lives of those against whom they discriminate (Krieger 2003).” This definition is useful because it calls out actions of the individual as well the policies that contribute to system level institutionalized racism. A further examination of the levels of racism put forth by Jones describes three levels, which include the above-described institutionalized and personally mediated racism, and introduces a third level, internalized racism, which she defines as “acceptance by members of the stigmatized races of negative messages about their own abilities and intrinsic worth (Jones 2000).” All three levels of racism contribute to poor health outcomes.

This indicator is the parent’s report of whether their child has been treated unfairly because of his or her race; there is evidence that parents’ and children’s experiences of racism are closely linked. An exploratory study utilizing focus groups of African American women found that women experienced racism throughout the life course, childhood experiences of racism seemed to have enduring effects, and women experienced racism directly, through the experiences of their children (Nuru-Jeter et al 2009). Similarly, in a study of the perceptions of racism among African American mothers participating in a pre-paid health plan, mothers were most concerned about their children being subject to institutionalized racism, such as being harmed or harassed by the police or getting stopped in a predominantly white neighborhood, and respondents who reported high levels of perceived racism also reported greater concern for their children (Vines and Baird 2009).

Implications for equity
Beginning with prenatal health and through adolescence, children of color are at higher risk of illness and death than whites at every stage of development. The stress experienced by women of color as a result of racism has been shown to negatively impact their birth outcomes, which puts children at a disadvantage from the beginning of life (Dominguez et al 2008). Even from a very young age the mental health of children of color can be affected by racism, through their parents’ responses to racism and discrimination (Caughy et al 2004, Sealy 2010). As children get older the effects of racism become more pronounced. One study found that for African American boys, in particular, perceived racism was associated with a variety of negative psychological outcomes (Nyborg and Curry 2003, Wang and Huguley 2012). Children of color experience detrimental effects to their academic achievement as a result of racial discrimination, without concerted efforts by their parents to prevent such problems (Wang and Huguley 2012, Stein and Gonzalez 2012).

While adverse events and exposures can be harmful at any life stage, using a life course approach, childhood (especially early childhood) is a critical and sensitive period of development where the potential for harmful impact of adverse exposures is greatest (Fine and Kotelchuck 2010). The development of racial awareness is an ongoing process that evolves over the cognitive and social development of a child (Fisher et al 2000, Sanders-Phillips et al 2009). Parental and
community socialization to race and racism are fundamental to shaping the coping mechanisms of children (Fisher et al 2000) and may have important effects on the well-being of children (Caughy et al 2004).

Educational attainment and lifelong earnings are affected by experiences of discrimination as a child. Latino and African American children are more likely to live in poverty and achieve lower levels of education than their white counterparts (Wickrama et al 2012). Minority children growing up with economic and educational disadvantage are more likely to have poor developmental outcomes and to witness violence than their white counterparts (Schuster et al 2012). Mothers of young children report discrimination and poor food quality related to food insecurity (Sealy 2010).

Perceived racism negatively affects the psychosocial development of racial/ethnic minority children and is associated with lower self-efficacy and higher levels of hopelessness in African American boys; these feelings can lead to both internalized behavior, such as anxiety, depression, and withdrawal, and externalized behavior, such as anger and aggression (Nyborg and Curry 2003; Sanders-Phillips 1997; Grant et al 2005). Latino youth who report discrimination have higher rates of depressive symptoms than their white peers (Stein et al 2012). Racism experienced by minority youth also results in anxiety and negative immunological/inflammatory responses (Sanders-Phillips et al 2009). Perceived discrimination by youth also can lead to increased risk of diabetes and cardiovascular disease (Borrell et al 2006).

As proposed by Lu and Halfon (2003), if the persistent disparity in outcomes is at least in part attributable to the impact of racism experienced by African Americans over generations, it is essential to monitor the experiences of racism reported by children as well as women’s experiences of discrimination immediately before and during pregnancy and the experiences of discrimination when receiving health care for all adults. These three life course indicators provide the field of MCH and our partners with a powerful picture of how pervasive experiences of racism are, which is the first step in being able to design strategies to reverse racism and restore equity.

**Public health impact**

Given the physiologic and psychological implications of experiencing racism described above, the potential impact on population health if racism was eliminated would be a narrowing of disparities on nearly every health outcome. Protecting the health and safety of children through programs that look to eliminate racism and reduce violence in partnership with minority communities could have a significant public health impact on accident, suicide and homicide rates, currently the first, second and fourth leading causes of death among minority children (Bernard et al 2007); African Americans have the highest rates of homicide for children aged one to 19 years (Bernard et al 2007).

Sealy (2010) describes how racism can impact food choices and availability for parents of six to 12 year olds in New York City neighborhoods; obesity has been linked to experience of discrimination, and parental food selection and behaviors are important factors for childhood obesity. Approximately one in four Latino and African American children are obese (Office of Minority Health, 2012), putting children at elevated risk of hypertension, high cholesterol, and diabetes. The financial cost of childhood obesity is estimated to be three billion dollars a year (CDC 2010).

In addition to impact on individual health behaviors and outcomes, discrimination plays a role in children’s living environments. Residential segregation, the enforced separation of various racial groups in a community, is associated with toxic air exposures and increased cancer risk due to air pollution (Lopez 2002). Cutler and Glaeser (1997) estimated that one standard deviation decrease in segregation would eliminate one third of the black-white differences in education and employment disparities. More information about racial residential segregation can be found in the narrative for that indicator.

**Leverage or realign resources**

Many public health agencies have begun to implement principles of cultural competence. Betancourt et al defined a framework for cultural competence that addresses barriers to appropriate care at the organizational (leadership/workforce), structural (processes of care), and clinical (provider-patient encounter) levels (Betancourt et al 2003). Experiences of racism occur at all levels of patient interaction, from receptionist to surgeon, and therefore work to ensure culturally and linguistically appropriate care must extend beyond just the provider-patient relationship. All members of facility or practice staff should be included in training and implementation of cultural competence. Health care systems also can reach out to community services that work to eliminate racism and engage in new partnerships to develop programs for their institution.
Efforts to address the experiences of discrimination in health care and health research have utilized the concepts of “undoing racism” and community-based participatory research (CBPR) to begin the conversations around racism and begin to establish trust (PISAB 2013, Yonas et al 2006). It should be noted that efforts to “un-do” racism and achieve equity require more than a short-term training and will include an authentic partnership between care providers, public health, and communities, including community leaders, to make strides toward improving experiences of care and equality in health care in the long term.

Elimination of racism is one step toward the reduction of racial and ethnic inequalities related to infant mortality, a key indicator of the health of any given community (Lu et al 2010). Because racism affects so many spheres of life for ethnic/racial minority children, it is essential for public health leaders to expand partnerships beyond the typical health care sphere.

Wildeman and Western (2010) describe a multifactorial etiology of racism, and therefore multiple and comprehensive solutions. The authors recommend everything from criminal justice reform, improved mental illness and addiction services to economic opportunity creation and immigration reform (Wildeman and Western).

**Predict an individual’s health and wellness and/or that of their offspring**

Racism and racial discrimination affect children physically, psychologically and socially at a time when their development is vulnerable to negative influences. More research is needed in this field, but a review of the literature by Pachter and Coll in 2009 found that most studies demonstrated a relationship between perceived racism and behavioral and mental health for children.

In their seminal paper on the life course perspective, Lu and Halfon posit that a portion of the racial and ethnic disparities in birth outcomes in the United States are attributable to the experience of discrimination on the basis of race (Lu and Halfon 2003). This assertion is bolstered by studies that have demonstrated associations between maternal perception of exposure to discrimination during pregnancy and giving birth to a very low birth weight infant, among low income African American women (Collins et al 2000), experiences of discrimination during prenatal care among African American women with limited incomes (Salm Ward et al 2012), and a review of studies demonstrating associations between perceptions of discrimination and poor birth outcomes including preterm birth, low birth weight, and very low birth weight (Giurgescu 2011). Further, there is evidence that race-based discrimination has impacts not only on a woman’s health and her birth outcomes, but also has impacts on birth outcomes across generations; studies focused primarily on birth weight have demonstrated that a mother who was born low birth weight is more likely to have a child born low birth weight, that the fetal environment (including the experience of stress by the mother during pregnancy) impacts the health of that adult, including coronary artery disease and hypertension risk, and that the impact of maternal weight on the weight of her offspring is independent of factors such as receipt of adequate prenatal care (Emmanuel 1986, Barker et al 1993, Coutinho et al 1997, Collins et al 2003). Children born preterm or low birth weight may experience lifelong health and developmental challenges, further compounding the risk associated with experiencing racism. Children born to African American women are twice as likely to die before their first year and more likely to be born low birth weight than their white counterparts (Martin et al 2010).

**Data Criteria**

**Data availability**

This survey, sponsored by the Maternal and Child Health Bureau of the Health Resources and Services Administration, examines the physical and emotional health of children ages zero to 17 years of age. The survey is administered using the State and Local Area Integrated Telephone Survey (SLAITS) methodology, and it is sampled and conducted in such a way that state-level estimates can be obtained for the 50 states, the District of Columbia, and the Virgin Islands. The survey has been designed to emphasize factors that may relate to the well-being of children, including medical homes, family interactions, parental health, school and after-school experiences, and safe neighborhoods. The Maternal and Child Health Bureau leads the development of the NSCH and NS-CSHCN survey and indicators, in collaboration with the National Center for Health Statistics (NCHS) and a national technical expert panel. The expert panel includes representatives from other federal agencies, state Title V leaders, family organizations, and child health researchers, and...
experts in all fields related to the surveys (adolescent health, family and neighborhoods, early childhood and development etc.).

MCH programs can readily gain immediate access to the data through datasets released by the National Center for Health Statistics, and on the MCHB sponsored National Data Resource Center for Child and Adolescent Health Website (www.childhealthdata.org). The Data Resource Center (DRC) website provides data nationwide, for all 50 states and the District of Columbia. Additionally, both the raw datasets and the website allow users to stratify measures by sociodemographic groups, including but not limited to age, sex, race/ethnicity, primary household language, household income, and special health care needs.

Data on child’s experience of discrimination was collected for the first time in the 2011/12 National Survey of Child Health as part of a larger module on Adverse Childhood Experiences. The question used to assess experience of discrimination was, “Was [child’s name] ever treated or judged unfairly because of [his/her] race or ethnic group?” This data became available for public use in 2013.

**Data quality**
The main limitation of the NSCH is that the information provided is from parent recollection of screenings received and perception of child’s health and development over the past year. The survey methodology does not provide an opportunity for confirmation with medical records or physical measurements. The NSCH is weighted to represent the national population of non-institutionalized children age zero to 17 years. According to the survey documentation, missing data for income were relatively high for 2011-2012 data, and a study of nonresponse patterns indicated that excluding records with missing income could impact the representativeness of the remaining data; therefore, a data file with imputed values for income is provided to be used with the datasets.

The NSCH documentation presents both response rates and completion rates. For 2011-2012 data, the combined national response rate for both landline and cell phone samples was 23 percent. The completion rate, which is calculated as the proportion of households known to include children that completed all sections up to and including Section 6 (for children less than six years of age) or Section 7 (for children six to 17 years of age), was 54.1 percent for the landline sample and 41.2 percent for the cell-phone sample.

Qualitative testing of the entire 2007 National Survey of Children’s Health was conducted by the National Center for Health Statistics. They conducted cognitive interviews with the 2007 NSCH Computer-Assisted Telephone Interview (CATI) to make sure the entire survey instrument was functioning properly. N=640 interviews were completed over three days in December 2006. The questionnaire was then revised and finalized based on feedback from participants in these interviews.

Previously validated questions and scales are used when available. All aspects of the survey are subjected to extensive literature and expert review. Respondents’ cognitive understanding of the survey questions is assessed during the pretest phase and revisions made as required. All final data components are verified by NCHS and DRC/CAHMI staff prior to public release. Face validity is conducted in comparing results with prior years of the survey and/or results from other implementations of items.

The experience of discrimination question was added to the questions about Adverse Childhood Experiences after a review of life course stressors in children’s lives by a Technical Expert Panel. This TEP included a representative group of experts in the field of survey methodology, children's health, community organizations, and family leaders. Input from the Technical Expert Panel and a period of public comment led to the inclusion of items on perceived discrimination, death of a parent, witness/victim of neighborhood violence, and socioeconomic hardship in the list of Adverse Family Experiences. The measure is the parent report of a child’s experience, which may introduce some bias into the responses if a parent chooses not to report discrimination their child has experienced. There are currently no reliability or validity data available for this item.

**Simplicity of indicator**
The level of complexity in calculating and explaining this indicator is low. The numerator and denominator are simple. Data weighting, indexing, or adjustments are not required and the statistical formula is straightforward.
This measure can be readily and simply explained. The community at large can easily identify and understand evidence suggesting that people who perceive more discrimination directed at themselves or other members of their group are at greater risk for reduced mental and physical health status (Paradies 2006, Williams 2002).

References


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Life Course Indicator: Perceived Experiences of Racial Discrimination in Healthcare among Adults

The Life Course Metrics Project

As MCH programs begin to develop new programming guided by a life course framework, measures are needed to determine the success of their approaches. In response to the need for standardized metrics for the life course approach, AMCHP launched a project designed to identify and promote a set of indicators that can be used to measure progress using the life course approach to improve maternal and child health. This project was funded with support from the W.K. Kellogg Foundation.

Using an RFA process, AMCHP selected seven state teams, Florida, Iowa, Louisiana, Massachusetts, Michigan, Nebraska and North Carolina, to propose, screen, select and develop potential life course indicators across four domains: Capacity, Outcomes, Services, and Risk. The first round of indicators, proposed both by the teams and members of the public included 413 indicators for consideration. The teams distilled the 413 proposed indicators down to 104 indicators that were written up according to three data and five life course criteria for final selection.

In June of 2013, state teams selected 59 indicators for the final set. The indicators were put out for public comment in July 2013, and the final set was released in the Fall of 2013.

Basic Indicator Information

Name of indicator: Perceived Experiences of Racial Discrimination in Health Care among Adults (LC-15)

Brief description: Percent of adults reporting racial discrimination in health care

Indicator category: Discrimination and Segregation

Indicator domain: Risk/Outcome

Numerator: Adults 18 and over reporting perceived racial discrimination in health care

Denominator: Total adults 18 and over

Potential modifiers: Race, ethnicity, age, SES, geographic location

Data source: Behavioral Risk Factor Surveillance System (BRFSS)

Notes on calculation: Numerator: Include those who answered 1 (1=Worse than other races) and 4 (4=Worse than some races, better than others) to the question "Within the past 12 months, when seeking health care, do you feel your experiences were worse than, the same as, or better than for people of other races?"

Recommendation: if you want to construct a comparison group, we recommend grouping 2 (The same as other races) and 3 (Better than other races) together. Analysts who use the raw datasets should apply the appropriate survey weights to generate the final estimates.

Similar measures in other indicator sets: None
Life Course Criteria

Introduction
As a life course indicator, the experience of racial discrimination in health care is critical to understanding the impact of racism across the lifespan and across generations, why disparities in health outcomes persist and what can be done to reverse these trends. For the purposes of this discussion, the phrases “perceived discrimination” and “experience of discrimination” will be treated as having the same meaning, which is to say that a person is reporting their lived experiences with discrimination; no self-report health survey is able to assess the intent of those inflicting the discrimination.

A key factor in exploring issues of discrimination is to use a clear definition of racism. Krieger defines racism as, “Institutional and individual practices that create and reinforce oppressive systems of race relations whereby people and institutions engaging in discrimination adversely restrict, by judgment and action, the lives of those against whom they discriminate” (Krieger 2003). This definition is useful because it calls out actions of the individual as well as the policies that contribute to system level institutionalized racism. A further examination of the levels of racism put forth by Jones describes three levels, which include the above-described institutionalized and personally mediated racism, and introduces a third level, internalized racism, which she defines as, “Acceptance by members of the stigmatized races of negative messages about their own abilities and intrinsic worth” (Jones 2000). All three levels of racism contribute to poor health outcomes.

Hausmann et al used the 2004 BRFSS perceived discrimination data from seven states to study the impact on health outcomes for the three largest racial/ethnic groups in the United States (white, African American, and Hispanic); African Americans perceived discrimination three times more often than white Americans, and those who perceived discrimination were twice as likely to report poor health status compared with those who did not (Hausmann et al 2008).

Implications for equity
Racial disparities in health outcomes persist in many areas of health care in the United States and are well documented (Lewit et al 1995). Disparities remain even after controlling for access to health care, health insurance status, and socioeconomic status.

Experience of racism is negatively associated with mental well-being and physical health. The mental and physical effects of racism have been compared to responses similar to those seen resulting from trauma (Mendez et al 2012, Purnell et al 2012). Patients who perceive that they are receiving sub-standard care because of their race/ethnicity or other characteristics are less likely to continue seeking care at that facility or any other facility (Ertel et al 2012).

Racism in health care can occur at the physician-patient level and at the health care system level; components of system-level racism can be characterized as institutionalized racism. As outlined in the Institute of Medicine’s Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care, racial and ethnic disparities are consistently present across a wide array of diseases, and the quality of health care services received varies by race and ethnicity, with African Americans and Hispanic/Latino Americans receiving poorer quality care than white Americans (Smedley 2009). Schulman et al found that the race and sex of the patient affected physician’s decisions about recommending cardiac catheterization even after adjusting for symptoms, clinical characteristics, and physician estimates of the probability of coronary disease; black females were least likely to be referred for cardiac catheterization compared with white males (Schulman et al 1999). This study, which used actors and controlled symptom scenarios, is supported by numerous epidemiologic studies of differences in treatment by race and sex (see list within references).

At least one factor that underlies the issue of discrimination in health care is what some call a legacy of racism in health care in the United States that has contributed to distrust in the health care system. The Tuskegee Syphilis Study, in which researchers from the government (the U.S. Public Health Service) withheld treatment from 400 black men with syphilis in Alabama, has been well described. Kennedy et al explore the historical context that contributes to distrust of the health care system, which includes experiences with slavery and segregation, feelings of being used as experimental guinea pigs, and belief of being treated differently from white patients (Kennedy et al 2007). Part of achieving equity is not just to provide equal access to health care, but to ensure that the access is equitable, meaning that it meets the needs of the person receiving it.
As proposed by Lu and Halfon (2003), if the persistent disparity in health outcomes is at least in part attributable to the impact of racism experienced by African Americans over generations, it is essential to monitor the experiences of discrimination when receiving health care for all adults, as well as women’s experiences of discrimination immediately before and during pregnancy and the experiences of racism reported by children. These three life course indicators provide the field of MCH and our partners with a powerful picture of the pervasive experience of racism, which is the first step in being able to design strategies to reverse racism and restore equity.

**Public health impact**

There is evidence to suggest that people who perceive more discrimination directed at themselves or other members of their racial/ethnic group are at greater risk for poor mental and physical health status (Ross et al 2012, Hummer et al 2010). Given the many studies that have documented the impact of differential treatment based on race that persists even when controlling for socioeconomic factors, a decrease in the experience of racism during health care interactions should lead to better health outcomes and a narrowing of health disparities on nearly every disease measure. Besides the long-term health outcome impacts, there are more immediate consequences of experiencing racism in health care, including dissatisfaction with the care received (Bird et al 2004, Bankert et al 2006), a decrease in the likelihood that a person will continue to seek care (Blanchard and Lurie 2004), and a decrease in receiving preventive health services (Trivedi and Ayanian 2006).

**Leverage or realign resources**

Many public health agencies have begun to implement principles of cultural competence. Betancourt et al defined a framework for cultural competence that addresses barriers to appropriate care at the organizational (leadership/workforce), structural (processes of care), and clinical (provider-patient encounter) levels (Betancourt et al 2003). Experiences of racism occur at all levels of patient interaction, from receptionist to surgeon, and therefore work to assure culturally and linguistically appropriate care must extend beyond just the provider-patient relationship. All members of facility or practice staff should be included in training and implementation of cultural competence. Health care systems also can reach out to community services that work to eliminate racism and engage in new partnerships to develop programs for their institution.

Efforts to address the experiences of discrimination in health care and health research have utilized the concepts of “undoing racism” and community-based participatory research (CBPR) to begin the conversations around racism and begin to establish trust (PISAB 2013, Yonas et al 2006). It should be noted that efforts to “un-do” racism and achieve equity require more than a short-term training and will include an authentic partnership between care providers, public health, and communities, including community leaders, to take strides toward improving experiences of care and equity in health care in the long-term.

**Predict an individual’s health and wellness and/or that of their offspring**

In their seminal paper on the life course perspective, Lu and Halfon posit that a portion of the racial and ethnic disparities in birth outcomes in the United States are attributable to the experience of discrimination on the basis of race (Lu and Halfon 2003). Further, there is evidence that race-based discrimination has impacts not only on a woman’s health and her birth outcomes, but also has impacts on birth outcomes across generations; studies focused primarily on birthweight have demonstrated that a mother who was born low birthweight is more likely to have a child born low birthweight, that the fetal environment (including the experience of stress by the mother during pregnancy) impacts the health of that adult, including coronary artery disease and hypertension risk, and that the impact of maternal weight on the weight of her offspring is independent of factors such as receipt of adequate prenatal care (Emmanuel 1986, Barker et al 1993, Coutinho et al 1997, Collins et al 2003).

Additionally, the concept of “weathering,” or early health deterioration among African American women, as introduced and explored by Geronimus (1992 and 1996), explicitly points to the cumulative nature of the impact of discrimination on the health of African American women; “This hypothesis suggests that maternal age be reexamined as being not only a developmental indicator but also a reflection of the ways in which social inequality, racial discrimination, or race bias in exposures to psychosocial or environmental hazards may, on a population level, affect differentially the health of black vs. white women who will become mothers, not only in absolute terms, but also interactively with each other and cumulatively as women age” (Geronimus 1996).
The experience of racism in health care is further compounded by experience of racism in other areas of life including residential segregation, which also is a life course indicator. According to Williams & Collins (2001), segregation is a main source of racial and ethnic differences in socioeconomic status (SES) by determining equitable access to education and employment opportunities, as well as environmental conditions that may impact health (e.g., health care access, healthy food or physical activity environments), all of which have great implications for racial and ethnic differences in health.

Data Criteria

Data availability
The Behavioral Risk Factor Surveillance System (BRFSS) is the world's largest, on-going telephone health survey system, tracking health conditions and risk behaviors in the United States annually since 1984. Currently, data are collected monthly in all 50 states, the District of Columbia, Puerto Rico, the U.S. Virgin Islands, and Guam. The Centers for Disease Control and Prevention (CDC) provides state and national level prevalence data on their website.

The CDC develops approximately 80 questions each year. Some of these are core questions asked each year, and some are rotating core questions asked every other year. There also are CDC supported modules that address specific topics that states can use. States may develop additional questions to supplement the core questions. Modules used by states are noted on the CDC website.

Local level estimates for BRFSS data can be obtained using the Selected Metropolitan/Micropolitan Area Risk Trends (SMART) data. Local areas are metropolitan or micropolitan statistical areas (MMSAs) as defined by the Office of Management and Budget. SMART data is currently available for data going back to 2002 for MMSAs with 500 or more respondents. The 2012 data files were released in August 2013, indicating an approximate eight month delay in availability.

The proposed indicator comes from a BRFSS optional module (Reactions to Race) that is not asked by all states and is not included within the BRFSS on a routine basis. It is estimated that no more than a 1/3 of the states actually use this module in any given year, but the module is available for use by all states.

Data quality
Numerous studies have compared estimates of chronic conditions and behaviors obtained from BRFSS to other national surveys, including the National Health Interview Survey and the National Health and Nutrition Examination Survey; while there are some differences, findings on overall health status and certain chronic conditions tended to be similar despite declining response rates for BRFSS.

Since some questions on the BRFSS address sensitive health conditions and behaviors, there is intermittent missing data throughout the dataset. However, refusal to answer generally accounts for a small proportion of responses for most data elements. The notable exception is income, where refusals accounted for more than 23 percent of the data in one state in 2010; the median percent missing across BRFSS for income in 2010 was 14 percent.

Quality control computer programs are used to check the raw data for values out of range. CDC performs quality checks for core questions, and each state has its own protocol for checking state-specific questions. Interviewers are monitored during the annual questionnaire pilot period and intermittently during the data collection period to determine whether any interviewer bias exists and to correct any bias that might be found. On an ongoing basis, 10 percent of interview calls are verified.

Prior to 2011, the sampling for BRFSS represented only adults living in a private residence with a landline telephone, but starting in 2011, the sample also included data from respondents living in cell phone-only households. Weighted response rates are presented by state. For 2011, the median weighted response rate for the combined cell phone and landline was 49.7 percent.

The survey adjusts for non-response to reduce the known differences between respondents and non-respondents. Although participants interviewed may not represent a state in terms of age, sex and race distribution, it is believed that
weighting the data corrects for this potential bias. As with other health surveys, estimates are based on self-report data and they may over- or underestimate the actual prevalence of a particular risk factor in the population. Despite some oversampling in states by geography, the annual sample size is too small to compute precise estimates at the county level. The child prevalence data are reliant on proxy report from the adult respondent to the BRFSS and may be subject to misclassification related to this method.

**Simplicity of indicator**

This indicator is relatively simple to calculate across geographic regions, once the data has been downloaded and made available. Because of the BRFSS sampling methods and it being a cross sectional telephone survey, the data must be weighted. Weights are included in the data sets. The indicator also is simple to explain to different audiences.

The question on BRFSS states “Within the past 12 months, when seeking health care, do you feel your experiences were worse than, the same as, or better than for people of other races?” For those who do not know about other people’s experiences when seeking health care, interviewers are to say: “This question is asking about your perceptions when seeking health care. It does not require specific knowledge about other people’s experiences.” Respondents who indicate 1 (1=Worse than other races) and 4 (4=Worse than some races, better than others will be included in the numerator of this indicator (Karlsen et al 2002).

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Life Course Indicator: Perceived Experiences of Racial Discrimination in Healthcare among Adults (LC-15)


Shulman, Epi evidence of differences in treatment by race and sex.


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Life Course Indicator: Racial Residential Segregation, by Community

The Life Course Metrics Project

As MCH programs begin to develop new programming guided by a life course framework, measures are needed to determine the success of their approaches. In response to the need for standardized metrics for the life course approach, AMCHP launched a project designed to identify and promote a set of indicators that can be used to measure progress using the life course approach to improve maternal and child health. This project was funded with support from the W.K. Kellogg Foundation.

Using an RFA process, AMCHP selected seven state teams, Florida, Iowa, Louisiana, Massachusetts, Michigan, Nebraska and North Carolina, to propose, screen, select and develop potential life course indicators across four domains: Capacity, Outcomes, Services, and Risk. The first round of indicators, proposed both by the teams and members of the public included 413 indicators for consideration. The teams distilled the 413 proposed indicators down to 104 indicators that were written up according to three data and five life course criteria for final selection.

In June of 2013, state teams selected 59 indicators for the final set. The indicators were put out for public comment in July 2013, and the final set was released in the Fall of 2013.

Basic Indicator Information

Name of indicator: Racial Residential Segregation, by Community (LC-16)

Brief description: Racial residential segregation as measured through the Dissimilarity Index, the differential distribution of individuals by race or other social or income factors.

Indicator category: Discrimination and Segregation

Indicator domain: Risk/Outcome

Numerator: Number of counties with dissimilarity index (DI) > 0.6 (very segregated)

Denominator: Total number of counties

Potential modifiers: race, ethnicity, sex, age, socioeconomic status (SES) make up of counties, geographic region

Data source: U.S. Bureau of the Census, American Community Survey

Notes on calculation:

\[ D = 5 \times \sum_{i=1}^{n} \left| \frac{x_i}{X} - \frac{y_i}{Y} \right| \]

Where \( n \) is the number of tracts (or smaller geographic area) in a metropolitan area, \( x_i \) is the population size of the minority group of interest in tract \( i \), \( X \) is the population of the minority group in the metropolitan area as a whole, \( y_i \) is the population of the reference group (usually non-Hispanic Whites) in tract \( i \), and \( Y \) is the population of the reference group in the metropolitan area as a whole. It is standard to view cities or other geographic areas with a DI under 0.3 as well integrated, those with a DI value between 0.3 and 0.6 as moderately segregated, and those with values above 0.6 as very segregated (10). This may also be calculated for various racial and ethnic groups.

Similar measures in other indicator sets: None
Life Course Criteria

Introduction
In the United States, racial/ethnic disparities across multiple health outcomes continue to persist (45). The failure to fully account for poorer health outcomes in racial/ethnic minority populations through individual-level factors such as genetics and socioeconomic status, highlights the need to look at social and environment factors (29). Exposure to neighborhood or community level stressors, such as concentrated poverty, can influence health behaviors, risks, and, in turn, health outcomes (56). Racial residential segregation is the degree to which two or more racial groups live separately from one another in a geographic area (62). Racial residential segregation creates differential exposure to neighborhood stressors (29), making this indicator a marker for racial and urban inequality. Racial residential segregation in U.S. metropolitan areas has often emphasized segregation between Black and White households. Segregation may be generated by Black self-segregation, collective action to exclude Black households from White neighborhoods, or individual moves by White households away from integrated neighborhoods (46). While segregation is generally associated with negative outcomes, some studies have demonstrated positive effects, perhaps shielding residents from the impacts of racism, stimulating healthy social networks, or promoting political solidarity (13, 14).

The racial residential segregation indicator is consistent with current life course science; the effects of discrimination contribute to cumulative exposure over the life course (1-3) and across a number of health outcomes. Racial residential segregation affects health outcomes through a variety of pathways including constraining the socioeconomic advancement of minority groups by limiting education quality and employment, as well as by diminishing the benefits of home ownership because disadvantaged neighborhoods have lower school quality, fewer job opportunities, and diminished property values (25). Additionally, racial residential segregation increases the exposure of minority groups to unfavorable neighborhood environments, including crime, environmental hazards, inferior municipal services, and food deserts (25). While neighborhood conditions may influence health outcomes in all age groups, exposure to neighborhood disadvantage during childhood may be particularly harmful, as the effects of this exposure may continue into adolescence and adulthood (27, 41). Minority children have limited access to neighborhoods with opportunities such as good schools and after-school programs, safe streets and playgrounds, and positive role models (27).

Many have hypothesized that racial discrimination may play a large role in disparities in birth outcomes in the United States (59,60,61). While poverty is a significant contributor to racial and ethnic disparities in birth outcomes, higher SES does not confer the same protection for Black women as for White women (12). While research on infant mortality and racial residential segregation has produced mixed results, possibly due to the complex, multidimensional nature of racial residential segregation, studies have found positive associations between segregation and maternal smoking as well as low birth weight among Black women. Racial residential segregation is associated with unequal access to health care resources including health care settings and quality of treatment (25). A study in Milwaukee, WI found Black mothers, regardless of income level, were almost eight times as likely as all White mothers to have inadequate prenatal care, which may have in part been due to living in less desirable areas than White mothers (61).

Implications for equity
The origins and persistence of U.S. racial residential segregation are rooted in manifestations of discrimination and racism (25,45,46), making this indicator a potential marker of institutionalized racism. Patterns of segregation among Black residents in the United States remain the highest of all racial/ethnic groups and higher than levels of economic segregation (38). Though recent national trends suggest that patterns of Black/White segregation have declined between 1980 and 2000, the declines occurred in areas with small Black populations, such as Portland, OR; whereas levels of high segregation in Northeastern and Midwestern metropolitan areas like New York City and Milwaukee have not abated over time (40). One way to quantify racial residential segregation is to examine the evenness of the distribution of the subject population using the Dissimilarity Index (DI). In the United States, non-Hispanic Black residents had an average level of Black residential DI of 0.67 in 2000 (values above 0.6 are considered very segregated), compared with Hispanics (DI = .52) and those who are foreign-born (DI = .44) (30). The dissimilarity index also may be used to examine segregation by income, e.g., residential segregation of the poor from the affluent. However, segregation by income level appears to be much lower than segregation by either race or ethnicity (11).
Similar trends in racial residential segregation hold true when looking specifically at children. Black and Latino children consistently live in more disadvantaged neighborhoods than White children, even the worst-off White children(25). About 74 percent of poor Black children and 60 percent of poor Hispanic children live where poverty rates are higher than those found in the neighborhoods of the worst-off poor White children(25). Further, less common among White children, a large fraction of Black and Latino children consistently experience “double jeopardy,” living in poor families and in poor neighborhoods (25). Children living in and educated in predominantly poor neighborhoods have lower health literacy compared to those in White communities (26, 37). Minority children manifest higher rates of asthma, elevated lead levels, and learning disabilities (27). Neighborhood factors, such as pervasive violence common in low-income communities, also are associated with high rates of obesity, accidental death and increased susceptibility to infectious diseases in youth(2). Racism negatively affects the psychosocial development of racial/ethnic minority children and is associated with lower self-efficacy and higher levels of hopelessness in Black male adolescents; these feelings can lead to both internalized behavior, such as anxiety, depression, and withdrawal, and externalized behavior, such as anger and aggression (47,48,49).

According to Williams & Collins (2001), segregation is a main source of racial and ethnic differences in SES because segregation has truncated socioeconomic mobility for non-Hispanic Black residents, which has in turn created inequitable access to education and employment opportunities (45). Racial residential segregation also exposes minority populations to environmental conditions that impact health (e.g., health care access, healthy food or physical activity) and contribute to racial/ethnic health disparities(45). Policies employed by federal housing, neighborhood organizations, banking institutions, and the real estate industry that deliberately discriminated by race historically restricted non-Hispanic Black residents to undesirable locations(45). Although these policies are now illegal, racism continues to operate internally, interpersonally, and institutionally to contribute to poorer health outcomes (16-23) and to likely account for part of the socioeconomic disadvantage in which many people from certain ethnic and racial groups are concentrated (23, 28).

**Public health impact**

While it is difficult to predict what actual outcomes may result from changes in racial residential segregation, a decrease in the amount of segregation may result in a decrease in a variety of public health indicators, as illustrated below. Research has linked segregation with higher rates of all-cause adult and infant mortality (29). Positive changes in health may differ based on a multitude of characteristics such as age, gender, socioeconomic status, etc. It is, however, also important to remember some of the potentially protective outcomes associated with segregation mentioned above(15).

A goal of the U.S. Department of Health and Human Services’ *Healthy People 2020* initiative is “to achieve health equity, eliminate disparities, and improve the health of all groups”(50). Reducing racial residential segregation could potentially reduce health disparities through decreasing racial/ethnic socioeconomic disparities and improving conditions in the physical and social environment (45). Economic mobility is affected by access to schools in youth and employment opportunities in adults. Due to the high correlation between poverty concentration and racial residential segregation, public schools highly populated with Black and Hispanic children are often also highly populated with low-income children and cannot afford to put the same resources into school quality as middle-class and high-income communities (45). Segregated, high minority population schools have lower test scores, fewer students in advanced placement courses, more deteriorated buildings, higher dropout rates, and higher levels of teen pregnancy when compared to schools in middle-class areas (45). As an adult, racial residential segregation, particularly in urban areas, can limit employment opportunities through a lack of high-paying, entry level jobs in urban, Black neighborhoods as well as through social isolation from positive employment role models and networking opportunities (46). Differences in SES account for portions of health disparities between black and white adults. Overall, Black adults are more likely to experience activity limitations due to chronic conditions and to rate their health as fair or poor compared to whites. However, when these indicators are stratified by economic status, the rates of both activity limitations and fair or poor health ratings are nearly equal between race groups (45).

Racial residential segregation contributes to poor health in minority populations, not just through SES differences but also through neighborhood effects (45,51). Differences in quality of neighborhood exist at all SES levels between Black and White families (45). Segregated, urban residential areas are less conducive to health due to reduced access to civic services, substandard housing conditions, higher exposure to pollutants and allergens, and reduced access to high-quality medical care (45). Reducing racial residential segregation could lead to creation of environments more conducive to the
practice of healthy behaviors in racial/ethnic minority groups. Lack of recreational facilities and personal safety concerns limit physical exercise in economically disadvantaged areas (45). Communities with high concentrations of minority populations are exposed to more targeted advertising by tobacco and alcohol companies and the stressors of these neighborhoods may also make residents more susceptible to using these products (45).

The positive effects on actual health outcomes gained by reducing racial residential segregation may vary by demographic characteristics. A study examining gender when assessing the impacts of racial residential segregation found while there was no relationship between segregation and obesity among men, the same does not hold true for women. Among Black women, in age-, nativity-, and metropolitan demographic-adjusted models, high segregation was associated with a 1.29 (95 percent confidence interval (CI): 1.00, 1.65) times higher obesity prevalence than was low segregation; medium segregation was associated with a 1.35 (95 percent CI: 1.07, 1.70) times higher obesity prevalence (15). Such data suggests that reducing racial residential segregation could lead to a decrease of obesity among Black women. Similar trends may hold true for breast cancer. Breast cancer mortality disparities were largest in racially mixed tracts located in high metropolitan statistical area (MSA)/micropolitan statistical area (MiSA) segregation areas (RR = 2.06, 95 percent CI 1.70, 2.50). For Black but not White women, as MSA/MiSA racial residential segregation increased, there was an increased risk for breast cancer mortality (HR = 2.20, 95 percent CI 1.09, 4.45). In this particular study, for all-cause mortality, MSA/MiSA segregation was not a significant predictor, but increasing tract percent black population was associated with increased risk for white but not Black women (HR 1.29, 95 percent CI 1.05, 1.58)(33).

When specifically considering an older population, a decrease in racial residential segregation may lead to a decrease in major decline and death. Sudano, et al found that after adjusting for demographic characteristics, residence in low, moderate and high location quotient for racial residential segregation (LQRRS) census tracts was associated with greater likelihood of major decline/death compared to those in minimal LQRRS tracts(43).

Leverage or realign resources

Issues of racial residential segregation traditionally rest outside of the public health domain, landing more frequently in the fields of housing and civil liberties. A wider range of sectors are now involved in such issues, including but not limited to representatives from: public health, food policy and justice, environmental justice, and urban planners. Discrimination takes many forms and may occur at multiple levels (8), impacting all facets of the socioecological model (i.e., individual, interpersonal, organizational, community, and public policy levels) (1, 2) and therefore the potential to leverage or realign resources is high. Reducing racial residential segregation will be a complex, long-term process, indicating there also is need for interventions that reduce the negative health impacts of segregation in the short term.

The Fair Housing Act of 1968 makes it illegal to discriminate when renting, selling, or negotiating for housing according to race, color, national origin, religion, sex, or familial status (54). Although the degree of differential treatment of Black buyers compared to White buyers by the real estate industry has declined since the Fair Housing Act, multiple studies indicate Black buyers face continued subtle discrimination by real estate agents and access to mortgages (46). Anyone who believes their rights under this act have been violated can file a complaint with the U.S. Department of Housing and Urban Development (HUD) through a Housing Discrimination Complaint Form available on the HUD website (54).

Federal housing programs are a key partner in addressing this indicator. The federal Housing Choice Voucher Program, formerly known as Section 8, provides subsidized housing vouchers to low-income families with the goal of allowing poor families to move out of high-poverty, predominantly Black neighborhoods (52). Although the HUD has tried to make vouchers acceptable to private landlords and has encouraged housing authorities to spread vouchers over a range of neighborhoods (52), beneficiaries of the program have often ended up limited in housing choices to areas of high economic and racial segregation (53). Housing mobility programs that work in conjunction with the Housing Choice Voucher Program can assist in eliminating barriers to using vouchers in higher opportunity urban neighborhoods and suburban communities. The Baltimore Housing Mobility Program aims to expand fair housing choice among recipients of the Housing Choice Voucher Program through financial counseling, housing counselors, and employment and transportation assistance (53). Since 2003 the Baltimore Housing Mobility Program has helped 1,522 families move to low-poverty, racially integrated suburban and city neighborhoods (53). Families in the program have experienced drastic changes in neighborhood quality, school quality, and enhanced quality of life (53). Nearly 80 percent of the Baltimore
Housing Mobility Program participants said they felt safer, more peaceful, and less stress after their move, while nearly 60 percent felt more motivated and nearly 40 percent felt healthier (53).

Addressing issues such as health care access, healthy food availability, and living wage jobs in areas of high racial residential segregation could work to reduce negative health outcomes resulting from segregation. A possible intervention to address health service availability in high minority population communities is increasing federally qualified health centers (FQHC) in these neighborhoods. Ko et al. found that in 2000, counties with a high non-White dissimilarity index and a high percentage of minority residents were more likely to have a federally qualified health center (FQHC). When the addition of new FQHCs from 2000 to 2007 was examined, the effects of both poverty and non-white dissimilarity indices were positive and significant (26). Residential segregation likely produces geographic segregation of health services, such that provider mal-distribution may explain the association between residential segregation and FQHC supply. Metropolitan areas that fail to achieve greater integration of poor and minority communities may require FQHCs to compensate for provider shortages (29).

An example of food policy work intersecting with racial residential segregation is the Pennsylvania Fresh Food Financing Initiative which provides economic incentives for supermarket chains to locate in underserved low and middle-income communities by providing financing options for them from a combination of public and private funds(26). The program aims not only to provide healthy food to low-wealth communities but also to create living wage jobs and train a qualified workforce. In 2010, more than 88 fresh food projects had been financed throughout Pennsylvania and were expected to bring 5,023 jobs into these communities (55).

**Predict an individual’s health and wellness and/or that of their offspring**

The association between racial discrimination and poor physical and mental health outcomes, morbidity, and mortality has been solidly established in the general population (4-8). Racial residential segregation has implications for the health of individuals at various points in their lives. Experiences of different forms of perceived discrimination, whether racial or other, contribute to poor health outcomes via multiple physiological and psychological mechanisms, such as impaired immune function, chronic activation of the hypothalamic-pituitary-adrenal axis, lowered perceived self-efficacy, as well as an increase in risk-taking and unhealthy behaviors (6, 24). A study examining residential segregation and mortality in 107 U.S. major cities found racial isolation was directly related to all-cause mortality for Black adults even after adjusting for SES. There also are associations of racial residential segregation on health at critical periods in life with the potential for impact on the health of future generations. For example, studies focusing on smoking, specifically smoking behaviors and smoking during pregnancy, both demonstrated a positive association between segregation and smoking (25,59). A 2011 study found a composite measure of segregation had a positive predictive relationship with low birth weight for Black and Hispanic infants, as well as mortality for Black infants (58). There also is evidence that racial residential segregation impacts the health of individual at critical transitional life stages, such as adolescents. Voucher-induced moves to lower poverty neighborhoods benefited adolescent girls’ mental health but harmed the mental health of adolescent boys, particularly when they had baseline health/ developmental issues or a recent history of violent crime victimization (31, 32).

Even at comparable levels of access, racial and ethnic minority groups may receive poorer quality health care than their White counterparts (34). Black pregnant women are less likely to receive medical advice, common prenatal treatments, and information about health risks and complications (35, 36). Lack of cultural sensitivity by providers at multiple levels continues to be a major issue in efforts to address discrimination and its consequences. Recent research suggests racial residential segregation is an important factor in place-based health care disparities. Where health care organization, financing, and availability are all related to community socioeconomic conditions, urban, poor neighborhoods do not have the health care infrastructure of middle-class to upper-class suburban neighborhoods (57). Health care institutions for the poor and uninsured serving segregated, disadvantaged neighborhoods have higher rates of adverse patient safety events (such as retained surgical objects, postoperative sepsis, and catheter-related bloodstream infection) and limited resources (57,63).

Institutional forms of racism are also evident outside the health care setting. The unequal distribution of resources, especially financial resources, is evident across the United States and can account for a substantial proportion of the racial and ethnic variation in health outcomes. Institutionalized racism, as evidenced by racial residential segregation, is still in existence, and Black families remain the most highly segregated racial group regardless of SES (30, 39). Neighborhood segregation leads to a concentration of crime, poverty, overcrowding, pollution, and decreases...
opportunities for quality education, employment, health care, parks, and healthy food options (42). Different dimensions of segregation may have a differential impact on health outcomes (44), however, given that segregation itself is a multifactorial construct (e.g., clustering may represent social capital or social support factors that may be beneficial vs. detrimental to health).

Data Criteria

Data availability
The American Community Survey (ACS) is an ongoing nationwide survey that collects and provides data annually on demographic, social, economic, and housing in the United States. The survey is administered by the U.S. Census Bureau and replaced the decennial census long form starting in 2010. The ACS is sampled each year, resulting in three million addresses selected and approximately two million final interviews. However, the sample drawn is substantially smaller than the one used for the previous Census long form; as a result, data must be pooled across years in order to provide reliable estimates for some geographic unites. The ACS provides yearly estimates for all states, as well as all cities, counties, metropolitan areas, and population groups of 65,000 people or more. For smaller areas, multiple survey years are combined to obtain reliable estimates: three survey years in areas with 20,000 to 65,000 people, and five survey years in areas with fewer than 20,000 people. ACS data are released the year following the year in which they were collected, making the estimates extremely timely. Data are available for all states and available in all 51 jurisdictions.

The data utilized to calculate the indicators are widely available, for every state and for varying geographies (i.e., census tract, zip code tabulation area, county, place or city-level), based on U.S. Census data. The necessary data files must be downloaded and the indicator requires calculation.

Data quality
Since the ACS is a sampled survey, there is uncertainty in the estimates. The Census Bureau takes steps to minimize the error associated with non-sampling error (reporting, coding, sampling frame, survey questionnaires, non-response, and interviewer bias) through the use of trained interviewers and careful review of all questionnaire design, sampling, and analytic steps. In addition, the Census Bureau began releasing margin of error data for ACS estimates starting in 2006; these estimates allow data users to calculate 90 percent confidence limits for all point estimates released from the ACS.

To account for the complex sampling design, the ACS employs an equally complex weighting scheme. The weighting process is well-documented in the survey methodology handbook, accessible on the web. Response rates for the ACS are calculated for housing units and group quarters (person). From 2000 to 2011, the housing unit response rate ranged from a low of 93.1 percent in 2004 to a high of 98 percent in 2009. Between 2006 and 2011, the group quarter response rate ranged from a low of 97.4 percent in 2006 to a high of 98 percent in 2008 and 2009. The quality of the data is excellent and consistent across all jurisdictions. Reliability is high. Sensitivity, specificity, positive predictive value and negative predictive value will vary by outcome of interest.

While different measures can capture certain aspects of segregation, none of them alone is sufficiently robust to depict segregation comprehensively and we must consider the modifiable areal unit problem (MAUP) in segregation examination (9). Both empirical and simulation results have shown that it is sensitive to scale and zoning. Wong (2008) has shown that dissimilarity may increase when the size of the enumeration unit becomes smaller and using smaller areal units produces relatively high segregation measures (9).

Simplicity of indicator
There are at least 20 different indices that can be used to examine segregation. These have been classified by Massey and Denton into five key dimensions of segregation: 1. evenness, 2. exposure, 3. concentration, 4. centralization, 5. clustering. Evenness involves the differential distribution of the subject population, exposure measures potential contact, concentration refers to the relative amount of physical space occupied, centralization indicates the degree to which a group is located near the center of an urban area, and clustering measures the degree to which minority group members live disproportionately in contiguous areas. Within each dimension, there are numerous indices that may be employed.

One of the most common measures of Evenness is the Dissimilarity Index, calculated as:
Life Course Indicator: Racial Residential Segregation, by Community (LC-16)

\[ D = 5 \sum_{i=1}^{n} \left| \frac{x_i}{X} - \frac{y_i}{Y} \right| \]

Where \( n \) is the number of tracts (or smaller geographic area) in a metropolitan area, \( x_i \) is the population size of the minority group of interest in tract \( i \), \( X \) is the population of the minority group in the metropolitan area as a whole, \( y_i \) is the population of the reference group (usually non-Hispanic Whites) in tract \( i \), and \( Y \) is the population of the reference group in the metropolitan area as a whole.

This indicator is not very simple to calculate across geographic regions, but simplicity is improved with appropriate code. This indicator may be calculated at different geographies and averaged up to state level (e.g., at census tract level, then average across counties and then state; or at county-level and average across state). Depending on the intended application, it may make more sense to calculate the indicator at the census tract level, which would entail using five-year ACS estimates; a county level calculation could be done annually. The ability to explain the meaning of the indicator is moderate.

References


Life Course Indicator: Early Intervention

The Life Course Metrics Project

As MCH programs begin to develop new programming guided by a life course framework, measures are needed to determine the success of their approaches. In response to the need for standardized metrics for the life course approach, AMCHP launched a project designed to identify and promote a set of indicators that can be used to measure progress using the life course approach to improve maternal and child health. This project was funded with support from the W.K. Kellogg Foundation.

Using an RFA process, AMCHP selected seven state teams, Florida, Iowa, Louisiana, Massachusetts, Michigan, Nebraska and North Carolina, to propose, screen, select and develop potential life course indicators across four domains: Capacity, Outcomes, Services, and Risk. The first round of indicators, proposed both by the teams and members of the public included 413 indicators for consideration. The teams distilled the 413 proposed indicators down to 104 indicators that were written up according to three data and five life course criteria for final selection.

In June of 2013, state teams selected 59 indicators for the final set. The indicators were put out for public comment in July 2013, and the final set was released in the Fall of 2013.

Basic Indicator Information

Name of indicator: Early Intervention (LC-17)

Brief description: Proportion of children aged zero to three years who received EI services of all children aged zero to three years

Indicator category: Early Life Services

Indicator domain: Service/Capacity

Numerator: Children aged zero to three years receiving Early Intervention services in a given state

Denominator: All children aged zero to three years

Potential modifiers: Race/ethnicity, age of referral, sex, type of eligibility

Data source: IDEA 618 Child Count

Notes on calculation: None

Similar measures in other indicator sets: Healthy People 2020 Maternal, Infant and Child Health (MICH) 29.1 – Proportion of Children (10-35 months) Who Have Been Screened for an Autism Spectrum Disorder (ASD) and Other Developmental Delays
**Life Course Criteria**

**Introduction**

Children from birth to three who are identified as having, or being at risk for, developmental delays are eligible for services under the Early Intervention Program for Infants and Toddlers with Disabilities under Part C of the *Individuals with Disabilities Educational Act* (IDEA) (Federal Registrar, 2011). Congress established the Part C Early Intervention program (hereafter referred to as EI) in 1986. Consistent with life course theory, EI is intended to affect the future needs and development of the children it serves. The goals of the program are to: 1) enhance the development of infant and toddlers with disabilities, 2) reduce educational costs by minimizing the need for special education, 3) minimize the likelihood of institutionalization, and maximize independent living, and 4) enhance the capacity of families to meet the needs of their children (ETAC, 2014).

All states, eligible territories (American Samoa, Guam, Northern Mariana Islands, Puerto Rico and the Virgin Islands) and the District of Columbia (hereafter referred to as the states) participate in EI. Because EI is a federal entitlement program, a condition of participation is that that the states must ensure access to the program to all eligible children and their families. This is accomplished through EI Child Find programs, which require school districts to identify, locate, and evaluate eligible children. Although the states are required to provide EI services to eligible children and families, they have flexibility in how they define developmental delay, whether they include children who are “at risk” for developmental delay in their eligibility criteria, and what state agency leads the program (e.g., public health or education department). This flexibility results in variability in the numbers of children covered and how the EI programs operate across the states. In federal fiscal year (FFY) 2013, almost 340,000 children, representing about 3 percent of the total child population, were served by the EI program. The EI appropriation for FFY 2013 was $438,500,000 (ECTAC, 2014).

**Implications for equity**

Although about 3 percent of children in the United States overall are served by the EI program, the percent of children enrolled in the program vary across the states. For example, the proportion of children enrolled in EI ranged from 1.5 percent in Georgia to 7.0 percent in Massachusetts in 2010 (U.S. Department of Education, 2010). This variability may be explained, in part, by the different state policies related to EI eligibility, including the state definition of developmental delay, but the enrollment differences also raise questions about whether all eligible children in a state are enrolled in EI.

There is some evidence that there are disparities in enrollment related to individual-related characteristics, but the research is equivocal, and more research is needed. Factors found to be associated with lower EI enrollment include poverty, lack of insurance, and race/ethnicity (Shapiro and Derrington, 2004, Feinberg et al., 2001). Additionally, children without diagnoses, or mild delays or conditions have been found to be more likely to have lower EI enrollment compared to those with diagnoses, or moderate or severe delays or conditions (McManus et al., 2009). A Massachusetts analysis also found that children born to older mothers, and those of higher income were more likely to be referred to EI, compared to younger and lower income mothers; and that children born to Asian, foreign-born and non-English speaking mothers were less likely to be referred than children born to White, American-born and English-speaking mothers (Clements, 2006, 2008).

Environmental factors and stressors may play a role in determining who receives and continues EI services. EI is a voluntary program for families, and ongoing involvement can be difficult for families experiencing multiple stressors. Families dealing with homelessness; domestic violence; substance abuse; or lack of social support, adequate shelter and clothing often have difficulty accessing services. Family beliefs and cultures about child development, and sensitivity on the part of families to identify developmental delays in their children may also be contributing factors in low EI enrollment. Research has identified parents’ concerns about diagnoses of developmental delays as a factor in using services (Glascoe, 2003, 2006). There also is some evidence that clinicians may respond differently to patients based on gender, clinical training and the child’s behavior, which could influence decision-making about possible diagnoses and EI referrals (Glascoe, 1993; Sices et al., 2004).

**Public health impact**

EI services are designed to identify and meet the needs of the child in five developmental areas including: physical development, cognitive development, social or emotional development, adaptive development and communications. EI services may be provided in many settings, but are required to be provided in the child’s natural environment (e.g., home).
as possible. Referrals to EI may be made from multiple sources, including physicians, parents or other family members, social workers and others working with the family. All children receiving EI have an Individualized Family Service Plan (IFSP) that specifies the child’s outcomes and services, based on an assessment by a multidisciplinary team. The services most often received by children enrolled in EI include: speech, occupational and physical therapy, as well as early childhood education (Raspa et al., 2010). Family members are critical participants in the EI process, and receive service coordination to support their children’s development.

EI involvement reduces the number of children referred to special education at the age of three years as well as after a child enters school. This impact provides significant cost avoidance to states. For example, in Massachusetts during fiscal year 2010, EI services resulted in a cost avoidance of more than $25 million (MDPH Budget Office, personal communication, Feb. 25, 2011). Although this amount refers to the cost of EI services in Massachusetts, similar savings may be seen across other states. The future savings from investment in EI services are becoming more important as the number of children enrolled nationally continues to rise.

Family-centered EI services can lead to improved developmental, social and educational outcomes. Children who are enabled to reach their fullest potential for school readiness are likely to have a more successful experience in school. Successful achievement, which is tied to academic performance, is a deterrent to juvenile delinquency and school dropout, which are both associated with negative socioeconomic and health outcomes. Schools that are prepared for these children during the transition process from EI to special education are positioned to help maximize the learning experience.

**Leverage or realign resources**

There are many opportunities for EI to leverage or realign resources. Per the 2011 regulations, states are required to coordinate their Child Find systems with specific agencies responsible for such programs as the early hearing detection and intervention, child abuse prevention and treatment, and the maternal and child health home visiting programs (Federal Register 2011). Additionally, the EI program works closely with educators to transition EI enrollees to Part C of the IDEA at the age of three, including Head Start, Early Start and Early Child Education programs, as appropriate. EI programs also coordinate with their Title V and Children with Special Health Care Need programs, as well as the Special Nutrition Supplement Program for Women and Infants and Children (WIC) and the Children’s Health Insurance Program (CHIP).

One of the major opportunities that states are exploring now is working with private and public insurers to cover EI services. This alignment may free up EI funds to potentially support more families (e.g., through expanded eligibility), but also can provide stronger coordination of care for the children and their families. Currently several states have legislation for coverage of EI services by private insurances, and other states are exploring this possibility (Benham 2014).

The Medicaid Program is a particularly important partner for EI. Medicaid covers about one third of the children in the United States, but the program also mandates Early, Periodic, Screening, Diagnosis and Treatment (EPSDT) services for children. These services closely align with EI services. Additionally most Medicaid programs have implemented care coordination activities, including medical homes that also align well with EI services. The majority of the states work with their Medicaid Programs. The Affordable Care Act also presents an opportunity for coverage of EI services in states’ essential benefits packages. Of 31 reporting states, 19 percent have included EI services in their benefits packages, and another 32 percent are still working through the inclusion of EI in their packages (Benham, 2014).

**Predict an individual’s health and wellness and/or that of their offspring**

The National Early Intervention Longitudinal Study found that overall infants and toddlers who participated in EI experienced increased motor, social and cognitive functioning; acquired age-appropriate skills and had reduced negative impacts of their disabilities (Hebbeler et al., 2007). Data for 2011-12 collected from the states showed more than two thirds of the children with greater than expected growth across three areas – social relations, use of knowledge and skills and taking action to meet needs (The Early Child Outcome Center). For this same period, more than 50 percent of the children left the program within age expectations for knowledge; and about 60 percent left within age expectations for social relationships.
Children who function within age expectations are more likely than their peers who do not function within age expectations to have positive life course outcomes. In addition, families who have learned to be better advocates for their children in EI will more than likely continue to do so with other systems and networks, providing more opportunities to improve the child’s health. Their children, in turn, may well become better advocates for themselves and their children, tying EI services into the life course.

**Data Criteria**

**Data availability**

Data collection for EI is outlined in the Federal Register notices. Each state must include a system for compiling and reporting timely and accurate EI data that meets the requirements of the federal regulations of Part C of IDEA. The data system required must include a description of the process that the State uses, or will use, to compile data on infants or toddlers with disabilities receiving early intervention services, including a description of the State’s sampling methods, if sampling is used, for reporting the data required by the Secretary under sections 616 and 618 of the Act and §§303.700 through 303.707. Each State must collect valid and reliable information as needed to report annually to the Secretary on the indicators established by the Secretary for the State Performance Plans and Annual Reports.

For the purposes of the annual report required by section 618 of the Act and §303.720, the lead agency must count and report the number of infants and toddlers receiving early intervention services on any date between Oct. 1 and Dec. 1 of each year. The report must include: 1) The number and percentage of infants and toddlers with disabilities in the state, by race, gender and ethnicity, who are receiving early intervention services (and include in this number any children reported to it by tribes, tribal organizations, etc.); 2) The number and percentage of infants and toddlers with disabilities, by race, gender, and ethnicity, who, from birth through age two, stopped receiving services from the EI program because of program completion or for other reasons; and 3) The number and percentage of at-risk infants and toddlers (as defined in section 632(1) of the Act), by race and ethnicity, who are receiving early intervention services under Part C of the Act.

Every state EI program reports annual Child Count data to the Department of Education, Office of Special Education Programs through the Annual Performance Report. This report includes the percentage of children birth to one and percentage of children birth to three with IFSPs compared to other states.

**Data quality**

The annual number of children served in Early Intervention by a given state as reported in the State’s Annual Performance Report is accurate and reliable. States have been reporting these data for more than 20 years, and there is a verification process in place with local EIIs to ensure the accuracy of the data. Each state must establish procedures to be used by the local EI in counting the number of children with disabilities receiving early intervention services. Each state must establish dates by which those EIIs must report to the lead agency to ensure that the state data are accurate, and obtain certification from the local EIP provider that an unduplicated and accurate count has been made. The state must maintain data for the purposes of audits on the child count.

**Simplicity of indicator**

The level of complexity in calculating and explaining this indicator is low. The numerator and the denominator are simple and straightforward. The numerator is the number of children birth to age three years receiving early intervention services as of a given date. The denominator is provided through census data of the population birth through three years.

Eligibility criteria for EI may vary from state to state; however, there is enough comparability among states for this indicator to be meaningful. For example, the Infant Toddlers Coordinators Association (OSEP DANS, 2012) has established categories of eligibility to include the following:

**Category A:** At Risk, Any Delay, Atypical Development, one standard deviation in one domain, 20 percent delay in two or more domains, 22 percent delay in two or more domains, 25 percent delay in one or more domains.

**Category B:** 25 percent delay in two or more domains, 30 percent delay in one or more domains, 1.3 standard deviations in two domains, 1.5 standard deviations in any domain, 33 percent delay in one domain.
Category C: 33 percent delay in two or more domains, 40 percent delay in one domain, 50 percent delay in one domain, 1.5 standard deviations in two or more domains, 1.75 standard deviations in one domain, two standard deviations in one domain, two standard deviations in two or more domains. Historical Child Count data and cumulative number of children served by each state are available on the ITCA website at ideainfanttoddler.org/pdf/2011-Child-Count-Data-Charts.pdf.

References


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**Life Course Indicator: WIC Nutrition Services**

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**Basic Indicator Information**

**Name of indicator:** WIC Nutrition Services (LC-18)

**Brief description:** Proportion of children aged two to five years receiving WIC services compared to proportion of children <185 percent federal poverty limit (FPL)

**Indicator category:** Early Life Services

**Indicator domain:** Service/Capacity

**Numerator:** Children aged two to five years participating in the WIC program

**Denominator:** Total children aged two to five years whose income is below 185 percent FPL

**Potential modifiers:** Categories of FPL, race/ethnicity, adjunctive eligibility in Supplemental Nutrition Assistance Program (SNAP), TANF, Medicaid. Per federal regulations, the WIC Program can use adjunctive eligibility in SNAP, TANF and/or Medicaid for income verification. In some states, the Medicaid eligibility limits are above 185 percent of the FPL.

**Data source:** WIC program data

**Notes on calculation:** To maintain a comparable indicator across states and jurisdictions, we recommend using a definition of participation based on the U.S. Department of Agriculture (USDA) regulatory definition for children where participants as those who use their WIC checks or EBT card on a monthly basis.

**Similar measures in other indicator sets:** Maternal, Infant, and Early Childhood Home Visiting (MIECHV) Benchmark Area Improvements in Family Economic Self-Sufficiency: Household income (including earnings, cash benefits, and in-kind and non-cash benefits)

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**The Life Course Metrics Project**

As MCH programs begin to develop new programming guided by a life course framework, measures are needed to determine the success of their approaches. In response to the need for standardized metrics for the life course approach, AMCHP launched a project designed to identify and promote a set of indicators that can be used to measure progress using the life course approach to improve maternal and child health. This project was funded with support from the W.K. Kellogg Foundation.

Using an RFA process, AMCHP selected seven state teams, Florida, Iowa, Louisiana, Massachusetts, Michigan, Nebraska and North Carolina, to propose, screen, select and develop potential life course indicators across four domains: Capacity, Outcomes, Services, and Risk. The first round of indicators, proposed both by the teams and members of the public included 413 indicators for consideration. The teams distilled the 413 proposed indicators down to 104 indicators that were written up according to three data and five life course criteria for final selection.

In June of 2013, state teams selected 59 indicators for the final set. The indicators were put out for public comment in July 2013, and the final set was released in the Fall of 2013.
Life Course Criteria

Introduction
The Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) provides federal grants to states for supplemental foods, health care referrals, and nutrition education for low-income pregnant, breastfeeding, and non-breastfeeding postpartum women, and to infants and children up to age five who are found to be at nutritional risk. WIC nutrition services can reduce a child’s risk of malnutrition and nutritional deficiencies, thereby positively impacting the life of low-income children. Additionally, children with improved nutrition are likely to become adults with good nutrition. Good nutrition among adult women, which is encouraged in WIC participants, is important for reducing the risk of poor pregnancy outcomes and for establishing healthy habits for the entire family.

Implications for equity
The WIC program provides nutrition education, breastfeeding support, food, and referrals to health care and social services to nutritionally at-risk low-income pregnant women, postpartum and breastfeeding women, infants, and children until age five years. The USDA Food and Nutrition Service estimated that the average monthly WIC population totaled 14.55 million in 2010. Children aged one to four years made up about 60 percent of the program’s eligible population.

The WIC program serves a racially and ethnically diverse population. The WIC Participant and Program Characteristics 2010 study, conducted by Abt Associates for the Food and Nutrition Service, collected information on WIC participant ethnicities and races (information was based on WIC enrollment not program participation). Among 10,021,138 participants in 2010, 6,107,270 (60.9 percent) were White, 1,934,966 (19.3 percent) were Black, 1,054,982 (10.5 percent) were American Indian, 420,407 (4.2 percent) were of multiple races, 273,040 (2.7 percent) were Asian, and 81,610 (0.8 percent) were Hawaiian/Pacific Islander. The ‘race not reported’ category accounted for the remaining 143,696 (1.4 percent) enrolled participants. Hispanic participants accounted for 4,212,041 (42.0 percent) of the population. Among WIC program enrollees, 2,356,368 (25.5 percent) were women, 2,366,705 (23.6 percent) were infants and 5,298,065 (52.9 percent) were children.

WIC program eligibility is based on income and family size, and the maximum eligibility for any WIC program is 185 percent of the FPL. Consequently, WIC participants come from some of the poorest households in the United States; in 2012, about 75 percent of WIC participants reported an income at or less than 100 percent of the FPL compared with only 15 percent of the general population (USDA 2012). WIC nutrition services can reduce a child’s risk of malnutrition and nutritional deficiencies, thereby positively impacting the lives of low-income children. As the risks for low-income populations have shifted to include overnutrition (taking in more calories than required for normal growth and development) and obesity, WIC has maintained efforts to promote and assist families with healthy eating. Children with improved nutrition are more likely to become adults with good nutrition.

WIC also provides low-income families with opportunities to improve on early childhood developmental outcomes through nutrition. Children whose mothers participated in the program prenationally had improved vocabulary scores, and children who participated in WIC after the first year of life experienced significantly improved memory (USDA 1987). In addition to nutrition services, the WIC program is often used as an entry point to assist families with other needed services or to introduce enhanced opportunities. For example, the Contra Costa health department has developed an initiative called Building Economic Security Today (BEST), which is an asset development pilot project that utilizes innovative strategies to reduce inequities in health outcomes for low-income Contra Costa families by improving their financial security and stability, for this and future generations; BEST is being rolled piloted with the WIC program and includes financial education classes to WIC clients and asset development educational materials and referrals for all clients (Contra Costa Health Services 2014).

Public health impact
The WIC program provides specifically designated supplemental foods, nutritional counseling and referrals to health and social programs with a goal of counteracting the impact of poverty on prenatal, infant and early childhood health. Childhood poverty is known to have lasting impacts on health outcomes (Sell et al 2010). Malnutrition affects brain development and contributes to child mortality worldwide (Bryce et al 2005). Iron deficiency negatively impacts motor and mental development, which can have delayed effects later in childhood (Lozoff et al., 2000). Nutrition interventions early in life, such as WIC, are especially important among lower income populations because lower income populations have
higher rates of diabetes, obesity and other chronic diseases. Trevino et al. demonstrated that low-income children have high levels of diabetes risk factors due to high obesity rates, consumption of high-energy low-nutrient foods, and low levels of physical activity (2008).

The USDA Office of Research and Analysis recently (January 2012) published a review of 16 studies conducted during 2002 to 2010 that evaluated WIC participation and infant and child dietary intake, food security, and related outcomes (USDA 2012). These studies also included data on diet quality, knowledge of infant feeding practices, and food labeling behaviors. Overall, the studies suggested that WIC participation is associated with improved diets, including increased iron density, fewer added sugars, and a greater variety of foods. WIC participation also is positively associated with gestational age and mean birth weight (USDA 2012) and WIC participants were more likely to be up-to-date on immunizations compared to non-eligible children of the same age cohort and WIC-eligible children who did not participate (Luman, 2003). WIC participation was associated with greater use of health care including preventative and restorative dental care (USDA 2012).

A major goal of the WIC Program is to improve the nutritional status of infants. Research has shown that there is no better food than breast milk for a baby's first year of life. Given this, WIC mothers are encouraged to breastfeed their infants. WIC provides ongoing support to breastfeeding mothers by providing peer counseling, extended participation in the WIC program, and enhanced food packages (USDA 2013a). This ongoing support provides many health, nutritional, economical and emotional benefits to mother and baby (USDA 2013b).

In addition to improving diets, WIC is a cost-effective program. As early as 1990, the federal government avoided $853 million in health expenditures for infant care by investing $296 million in prenatal WIC benefits (USGAO, 1992). This expenditure translated to $1 billion savings in health and education related expenditures for the first 18 years of life. Investment in WIC also has saved Medicaid money. Every dollar spent on pregnant WIC participants saved Medicaid between $1.92 to $4.21 (Devaney, Bilheimer, & Schore, 1991). Additionally, the nutrition benefits given to pregnant WIC participants reduced their risk of delivering a low birth weight infant, which resulted in further Medicaid savings (Devaney, 1992).

Leverage or realign resources
This indicator presents opportunities for leveraging and realigning resources in sectors such as health care, employers, education, childcare facilities, and government programs, all of which are a critical touch point for pregnant and postpartum women, and infants. WIC is administered by state agencies and operated through local agencies in clinic sites, state health departments, and Indian Tribal Organizations. Specific examples of agencies that administer WIC services include county health departments, hospitals, schools, public housing sites, community centers, hospitals, and migrant health centers and camps.

The number of women, infants, and children receiving WIC benefits in FY2013 was nearly nine million per month (USDA 2013a). Since 1996, the USDA Food and Nutrition System has allocated a minimum expenditure for breastfeeding promotion and support activities equal to $21 multiplied by the number of pregnant and breastfeeding women in the WIC Program, based on the average of the last three months for which USDA has final data. State agencies must spend a specified amount of the total funding for breastfeeding promotion and support. Efforts to increase and support the number of women breastfeeding have also included enhanced food packages for women breastfeeding up to 12 months and the implementation of the Peer Counseling Program (USDA 2013b).

The target population for WIC participants is low-income, nutritionally at risk pregnant women, breastfeeding women, non-breastfeeding postpartum women, infants and children up to their 5th birthday (USDA 2013b). Given this, there is an additional opportunity for leveraging and aligning resources with early childhood centers, such as Head Start. Head Start promotes the school readiness of young children from low-income families through agencies in their local community (ACF About Head Start 2013). WIC and Head Start share common goals to promote health and nutrition for young families, and assistance in accessing on-going preventive health care. By working together, these programs have an opportunity to promote health to families and support their continuum of care, making a positive impact on good health and nutrition.
Children living below the 185 percent FPL (maximum qualification for any WIC program) are more likely to qualify for SNAP benefits later and free or reduced school lunches and they are more likely to experience developmental delays due to poor nutrition and limited resources. Given this, education and social services are more likely to work with these children after they no longer qualify for WIC. WIC participation is associated with better nutrition among school-aged children, and those children are likely to perform better in school, further supporting education’s interest in WIC (Carlson & Senauer, 2003; Schneider et al., 2008; Siega-Riz et al., 2004; Rush et al., 1986 and USDA, 2013a). Given the overlap, education and social services may be interested in supporting WIC services in order to support families being healthy and also to reduce the need for costly services later.

**Predict an individual’s health and wellness and/or that of their offspring**

WIC produces positive prenatal outcomes. WIC participation is especially protective for high-risk women (El-Bastawissi et al., 2007), and significantly increases the number of women receiving adequate prenatal care (Rush et al., 1986). WIC participation is associated with improved birth outcomes (Bitler and Currie 2005, USGAO, 1993) and reduces low birth weight among WIC participants (Figlio et al., 2009). Improving the health and pregnancy outcomes of mothers lays the foundation for improving the nutrition of their children.

WIC improves infant health. WIC participation reduced infant mortality during the first 28 days in four out of five states (Devaney & Schirm, 1993). It contributed to increased breastfeeding rates among participating mothers (USGAO, I993) and had a positive impact on infant weights, statures and health compared to eligible non-participating infants (Black et al 2004). More recently, a study demonstrated that WIC participation had a positive impact on increasing average infant birth weight and was able to decreased the proportion of births categorized as low birth weight (Hoynes et al 2011).

WIC improves children’s health so that they start school ready to learn (Rush et al., 1986). WIC reduces the prevalence of iron deficiency anemia (Schneider 2008). Children in households participating in the WIC program are significantly more likely to be in excellent health (Carlson and Senauer 2003). WIC participation has a positive impact on preschoolers’ diets (Siega-Riz et al., 2004) and has beneficial effects on change in height for age (USDA 2013a). Addressing adequate nutrition at critical and sensitive periods in the life course, through prenatal and early childhood nutritional support of the WIC program, provides families with the opportunity for a healthier life trajectory through improved health and developmental outcomes as well reduced economic stress and support through connection to other public programs and partnerships.

**Data Criteria**

**Data availability**

To calculate the numerator, data can be obtained from a state health department WIC program. Potential regulations regarding state data may mean the data are less accessible, but the data are available. Every state WIC program collects data for the number of children aged two to five years participating in the WIC program and report the data to the USDA, ensuring data reliability. Therefore, the USDA may be another potential source for obtaining WIC data. Publicly available data for WIC do not include the specific age range needed for this indicator by state so a special request might need to be made.

WIC programs also maintain the numbers of WIC eligibles, which is the denominator for this indicator. USDA uses the American Community Surveys (ACS) as the basis for state WIC eligibility estimates. Medicaid enrollment information is used for estimating adjunctive eligibility. The number of children ages two to five below 185 percent of the FPL can also be obtained from Current Population Surveys (CPS). The CPS is a household survey primarily used to collect employment data. The sample universe for the basic CPS consists of the resident civilian non-institutionalized population of the United States. Therefore, persons living in institutions and homeless persons are not included in the sample. Some states use Current Population Surveys — Annual Social and Economic Supplement (CPS-ASEC), while others use the ACS in addition to CPS. Because of its detailed questionnaire and its experienced staff, the CPS ASEC is a high-quality source of information used to produce the official annual estimate of poverty and estimates of a number of other socioeconomic and demographic characteristics.
**Data quality**
The U.S. Census Bureau's quality standards apply to all products released, including the CPS ASEC and the ACS. The Census Bureau makes every effort to ensure the data are accurate and reliable. The Office of Management and Budget (OMB) released Standards and Guidelines for Statistical Surveys with requirements for federal statistical agencies in 2006 (OMB 2006). In 2012, the U.S. Census Bureau reissued their statistical quality standards in 2012, which complement the 2006 OMB standards ensuring data quality (USCB 2012).

**Simplicity of indicator**
Calculating this indicator is straightforward. It compares the number of children participating in WIC to the total number of children below 185 percent FPL who are eligible for WIC. There are few points that may impact the interpretation of the indicator. For example, the term “participating” can have more than one meaning. A participant can be enrolled in the program but not use their benefits every month. This participant would be active in the state system but not be considered participating for USDA reimbursement purposes. USDA pays states based on the numbers of participants that use their WIC checks or EBT card on a monthly basis. Participation based on the USDA definition would allow consistency of the metric across states.

Explaining the indicator is slightly more difficult but still straightforward. WIC nutrition services are important for ensuring low-income children receive the nutrients they need to stay healthy and grow. The majority of people would understand using a measure to monitor the number of children utilizing WIC services. The challenge might be in explaining the particular definition chosen for WIC participation and why all children below 185 percent FPL is the comparison population, since each state WIC program sets its own income standard eligibility requirement that can range from 100 to 185 percent. The cutoff of 185 percent of the FPL was chosen to demonstrate the capacity of the WIC program to serve all potentially eligible children in the United States.

**References**


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The Life Course
Metrics Project

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Using an RFA process, AMCHP selected seven state teams, Florida, Iowa, Louisiana, Massachusetts, Michigan, Nebraska and North Carolina, to propose, screen, select and develop potential life course indicators across four domains: Capacity, Outcomes, Services, and Risk. The first round of indicators, proposed both by the teams and members of the public included 413 indicators for consideration. The teams distilled the 413 proposed indicators down to 104 indicators that were written up according to three data and five life course criteria for final selection.

In June of 2013, state teams selected 59 indicators for the final set. The indicators were put out for public comment in July 2013, and the final set was released in the Fall of 2013.

Basic Indicator Information

Name of indicator: Early Childhood Health Screening – EPSDT (LC-19)

Brief description: Percent of Medicaid-enrolled children who received at least one initial or periodic screen in past calendar year

Indicator category: Early Life Services

Indicator domain: Service/Capacity

Numerator: Number of Medicaid enrollees ages zero to 21 (enrolled for 90+ continuous days) receiving at least one initial or periodic screen

Denominator: Total Medicaid-enrolled children ages zero to 21 enrolled for 90+ continuous days

Potential modifiers: Age group, sex, race/ethnicity

Data source: CMS - Annual Medicaid EPSDT Participation Report

Notes on calculation: The Annual Medicaid EPSDT Participation Report can be found here: http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Benefits/Early-Periodic-Screening-Diagnosis-and-Treatment.html(towards bottom of the page). The report does not provide breakdowns by sex or race/ethnicity; Medicaid data from the state or jurisdiction would be needed to examine this indicator by those potential modifiers.

Similar measures in other indicator sets: Title V Health Systems Capacity Indicator #02 – The percent of Medicaid enrollees whose age is less than one during the reporting year who received at least one initial periodic screen; MIECHV (Maternal, Infant, and Early Childhood Home Visiting Benchmark 1 – Maternal and Newborn Health – Construct 1.7: Well-Child Visits)
Life Course Criteria

Introduction
Medicaid is the major public health insurance program for children and adolescents through the age of 20 in the United States. Early, Periodic, Screening, Diagnosis and Treatment (EPSDT) is the federally mandated package of services that Medicaid children receive. The emphasis of EPSDT is health promotion, prevention and comprehensive care. Through EPSDT, assessments are made and problems are identified early (Early); children's health is checked at age-appropriate intervals (Periodic); physical, mental, developmental, dental hearing, vision and other screening tests are provided to detect problems (Screening); diagnostic tests are performed to follow up when a health risk is available (Diagnostic); and treatment is provided to correct, reduce or control an identified health problem (Treatment) (Medicaid.gov). The goals of EPSDT are to identify early conditions that can impede child growth and development to avoid the costs and health effects of disability and to ameliorate acute and chronic medical and mental health conditions. Consistent with life course theory, EPSDT plays a critical role in early and sensitive periods of child and adolescent growth and development when conditions can be detected and treated, thus improving outcomes, saving costs and potentially decreasing inequities.

Implications for equity
Children and adolescents covered by Medicaid are more likely to be born with low birth weights, have poor health, developmental delays or learning disabilities and medical conditions such as asthma that require ongoing care and medications, making EPSDT an important vehicle through which low-income children and adolescents receive quality health care (Medicaid.gov). EPSDT has been especially important to children with disabilities enrolled in Medicaid. These children are more likely to need services, such as physical, occupational and speech therapy and mental health services that are covered through EPSDT, but are often excluded or limited in other health plans (Kaiser Commission on Medicaid and the Uninsured, 2005).

Children and adolescents who participate in Medicaid are often at higher risk for poorer health outcomes, making it important to ensure that they receive the care they need through EPSDT. According to the 2013 Annual EPSDT Participation report (medicaid.gov), there is room for improvement in meeting the EPSDT screening schedule, particularly among the older age groups. In 2013 (for DC and all but one state), only 33 percent of Medicaid enrollees 19 to 20 years old, 58 percent of those 15 to 18 years old, 69 percent of those 10 to 14 years old and 78 percent of the six to nine year old enrollees received the expected number of screens. The highest percent of screens were found among two year olds (100 percent), and those under one (97 percent). By age three, this number dropped to 87 percent. The data on the percent of Medicaid children and adolescents who received at least one of the expected initial or periodic screens were similar. Only 25 percent of 19 to 20 year olds and 46 percent of 15 to 18 year olds, compared to 90 percent of those under one, received these screens.

The percentages above were based on the periodicity scheduled established by the states, and there are differences. States may develop their own schedules, as long as they have input from pediatric providers. For example, whereas three quarters of the states require six or seven visits in the first year, about 20 percent require only five, and one state requires four visits. Among six to nine year olds, about one half of the states required four visits, another half require two visits, and one state requires one visit. It also is important to note that there is not a consensus on the numbers of visits needed, but many of the states follow the guidelines of the Academy of Pediatrics (American Academy of Pediatrics, 2014).

One explanation for the low screening rates could be the availability of pediatric and adolescent providers who accept Medicaid; a major factor has been Medicaid’s historically low reimbursement rates compared with private insurers (Adams, 2001). The availability of Medicaid providers may become an even larger issue with Medicaid expansions and the need for additional providers. It will be important to determine who the children and adolescents are that will be covered under the expansion to conduct additional outreach.

Public health impact
With its emphasis on health promotion and prevention, EPSDT represents a major public health effort that impacts some of the most vulnerable children and adolescents in the United States. Through EPSDT, children and adolescents receive preventive services (e.g., vaccinations), as well as the management and treatment of medical and developmental issues. Annually, EPSDT touches millions of lives. In 2010, more than 32 million children and adolescents, representing about one third of this population, were enrolled in Medicaid (DHHS, 2010). Through EPSDT, Medicaid children and adolescents
receive comprehensive services designed to ensure the best possible outcomes in both the short and long term. In the early years of EPSDT, a cost benefit analysis of the program demonstrated substantial savings if the program was introduced nationally. In 1974, a study at the University of Texas estimated a $30 billion savings from EPSDT over 20 years (Britt et al., 1974). More research is needed, however, especially given the current variability in the EPSDT schedules across the states.

**Leverage or realign resources**

EPSDT offers many opportunities to leverage and align resources. Professional organizations, such as the American Academy of Pediatrics (AAP) and state medical societies are strong collaborators. An important collaboration with AAP has been the alignment of the EPSDT periodicity schedules in many states with the AAP/Bright Futures well-child visit schedules.

States also have opportunities to leverage federal programs, like the Title V programs for maternal and child health and children with special health care needs to improve EPSDT services. By federal law, Medicaid and the Title V agencies are required to collaborate to improve child health. Partnering with the other initiatives like the Maternal, Infant and Early Childhood Home Visiting (MIECHV) program and Early Childhood Comprehensive System initiatives also could facilitate coordination of services for families.

There also are many opportunities to partner with the Center for Medicare and Medicaid Services (CMS) and providers, such as those in Federal Qualified Health Centers and other “look alike” community health centers. In December 2010, CMS convened a National EPSDT Improvement Workgroup to help CMS identify the most critical areas for improvement of EPSDT. The group discussed steps that the federal government might undertake in partnership with states and others to both increase the number of children accessing services, and improve the quality of the data reporting that enables a better understanding how effective the U.S. Department of Health and Human Services (HHS) is putting EPSDT to work for children. Community health centers have long histories of providing comprehensive care to low-income children and adolescents, and are natural partners in quality improvement initiatives around the care of children and adolescents.

Finally, as the Patient Protection and Affordable Care Act (ACA) continues to roll out, with Medicaid expansions providing coverage to more people and states finalizing their essential benefit packages, there will be opportunities to provide more EPSDT services to Medicaid children and adolescents and there may be opportunities to add EPSDT-like coverage to other plans like the Children’s Health Insurance Program (CHIP), which covers children whose family incomes exceed Medicaid but are too low for private insurance, as well as other health plans.

**Predict an individual’s health and wellness and/or that of their offspring**

There is some research on the use of EPSDT on outcomes, but more research is needed. One of the challenges in assessing the effects of EPSDT on health and well-being is the variability in the EPSDT schedules, but also in the numbers of children and adolescents that receive services according to the established schedules. AAP has recommended further research on the effectiveness of EPSDT. Although more research is needed, EPSDT does give providers the opportunity to provide advice and guidance to families on topics, such as tobacco use, nutrition and exercise, which can have long-lasting effects on the health of children through adulthood.

One study found that children who were up-to-date on their visit schedules were less likely to be hospitalized than those who were not up-to-date (Hayim and Bye, 2001). Another study found that children with the recommended EPSDT visits (per the AAP schedule) had 23 percent higher adjusted odds of being ready for school than those that did not (Pittard et al., 2012). Additionally, there is established evidence of the effect of childhood immunization on reduced mortality and morbidity (CDC, 1999, Roush and Murphy, 2007); and immunizations are a core EPSDT service.

**Data Criteria**

**Data availability**

The Form CMS-416 is used by CMS to collect basic information on state Medicaid and CHIP programs to assess the effectiveness of EPSDT. Annually, states must provide CMS with the following information on three key aspects of the mandatory EPSDT benefits package: 1) Number of children provided child health screening services; 2) Number of children referred for corrective treatment; and 3) Number of children receiving dental services. States also provide data on
the expected vs. received total screens as well as at least one of the initial or scheduled screens. The most current data available for all states are 2010; 2013 data are available for all but one state.

**Data quality**

As noted above, periodicity schedules are established by the states, so the data collected for this indicator are based on the states’ periodicity schedule, not a universal schedule. However, this indicator is assessing whether at least one initial or periodic screen was received, not the adherence to the periodicity schedule established by the state and therefore is comparable across state Medicaid programs. This indicator is used in another form by Title V (percent of Medicaid enrollees less than one who received at least one initial periodic screen. The indicator is comprised of unduplicated counts of Medicaid enrollees, and therefore relies on the ability of the Medicaid program to accurately track and deuplicate enrollees. The instructions for completing the form can be found here: medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Benefits/Downloads/CMS-416-instructions.pdf.

**Simplicity of indicator**

This indicator is already calculated in the Medicaid report from CMS and is therefore simple to calculate. As noted above, other programs such as Title V and MIECHV use similar indicators around receiving initial or periodic screens from Medicaid. This indicator should be easy to interpret and explain.

**References**


Life Course Indicator: High School Graduation Rate

The Life Course Metrics Project

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Basic Indicator Information

Name of indicator: High school graduation rate (LC-20)

Brief description: High school graduation rate (four year cohort) as measured by the Adjusted Cohort Graduation Rate.

Indicator category: Economic Experiences

Indicator domain: Risk/Outcome

Numerator: Number of students who graduate in four years with a regular high school diploma

Denominator: Number of students who form the adjusted cohort for the graduating class

Potential modifiers: Age, Race, Ethnicity, Gender, Income, Disability Status

Data source: National Center for Education Statistics

Notes on calculation: The adjusted cohort that forms the denominator is created by NCES as the number of students who are entering 9th grade or the earliest high school grade for the first time. The cohort number is adjusted by adding the numbers of students who subsequently transfer into the cohort and subtracting the numbers of students who subsequently transfer out, emigrate to another country, or die.

Similar measures in other indicator sets: HP 2020 Focus Area AH-5.1; Chronic Disease Indicators; United Health Rankings Core Measure
Life Course Criteria

Introduction
Socioeconomic environments are strongly related to health, whether health is self-reported or defined by particular acute, chronic, or disabling conditions (e.g., Kitigawa and Hauser 1973; Lynch 2003; Marmot 2006; Moore and Hayward 1990; Morenoff 2003). Socioeconomic environments are often determined by a combination of education, income, and occupation. Graduation from high school (or equivalent) is a pre-requisite for any post-secondary education, which drives occupational status and income.

The U.S. Bureau of Labor Statistics documents trends in earnings as related to educational attainment, exemplifying the association between educational attainment and income. As level of education increases, so do weekly earnings – on average, persons working with less than a high school diploma make $471.00 USD weekly; persons working with a high school diploma make $652.00 USD weekly; persons with a Bachelor’s degree make $1,066 USD weekly; and persons with a Professional degree make $1,735.00 USD weekly (Bureau of Labor Statistics 2013).

Whether an individual graduates high school, and within a four year period, is tightly correlated with that individual’s earning potential and contributes to current and future socioeconomic status. As a marker of educational attainment, a state’s high school graduation rate speaks to the economic experiences, social capital, and health trajectories of its residents (in particular youth) and is therefore an indicator for life course health.

Implications for equity
As a dimension of socioeconomic status, high school graduation rate has strong implications for social equity across populations. Different populations across the United States experience different rates of high school graduation: trend analysis of data from the past forty years shows non-Hispanic Black and Hispanic populations having had lower completion (graduation) rates than other racial/ethnic populations. In 2009, among 18-24 year olds not currently enrolled in high school, Asian/Pacific Islander (95.9) and Whites (93.8) had completion rates of more than 90 percent. For the same year, Blacks (87.1), American Indians/Alaska Natives (82.4), and Hispanics (76.8) had rates below 90 percent (Chapman et al 2011).

In addition, students living in low-income families have higher rates of dropout (non-completion) than their peers from high-income families. In 2009, the national event dropout rate of students living in low-income families was about five times greater than the rate of their peers from high-income families (7.4 percent vs. 1.4 percent). This difference is consistent with trend analysis of data over the past four decades. (Chapman et al 2011)

Beyond race/ethnicity and income, individuals with disabilities also experience lower high school completion rates than individuals without a disability. In 2009, 16-24 year olds with disabilities had a dropout rate of 15.5 percent compared to an overall rate of 7.8 percent among their peers living without a disability.

Overall educational attainment is also a “protective” factor for overall health (Richardson et. al. 2013). There is a well known and persistent association between education and health. This relationship has been observed in many geographies and time periods, and for a wide variety of health measures (see Predict Individual’s Health section below). As a protective factor, educational attainment has implications for equity because it may contribute to resilience against additional social risk factors.

Public health impact
The benefits of investments in educational attainment are shared by individual students and the societies of which they are a part. Investments in educational attainment are investments in a knowledgeable, skilled, educated population. This population will provide higher quality workers and improved quality of life in general on both individual and community levels.

Increased academic achievement impacts individuals’ lifetime health and well-being, as well as influences the health and well-being of their offspring and ameliorates the effects of socioeconomic and familial disadvantage (Wickrama et al., 2012). (In addition, see Predict Individual’s Health section below.) As a ‘return on investment’, each additional year of education is associated with an increase in health promoting behaviors (Cutler and Lleras-Muney 2006).
In addition, educational attainment has larger societal benefits for families, which influence wider community benefits. High school graduation is necessary, but not sufficient, for post-secondary level education and subsequent employment. Research on the impact of higher education opportunities on individual and social outcomes suggests individuals with college degrees, and to a lesser extent those who have some college experience but do not have a degree, earn more than others and enjoy better working conditions. They contribute more to society, both through higher tax payments and through their civic participation, and are lower sources of spending for many social programs, such as unemployment compensation, food stamps, and Medicaid. Finally, college-educated adults give their children benefits that increase the prospects that the next generation will prosper and will be in a position to contribute to society in a variety of ways (Baum and Payea 2010). Overall, increases in high school graduation rates can lead to more positive outcomes for individuals and for their children and communities. These positive (or negative) outcomes persist across the life course.

**Leverage or realign resources**
As a societal factor, education is a powerful predictor of health, but the public health field has very little control over increasing educational attainment. This indicator has the potential to leverage or realign resources as multiple potential partners, including many non-traditional public health partners, have a vested interest in students graduating high school. Some examples of potential new or strengthened partnerships include:

- New or strengthened partnerships with public school systems as graduation rates are national performance measures for schools
- New or strengthened partnerships with business, commerce and union associations as employers need employees who are well trained
- New or strengthened partnerships with justice system stakeholders as there is a strong correlation between and involvement in the justice system and educational attainment, and this indicator could open new avenues for collaborative public policy and strategies

This indicator provides information which can be used as leverage points for addressing improvement in the high school graduation rate by focusing on early intervention in preschool and early elementary school and targeted programs serving high-risk students at the middle and high school level. A number of such community-based programs exist, many of which focus on connecting high risk students to mentors and community resources to navigate intra- and interpersonal stresses, including health and relationships with peers, and community settings that may contribute to engagement and attainment in school. Programs like the Incentive Mentoring Program in Baltimore, MD (incentivementoringprogram.org), The Link in Minneapolis, MN (thelinkmn.org/school-matters), or earlier in the life course – Big Brothers, Big Sisters – focus on the complex interactions between individual, family, and community resources and the ability to reach one’s potential as a method of increasing resiliency in youth. Such programs are one of many opportunities for public health practitioners to partner with community organizations and education agencies to improve high school graduation rates.

From the standpoint of developing resilience, the positive youth development (PYD) model is an approach that can be used to promote and support protective factors or influences in a young person’s life. The Family and Youth Services Bureau of the Administration for Children & Families has committed to promoting a PYD approach among federal agencies, their partners, youth workers, and the general public (http://www.acf.hhs.gov/programs/fysb/positive-youth-development). Rather than focusing on risk factors, PYD focuses on developing leadership skills and seeing youth as assets to be developed. Being involved with school and having strong links between home, school and the community are integral components of PYD and are likely to contribute to improving graduation rates as well.

**Predict an individual’s health and wellness and/or that of their offspring**
There is a large and persistent association between education and health. The connection between education and health has been well documented and spans almost all health conditions (Ross 1995). There is a positive association between education and health behaviors, health status, and particular acute, chronic, or disabling health conditions. Educational attainment also is a strong predictor of overall life expectancy. In addition to these positive associations, the effect of education increases with increasing years of education (Molla et al 2004; Lleras-Muney 2005).

Educational attainment also is a predictive factor for the health and wellness of an individual’s offspring. Multiple individual research studies as well as meta-analyses have shown the very strong predictive relationship between level of parent’s education on educational achievement and thus future health and well-being for children (Klebanov et. al. 1994; Haveman...
& Wolfe 1995; Smith et. al. 1997). In particular, a mother’s education level has a large, positive association on the health of her children. That relationship, observed in many small studies in rich countries, turns out to be true everywhere on the globe. A recent meta-analysis of global data illustrates half the reduction in child mortality over the past 40 years can be attributed to the better education of women; for every one-year increase in the average education of reproductive-age women, a country experienced a 9.5 percent decrease in the child deaths (Gakidou 2010).

Data Criteria

Data availability

The National Center for Education Statistics (NCES) is the primary federal entity for collecting and analyzing data related to education in the United States and other nations. Within the NCES are a number of programs and assessments, including the National Assessment of Educational Progress (NAEP) and the Common Core of Data (CCD). The CCD reports the number of dropouts from each grade nine to 12 and the relevant event dropout rate (The event dropout rate describes the proportion of students who drop out in a single year. The rate is the number of students who drop out of a given grade divided by the number of students enrolled in that grade at the beginning of that school year). It also reports the number of high school diploma recipients, other high school completers (defined as students who receive an alternate credential such as a certificate of attendance or an equivalency credential), and the Averaged Freshman Graduation Rate (AFGR).

Beginning in the 2010–2011 academic year, all state education agencies were required to report graduation rates based on the Adjusted Cohort Graduation Rate (ACGR), which is considered to be a more rigorous and uniform standard than the AFGR. The ACGR tracks a cohort of ninth graders who are entering high school for the first time, adding and subtracting dropouts and transfers, and calculating the fraction earning a regular diploma after four years (U.S. Department of Education 2013). The NCES explains that reporting for the AFGR will continue to provide well understood and comparable statistics until evaluation of the newer measure of ACGR has been completed, and so data users can continue to analyze trends in graduation rates. The ACGR is available for most states starting with the graduating class of 2011. For trend analysis, it is recommended data users use the AFGR, with the goal of transitioning to the ACGR as multiple years of data become available.

The most recent data set available from NCES is for 2010-2011, which includes only the AFGR, and was first made available in June 2012. After the publication of the survey data on the NCES website (denoted as version a on the website), state education agencies have one year to revise the data (revised data is denoted as version b). Both the revised and unrevised data sets are available on the NCES website (http://nces.ed.gov/ccd/stnflis.asp). The Department of Education, Office of Elementary and Secondary Education released a preliminary ACGR for 2010-2011 on Nov. 28, 2012 through their ED Data Express online data tool (http://eddataexpress.ed.gov). Local level data are not available for this indicator through the National Center for Education Statistics.

Data quality

The data quality for ACGR is good at the present time. Adjustments are made for students who move into or out of the state, territory, county, or district. Data for private schools and for enrollment for very low numbers (e.g., n<10 students) are not available. The first year that states were required to use the regulatory cohort rate was 2010-11; prior year data are not necessarily comparable to the 2010-11 rates. Because ACGR is a new addition, and evaluation of the measure is not yet complete, the following pertains to the AFGR:

From the National Center for Education Statistics (http://nces.ed.gov/pubs2013/2013309/appendix_a.asp):
There is variation in the degree of rigor with which the states or school districts verify their data. Those states that collect dropout or graduation data through student-level records systems are better able to verify students’ enrollment and graduation status than are those agencies that collect aggregate data from schools and districts. In the past NCES did not audit state reports. Starting with the 2006–07 collection, NCES has been more aggressive in verifying data that do not appear to be accurate. NCES also required that some aggregate-level data be confirmed or revised. For 2009–10, NCES contacted Alabama, the District of Columbia, Illinois and Puerto Rico because the submitted dropout counts produced dropout rate estimates that were low when compared to other states and data from earlier years. Alabama and Illinois confirmed the reported counts. The District of Columbia and Puerto Rico did not confirm their dropout counts. As the unconfirmed dropout counts resulted in a calculated dropout rate of less than one percent, NCES suppressed dropout
counts for the District of Columbia and Puerto Rico at the LEA level. The state-level dropout data were imputed for the District of Columbia based on prior year rates. The state-level dropout data for Puerto Rico were suppressed because prior year data was not available. For 2009–10, NCES contacted Connecticut because the submitted high school diploma counts produced AFGR estimates that were high compared to other states and data from earlier years. Connecticut did not confirm their diploma counts. The unconfirmed diploma count represented a 29 percent increase from the prior year, 110 percent of the 12th-grade student enrollments in-year, and resulted in a calculated AFGR of 98 percent. Accordingly, NCES suppressed diploma counts for Connecticut at the LEA level and imputed the counts at the state level using prior year rates. States have been made aware of the new NCES protocols and understand that NCES is working to develop further methods to audit their end of year data.

Additionally for 2009–10, dropout data reported at the LEA-level for Kentucky, Maine, and Mississippi accounted for less than 85 percent of the SEA-level reporting. These cross-level discrepancies were noted on data error reports to all three of these states and the states did not submit any revisions to these data as of Jan. 1, 2013. NCES has thereby suppressed the LEA-level dropout counts for these states because these data do not meet NCES data quality and coverage standards.

Cautions in interpreting the Averaged Freshman Graduation Rate. Although the AFGR was selected as the best of the available alternatives, several factors make it fall short of a true on-time graduation rate. First, the AFGR does not take into account any imbalances in the number of students moving in and out of the nation or individual states over the high school years. As a result, the averaged freshman class is at best an approximation of the actual number of freshmen, where differences in the rates of transfers, retention, and dropping out in the three grades affect the average. Second, by including all graduates in a specific year, the graduates include students who repeated a grade in high school or graduated high school early and thus are not on-time cohort graduates in that year.

While the AFGR is a reasonable proxy at the aggregate national or state level, the potential effects of three factors should be taken into account when interpreting the results for individual states. First, if more high school students moved out of a population than transferred in during the high school years, the number of graduates in the numerator would be smaller and the estimated graduation rate would be lower than the actual on-time rate for that group of freshmen. On the other hand, if more high school students moved into a population than moved out during this four-year period, the number of graduates in the numerator would be increased and the estimated on-time graduation rate would be higher than the actual rate for that group of freshmen. This can lead to estimated graduation rates of more than 100 percent for small groups; such cases have been edited to 100 percent in this report.

Second, including the estimate of eighth-graders from the previous year in order to remove the effect of freshmen who were retained, and thus are not first-time freshmen, ignores the fact that in some cases there may be real change in the number of eighth-graders relative to counts of ninth-graders due to transfers between public and private schools. If more students transfer to public schools during these years, using a count of 8th-graders that does not include those students would serve to artificially decrease the estimated number of ninth-graders, and as a result increase the graduation rate for that class. Conversely, if more students were to transfer out of public schools between the eighth and ninth grades, using the eighth-grade count that includes students leaving the population would artificially increase the estimated number of ninth-graders and in turn, decrease the graduation rate.

Third, there may be a tradeoff between the edits for retentions and grade specific differences in the number of dropouts. The use of the 10th-grade enrollment count helps to dampen the effect of ninth-grade retentions, but ignores the fact that ninth-grade dropouts result in a smaller 10th-grade population. Excluding these ninth-grade dropouts would lower the estimate of freshmen and as a result increase the graduation rate.

Simplicity of indicator
The National Center for Education Statistics collects enrollment and completion data and estimates the graduation rate for each state. The AFGR is the number of graduates divided by the estimated count of freshmen four years earlier. This estimated count of freshmen is the sum of the number of eighth graders five years earlier, the number of ninth graders four years earlier and the number of 10th graders three years earlier divided by three. Enrollment counts also include a proportional distribution of students not enrolled in a specific grade. The ACGR tracks a cohort of ninth graders who are entering high school for the first time, adding and subtracting dropouts and transfers, and calculating the fraction earning a
regular diploma after four years. Despite the potential confusion created by the use of the two indicators, and the movement away from AFGR to ACGR, this indicator is generally easy to understand and communicate. It does not require linkage or complex analyses on the part of the data user.

References


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The Life Course Metrics Project

As MCH programs begin to develop new programming guided by a life course framework, measures are needed to determine the success of their approaches. In response to the need for standardized metrics for the life course approach, AMCHP launched a project designed to identify and promote a set of indicators that can be used to measure progress using the life course approach to improve maternal and child health. This project was funded with support from the W.K. Kellogg Foundation.

Using an RFA process, AMCHP selected seven state teams, Florida, Iowa, Louisiana, Massachusetts, Michigan, Nebraska and North Carolina, to propose, screen, select and develop potential life course indicators across four domains: Capacity, Outcomes, Services, and Risk. The first round of indicators, proposed both by the teams and members of the public included 413 indicators for consideration. The teams distilled the 413 proposed indicators down to 104 indicators that were written up according to three data and five life course criteria for final selection.

In June of 2013, state teams selected 59 indicators for the final set. The indicators were put out for public comment in July 2013, and the final set was released in the Fall of 2013.

Basic Indicator Information

Name of indicator: Mother’s Education Level at Birth (LC-21)

Brief description: Percent of births by maternal education levels (<high school, high school, and some college)

Indicator category: Economic Experiences

Indicator domain: Risk/Outcome

Numerator: Number of women delivering a live birth with <high school, high school, and some college

Denominator: All live births

Potential modifiers: Race, ethnicity, sex, age, SES, marital status, geographic location

Data source: National Vital Statistics System (NVSS) Records

Notes on calculation: Women who have an eighth grade or less education level and ninth through 12th grade but no diploma will be placed into the “less than high school” category. Those who are high school graduates or completed a GED, some college credit but no degree will be in the “high school” category. Those with Associate degrees (e.g. AA, AS) or higher will be in the “greater than high school” category. The numerator will consist of the number of births at each of the noted education levels and the denominator for each will be total live births. When using the NVSS Public Use File, Mother’s Education is located in the data file at column 155 with variable name MEDUC; this data is included in the public use file only for states and jurisdictions that have implemented the 2003 revision of the birth certificate.

Similar measures in other indicator sets: Maternal, Infant, and Early Childhood Home Visiting (MIECHV) Benchmark Area Improvements in Family Economic Self-Sufficiency: Employment or education of participating adults
Life Course Criteria

Introduction
Socioeconomic inequalities throughout the life course may be partially accounted for by parental socioeconomic position (SEP) at time of birth and throughout early childhood. Maternal education specifically is a common proxy for parental socioeconomic position. A pioneering paper in 1979 considered demographic data to examine the role of education in child mortality. The paper argued that children of mothers who are more educated experience lower mortality than do children of mothers who are less educated (23). Subsequent analyses and demographic studies have demonstrated various associations between maternal education and markers of child health. Maternal education has been shown to have a statistically significant association with infant mortality, children’s immunization status, and height-for-age (17). Functioning as both a proxy for SEP and for mothers’ awareness and knowledge of healthy behaviors, maternal education may influence nutritional choices during pregnancy, which might affect birth weight, infant mortality, and height-for-age measures (18).

Maternal education at birth is a life course in a few ways. First, an increase in education at any point in a mother’s life is likely to be beneficial for the betterment of the mother and her family. Having higher levels of education will help mothers make informed decisions about their child’s health, education and nutrition. Second, maternal education at the time of birth may also be a marker for adversity in her own life, e.g., with early onset psychopathology (6) and early abuse (9) linked to the risk of teen pregnancy.

Implications for equity
Social conditions such as education, occupation, income and socioeconomic status are all influenced by maternal education level. Higher individual educational achievement often leads to higher earning potential (5). Higher educational achievement in individuals and across a population is associated with safer housing, food security, and access to medical care and more opportunities for education (2-4). Education likely conveys an increase in knowledge and skills that may make an individual more receptive to health information, able to process complex topics, and make health-related choices based upon current and future circumstances. Maternal education specifically is hypothesized to lead to changes in maternal behavior that result in better health outcomes in childhood (8).

Significant disparities persist in educational attainment between racial and ethnic groups. For example, population groups across the United States experience different rates of high school graduation: trend analysis of data from the past forty years shows non-Hispanic Black and Hispanic populations have lower completion (graduation) rates than other racial/ethnic populations. In 2009, among 18-24 year olds not currently enrolled in high school, Asian/Pacific Islander (95.9) and Whites (93.8) had completion rates of more than 90 percent. For the same year, Blacks (87.1), American Indians/Alaska Natives (82.4), and Hispanics (76.8) had rates below 90 percent (30) (See life course indicators narratives for LC-20: High School Graduation Rate and LC-57: Fourth Grade Proficiency).

Educational attainment is also a “protective” factor for overall health (31). There is a well known and persistent association between education and health (25-27). This relationship has been observed in many geographies and time periods, and for a wide variety of health measures. As a protective factor, educational attainment has implications for equity because it may contribute to resilience against additional social risk factors; in the case of maternal education at birth, this resilience benefits the mother, child, and family.

Communities with strong education systems and high educational attainment tend to have greater social capital. Social capital is the collection of features of social organization – such as civic participation, norms of reciprocity, and trust in others – that help facilitate cooperation for mutual benefit (36). As such, social capital is a collective resource that benefits communities and can be distinguished from the individual health effects of social networks and support (37). The World Bank summarizes the fundamental ways social capital is produced through education as:

- development and practice of social capacity skills such as participation and reciprocity
- provisions of forums for community activity
- delivery of civil education to learn how to participate responsibly in their society
- contribute or promote overall societal cohesion and strengthened citizenship when children of all socio-economic backgrounds are enrolled in the public education system (24)
**Public health impact**
As education is directly linked to family socioeconomic situation, which in itself is a determinant of child health, increases in maternal education benefit not only the child but the family as a whole. Mothers who are more educated spend more time in engaging child activities and adjust the type and level of care according to the child’s age, more so than mothers who are less educated (12). This in turn leads to children performing better in schools and improving educational achievement.

Achieving higher levels of education is associated with increased social support among women and has been documented to enhance parenting skills. The greater the education level, the stronger social ties a person has, which is associated with more positive health outcomes (13). For example, strong social networks help women to combat psychosocial pressures such as depression and hopelessness (3). With regard to parenting, mothers who are more educated spend significantly more time in four parenting activities across child age subgroups (1) basic care, i.e. feeding, bathing, and physical care; (2) play, games, art, and make believe; (3) teaching, reading and helping with homework; and (4) management of the child’s life outside the home environment (12). These four activities are considered investments in the child’s future for further child educational attainment, social mobility, and future success. Additional evidence of a wider public health impact is found in the link between maternal education and increases in childhood immunization, both an increased likelihood of utilizing immunizations and an increase in following the proscribed schedule (9). Increasing the number of children immunized every year is one of the greatest public health advantages resulting from improving maternal education. Through this lens, focusing on improving the education of girls and women can be considered an investment in current and future generations with regard to closing achievement gaps and improving earning potential and socioeconomic position, as well as accruing significant societal benefits.

**Leverage or realign resources**
In order to successfully increase the level of maternal education prior to pregnancy, broad investments in the education and advancement of young women and girls are required. These investments would reinforce a growing understanding of the continued empowerment of women’s voices and priorities across health and social issues, signified in part by the establishment of the White House Council on Women and Girls.

In addition to improving the educational outcomes of women in the preconception period, opportunities exist to improve and support the educational attainment of new parents for the benefit of that child and future children. Parents of young children account for around a quarter of undergraduate students, and half of those parents are single parents. Providing these parents with day care options in order to finish degree programs is vital for them to be able to attend class with minimum interruption (7). Other interventions can be used to encourage mothers to finish high school degrees, such as offering smaller class sizes where children can be in the classroom, collaborating with community groups to provide support, and offering counseling and other mental health support activities. Additional classes could be tailored to the child care and family health needs of the mothers to instruct them on topics such as childhood nutrition and proper immunization schedules.

Education is a powerful predictor of health, but the public health field has very little control over increasing educational performance. This indicator has the potential to leverage or realign resources as multiple potential partners, including many non-traditional public health partners, have a vested interest in improving educational outcomes. Some examples of potential new or strengthened partnerships include:
- New or strengthened partnerships with public school systems as completion rates are national performance measures for schools
- New or strengthened partnerships between family planning and contraceptive services and educational programs
- New or strengthened partnerships with business, commerce and union associations as employers need employees who are well trained.
- New or strengthened partnerships with justice system stakeholders as there is a strong correlation between education and involvement in the justice system, and this indicator could open new avenues for collaborative public policy and strategies.

**Predict an individual’s health and wellness and/or that of their offspring**
Increasing the educational level of mothers would have a significant impact on their health as well as the health and well-being of their children. The connection between education and health spans almost all health conditions including general health status, and particular acute, chronic, or disabling health conditions. Educational attainment is also a strong predictor of overall life expectancy (28-29).

In addition, maternal education attainment has been linked to various child health outcomes. Baughcum et al, showed that the lower the educational attainment of the mother the greater the prevalence of maternal obesity, and in turn, preschool aged children of mothers who are obese were more likely to be overweight (1). Also mothers who are obese were less likely to recognize their children as being overweight. They hypothesized that this may be due to a lack of awareness of the health risks associated with obesity. Guryan et al. hypothesized that educated parents consider time spent with children as an investment in their future (10). As such, children of mothers who are educated may develop faster language growth (14) and educational growth (12). The greater the education level, the stronger social ties a person has, which is associated with more positive health outcomes (19).

**Data Criteria**

**Data availability**

The National Vital Statistics System is an intergovernmental sharing of data whose relationships, standards, and procedures form the mechanism by which the National Center for Health Statistics collects and disseminates the Nation's official vital statistics. Vital event data are collected and maintained by the jurisdictions that have legal responsibility for registering vital events; these entities provide the data via contracts to NCHS. Vital events include births, deaths, marriages, divorces, and fetal deaths. In the United States, legal authority for the registration of these events resides individually with the 50 states, two cities (Washington, DC, and New York City), and five territories (Puerto Rico, the Virgin Islands, Guam, American Samoa and the Commonwealth of the Northern Mariana Islands).


National estimates of maternal education generated from NVSS data are therefore representative of only those states implementing the 2003 revision of the birth certificate in that data year; for 2011 this is 83 percent of all births and for 2012 this is 86 percent. Those with access to their own jurisdiction’s birth certificate data can generate estimates for maternal education regardless of whether that jurisdiction’s data are included in the NVSS. However, it may not be appropriate to compare data with the national estimate given the differences in how the data are collected.

Data must be downloaded from CDC vital statistics and then imported into data analysis software. Protocols and procedures of obtaining and analyzing data are on the CDC website. CDC Vital Statistics Birth Data Files, 2003 Revised Live Birth Certificate (all states are required to be using the revised certificate by Jan. 1, 2014), [http://www.cdc.gov/nchs/nvss/vital_certificate_revisions.htm](http://www.cdc.gov/nchs/nvss/vital_certificate_revisions.htm).

**Data quality**
Standard forms for the collection of the data and model procedures for the uniform registration of the events are developed and recommended for state use through cooperative activities of the States and NCHS. As reported in the NCHS publication *U.S. Vital Statistics System, Major Activities and Developments, 1950-1995*, efforts to improve the quality and usefulness of vital statistics data are ongoing. NCHS uses techniques such as testing for completeness and accuracy of data, querying incomplete or inconsistent entries on records, updating classifications, improving timeliness and usefulness of data, and keeping pace with evolving technology and changing needs for data. Work with state partners to improve the timeliness of vital event reporting is ongoing, and NCHS is working closely with National Association of Public Health Statistics and Information Systems and the Social Security Administration to modernize the processes through which vital statistics are produced in the United States, including implementation of the 2003 revised certificates.

According to the National Vital Statistics Report *Births: Final Data for 2012*, thirty-eight states, DC, and three territories implemented the revised birth certificate as of January 1, 2012 (32). The jurisdictions implementing the revisions represent 86 percent of all 2012 U.S. births. The revised reporting areas are: California, Colorado, Delaware, the District of Columbia, Florida, Georgia, Idaho, Illinois, Indiana, Iowa, Kansas, Kentucky, Louisiana, Maryland, Massachusetts, Michigan, Minnesota, Missouri, Montana, Nebraska, Nevada, New Hampshire, New Mexico, New York, North Carolina, North Dakota, Ohio, Oklahoma, Oregon, Pennsylvania, South Carolina, South Dakota, Tennessee, Texas, Utah, Vermont, Washington, Wisconsin, Wyoming, Guam, the Northern Marianas and Puerto Rico. Virginia implemented the revised birth certificate in 2012, but after Jan. 1. Educational attainment is a key data item that is not comparable between the 1989 and 2003 birth certificate revisions; data on this element is not included in the National Vital Statistics Reports but can be accessed in the User Guide (33) for revised states.

When using birth certificate data, accuracy and completeness of the data elements being analyzed should be considered; incomplete or inaccurate reporting of data elements can result in information bias. Researchers have found that sensitivity, specificity, and positive and negative predictive values of birth certificate data, as compared to medical record data, vary between teaching and non-teaching hospitals (11). A study by DiGiuseppe and colleagues found that for maternal demographic information (notably not including maternal education) the kappa statistic for agreement between medical records and birth certificate data for patients in all hospitals was 0.868, with nonteaching hospital kappa=0.769 and teaching hospital kappa=0.921. While other studies have not included maternal education among inquiries into data quality, reliability for demographic data has been found to be consistent (15, 16).

**Simplicity of indicator**

The indicator is easy to calculate once data are obtained. The data will not require any linkage as when the data is obtained from vital records, the indicator will be in the data file. The indicator will contain actual population numbers of live births, therefore weighting or stratifying of data is not necessary. Birth certificates of all live births in a given calendar year must be obtained. As noted in the above sections on availability and quality, states who have not implemented the 2003 revision of the birth certificate do not have data for maternal education included in the nationally available public use data and CDC WONDER. Those using state data, particularly those from jurisdictions that are not implementing the 2003 revision, should note this and use caution in comparing to the national estimate.

**References**


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The Life Course Metrics Project

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In June of 2013, state teams selected 59 indicators for the final set. The indicators were put out for public comment in July 2013, and the final set was released in the Fall of 2013.

Basic Indicator Information

Name of indicator: Unemployment (LC-22)

Brief description: Prevalence of unemployment

Indicator category: Economic Experiences

Indicator domain: Risk/Outcome

Numerator: Number of persons age 16 and older in the labor force who are unemployed (and actively seeking work)

Denominator: Number of persons age 16 and older

Potential modifiers: Race, ethnicity, sex, age, marital status, socioeconomic status, geographic location

Data source: American Community Survey (ACS)

Notes on calculation: None

Similar measures in other indicator sets: Maternal, Infant, and Early Childhood Home Visiting (MIECHV) Benchmark Area Improvements in Family Economic Self-Sufficiency: Employment or education of participating adults
Life Course Criteria

Introduction
Unemployment triggers risks across the future life course of the individual as well as those dependent on the individual, including offspring and other family members. Being unemployed often means that an individual and their dependents will have reduced assets and access to health services. Compounded over time and across generations, long term unemployment or periods of unemployment can impact overall economic experiences.

Implications for equity
Unemployment is often used as a marker of socioeconomic position (SEP); greater unemployment may lead to reduced material and psychosocial resources for an individual and their family, including access to health care and financial resources. The indicator has many implications for equity, given the dramatic gradient in unemployment by education and race/ethnicity, gender, education and other characteristics (15, 16). The unemployment gap between those with less than a high school diploma versus college graduates was 10.5 percentage points in 2010. The unemployment gap is greatest between whites and blacks and smaller between whites and Hispanics. Characteristics of the unemployed include: aged under 25 (particularly females), non-white, low educational attainment, unskilled (males), skilled and partly-skilled (females), unmarried, in rented accommodation, working in construction, and no fixed job or occupation (16).

The rates of unemployment and the growing numbers of uninsured people may exacerbate health disparities in low income and minority communities that already suffer from barriers to care and higher rates of chronic disease. Reducing unemployment among groups who experience more detrimental health outcomes has significant implications for health equity and would likely have a direct influence in health improvements for higher burden populations (22, 23).

Public health impact
Decreasing unemployment would have a significant positive public health impact. Unemployment has been linked to many adverse health outcomes (9, 10). Conditions associated with worse health through unemployment may occur through a variety of mechanisms, including lack of material resources for those who are unemployed, social isolation, loss of self-esteem, stress of job loss and conditions of job security, as well as implications for children living with unemployed parents. Because the majority of Americans rely on employer-provided insurance, unemployment affects access to health services and prescription drugs (18). Addressing the rate of unemployment, and decreasing the duration of such occurrences, would impact public health in a myriad of ways. First, as unemployment events are tied to decreased mental health and well-being, such that each occurrence compounds and worsens the effects of previous episodes of unemployment, reducing unemployment also will serve as prevention for mental health problems (1, 3). The association of the duration of these episodes of unemployment with suicide attempts and mortality grows stronger with longer duration, indicating that resolving unemployment in a timely fashion is important to protecting mental health (14, 21). Second, while unemployment has well-known associations with alcohol use and depression, it also has been shown to be associated with infertility (26) and lower rates of smoking cessation success (27). Third, at the community level, higher unemployment rates are associated with higher levels of crime and depression (28, 29) as well as teen pregnancy. The strong economy of the 1990s was accompanied by significant declines in violent crime and teen pregnancy rates. Between 1993 and 2001, the violent crime rate declined by 60 percent (31) and between 1990 and 2004, teen pregnancies declined by 46 percent (33).

Like poverty and other markers of SEP, unemployment may be transmitted across generations resulting in a public health impact potential of unemployment which spans beyond the current workforce. In addition to the challenges that reduced income creates for caring for children, children’s exposure to parents’ compromised mental health, financial security and assets, insurance access and more may have a lasting impact on future generations. Experiencing unemployment and subsequent poverty, particularly during important and transitive phases in the life course, will have an adverse impact on future health. SEP has an association with health that remains consistent over the life span. A mother’s SEP is associated with an infant’s health outcomes, including breastfeeding, maternal diet, and early childhood nutrition, into CVD risks, tobacco use, and alcohol consumption in young adults. Childhood SEP also has associations with adult self-rated health and CVD – its associations with mental health carry over into both adult SEP and health. As an adult, the later in life SEP changes for the worse, the more extreme the health effects. It has associations with everything from spontaneous abortion and depression to diabetes and early morbidity and mortality.
Leverage or realign resources

The potential to leverage or realign resources to address unemployment is high, including engagement of fields such as housing, urban planning, environmental justice, education and civil liberties. Examples of non-traditional collaborations can include: increased job training, incentivizing businesses to relocate to areas with high incarceration rates and to hire ex-offenders, programs targeting completion of education among youth, and Department of Housing and Education partnerships.

Monitoring and reporting on unemployment, particularly as disaggregated by race/ethnicity, sex, age, geography, and other characteristics will open opportunities for collaboration and partnerships outside the traditional MCH and public health fields.

Predict an individual’s health and wellness and/or that of their offspring

Unemployment has many implications for the unemployed individual’s health, the health of their children, and the health of their communities. For adults, unemployment may lead to decreased well-being that is never fully recovered, even after regaining employment (1, 2). Unemployment not only decreases life satisfaction, but increases future insecurities, contributing to psychological damage and well-being (3, 4). And while some behavioral and emotional problems in childhood are associated with adult unemployment, they do not attenuate the emotional and psychological impacts of unemployment (5, 6). Furthermore, the occurrence may trigger a spike in anxiety, alcohol abuse, and injuries, which may be detrimental not only to themselves but to their family. Each unsuccessful attempt to regain employment may further damage psychological well-being and decrease life satisfaction and self-reported social livelihood (7, 8). Unemployment has been shown to have a cumulative effect on acute myocardial infarction, early stroke, psychological distress, cardiovascular disease risks, and morbidity and mortality (1, 3, 5, 11-14). These negative health events may in turn reduce an individual’s capacity to work. Unemployment also may negatively impact marital relations (19, 20).

Parental unemployment also can be a predictor of children’s health outcomes. Parental unemployment has been linked to physical abuse of children (24, 25). Because unemployment may cause psychological disintegration (30), this may lead to harsher punitive and impulsive parental behavior (32). Parental unemployment also has been shown to lower children’s self-esteem and increase self-destructive behavior among adolescents (34). Maternal unemployment also has been associated with increased BMI among children (35), and both parents being unemployed has been found to be associated with preterm birth (36). In regards to family planning, unemployment has been shown to have opposite effects on men and women’s probabilities of having a first child- for men it is decreased, while for women it is increased (37).

On a community or ecological level, unemployment rates have been associated with increased cardiovascular risks (38) and crime rates (39), as well as low birth weight (40). Furthermore, unemployment is associated with a variety of disparities, from health and racial discriminations preceding unemployment to gender and racial differences in morbidity and mortality risks and outcomes.

Data Criteria

Data availability

The American Community Survey (ACS) is an ongoing nationwide survey that collects and provides data annually on demographic, social, economic, and housing characteristics in the United States. The survey is administered by the U.S. Census Bureau and replaced the decennial census long form starting in 2010. The ACS is sampled each year, resulting in three million addresses selected and approximately two million final interviews. However, the sample drawn is substantially smaller than the one used for the previous Census long form; as a result, data must be pooled across years in order to provide reliable estimates for some geographic units. The ACS provides yearly estimates for all states, as well as all cities, counties, metropolitan areas, and population groups of 65,000 people or more. For smaller areas, multiple survey years are combined to obtain reliable estimates: three survey years in areas with 20,000 to 65,000 people, and five survey years in areas with fewer than 20,000 people. ACS data are released the year following the year in which they were collected, making the estimates extremely timely. FactFinder provides tables by year, state and county, or data can be downloaded from FTP site.
Data are available for all 51 jurisdictions. The data utilized to calculate the indicators are widely available, for every state and for varying geographies (i.e., census tract, zip code tabulation area, county, place or city-level), based on U.S. Census data.

**Data quality**

Since the ACS is a sampled survey, there is uncertainty in the estimates. The Census Bureau takes steps to minimize the error associated with non-sampling error (reporting, coding, sampling frame, survey questionnaires, non-response, and interviewer bias) through the use of trained interviewers and careful review of all questionnaire design, sampling, and analytic steps. In addition, the Census Bureau began releasing margin of error data for ACS estimates starting in 2006; these estimates allow data users to calculate 90 percent confidence limits for all point estimates released from the ACS.

To account for the complex sampling design, the ACS employs an equally complex weighting scheme. The weighting process is well-documented in the survey methodology handbook, accessible on the web. Response rates for the ACS are calculated for housing units and group quarters (person). From 2000 to 2011, the housing unit response rate ranged from a low of 93.1 percent in 2004 to a high of 98 percent in 2009. Between 2006 and 2011, the group quarter response rate ranged from a low of 97.4 percent in 2006 to a high of 98 percent in 2008 and 2009.

The data quality is excellent, although data may not capture discouraged workers that drop out of the workforce, or some workers who are part-time because of economic circumstance (vs. by choice). Sensitivity, specificity, predictive value positive and reliability will vary depending on the outcome. In 2011, Kromer and Howard published a working paper comparing employment estimates between the ACS and the Current Population Survey (CPS). The authors found significant differences between the two estimates in 2007; however, question changes implemented in the 2008 ACS helped improve consistency between the two surveys in regard to both employment and unemployment estimates. The number of states with statistically different unemployment estimates between the ACS and CPS dropped from 47 in 2007 to 21 in 2009 after implementation of the question change (17).

**Simplicity of indicator**

This indicator is calculated by the American Community Survey and can be obtained in one-, three- and five-year estimates. The indicator is defined as persons age 16 and older in the labor force who are unemployed (and actively seeking work) and denominator is the total persons age 16 and older in the workforce. The data to calculate this indicator is available in ACS.

Despite the accessibility of data through FactFinder, both the website and data downloads are not very user-friendly.

The indicator is simple to explain and to understand. No data linkage is required for this indicator.

**References**


**Life Course Indicator: Unemployment (LC-22)**


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The Life Course Metrics Project

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Basic Indicator Information

Name of indicator: Adolescent Smoking (LC-23)

Brief description: Percent of adolescents who smoked cigarettes in the past 30 days.

Indicator category: Family Well-being

Indicator domain: Risk/Outcome

Numerator: Total ninth through 12th graders who smoked cigarettes ≥ one day during the past 30 days

Denominator: Total population of ninth through 12th graders

Potential modifiers: Race, ethnicity, age, education, socioeconomic status

Data source: Youth Risk Behavior Surveillance System (YRBSS)

Notes on calculation: Analysts who use the raw datasets should apply the appropriate survey weights to generate the final estimates.

Similar measures in other indicator sets: Preconception Health Indicator E1; HP 2020 Focus area TU-2 (TU-2.2 is a Leading Health Indicator); CDC Winnable Battle (Decrease the percentage of youth who smoke cigarettes by 11 percent); MIECHV Benchmark Area Improved Maternal and Newborn Health: Parental use of alcohol, tobacco, or illicit drugs; Chronic Disease Indicator
Life Course Criteria

Introduction
Cigarette smoking has long been recognized as having high mortality, morbidity, and economic costs (OSH, 2004; Thorne, 2007). Because of the addictive nature of nicotine (OSH 2001; Fiore, 2000), preventing cigarette smoking is an especially important societal goal (OSH, 2000; WHO, 2002), and has recently been identified by the Centers for Disease Control and Prevention (CDC) as a Winnable Battle that will have a significant impact on our nation’s health (CDC, 2012).

Data on the longand short-term effects of cigarette smoking is vast and compelling. Since the publication of the Surgeon General’s first report on smoking, an extensive amount of evidence has been identified to support the detrimental effect that smoking cigarettes has on those who engage in the behavior, particularly the lifelong health effects and price tag associated with the treatment of smoking-related diseases, such as lung cancer and chronic obstructive pulmonary disease (COPD).

Although there is some evidence that the age of initiation may be increasing, most regular smokers smoke their first cigarette by age 18 years. (Lantz, 2003; OAS, 2006). Because smoking initiation rarely occurs at later ages, the critical time for prevention occurs in adolescence and early adulthood (Musto, 1999; Giovino, 2002).

Implications for equity
Smoking behaviors within a given geographic location are related to both compositional factors (socioeconomic and demographic characteristics of individuals/households) and contextual factors (area characteristics and policies). Compositional characteristics associated with smoking include poverty, education, occupation, race, nativity, gender, marital status and age (Acevedo-Garcia et al., 2005, Barbeau et al., 2004, Geronimus et al., 1993, Pampel, 2009, Siahpush et al., 2005 and Williams and Jackson, 2000). Contextual characteristics have shown to be associated with smoking after controlling for individual covariates; these include neighborhood poverty, proximity of cigarette advertisements, and rules of smoking in workplaces and homes (Diez Roux et al., 1997, Duncan et al., 1999, Kandula et al., 2009, Reijneveld, 1998, Ross, 2000 and Tseng et al., 2001).

Of note, racial/ethnic minorities in the United States experience a disproportionate burden of smoking-related diseases, including cancer and heart disease, despite having larger proportions of light and intermittent smokers and generally lower adult smoking prevalence rates than non-Hispanic Whites (Jemal et al., 2008; Trinidad et al., 2009). Racial/ethnic minorities are also less likely to quit smoking successfully than are non-Hispanic Whites (Okuyemi et al., 2007; Cokkinider et al., 2008).

Despite the fact that Black smokers smoke fewer cigarettes per day than White smokers, there is ample evidence that Black smokers are more susceptible than White smokers to smoking-related health consequences such as lung-cancer, heart disease and stroke (Haiman et al., 2006; Hebert, 2005; U.S. Department of Health and Human Services, 1998). The adverse public health consequences of smoking among Latinos are severe, as three of the four leading causes of death among Latinos are smoking-related (i.e., cancer, heart disease, and stroke (CDC, 2009).

Moreover, evidence shows that cigarette smoking is a major contributor to mortality according to education level (Jemal et al., 2008; Lauderdale, 2001; Pappas et al., 1993; Warren and Hernandez, 2007): smoking, which has become increasingly concentrated in low education groups (e.g., Pampel, 2005), greatly increases the risk of premature adult mortality (e.g., Rogers et al., 2005).

Among addictive behaviors, cigarette smoking is the one most likely to become established during adolescence (DASH, NCCDPHP, CDC, 2008). Each day in the United States, approximately 3,800 young people under 18 years of age smoke their first cigarette, and an estimated 1,000 youth in that age group become daily cigarette smokers (USDHSS, 2011). More specifically, the percentage of middle school students who were current cigarette smokers in 2009 was 3.9 percent. Of these, 3.2 percent were female students and 4.6 percent were male students. Racial and ethnic differences are present among this population of middle school students who were current smokers: 4.7 percent were black, non-Hispanic students, 1.4 percent were Asian, non-Hispanic students, 6.2 percent were Hispanic students and 3.0 percent were white, non-Hispanic students (CDC, 2010).

Public health impact
From 2000 to 2004, cigarette smoking and exposure to tobacco smoke resulted in at least 443,000 premature deaths, approximately 5.1 million years of potential life lost (YPLL), and $96.8 billion in productivity losses annually in the United States (USDHHS, 2008). Lightwood and colleagues (2008) examined the economics of tobacco use and revealed that investments in tobacco control programs led to substantial savings in health care expenditures. The authors showed that the $1.8 billion spent on California’s tobacco control programs over 15 years (1989–2004) yielded a 50-fold return ($86 billion) in reduced health care costs. In addition to effectively reducing smoking – a significant public health goal in itself – the benefits of the programs included “substantial, rapid, and growing reductions in per capita state health care expenditures” (Lightwood et al., 2008).

Policies to combat smoking have resulted in substantial progress with national smoking prevalence declining from 24.5 percent in 1992–1993 to 18.5 percent in 2006–2007 (Giovino, Chaloupka, and Hartman, 2009). However, tobacco remains a leading cause of preventable and premature death, killing more than 1,200 Americans every day. For every tobacco-related death, two new young people under the age of 26 become regular smokers. Nearly 90 percent of these replacement smokers try their first cigarette by age 18, and approximately three out of four high school smokers continue to smoke well into adulthood (USDHSS, 2012).

Smoking during adolescence and young adulthood can have immediate adverse health effects and lasting impacts throughout the life course. Additionally, exposure to tobacco can also impact future generations. This broadened concern reflects the emergence of a body of evidence linking risk exposures in early life, even in the antenatal period, to risk for chronic disease in adulthood (USDHSS, 2006).

**Leverage or realign resources**

There are a number of opportunities to use resources to improve the adolescent smoking indicator. These opportunities include:

- School administrators and counselors working with parents of adolescents to development awareness campaigns and also create a smoking cessation plan for adolescents who smoke
- Community and school programs, policies and interventions coordinated and implemented in conjunction with efforts to create tobacco-free social norms
- Prohibiting smoking on school grounds, and in worksites and public places
- Care managers/coordinators working with providers to target education and self-education
- Using home visiting as an opportunity to share education and smoking cessation information
- Engage stakeholders in the key actions from the CDC Winnable Battles for Tobacco, including: Monitor tobacco use and prevention policies; Protect people from secondhand smoke; Offer help to quit tobacco use; Warn about the dangers of tobacco; Enforce bans on tobacco advertising, promotion and sponsorship; and Raise taxes on tobacco

Schools and workplaces are both stakeholders in reducing adolescent smoking because complications from smoking are responsible for absenteeism from both school and work. The CDC Winnable Battles progress report indicates that school programs to prevent smoking among middle- and high-school students are a good investment: every dollar invested in school tobacco prevention programs saves almost $20 in medical care costs (CDC 2013). While adolescents may not be part of the workforce yet, it is understood that their future involvement in the economy will have a significant effect on the cost for society at large. Therefore, given the changing environment of health care in the United States, private as well as public entities could benefit from a joint effort to curb smoking initiation in adolescents.

Lastly, adolescent smoking is a major risk factor for chronic diseases later in life. As such, chronic disease programs may invest in adolescent smoking prevention programs that may ultimately help to reduce the incidence of future adult chronic diseases.

**Predict an individual’s health and wellness and/or that of their offspring**

Smoking is a leading risk factor for mortality, cardiovascular disease, respiratory disease, and a variety of other health outcomes, contributing to an estimated 443,000 deaths annually in the United States (CDC, 2007). Smoking also has a detrimental effect on reproductive health. For instance, smoking during pregnancy is associated with increased risk for premature rupture of membranes, abruptio placentae (placenta separation from the uterus), and placenta previa (abnormal location of the placenta, which can cause massive hemorrhaging during delivery. Additionally, smoking also is
associated with a modest increase in risk for preterm delivery (CDC, 2001). Moreover, infants born to women who smoke during pregnancy have a lower average birth weight and are more likely to be small for gestational age than infants born to women who do not smoke. Low birth weight is associated with increased risk for neonatal, perinatal, and infant morbidity and mortality. The longer the mother smokes during pregnancy, the greater the effect on the infant's birth weight. The risk for perinatal mortality, both stillbirths and neonatal deaths, and the risk for sudden infant death syndrome (SIDS) are higher for the offspring of women who smoke during pregnancy (CDC, 2001).

The adverse health effects of smoking can accumulate over the lifetime of the smoker. Moreover, those who quit smoking will, over time, see a significant reduction in the adverse effects with some disappearing entirely (Trannah et al, 2011, USDHHS, 2010). Therefore, it is clear that the opportunity to intervene when smoking behaviors are initiated, which is most often during adolescence, can potentially avoid the cost of treating future poor health outcomes.

Data Criteria

Data availability
Data on adolescent smoking prevalence in the United States is vast and readily available. The majority of the data is generated by the CDC, through its office on Smoking and Health. More specifically, The Youth and Young Adult Data Youth Risk Behavior Surveillance System (YRBSS) monitors priority health-risk behaviors and the prevalence of obesity and asthma among youth and young adults. The YRBSS includes a national school-based survey conducted by the CDC, state, territorial, and local education and health agencies and tribal governments. YRBSS monitors six categories of priority health-risk behaviors among youth and young adults, including behaviors that contribute to unintentional injuries and violence; sexual behaviors that contribute to unintended pregnancy and sexually transmitted diseases, including HIV infection; alcohol and other drug use; tobacco use; unhealthy dietary behaviors; and inadequate physical activity. In addition, YRBSS monitors the prevalence of obesity and asthma.

The YRBSS is administered every other year (odd years), generally in the spring semester in schools via a pencil and paper mode. The YRBSS survey contains no skip patterns. In the even-numbered years, CDC leads a process of examining and revising the questionnaire, using both expert opinion and votes from the YRBSS coordinators in states. The final result is a standard questionnaire that can be modified by states to meet their needs, but modifications must be within certain parameters.: 1) the modified questionnaire must contain at least two-thirds of the original standard questionnaire, 2) questions that are added are limited to 8 mutually exclusive response options, 3) the questionnaire may not have skip patterns or fill in the blanks, and 4) the questionnaire may not exceed 99 questions, and the state must retain the height and weight questions. The 2011 YRBSS included a national school-based survey conducted by CDC and 47 state surveys, six territory surveys, two tribal government surveys, and 22 local surveys conducted among students in grades nine through 12 during October 2010-February 2012. Data collected by CDC represent both public and private schools with students in grades nine through 12; data collected by states, territories, tribes, and localities represents primarily public school students.

This measure does not require the linkage of datasets. MCH programs can readily gain immediate access to the data on an annual basis and possibly provisionally. The survey question of interest is “During the past 30 days, on how many days did you smoke cigarettes?”

Data quality
From the available YRBSS documentation, the 2011 national YRBS school response rate was 81 percent; the student response rate was 87 percent; and the overall response rate was 71 percent. Comparisons between estimates for states and districts from the national data collection effort and the surveys collected by states, territories, tribes, and localities can be found on the CDC YRBSS website. Each jurisdiction reached a minimum site response rate of 60 percent and therefore had weighted data for that year. Weighted data allows a jurisdiction to make statements from the data that generalize to all high school students in that jurisdiction.

Studies by CDC and others indicate that data about risk behaviors can be gathered as credibly from adolescents as from adults. YRBSS performs internal reliability checks to help identify the small percentage of students who falsify their answers. To obtain truthful answers, students must perceive the survey as important and know procedures have been developed to protect their privacy and allow for anonymous participation.
A test-retest study of the 1999 version of the questionnaire (Brener 2002) found that 47 percent of items had at least “substantial” reliability, with kappa statistics of agreement of 61 percent or greater, and 93 percent of items had at least “moderate” reliability, with kappas of 41 percent or greater. The study found no differences in reliability by gender, grade, or race/ethnicity. The study found that items related to tobacco use, alcohol and other drug use, and sexual behavior had the highest reliability. By comparison, items asking about dietary behaviors, physical activity, and other health-related topics were less reliable. A study of mode and setting using the YRBSS questions (Brener 2006) determined that students were more likely to report risk behaviors when they took the survey at school compared with taking the survey at home.

Data availability and quality for the YRBS varies by year and it depends on the participation status for states, districts, territories, and tribal governments (CDC, 2013). Survey response rates can vary substantially by jurisdiction. In the Brener (2002) study, the smoking indicator had “substantial” reliability (Brener, et. al, 2002). The prevalence of “Smoked cigarettes ≥ one day during the past 30 days,” which can be used as an indicator of current adolescent smoking, was 27.2 at Time 1 and 27.5 at Time 2. The kappa statistic was 81.9.

**Simplicity of indicator**

The level of complexity in calculating and explaining this indicator is relatively low. YRBS results do require statistical weighting provided by CDC to approximate representativeness of the student population. Although somewhat controversial, adolescent smoking prevalence is calculated based on daily smoking. For instance, evidence suggests that adolescents have a varied perception of what constitutes different classifications of smokers and smoking. For example, Leatherdale and McDonald (2006) found that approximately 52 percent of students who were categorized by researchers as “regular smokers” and 98 percent categorized as “experimenters” did not actually consider themselves to be smokers. Evidence also suggests that less frequent smoking, being younger, and social smoking, are related to less likelihood of an individual identifying themselves as a smoker (Berg et al., 2009; Levinson et al., 2007; Moran, Wechsler, & Rigotti, 2004).

However, the standard manner in which YRBS assesses adolescent smoking may circumvent these issues. The survey asks respondents to state whether or not they “smoked ≥ 20 cigarettes per day on the days smoked during the past 30 days.” This number is divided by the number of nine through 12 grade respondents. Also, to better capture frequency or intensity, YRBS also prompts students to state whether they “smoked ≥ 20 cigarettes per day on the days smoked during the past 30 days” (Brenner, et. al, 2002).

**References**


General. Atlanta (GA): U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, Coordinating Center for Health Promotion, National Center for Chronic Disease Prevention and Health Promotion, Office on Smoking and Health, 2006.


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Life Course Indicator: Adolescent Use of Alcohol

The Life Course Metrics Project

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Basic Indicator Information

Name of indicator: Adolescent Use of Alcohol (LC-24)

Brief description: Percent of adolescents using alcohol during the past 30 days

Indicator category: Family Well-being

Indicator domain: Risk/Outcome

Numerator: Number of adolescents aged 12 to 17 years reported use of alcohol during the past 30 days

Denominator: Total National Survey on Drug Use and Health survey respondents ages 12-17 years old

Potential modifiers: Race/ethnicity, sex, parental drug use

Data source: National Survey on Drug Use and Health (NSDUH), Substance Abuse and Mental Health Services Administration (SAMHSA)

Notes on calculation: None

Similar measures in other indicator sets: Preconception Health Indicator E5; HP 2020 focus area SA-2.3; Maternal Infant and Early Childhood Home Visiting (MIECHV) Benchmark Area Improved Maternal and Newborn Health: Parental use of alcohol, tobacco, or illicit drugs; Chronic Disease Indicator
Life Course Criteria

Introduction
In 2012, the rate of current alcohol use among youth aged 12 to 17 was 12.9 percent (7), which is a higher rate of use than any other drug including tobacco (22). Adolescent alcohol use is associated with common sources of morbidity and mortality in youth including motor vehicle crashes and other accidental injuries and fatalities, depression, suicide, and interpersonal violence (11, 16). Evidence also shows initiation of alcohol use in early adolescence has consequences throughout the life course including hindered physical and mental development and propensity for substance use, abuse, and dependence in adulthood (20, 23). Alcohol use among adolescents is concerning not just due to the direct associated health effects but also due to the increased likelihood for other risk taking behaviors such as risky sexual activity and use of tobacco and other drugs (15, 16). Brookmeyer and Henrich (2009) found alcohol was a present factor in risk taking behaviors in adolescents including delinquency and sexual risk behaviors (15). Thus, delaying onset of alcohol use may have a positive effect on other important adolescent risk taking behavior (15).

Implications for equity
Rates of past-month alcohol use vary by race/ethnicity. The 2012 NSDUH showed rates of current alcohol use were lowest for Asian youth (4.9 percent) and highest for non-Hispanic White youth (14.6 percent) (7). Current alcohol use rates for other racial/ethnic groups include 9.3 percent for non-Hispanic Black youth, 10.0 percent for American Indian/Alaskan Native youth, 11.7 percent for multiracial youth, and 12.8 percent for Hispanics (7).

Risk of current alcohol use in adolescents increases with age. National results from the 2013 Youth Risk Behavior Survey (YRBS) show 24.4 percent of U.S. ninth graders drank alcohol on a least one day during the past 30 days before the survey, compared to 30.9 percent of 10th graders, 39.2 percent of 11th graders, and 46.8 percent of 12th graders (9). While rates of past month drinking are currently comparable between high school males (34.4 percent) and high school females (35.5 percent), problem use of alcohol such as binge drinking has historically had a higher prevalence among males (9,11). However, underage female binge drinking practices are increasingly similar to underage male binge drinking practices, which puts young females at an increasing risk of alcohol-related problems, including sexual violence (11).

A number of community- and family-level factors are associated with adolescent alcohol use including parental education attainment and parental substance use, perceived availability of alcohol, community norms favoring alcohol use, and other social circumstances surrounding adolescent life such as social networks, poverty and peer groups (2, 8). Adolescent behaviors are influenced by people in their environment such as family members and peers (10). There is evidence that adolescents who perceive greater support for alcohol consumption among their peers, community, and parents are more likely to engage in alcohol consumption and alcohol-related behavior (10). Youth who have parents who binge drink are twice as likely to binge drink themselves and to be classified as alcohol dependent than youth who have parents that do not engage in binge drinking (11). Increased likelihood of alcohol use and problem alcohol use in youth with parents who exhibit problem use of alcohol may not just be due to perceived norms in youth but also genetics, cultural values, and drinking practices prevalent in their communities (11).

Public health impact
Alcohol is the most popular substance of abuse among adolescents in the United States and leads to negative health and social effects on adolescents, their families, and their communities (11). Each year, alcohol is involved in the death of approximately 4,700 U.S. youth, which reduces the life span of these youth by an average of 60 years (11). Youth drinking is a factor in numerous costly health and social issues including motor vehicle accidents, suicide, violence, unintentional injuries (the leading cause of death in U.S. adolescents), brain impairment, risky sexual activity, academic problems, alcohol poisoning, and future alcohol dependence (11). Adolescents typically consume alcohol at less frequent intervals than adults; however, they are more likely than adults to partake in binge drinking, which increases their risk for negative health consequences (11).

Alcohol use increases the likelihood an adolescent driver will be involved in a motor vehicle crash, which is the largest contributor to unintentional injury in youth, and in 2010 4.1 percent of 16 year olds and 7.6 percent of 17 year olds reported driving under the influence of alcohol in the past year (11, 24). In 2010, 22 percent of drivers aged 15 to 20 killed in motor vehicle crashes had been using alcohol (25).
Engaging in sexual behaviors that increase the risk of unplanned pregnancies and contracting sexually transmitted diseases (STDs) is associated with adolescent use of alcohol (4, 11). Reducing alcohol use by adolescents may have the potential to reduce sexual and other risk taking behaviors (15). Risky sexual behaviors that are associated with alcohol use in adolescents include unwanted, unintended, and unprotected sexual activity, as well as sex with multiple partners (11). Adolescent girls also are more likely than adult women to drink alcohol during pregnancy (13), which increases their risk for miscarriage and still birth, and puts their offspring at an increased risk for a wide range of disabilities known as fetal alcohol spectrum disorders (FASDs)(12, 14).

Reducing the use of alcohol among adolescents age 12 to 17 years could reduce the burden of emergency department visits. In 2009, there were 54,726 emergency department visits by adolescents aged 12 to 17 caused by alcohol alone, another 22,192 emergency department visits by this age group resulted from alcohol combined with other drug use (3).

Adolescent alcohol use increases the risk of alcohol dependency in adulthood which can influence community and society at large. A study by Grant and Dawson found 40 percent of people who began using alcohol before age 13 were diagnosed as alcohol dependent at a later time in their lives while only 16.6 percent of people who began drinking alcohol at age 18 were classified as alcohol dependent (16).

**Leverage or realign resources**

A range of evidence-based alcohol use prevention programs and policies exist as interventions through schools, extracurricular activities, families, and communities. Schools are an important partner to engage in preventing alcohol use in adolescents due to the continuous and intensive contact schools have with this population. School-based alcohol prevention programs are typically targeted towards middle school and high school aged youth as rates of drinking initiation peak between grades seven to 11 (11). The SAMHSA National Registry of Evidence-based Programs and Practices contains a number of alcohol use prevention programs designed for schools (18). Youth extracurricular activities also can be used to prevent alcohol use. These programs may be structured as alternative programs, designed to engage youth in more positive activities than substance use such as sports, or peer programs, designed to teach social and life skills that empower youth to refuse alcohol and drugs (19). Reviews of these types of programs have shown peer programs to be overall more effective than alternative programs, but that alternative programs have higher success with high-risk youth (19).

Where family factors including parent-child relationships, parental involvement, family communication, and discipline methods can significantly impact adolescent alcohol use, family-centered interventions also are critical for improvement in this indicator (19). A review of family centered programs found that well-integrated programs that address entire families and not only parents or adolescents alone are more successful in improving adolescent substance use and abuse (, 5).

Community-level changes to affect this indicator could be impacted by media campaigns, enforcement of underage alcohol sale restrictions, and other policies and regulations that restrict access and availability to alcohol (19). Overall, when interventions targeting changes in individual level behaviors are accompanied by community and policy level changes, greater impact on the use of alcohol in adolescents is shown (6). Comprehensive approaches that incorporate families, schools, and communities may be more effective than focusing on one area of influence (19). Project Northland is a middle school-based alcohol intervention in northeastern Minnesota designed to delay onset of alcohol use, reduce alcohol use in students who already drink, and limit alcohol-related problems in young drinkers (17). Although it is based in schools, Project Northland also incorporates community, peer, and family components (17). An evaluation of Project Northland found students’ weekly drinking was 30 percent less in those that had received the intervention compared with those who had not been a part of Project Northland (17).

**Predict an individual’s health and wellness and/or that of their offspring**

Adolescents who consume alcohol are at a higher risk for a wide range of physical, mental, and social problems including physical illnesses, suicide, interpersonal violence, unplanned or unwanted sexual activity, physical and sexual assault, abuse of other drugs, disruption of normal growth and development, academic problems, and alcohol poisoning (11, 22). The risks of these issues increase in youth who participate in binge drinking (22). Adolescence is a key period of development for an individual, and heavy alcohol use during this time period may have adverse effects on normal physical development and brain functioning resulting in long-term consequences (11, 20, 22). Adolescents who engage in heavy
alcohol use may have decreased ability in planning, memory, speeded processing, attention, and spatial operation, all of that could lead to academic disadvantage (11).

Youth who use alcohol are at a higher risk for accidental injury and death (21). Alcohol is involved in nearly half of all motor vehicle crashes among adolescents 15 to 19 and a quarter of 15 to 19 year old fatally injured drivers are under the influence of alcohol (21). Alcohol also increases risk of other causes of unintentional injury and death in adolescents by impairing judgment and ability to perform tasks, and through exacerbation of injury severity. Alcohol increases risk of bicycle and pedestrian accidents and is involved in nearly 40 percent of all adolescent drowning instances (21).

Early age of alcohol use initiation is a predictor of future alcohol dependence or alcohol abuse later in life (11). Furthermore, adolescents who use illicit drugs often have a history of alcohol use (23). Twin studies have provided evidence that the association between early alcohol use initiation and future alcohol and drug use, abuse and dependence goes beyond genetics and family environment (23). Evidence supports delaying the onset of drinking alcohol will decrease an individual’s risk of lifetime alcohol dependence and other drug use disorders (23).

**Data Criteria**

**Data availability**

Data on adolescents using alcohol and any illicit drugs during the past 30 days is captured through the administration of the NSDUH funded by SAMHSA, an agency of the U.S. Department of Health and Human Services (HHS). The NSDUH is a nationwide survey administered annually since 1971 and involves interviews with randomly selected individuals aged 12 and older across all 50 states in the United States and District of Columbia.

The indicator is based on the length of time since the survey respondent last drank an alcoholic beverage “within the past 30 days” as one of the response options. The NSDUH uses multistage area probability sampling for each of the 50 states and the District of Columbia and oversamples youth and young adults who represent three major age groups of 12 to 17 years, 18 to 25 years, and 26 years or older. The NSDUH data is available for download through the SAMHSA Substance Abuse and Mental Health Data Archive (SAMHDA) (samhsa.gov/data/) and is readily available to any MCH program in the country. This website provides links to the public-use data files as well as restricted-use data files that list information on use of some illicit drugs. The SAMHDA website also allows users to generate quick tables for the target age group of 12-17 years and allows for required variable searches across the different years of data.

**Data quality**

A reliability study was conducted for the NSDUH in 2006 by the Office of Applied Studies of SAMHSA, based on a directive of the federal government’s Office of Management and Budget to evaluate the quality of federally funded surveys. The reliability study was conducted on a subsample of the main study by administering a second interview in addition to the interview conducted for the main study. A total of 3,136 interviews were completed and they were done five to 15 days after the initial interview for the main study. The interview for the reliability study followed the same procedure for data collection as the main study. The study found perfect reliability for indicators that measure lifetime substance use, as well as substantial reliability for substance dependence and abuse indicators.

NSDUH is the primary source of statistical information on the use of illegal drugs by the U.S. population. Prior to 2002, the NSDUH was called the National Household Survey on Drug Abuse (NHSDA) with the first round of surveys being conducted in early 1970s with 3,000 respondents. As the data collected through this survey gained importance, the Office of National Drug Control Policy advocated for expansion of the sample in the early 1980s for tracking data about illicit drug use. Also, a series of studies were conducted to evaluate the survey methods and questionnaire that lead to the redesign of the survey in 1994. Following this redesign of the survey, SAMHSA pursued the use of a newly emerging data collection technology, audio computer-assisted self-interviewing (ACASI), simultaneously with new sampling design to produce state-level estimates from survey responses. Since this initial redesign, there has been routine evaluation of the survey methodology and periodic improvements of the survey design and implementation.

The measure is utilized by the HHS Health Resources and Services Administration, and the Maternal and Child Health Bureau for their Child Health USA report (1).
**Simplicity of Indicator**

The indicator is widely used by many federal and state agencies and other organizations interested in the use of tobacco, alcohol, illicit drugs (including non-medical use of prescription drugs), and mental health in the United States. The indicator is used by HHS Health Resources and Services Administration, and the Maternal and Child Health Bureau for their Child Health USA report (1). The data for the indicator are readily available, and the numerator and denominator for this indicator are simple. Adolescent use of alcohol is a common focus area among professionals and communities and one that community members can understand.

Numerous government, national, and community groups use this indicator for advocacy or improving public health programs. The White House Office of National Drug Control Policy uses NSDUH data to track progress toward goals in the National Drug Control Strategy. SAMHSA prepares statistical reports on substance use patterns and trends and uses the data to identify populations and geographic areas with particular substance abuse problems so federal resources can be used efficiently for prevention and treatment programs. The Partnership for a Drug-Free America uses NSDUH data to design media advertising campaigns for the prevention of substance use and abuse. Based on the trends and patterns of substance use evident in the data, the National Institute on Drug Abuse develops research programs targeted toward populations and types of drug use problems where the need is greatest. University-based researchers use NSDUH data to conduct research on important substance use issues, such as the risk and protective factors associated with substance use, personal and societal consequences of substance use, and the impact of policy decisions for dealing with the substance abuse problem. Substance abuse agencies at the state and local levels use NSDUH data to assess the potential need for treatment services and to design programs that fit the needs of populations served. State and local health departments use NSDUH data to assess area substance use problems and to develop appropriate funding strategies and prevention measures. The U.S. Department of Education uses the data to inform drug use prevention and education programs and provide educational materials for teachers and administrators. The U.S. Department of Transportation uses NSDUH data on driving after alcohol and illicit drug use to develop prevention programs and materials on impaired driving.

**References**


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Life Course Indicator: Children and Youth with Special Health Care Needs (LC-25)

The Life Course Metrics Project

As MCH programs begin to develop new programming guided by a life course framework, measures are needed to determine the success of their approaches. In response to the need for standardized metrics for the life course approach, AMCHP launched a project designed to identify and promote a set of indicators that can be used to measure progress using the life course approach to improve maternal and child health. This project was funded with support from the W.K. Kellogg Foundation.

Using an RFA process, AMCHP selected seven state teams, Florida, Iowa, Louisiana, Massachusetts, Michigan, Nebraska and North Carolina, to propose, screen, select and develop potential life course indicators across four domains: Capacity, Outcomes, Services, and Risk. The first round of indicators, proposed both by the teams and members of the public included 413 indicators for consideration. The teams distilled the 413 proposed indicators down to 104 indicators that were written up according to three data and five life course criteria for final selection.

In June of 2013, state teams selected 59 indicators for the final set. The indicators were put out for public comment in July 2013, and the final set was released in the Fall of 2013.

Basic Indicator Information

Name of indicator: Children & Youth with Special Health Care Needs (CYSHCN) (LC-25)

Brief description: Percent of children (0-17 years) with a special health care need

Indicator category: Family Wellbeing

Indicator domain: Risk/Outcome

Numerator: Children, ages 0-17 years with a special health care need

Denominator: Children, ages 0-17 years

Potential modifiers: Race, ethnicity, sex, age, SES/poverty, geographic location, access, language, medical home status, insurance status

Data source: National Survey of Children’s Health (NSCH)

Notes on calculation: Children with special health care needs (CSHCN) are defined in the National Survey of Children’s Health (NSCH) as those who have one or more chronic physical, developmental, behavioral or emotional conditions for which they require an above routine type or amount of health and related services, based on the definition set forth by the Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau (MCHB). On the NSCH, to be counted as a child with special health care needs, a respondent must have qualifying responses on one or more of the five CSHCN Screener criteria (K2Q12; K2Q15; K2Q18; K2Q21; K2Q23). Analysts who use the raw datasets should apply the appropriate survey weights to generate the final estimates.

Similar measures in other indicator sets: HP 2020 Focus areas MICH-30 and MICH-31 are specific to CSHCN; Title V Programs report the number of CSHCN served but not prevalence.
Life Course Criteria

Introduction
Children and youth with special health care needs (CYSHCN) is an indicator consistent with current life course science. When compared to non-CYSHCN, CYSHCN and families with CYSHCN experience lifetime societal barriers and face significant disparities, particularly in health care access and health equity. Additionally, the complex relationships between socioeconomic status, race/ethnicity, and access to programs, services, and supports for families points to significant implications of the indicator for the components of life course theory specific to the socio-ecological model.

Implications for equity
CYSHCN and families with CYSHCN face a myriad of barriers which contribute to health disparities and health inequity. Disparities found within the general child population are mirrored, and sometimes exacerbated, within the CYSHCN population. Factors contributing to equity issues for minority CYSHCN include: poverty, insurance and underinsurance, partnership in decision making, access to care, cultural competency, and communication and language barriers. [5]

Research suggests the following observations provide evidence to support implications for inequity among children and youth with special health care needs:

- Low income, minority children are more likely to report childhood disability. [6]
- Children with special health care needs are more likely to suffer from depression and other mental health problems. CYSHCN also are more likely to experience negative psychological and social impacts throughout the life course. [7]
- When compared to white families with CYSHCN, Hispanic and non-white families with CYSHCN report having a more difficult time accessing and utilizing community-based services due to a lack of available services, long wait times, and the absence of linguistic services. [8]
- Children with special health care needs are at risk for diminished health-related quality of life. Families of CYSHCN devote considerable time and effort to providing health-related care, and often experience financial burden, work loss, poor mental and physical health, and negative social consequences. [6]
- Communities and health systems are frequently unable to provide adequate resources necessary to achieve optimal health and social outcomes for children with special health care needs and their families. [6]

In summary, a large body of research suggests that the indicator measuring CYSHCN inherently reflects equity-related measures. These inequity measures include, but are not limited to: racial and ethnic minority disparities, cultural competency issues, socioeconomic status disparities, insurance status issues, language barriers, access to care and ease of use, strained relationships with health care professionals, and limited physical environments. [5] Public health systems must prioritize the elimination of health inequities in order to ensure all CYSHCN face positive trajectories throughout the life course.

Public health impact
Data from the 2011-2012 NSCH indicates 19.8 percent of children residing in the United States have a special health care need. [9] This translates to nearly 1 in 5 children, indicating a significant portion of the U.S. child population. As mentioned previously, CYSHCN and families with CYSHCN face lifelong barriers, ongoing care and access issues, and complicated health trajectories. Many CYSHCN require highly specialized or ongoing care, placing a burden on care providers and families. The current changing health care environment provides opportunities for health care systems to address managed care for CYSHCN and enhance systems of care serving CYSHCN.

Families with CYSHCN face significant financial burdens throughout the life course. When compared to families with typical children, families with CYSHCN are more likely to have public insurance, less likely to live in higher income families, and more likely to face financial problems. [10]

Financial burdens for the overall public health system also are vast. Economists predict that CYSHCN are a very high cost population for public and private insurers. For example, in 2004, the per-member, per-month (PMPM) cost for CYSHCN averaged $328 compared with a PMPM of $84 for non-CYSHCN. Additionally, children with catastrophic conditions had an average PMPM cost of $2,867. [11] Given the high cost of this population, there is a vested economic and public health interest in controlling costs for this population while also continuing to provide quality care.
**Leverage or realign resources**

Establishing quality national, state, and local systems of care for CYSHCN is crucial for this population. In order to establish a robust system, multiple entities must communicate and collaborate across agencies and sectors. Potential partners at the federal, state, and local level include, but are not limited to: federal agencies (HRSA, CDC, NIH, CMS); Title V agencies in state departments of health; labor departments; education departments; school systems; national resource centers; the foster care system; housing agencies; social service agencies (WIC, TANF, etc.); mental and behavioral health entities; local non-profit organizations; Medicaid and health plans; early intervention services such as Head Start and Early Head Start; family-involvement organizations, and direct service providers such as pediatricians, primary care physicians (PCPs), specialists, and hospitals. Potential partnerships are further discussed below.

Multiple child serving entities provide screening for various pediatric conditions. Local schools, public health entities, and pediatric providers could potentially screen the same child for the same conditions. Therefore, establishing linkages between service providers and public health agencies is crucial. By realigning screening and eligibility services for CYSHCN, systems of care can avoid redundancy and waste for CYSHCN, and improve coordinated services. Additionally, Head Start and Early Head Start programs focus on early childhood development and often provide screening services; therefore, a relationship with this partner could result in better screening and enrollment into programs for CYSHCN.

As mentioned previously, having a special health care need is highly associated with behavioral and mental health issues. Therefore, engaging mental and behavioral health partners is pertinent to building a quality, comprehensive system of care for CYSHCN. Federal partners such as SAMSHA and local organizations such as counseling centers have the potential to work together to collaboratively serve CYSHCN.

Since many CYSHCN require ongoing or complicated care, adequate relationships and partnerships with Medicaid, local health plans, pediatricians, subspecialists, hospitals, and managed care entities could result in successful care management for CYSHCN. Use of medical homes, managed care, and/or care coordination services has the potential to foster such partnerships; however, these types of care management are not successful without good relationships between CYSHCN-serving entities.

Many national organizations share a vested interest in CYSHCN and could provide strong partnerships to merge efforts. National resource centers such as the Catalyst Center and Got Transition? provide comprehensive resources for CYSHCN at critical times in the life course (e.g. transition from pediatric to adult care).

Incorporating family-centered care is vital for building quality systems of care for CYSHCN. Family Voices is a national organization committed to improving family-centered systems of care for CYSHCN. Family Voices advocates for and assists parents and families raising CYSHCN by partnering with state affiliates throughout the nation. Other family organizations include, but are not limited to: Parent to Parent, Parent Information Centers, Family Health Information Centers, Federation for Children with Mental Health, the National Alliance on Mental Illness (NAMI), and hundreds of condition-specific (e.g. autism, rare diseases such as muscular dystrophy) or system specific (e.g. newborn screening, special education) family-led health advocacy organizations. Family advocacy organizations are strong partners and can help identify system issues.

The CYSHCN population varies vastly and encompasses children with minor learning disabilities such as ADHD to children who face catastrophic conditions such as cystic fibrosis and hemophilia. Given the variability with this population, programs serving CYSHCN have the ability to merge partnerships with a vast number of stakeholders. The partners discussed above merely encompass a snapshot of potential partners and resources.

**Predict an individual’s health and wellness and/or that of their offspring**

The indicator of CYSHCN reflects the time and trajectory components of life course theory, and in particular, critical and sensitive periods throughout life. Delaney and Smith [7] suggest that childhood physical and mental health conditions result in poorer adult health. Furthermore, Aron and Loprest [7] describe how childhood disability impacts educational achievement, and show that special education students lag behind their peers in educational achievements. These
findings contribute to socioeconomic and health status in adulthood. In this respect, the indicator of children and youth with special health care needs is an adequate predictor of the individual's future health and wellness.

Although many conditions and illnesses CYSHCN face are not preventable, many developmental disabilities can be reversed or screened during early childhood to prevent or decrease adverse outcomes during adolescence and adulthood. Children with special health care needs who receive early intervention services are more likely to reach their full potential later in life. Therefore, the importance of early intervention and screening truly mirror the importance of the life course trajectory for CYSHCN.

Another life course issue for CYSHCN is transition. Since CYSHCN often require long-term, ongoing care, transition from pediatric care to adult care is crucial for maintaining health in adulthood. Therefore, current public health priorities for CYSHCN are focused on transition, medical homes, care coordination, and care management approaches. Transitioning into adequate adult care from pediatric care presents a vulnerable period during the life course for CYSHCN.

It is not clear whether this indicator is an adequate predictor of the health and wellness of the offspring of CYSHCN since research is limited in this area. In some instances, the causes of special health care needs are hereditary (e.g. some forms of deafness or genetic conditions).

**Data Criteria**

**Data availability**
The National Survey of Children's Health (NSCH), sponsored by MCHB of the Health Resources and Services Administration, examines the physical and emotional health of children 0-17 years of age. The survey is administered using the State and Local Area Integrated Telephone Survey (SLAITS) methodology, and it is sampled and conducted in such a way that state-level estimates can be obtained for the 50 states, the District of Columbia, and the Virgin Islands. The survey has been designed to emphasize factors that may relate to the well-being of children, including medical homes, family interactions, parental health, school and after-school experiences, and safe neighborhoods. The MCHB leads the development of the NSCH and NS-CSHCN survey and indicators, in collaboration with the National Center for Health Statistics (NCHS) and a national technical expert panel. The expert panel includes representatives from other federal agencies, state Title V leaders, family organizations, and child health researchers, and experts in all fields related to the surveys (adolescent health, family and neighborhoods, early childhood and development etc.). The most recent data set, the 2011-2012 NSCH, encompasses a sample size of more than 95,000 children with approximately 1,800 interviews completed in each of the 50 states and the District of Columbia.

MCH programs can readily gain access to the data through datasets released by the NCHS, and on the MCHB sponsored National Data Resource Center for Child and Adolescent Health Website (www.childhealthdata.org). Data from the 2011/2012 NSCH were made available in early 2013. The survey questionnaire and raw dataset are available for download on the CDC NCHS website in SAS format. The Data Resource Center (DRC) website provides data nationwide, for all 50 states and the District of Columbia. Additionally, both the raw datasets and the website allow users to stratify measures by sociodemographic groups, including but not limited to age, sex, race/ethnicity, primary household language, household income, and special health care needs. Cleaned, state-specific datasets with new variables that include national and state indicators are available at no cost in SAS and SPSS formats. For information on how to order state-specific sets, contact cahmi@ohsu.edu. Local data is not searchable. The NSCH is not administered annually. Over the past decade, the NSCH has been administered four times.

Sources: [http://www.cdc.gov/nchs/slaits/nsch.htm](http://www.cdc.gov/nchs/slaits/nsch.htm)  
[http://www.childhealthdata.org](http://www.childhealthdata.org)

**Data quality**
As noted from the DR/CAHMI documentation, the NSCH uses the CSHCN Screener© to identify children with special health care needs. The Screener is a five item, parent-reported tool designed to reflect the federal Maternal and Child Health Bureau consequences-based definition of children with special health care needs. The screener is a more comprehensive and robust assessment of children's needs and health care system performance than is attainable by
focusing on a single diagnosis or type of special need because it identifies children across the range and diversity of childhood chronic conditions and special needs. The available documentation notes that this instrument has been used in several national surveys including the Promoting Healthy Development Survey, the CAHPS-CCC, the NSCH, the NS-CSHCN, and MEPS. The CSHCN Screener was developed by the Child and Adolescent Health Measurement Initiative (CAHMI). For the 2011-2012 version of the NSCH, the DRC/CAHMI has included scoring syntax to illustrate how the CSHCN items are used to create component variables for each of the five domains and the final screener result. The main limitation of the NSCH is that the information provided is from parent recollection of screenings received and perception of child’s health and development over the past year. The survey methodology does not provide an opportunity for confirmation with medical records or physical measurements. Although literature regarding parental reporting as a proxy measure is contradictory, research supports the use of parents as proxy measures when obtaining child health information. [2-4]

The NSCH is weighted to represent the national population of non-institutionalized children age 0-17 years. According to the survey documentation, missing data for income were relatively high for 2011-2012 data, and a study of nonresponse patterns indicated that excluding records with missing income could impact the representativeness of the remaining data; therefore, a data file with imputed values for income is provided to be used with the datasets.

The NSCH documentation presents both response rates and completion rates. For 2011-2012 data, the combined national response rate for both landline and cell phone samples was 23 percent. The completion rate, which is calculated as the proportion of households known to include children that completed all sections up to and including Section 6 (for children less than six years of age) or Section 7 (for children six to 17 years of age), was 54.1 percent for the landline sample and 41.2 percent for the cell-phone sample.

Qualitative testing of the entire 2007 National Survey of Children’s Health was conducted by the National Center for Health Statistics. They conducted cognitive interviews with the 2007 NSCH Computer-Assisted Telephone Interview (CATI) to make sure the entire survey instrument was functioning properly. N=640 interviews were completed over 3 days in December 2006. The questionnaire was then revised and finalized based on feedback from participants in these interviews.

Previously validated questions and scales are used when available. All aspects of the survey are subjected to extensive literature and expert review. Respondents’ cognitive understanding of the survey questions is assessed during the pretest phase and revisions made as required. All final data components are verified by NCHS and DRC/CAHMI staff prior to public release. Face validity is conducted in comparing results with prior years of the survey and/or results from other implementations of items.

The most recent CYSHCN indicator data from the 2011-2012 NSCH was released in March 2013. Given the recent release of the data, literature regarding validity and reliability is not currently published or available. However, many mechanisms were used to ensure data quality. All surveyors utilized a comprehensive script to reduce inaccuracies and inconsistencies. Additionally, the DRC ensures data quality because the data is standardized nationally, can be stratified by subgroups, is highly relevant and valid, and is readily available. [1]

**Simplicity of indicator**

The level of complexity in calculating and explaining this indicator is low. The indicator requires no weighting, indexing, linkage, or adjustment by the data user. There are only two data elements for calculating the indicator – the numerator (number of children 0-17 with a special health care need) and the denominator (number of children 0-17). Additionally, the data are readily available, straightforward, and easy to communicate to the public.

**References**


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Life Course Indicator: Diabetes

The Life Course Metrics Project

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In June of 2013, state teams selected 59 indicators for the final set. The indicators were put out for public comment in July 2013, and the final set was released in the Fall of 2013.

Basic Indicator Information

Name of indicator: Diabetes (LC-26)
Brief description: Percent of adults with diagnosed diabetes
Indicator category: Family Well-being
Indicator domain: Risk/Outcome
Numerator: Total diabetes cases among adults ≥ 18 years
Denominator: Total adult population
Potential modifiers: Race/ethnicity, age, income, education, gender
Data source: Behavioral Risk Factor Surveillance System (BRFSS)
Notes on calculation: Analysts who use the raw datasets should apply the appropriate survey weights to generate the final estimates.

Similar measures in other indicator sets: Preconception Health Indicator I1; HP 2020 Focus area D-1; Chronic Disease Indicator; United Health Rankings Core Measure
**Life Course Criteria**

**Introduction**
Diabetes is a chronic metabolic condition in which the body cannot adequately make (type 1) or use (type 2) the hormone, insulin. Type I diabetes is typically diagnosed in childhood or adolescence and the cause of onset remains unclear. There is no known way to prevent onset of type I diabetes and management after diagnosis is critical to avoiding associated morbidity and complications. Type 2 diabetes accounts for 90 to 95 percent of adult cases and is usually preventable. Chronic excess energy – due to a combination of high caloric intake and low physical activity – is thought to be the primary driver for development of type 2 diabetes in susceptible individuals. Due to resulting insulin resistance, individuals with diabetes accumulate high concentrations of glucose in their blood. If undiagnosed or left unmanaged, high blood glucose (also known as high blood sugar) can lead to a number of severe complications, including heart disease, blindness, kidney failure, limb amputation or death. Diabetes was the seventh leading cause of death in the United States in 2010, contributing to more than 234,000 deaths annually. In addition, self-reported diabetes prevalence has steadily increased in the United States over the past two decades, from 4.9 percent in 1990 to 7.3 percent in 2000 and 8.7 percent in 2010. The Centers for Disease Control and Prevention (CDC) now estimates that 28.9 million (12.3 percent) U.S. adults aged 20 and older are currently living with diabetes, including approximately 8.1 million living with undiagnosed disease. This narrative focuses mainly on the preventability of type 2 diabetes as an avenue for positively affecting this indicator, however, both type I and type 2 diabetes have implications for health over the life course and proper management of both types is crucial for improving health outcomes.

**Implications for equity**
Type 2 diabetes and its complications disproportionately affect individuals from racial and ethnic minority groups. In 2012, the rate of diagnosed diabetes was highest among American Indians and Alaska Natives, affecting an estimated 15.9 percent of this population. In the same period, age-adjusted prevalence of diabetes was 13.2 percent among non-Hispanic Black adults; 12.8 percent among Hispanic adults; 9.0 percent among Asian American adults; and 7.6 percent among non-Hispanic White adults. Significant variation exists within these populations, as well. Among Hispanic adults, Mexican Americans (13.9 percent) and Puerto Ricans (14.8 percent) displayed disproportionately high prevalence rates. Likewise, high diabetes prevalence is found in American Indians in southern Arizona (24.1 percent), while Alaskan Natives have a much lower prevalence of 6 percent.

Researchers have identified a number of genes associated with type 2 diabetes, and heritability is high. The risk of diabetes in children is two to six times higher where one or more first-degree relatives are affected with diabetes, however, not all susceptible individuals will develop the disease. Susceptibility genes may be activated, or triggered, by complex social and environmental exposures, especially during critical periods of development. Evidence suggests that metabolic health status is highly sensitive to epigenesis, the biochemical processes that may result from social and environmental exposures and affect which genes are expressed. Racial health disparities may be partially attributable to epigenetic effects caused by stress and environmental conditions experienced by minorities due to discrimination and racism including inadequate housing, crowded and violent environments, and low educational attainment.

Varied exposure to a complex set of risk and protective factors at critical life stages can significantly alter individuals’ metabolic health trajectories, contributing to persistent disparities and increased risk of diabetes among certain groups. Factors placing individuals at increased risk for diabetes include gestational diabetes, propensity toward bottle feeding for infants, poor diet, sedentary lifestyle and unhealthy sleep patterns. Inequities in social, economic, and environmental conditions may increase these factors in racial minorities.

To illustrate, African American women are less likely to breastfeed, a known protective factor for diabetes, than White or Hispanic women. Lower breastfeeding rates in African American women may be due to cultural norms, negative perceptions about breastfeeding, lack of partner support, or unsupportive work environments. In order to reduce disparities in diabetes and improve health equity, increasing protective factors such as breastfeeding in high-risk populations should be examined.

Early onset of diabetes in youth, including type I diabetes, and poor glycemic control have been associated with lower educational attainment and unemployment, which may limit access to health insurance and preventive health care services, as well as impact health-seeking behaviors. Underlying inequities in social, economic and environmental...
conditions can also impact the ability of individuals to engage in healthy lifestyle and self-management activities that support the control of diabetes both prior to and after its onset. For example, low-income families and households with limited access to affordable produce are less likely to maintain a healthy diet than those with higher incomes and who live in close proximity to a grocery store.\textsuperscript{27,28} Similarly, individuals who live in unsafe neighborhoods with high crime rates or that lack sidewalks, parks and other green space are less likely to maintain recommended levels of physical activity.\textsuperscript{29,30}

Public health impact
Currently, 29.1 million people in the United States have diabetes, which is 9.3 percent of the population. Diabetes results in a total of $245 billion in direct medical costs ($176 billion) and indirect costs due to disability, work loss, and premature mortality ($69 billion).\textsuperscript{22} Type 2 diabetes currently accounts for the majority of diagnosed diabetes cases in adults (90-95 percent), and an estimated 1.7 million new cases were diagnosed in 2012.\textsuperscript{22} Onset of type 2 diabetes can be prevented by reducing risk factors such as overweight (taking in more calories than required for normal growth and development), physical inactivity, and overweight or obesity.\textsuperscript{3}

An important predictor of future burden, an estimated 86 million adults in the United States are currently living with prediabetes, or impaired glucose tolerance.\textsuperscript{22} CDC reports that 15 to 30 percent of these individuals will develop type 2 diabetes in the next five years without weight loss or changes in diet and exercise to reduce their risk.\textsuperscript{31} This represents a substantial opportunity for impact through public health interventions. In 2010, an evaluation of clinical trials found that a modest weight loss of less than 20 pounds could substantially reduce the risk of diabetes; the study also found that moderate to intense physical activity (e.g. brisk walking for ≥150 minutes per week) could reduce diabetes risk, even without weight loss.\textsuperscript{10}

In the absence of intervention, it is currently projected that more than 30 percent of individuals in the United States will develop diabetes in their lifetime.\textsuperscript{32} Given the increasing prevalence of type 2 diabetes at younger ages, an increasing number of women are entering pregnancy with the disease.\textsuperscript{37} Those who enter pregnancy with uncontrolled diabetes are more likely to experience complications, such as preeclampsia, macrosomia (birth weight >4,500 grams), congenital malformations, or perinatal death.\textsuperscript{33} Obesity and diabetes increase risk for maternal morbidity,\textsuperscript{35,36} which makes prevention of these conditions a valuable preconception health opportunity. Diabetes is a risk factor for two main causes of severe maternal morbidity including cardiac conditions and preeclampsia.\textsuperscript{36} Although screening for gestational diabetes is recommended at 24 weeks,\textsuperscript{38} greater awareness of diabetes prevention in women of childbearing age could help to reduce the impact diabetes has on women and families.\textsuperscript{37} Gestational diabetes is discussed in more depth in the life course indicator narrative LC-49.

According to the CDC, strong correlation also exists between diabetes and the presence of comorbidities, such as heart disease and stroke.\textsuperscript{8} A review of 2004 death certificates revealed that heart disease was reported in 68 percent of diabetes-related deaths.\textsuperscript{8} Screening for type 2 diabetes is now recommended for adults with high blood pressure and other cardiovascular risk factors in order to identify and manage undiagnosed cases.\textsuperscript{9}

The consequences of uncontrolled diabetes can be devastating for individuals, their families, and their communities. In 2011, diabetes was the leading cause of blindness among adults age 20 to 74 years.\textsuperscript{8} Diabetes also accounted for an estimated 60 percent of non trauma-related lower-limb amputations and 44 percent of end-stage renal failure in adults.\textsuperscript{8} A number of other morbidities have been linked to diabetes including gum disease, hearing loss, non-alcoholic fatty liver disease, erectile dysfunction, depression, polycystic ovarian disease, complications of pregnancy, and some cancers.\textsuperscript{17-20,23} As a result of their higher risk for comorbid conditions, individuals with diabetes, on average, incur more than twice the medical costs as those who do not have diabetes.\textsuperscript{8}

Leverage or realign resources
Given the complex set of social, economic, and environmental factors associated with the onset of type 2 diabetes, investment in a multi-sector approach offers the most promising route to its prevention and management. A wide range of possible diabetes prevention partners exist for maternal and child health (MCH) programs including other state or local level programs (e.g. transportation, parks and recreation), community or faith-based organizations (e.g. churches), community recreation facilities, universities, private companies (e.g. sporting goods, restaurants, corner stores), and health care organizations. A number of groups at the national level have been addressing diabetes through web-based resources and community integration programs including:
Overweight and obesity are associated with risk for type 2 diabetes, making prevention strategies for type 2 diabetes similar to those employed in overweight and obesity prevention. State or local level policies such as the New York City local government’s requirement for posting nutrition information on menus and limiting the size of beverage cups make healthy nutrition choices easier and may make consumers more aware of nutrition. Other interventions that are shown to be effective in reducing incidence and effectively managing type 2 diabetes include combined diet and physical activity promotion programs in clinical or community settings, case management to monitor and improve glycemic control, and type 2 diabetes self-management education in community gathering locations.

Medicare and Medicaid have a significant interest in diabetes prevention due to health care costs. The Medicaid Incentives for the Prevention of Chronic Disease (MIPCD) grant program currently funds state programs designed to address chronic disease prevention goals including controlling or reducing weight, preventing diabetes onset, and improving management of diabetes. In Minnesota, the state health department and local YMCAs partner to enroll Medicaid beneficiaries in a weight loss and control program funded by MIPCD designed to reduce diabetes and improve cardiovascular health. In Hawaii an MIPCD grant funds the Hawaii Patient Rewards and Incentive for Supporting Empowerment Project (HI-PRAISE), which focuses on prevention of diabetes and managing the disease through incentives for activities such as blood tests, eye exams, behavioral health counseling and education. Currently, Medicare covers diabetes screening tests and tools needed for diabetes self-management such as insulin and other medications. Also, through the Affordable Care Act, preventive services such as type 2 diabetes screening, diet counseling, and blood pressure screening are covered without cost sharing.

The Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) works with low-income women and children who are at risk for developing type 2 diabetes and may mitigate risk factors through provision of nutrition education and healthy foods. WIC not only provides families with healthy food options such as fruits, vegetables, and whole grains, but also promotes breastfeeding among participants, which is a protective factor against diabetes for children.

Type 2 diabetes is increasingly being diagnosed among children and adolescents, making schools a key partner in prevention. Beyond nutrition and physical problems, diabetes in school-age children increases risk for academic disadvantage (i.e., poor student attendance, impaired cognitive ability, or reduced academic achievement). A study done by Datar, et. al. found an association between overweight children and lower standardized test scores in math and reading. In addition, adolescents ages 15-17 who are overweight tend to show signs of depression, shame, and being victims and perpetrators of bullying. Many schools already have interventions in place that promote physical activity and behavioral changes. Some have been successful in diet modification and increasing physical activity, but more research is needed about long-term effects of school interventions, and whether or not the interventions are being followed through outside of the school environment.

**Predict an individual’s health and wellness and/or that of their offspring**

As noted above, improperly managed diabetes can lead to damage to the heart, blood vessels, eyes, kidneys, mouth, gums, teeth, and nerves leading to multiple serious health problems including cardiovascular disease, blindness, kidney failure, and lower limb amputations. Diabetes causes damage to small blood vessels in the kidneys creating high risk for chronic kidney disease, which presents in 35 percent of adult diabetics. Multiple risk factors for cardiovascular disease are common in individuals with diabetes, particularly type 2 diabetes. Type 2 diabetics also have a higher risk for high blood pressure, high cholesterol, obesity, and/or high triglyceride levels. A clustering of three or more of these cardiovascular disease risk factors in an individual is known as metabolic syndrome. In an estimated 50 percent of diabetics, some form of diabetic neuropathy (nerve damage) will occur, with risk increasing with the duration of diabetes. Neuropathy results in numbness, pain and weakness in limbs, hands, and feet. Lastly, there is also evidence that people with diabetes are at double the risk of depression compared to people without diabetes. Elevated risk for depression may be due to stress related to having diabetes or could be linked to the effect diabetes has on brain function.

The ‘developmental origins of adult disease’ hypothesis, also known as the ‘Barker hypothesis’ states changes in physiology and metabolism occur due to early developmental experiences, particularly intrauterine experiences, creating
an increased risk for disease in adulthood. Increased health risks for infants born to diabetic mothers may illustrate this hypothesis. Infants born to diabetic mothers are at a high risk for spontaneous abortion, congenital malformations, stillbirth, and perinatal morbidity and mortality. Maternal diabetes may cause infants to produce excess insulin, leading to increased growth rates and macromomia (birthweight > 4,000 to 4,500 grams). Maternal diabetes also leads to a higher risk for breathing problems and low blood glucose levels in infants. In childhood and adolescence children born to diabetic mothers are at a higher risk for obesity and development of type 2 diabetes. The elevated risk of diabetes in children and adolescents born to mothers with diabetes during pregnancy creates a cycle of diabetes that persists across generations. Greater awareness, prevention and management of diabetes across the lifespan will reduce the impact diabetes has on women, children, and families.

Data Criteria

Data availability
The Behavioral Risk Factor Surveillance System (BRFSS) is the world’s largest, on-going telephone health survey system, tracking health conditions and risk behaviors in the United States yearly since 1984. Currently, data are collected monthly in all 50 states, the District of Columbia, Puerto Rico, the U.S. Virgin Islands, and Guam for adults 18 years and older. CDC provides state and national level prevalence data on their web site.

The CDC develops approximately 80 questions each year. Some of these are core questions asked each year, and some are rotating core questions asked every other year. There are also CDC supported modules that address specific topics that states can use. States may also develop additional questions to supplement the core questions. Modules used by states are noted on the CDC websites.

Local level estimates for BRFSS data can be obtained using the Selected Metropolitan/Micropolitan Area Risk Trends (SMART) data. Local areas are metropolitan or micropolitan statistical areas (MMSAs) as defined by the Office of Management and Budget. SMART data is currently available for data going back to 2002 for MMSAs with 500 or more respondents.

Data on self-reported physician diagnosis of adult diabetes is available in all 50 states and the District of Columbia through the CDC BRFSS. Included within the core BRFSS module of questions used by all states, diabetes data also are available annually for select MMSAs. In many states, BRFSS may be the only source of timely data on adult diabetes.

BRFSS was selected as the primary data source because adults have a higher incidence and burden of diabetes than children or adolescents. Juvenile diabetes is also a major public health issue; however, analysts may have insufficient cases and statistical power to make meaningful interpretations of the data.

Data quality
Numerous studies have compared estimates of chronic conditions and behaviors obtained from BRFSS to other national surveys including the National Health Interview Survey and the National Health and Nutrition Examination Survey; while there are some differences, findings on overall health status and certain chronic conditions tended to be similar despite declining response rates for BRFSS.

Since some questions on the BRFSS address sensitive health conditions and behaviors, there is intermittent missing data throughout the dataset. However, refusal to answer generally accounts for a small proportion of responses for most data elements. The notable exception is income, where refusals accounted for over 23 percent of the data in one state in 2010; the median percent missing across BRFSS for income in 2010 was 14 percent.

Quality control computer programs are used to check the raw data for values out of range. CDC performs quality checks for core questions, and each state has its own protocol for checking state-specific questions. Interviewers are monitored during the annual questionnaire pilot period and intermittently during the data collection period to determine whether any interviewer bias exists and to correct any bias that might be found. On an ongoing basis, 10 percent of interview calls are verified.

Prior to 2011, the sampling for BRFSS represented only adults living in a private residence with a landline telephone, but starting in 2011, the sample also included data from respondents living in cell phone-only households. Weighted response
rates are presented by state. For 2011, the median weighted response rate for the combined cell phone and landline was 49.72 percent.

The survey adjusts for non-response to reduce the known differences between respondents and non-respondents. Although participants interviewed may not represent a state in terms of age, sex and race distribution, it is believed that weighting the data corrects for this potential bias. As with other health surveys, estimates are based on self-report data and they may over- or underestimate the actual prevalence of a particular risk factor in the population. Despite some oversampling in states by geography, the annual sample size is too small to compute precise estimates at the county level. The child prevalence data are reliant on proxy report from the adult respondent to the BRFSS and may be subject to misclassification related to this method.

Data on adult diabetes is based on self-reported information, without provider confirmation of diagnosis. Survey participants are asked to respond to the question, “Have you ever been told by a doctor that you have diabetes?” However, past studies have found that BRFSS data on diabetes is reliable. Prior to this study, Brownson and colleagues (1994) conducted a test-retest study of the Missouri BRFSS. The authors examined self-reported, diagnosed diabetes, among several chronic disease survey questions. In this study, the prevalence of diabetes was 7 percent among 222 respondents. Percent agreement was 98 percent and Kappa was 0.86, indicating excellent agreement after accounting for chance.²

**Simplicity of indicator**
The numerator and denominator for this indicator is simple, therefore the level of complexity for diabetes as an indicator is low. The data do not require linkage, and BRFSS provides pre-calculated rates for every state and for several counties and cities. Data weighting and adjustments are calculated by state health departments and the CDC prior to posting on their website.

**References**


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Life Course Indicator: Exclusive Breastfeeding at Three Months

**Basic Indicator Information**

Name of indicator: Exclusive breastfeeding at three months (LC-27)

Brief description: Percent of children exclusively breastfed through three months of age

Indicator category: Family Wellbeing

Indicator domain: Risk/Outcome

Numerator: Estimate of the number of children exclusively breastfed through 3 months of age

Denominator: Number of individuals surveyed

Potential modifiers: Age, race, maternal education, income level, social and family support, marital status

Data source: Primary: National Immunization Survey (www.cdc.gov/breastfeeding/data/NIS_data/index.htm) to get annual estimates; Comparison: National Survey on Children’s Health (www.childhealthdata.org) to look at risk and supportive factors.

Notes on calculation: Exclusive breastfeeding is defined as ONLY breast milk – NO solids, no water, and no other liquids.

Similar measures in other indicator sets: HP 2020 Focus area MICH-21.4; CDC Winnable Battle (Increase the proportion of infants who are breastfed by 15 percent); Title V Performance Measure #11 (similar); MIECHV Benchmark Area Improved Maternal and Newborn Health: Breastfeeding; Chronic Disease Indicator

The Life Course Metrics Project

As MCH programs begin to develop new programming guided by a life course framework, measures are needed to determine the success of their approaches. In response to the need for standardized metrics for the life course approach, AMCHP launched a project designed to identify and promote a set of indicators that can be used to measure progress using the life course approach to improve maternal and child health. This project was funded with support from the [W.K. Kellogg Foundation](http://www.wkkf.org).

Using an RFA process, AMCHP selected seven state teams, Florida, Iowa, Louisiana, Massachusetts, Michigan, Nebraska and North Carolina, to propose, screen, select and develop potential life course indicators across four domains: Capacity, Outcomes, Services, and Risk. The first round of indicators, proposed both by the teams and members of the public included 413 indicators for consideration. The teams distilled the 413 proposed indicators down to 104 indicators that were written up according to three data and five life course criteria for final selection.

In June of 2013, state teams selected 59 indicators for the final set. The indicators were put out for public comment in July 2013, and the final set was released in the Fall of 2013.
Life Course Criteria

Introduction
Breastfeeding impacts women and infants in the immediate postpartum period and infancy and confers lifelong benefits to both. It is consistent with the life course model which states that early exposures during a critical or sensitive period during childhood influence adult health outcomes. Breastfeeding also can reduce cumulative exposures to health risks over time for both the mother and infant.¹

Implications for equity
Compared with white infants, breastfeeding initiation and continuation rates for Black infants are approximately 50 percent lower. Although the reason for this is not yet fully understood, the need to return to work earlier and lack of social support for Black women desiring to breastfeed are thought to be contributing factors to lower breastfeeding initiation and duration rates than White women.² However, breastfeeding can improve food security as it is usually readily available, low cost, and requires no preparation to provide an infant feeding.³,⁴,⁵ Breastfeeding also may reduce financial strain as families can save $1,200-$1,500 in the cost of non-specialty formula during the first year of a baby’s life depending on the type, brand, and amount of formula purchased.⁶ Breastfeeding improves infant health and has been shown to decrease direct and indirect insurance claims cost and lost days from work due to caring for a sick infant; cost savings for infant illness are estimated at 3.6 billion annually in direct and indirect health care.⁷,⁸

Additionally, the relationship of breastfeeding rates to lower income is demonstrated in the studies done by the U.S. Department of Agriculture (USDA) Supplemental Nutrition Program for Women, Infants, and Children (WIC). This study found that sociodemographic factors such as WIC participation, for which eligibility is based on income, and maternal education, are inversely related with the likelihood to have ever breastfed and similarly up to six and twelve months duration.

Breastfeeding has psychosocial impacts; breastfeeding has been shown to improve bonding between a mother and her newborn as well as lower postpartum depression, which affects approximately 13 percent of all mothers. Reducing postpartum depression helps a mother better care for her needs as well as the needs of her infant.⁹ Improved maternal-infant bonding could reduce the potential for later child abuse and neglect.¹⁰

Human milk is renewable and requires no containers, paper, or fuel to prepare, transport or deliver. Widespread breastfeeding could conserve resources and energy, contributing to environmental justice.¹¹ For every one million formula fed infants, 150 million formula containers are discarded, many into landfills that pollute neighborhoods already burdened by health disparities.¹²

Public health impact
Infants who are exclusively breastfed or breastfed to any extent experience significantly fewer infections and diseases than formula fed infants. Longer and more exclusive breastfeeding also is associated with better health outcomes. A 2010 Pediatrics study demonstrated that the United States incurs $13 billion in excess costs annually and suffers more than 900 preventable deaths per year because breastfeeding rates fall far below medical recommendations.¹³

Economic effects of breastfeeding can be experienced by families, insurers, employers, schools, society as a whole through decreased health care cost, missed work and school, cost of formula for families and society, etc. It is estimated that the United States could save $10.5 billion per year in additional healthcare costs associated with breastfeeding. A cost savings to families for breastfeeding versus purchasing formula for a year is estimated to be $1,200-$1,500 depending on the type, brand, and amount of formula purchased.⁶

Although exclusive breastfeeding for longer than three months is recommended, this indicator is not meant as guidance. The World Health Organization and the American Academy of Pediatrics recommend exclusive breastfeeding through six months of age, and breastfeeding through six months of age is a national performance measure for the Title V MCH Services Block Grant. The Healthy People 2020 objectives for exclusive breastfeeding through 3 and 6 months of age are 46.2 percent and 25.5 percent. However, given the persistent challenge of attaining exclusive breastfeeding at six months for a large portion of the population, and the complex circumstances that align to enable a woman to breastfeed her child...
to six months of age, a three month indicator allows states to understand where there might be drop off in breastfeeding from birth to three months, to allow for adjustments in policy and practice to help mothers breastfeed for longer durations.

**Leverage or realign resources**

The United States differs from many other developed countries that provide job-protected leave – often paid — for childbirth and newborn care. Only 59 percent of U.S. workers are eligible for the Family Medical Leave Act (FMLA), which provides job protection and unpaid leave up to 12 weeks for, among other things, maternity leave and newborn care. Working with the Department of Labor to expand or improve access to FMLA benefits (especially for small businesses under 50 people) could be a strategy to improve lagging U.S. breastfeeding rates. Some states have already adopted maternity leave laws to provide mothers with job reinstatement after maternity leave and financed this with temporary disability insurance programs to provide longer maternity leave.14

Other potential partners include working with the Department of Labor to utilize the Health Resources and Services Administration (HRSA) developed Business Case for Breastfeeding report to implement breastfeeding-friendly practices in the workplace. Additionally, state agencies need to partner with community/private physicians to support breastfeeding at the private practice level. Employers have a responsibility to provide support to breastfeeding employees since studies show that employed breastfeeding women have lower breastfeeding initiation and shorter duration rates than those who are not employed while breastfeeding.15

On March 23, 2010, the break time for nursing mothers requirement included in the ACA was signed into law. The law requires “employers to provide a nursing mother reasonable break time to express breast milk after the birth of her child.” The law also requires that employers provide “a place, other than a bathroom, that is shielded from view and free from intrusion from coworkers and the public, which may be used by an employee to express breast milk.” The duration of this requirement applies to breastfeeding employees up to the time the child is 12 months of age and applies to employers with 50 or more employees.16

Also under the ACA, women’s preventive services are covered by health plans without cost sharing. Included in these services are “comprehensive lactation support and counseling, by a trained provider during pregnancy and/or in the postpartum period, and costs for renting breastfeeding equipment.”17 The ACA also provided states with an opportunity to improve the health of MCH populations through the Maternal, Infant, and Early Childhood Home Visiting (MIECHV) program. The law provides $1.5 billion over five years to states, tribes and territories to develop and implement one or more evidence-based home visitation models. As part of the MIECHV program, grantees must establish and collect data on quantifiable, measurable three to five year benchmarks demonstrating that the program results in improvements in many indicators including improved maternal and newborn health.18 States have the flexibility in the program to include indicators on many facets of breastfeeding from intention and support to actual duration.

Another far-reaching program that supports breastfeeding women and families is the WIC program. The number of women, infants, and children receiving WIC benefits in 2011 was nearly 9 million per month.19 Since 1996, the USDA Food and Nutrition System has allocated a minimum expenditure for breastfeeding promotion and support activities equal to $21 multiplied by the number of pregnant and breastfeeding women in the WIC Program, based on the average of the last three months for which USDA has final data. State agencies must spend a specified amount of the total funding for breastfeeding promotion and support. Efforts to increase and support the number of women breastfeeding also have included enhanced food packages for women breastfeeding up to 12 months and the implementation of the Peer Counseling Program.20

**Predict an individual’s health and wellness and/or that of their offspring**

Breastfeeding is the standard method for infant feeding across multiple cultures. The health risks of not breastfeeding for mother and child are well documented.21 Infants who are not breastfed have a higher risk for ear infections, atopic dermatitis, gastroenteritis, necrotizing enterocolitis, type 2 diabetes, sudden infant death syndrome (SIDS) and reduced cognitive function.22,23,24,25,26,27,28,29,30,31,32,33 Research shows that not breastfeeding may contribute to overweight and obesity of the child in the teenage years and even adulthood.34

Women who do not breastfeed are at greater risk for heavier postpartum bleeding, a slower return of uterine tone after childbirth, and an earlier return to ovulation (reducing adequate child spacing).35,36,37 Women who do not breastfeed also

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*Life Course Indicator: Exclusive breastfeeding at three months (LC-27)*
are at higher risk for type 2 diabetes, ovarian cancer, breast cancer, postpartum depression, hypertension, and cardiovascular disease.\textsuperscript{36,39,40}

**Data Criteria**

**Data availability**

**National Immunization Survey (NIS)\textsuperscript{41}**

The NIS is a list-assisted random-digit-dialing telephone survey followed by a mailed survey to children's immunization providers that began data collection in April 1994 to monitor childhood immunization coverage. The survey is conducted jointly by the National Center for Immunizations and Respiratory Diseases and the National Center for Health Statistics, Centers for Disease Control and Prevention (CDC).

The study collects data by interviewing households in all 50 States, the District of Columbia, and selected large urban areas. The target population for the NIS is children between the ages of 19 and 35 months living in the United States at the time of the interview. Survey data are used to calculate vaccine coverage rates based on the recommended number of doses to be considered up to date, as recommended by the Advisory Committee on Immunization Practices. Estimates are produced for the nation and non-overlapping geographic areas consisting of the 50 states, the District of Columbia, and selected large urban areas. Data files for the NIS are available starting with 1995.\textsuperscript{42} NIS data are made available approximately nine months after the close of a survey period.

Breastfeeding data have been collected annually since 2001 through the NIS. The full reports starting from 2000 contain United States, state, and local areas breastfeeding rates by infant's age and selected socio-demographic factors (+/- half 95 percent CI) for the following indicators:

- Infants ever breastfed
- Infants breastfeeding at six months
- Infants breastfeeding at 12 months
- Infants breastfeeding at every age (birth to 18 months – United States rates only)

NIS breastfeeding data starting from 2004 contain exclusive breastfeeding rates (ONLY breast milk – NO solids, no water, and no other liquids) by selected socio-demographic factors for the U.S. and state and local areas (+/- half 95 percent CI) for the following indicators:

- Exclusively breastfed at three months
- Exclusively breastfed at six months
- Infants exclusively breastfeeding and breastfeeding at every age (birth to 18 months–United States rates only)

NIS breastfeeding data starting from 2004 also include data on formula supplementation for the U.S., state, and local areas (+/- half 95 percent CI) by socio-demographic data. Data from the NIS, along with data from other sources, are used to compile the CDC Breastfeeding Report Card which provides easily accessible state-to-state comparisons of breastfeeding indicators. The CDC Breastfeeding Report Card was first released in 2007 and is updated annually. Indicator data sources and National Immunization Survey statistical information are available at: www.cdc.gov/breastfeeding/data/.

NIS questions starting in 2006:

1. Was [child] ever breastfed or fed breast milk?
2. How old was [child's name] when [child's name] completely stopped breastfeeding or being fed breast milk?
3. How old was [child's name] when (he/she) was first fed formula?
4. This next question is about the first thing that [child] was given other than breast milk or formula. Please include juice, cow's milk, sugar water, baby food, or anything else that [child] may have been given, even water. How old was [child's name] when (he/she) was first fed anything other than breast milk or formula?

**National Survey of Children's Health (NSCH)\textsuperscript{43}**

The NSCH is a second data source available through the Data Resource Center for Child and Adolescent Health (DRC). It is sponsored by the Maternal and Child Health Bureau (MCHB), HRSA. The survey is administered using the State and Local Area Integrated Telephone Survey (SLAITS) methodology, and it is sampled and conducted in such a way that
state-level estimates can be obtained for the 50 states, the District of Columbia, and the Virgin Islands. The survey has been designed to emphasize factors that may relate to the well-being of children, including medical homes, family interactions, parental health, school and after-school experiences, and safe neighborhoods. The MCHB leads the development of the NSCH and NS-CSHCN survey and indicators, in collaboration with the National Center for Health Statistics (NCHS) and a national technical expert panel. The expert panel includes representatives from other federal agencies, state Title V leaders, family organizations, child health researchers, and experts in all fields related to the surveys (adolescent health, family and neighborhoods, early childhood and development etc.).

The most recent data set, the 2011-2012 NSCH, encompasses a sample size of more than 95,000 children with approximately 1,800 interviews completed in each of the 50 states and the District of Columbia. MCH programs can readily gain access to the data through datasets released by the NCHS, and on the MCHB sponsored National Data Resource Center for Child and Adolescent Health Website (www.childhealthdata.org). Data from the 2011/2012 NSCH were made available in early 2013. The survey questionnaire and raw dataset are available for download on the CDC NCHS website in SAS format. The Data Resource Center (DRC) website provides data nationwide, for all 50 states and the District of Columbia. Additionally, both the raw datasets and the website allow users to stratify measures by sociodemographic groups, including but not limited to age, sex, race/ethnicity, primary household language, household income, and special health care needs. Cleaned, state-specific datasets with new variables that include national and state indicators are available at no cost in SAS and SPSS formats. For information on how to order state-specific sets, contact cahmi@ohsu.edu. Local data is not searchable. The NSCH is not administered annually. Over the past decade, the NSCH has been administered four times. The DRC also provides mapping with state rankings for indicators.44

Breastfeeding data are collected and percentages are pre-calculated at national, state, and HRSA region levels and by selected socio-demographic characteristics at the Data Resource Center.

The 2003 NSCH included the following breastfeeding indicators:
- Percent of children ever breastfed
- Age breastfeeding stopped
- Children who were breastfed zero to five years
- Percent of children six months to five years received breast milk any length of time

The 2007 NSCH included the following breastfeeding indicators:
- Never breastfed or given breast milk
- Exclusively breastfed or given breast milk for first six months
- Breastfed but not exclusively for first six months
- Breastfed exclusivity not known
- Age at which breastfeeding stopped
- Age at which child was first fed formula
- Age at which other foods introduced45

Data quality
NIS
For the NIS, parents and guardians are asked for consent for a second phase of the study in which the child’s pediatrician is contacted. The provider receives an immunization history questionnaire to fill out for the selected child; this information is used to ensure the accuracy and precision of the vaccination coverage estimates. CDC publishes an NIS “Guide to Quality Control Procedures” that describes the procedures used to ensure the quality of the data through all phases of the sampling, data collection, and processing.

The data are weighted to reduce potential biases from non-response and non-coverage. In addition to households with an eligible child that do not respond to the survey, an additional source of potential error is a household that responds but does not have complete provider information. Item non-response for the NIS is typically very low. However, for data elements used in weighting, the hot-deck method of imputation is used. Although in one year a total of about 14,000 data elements are imputed, these account for only 0.08 percent of all data items in the file.

Breastfeeding prevalence is calculated at the 95 percent CI for each year and estimated as weighted percentages. Household response rates for NIS ranged from 61.6 percent to 74.2 percent during the survey years examined.46
NSCH
The main limitation of the NSCH that the information provided is from parent recollection of screenings received and perception of child’s health and development over the past year survey (families are asked about breastfeeding activities that occurred primarily or exclusively before the survey collection of the child’s age at 19-35 months). The survey methodology does not provide an opportunity for confirmation with medical records or physical measurements. The NSCH is weighted to represent the national population of non-institutionalized children age 0-17 years. According to the survey documentation, missing data for income were relatively high for 2011-2012 data, and a study of nonresponse patterns indicated that excluding records with missing income could impact the representativeness of the remaining data; therefore, a data file with imputed values for income is provided to be used with the datasets. Other limitations of the survey include uncertainty of the definition of exclusive breastfeeding, limited frequency of data collection, and changes to the questions that make comparison between years difficult.

The NSCH documentation presents both response rates and completion rates. For 2011-2012 data, the combined national response rate for both landline and cell phone samples was 23 percent. The completion rate, which is calculated as the proportion of households known to include children that completed all sections up to and including Section 6 (for children less than six years of age) or Section 7 (for children six to 17 years of age), was 54.1 percent for the landline sample and 41.2 percent for the cell-phone sample.

Qualitative testing of the entire 2007 National Survey of Children’s Health was conducted by the NCHS. They conducted cognitive interviews with the 2007 NSCH Computer-Assisted Telephone Interview (CATI) to make sure the entire survey instrument was functioning properly. N=640 interviews were completed over three days in December 2006. The questionnaire was then revised and finalized based on feedback from participants in these interviews.

Previously validated questions and scales are used when available. All aspects of the survey are subjected to extensive literature and expert review. Respondents’ cognitive understanding of the survey questions is assessed during the pretest phase and revisions made as required. All final data components are verified by NCHS and DRC/CAHMI staff prior to public release. Face validity is conducted in comparing results with prior years of the survey and/or results from other implementations of items. At this time, information on the validity and reliability of the specific breastfeeding indicator is not available.

**Simplicity of indicator**
Exclusive breastfeeding at three months is an indicator that is neither difficult to explain nor conceptually understand. NIS is a simple data source to use with pre-calculated percentages of three-month exclusive breastfeeding at national and state levels. Data also is available for selected socio-demographic groups. NSCH is a simple data source to use with pre-calculated percentages on a variety of breastfeeding indicators at national, state, and HRSA region levels and for selected socio-demographic groups.

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*Life Course Indicator: Exclusive breastfeeding at three months (LC-27)*

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References


Life Course Indicator: Exposure to Secondhand Smoke Inside the Home

The Life Course Metrics Project

As MCH programs begin to develop new programming guided by a life course framework, measures are needed to determine the success of their approaches. In response to the need for standardized metrics for the life course approach, AMCHP launched a project designed to identify and promote a set of indicators that can be used to measure progress using the life course approach to improve maternal and child health. This project was funded with support from the W.K. Kellogg Foundation.

Using an RFA process, AMCHP selected seven state teams, Florida, Iowa, Louisiana, Massachusetts, Michigan, Nebraska and North Carolina, to propose, screen, select and develop potential life course indicators across four domains: Capacity, Outcomes, Services, and Risk. The first round of indicators, proposed both by the teams and members of the public included 413 indicators for consideration. The teams distilled the 413 proposed indicators down to 104 indicators that were written up according to three data and five life course criteria for final selection.

In June of 2013, state teams selected 59 indicators for the final set. The indicators were put out for public comment in July 2013, and the final set was released in the Fall of 2013.

Basic Indicator Information

Name of indicator: Exposure to Secondhand Smoke Inside the Home (LC-28)

Brief description: Percent of children living in a household where smoking occurs inside home.

Indicator category: Family Well-being

Indicator domain: Risk/Outcome

Numerator: Number of children who live in a household with someone who smokes and smoking occurs inside home

Denominator: Children age zero to 17 years

Potential modifiers: When the Exposure to Secondhand Smoke in Home measure was administered in its most recent form, in the 2011/12 National Survey of Children’s Health, the survey included a number of child demographic variables that allow for stratification of the findings by possible vulnerability:

- Age
- Gender
- Geographic location- State, HRSA Region, National level
- Rural Urban Commuter Areas (RUCA)
- Race/ethnicity
- Health insurance- type, consistency
- Primary household language
- Household income
- Special Health Care Needs- status and type

Data source: National Survey of Children’s Health (NSCH)

Notes on calculation: Analysts who use the raw datasets should apply the appropriate survey weights to generate the final estimates.

Similar measures in other indicator sets: HP 2020 Focus area TU-11; NQF measure 1346; MIECHV Benchmark Area Improvements in School Readiness and Achievement: Child’s physical health and development
Life Course Criteria

Introduction
Secondhand smoke consists of the smoke from the burning end of a cigarette, pipe, or cigar, as well as the smoke exhaled out of the smoker's lungs. Secondhand smoke contains more than 7,000 different chemicals and chemical compounds, of which 250 are known to be harmful and 70 of which are known carcinogens including arsenic, benzene, and chromium [3, 23]. There is no safe level of exposure to secondhand tobacco smoke. The U.S. Environmental Protection Agency (EPA), the U.S. National Toxicology Program, the U.S. Surgeon General, and the International Agency for Research on Cancer have all labeled secondhand smoke as a known cancer-causing agent [23]. Secondhand smoke is a cause of more than 7,500 lung cancer deaths in nonsmokers each year [3], however, cancer is not the only negative health outcome attributed to secondhand smoke. Since 1964, 2.5 million nonsmokers have died from various causes as a result of secondhand smoke [24]. Second hand smoke has damaging effects on the heart and blood vessels which may increase the risk of heart disease and stroke [3]. Children suffer from serious health risks due to second hand smoke exposure including new cases of asthma and exacerbation of asthma symptoms. Sudden Infant Death Syndrome (SIDS), pneumonia, bronchitis, and middle ear infections [4]. Health issues caused by secondhand smoke create a personal, societal, and economic burden through morbidity and mortality that could be greatly reduced by smoking behavior changes in the home, the place where children are most commonly exposed [4]. Programs, services, and policies in a variety of sectors have the ability to reduce the percentage of children exposed to secondhand smoke and could alleviate significant individual health risks and public health disease burden if leveraged appropriately.

Implications for equity
In the United States, the percent of children who live in a household where someone uses cigarettes, cigars, or pipe tobacco was reduced between 2007 and 2011 (26.2 percent to 24.1 percent of children) [7,25]. Additionally, the overall percent of children living in a household where someone smokes tobacco inside the child’s home declined from 7.6 percent in 2007 to 4.9 percent in 2011 [7,25]. Although reductions are encouraging, risk of exposure to secondhand smoke is disproportionately higher in certain populations.

Two of the most important predictors of childhood exposure to secondhand smoke in the home are socioeconomic status and race/ethnicity. Poverty, a marker for socioeconomic status, has significant systematic effects on child exposure to secondhand smoke within the home, with low-income children facing the greatest odds of exposure to secondhand smoke across all racial/ethnic groups [7]. Compared to children living at 400 percent FPL or greater, children living below 100 percent FPL, have 3.23 times the odds of exposure to secondhand smoke inside the home [7]. Nationally, the percentage of African American children who live in a household where someone uses cigarettes, cigars or pipe tobacco (25.0 percent) is lower than White non-Hispanic children (26.1 percent), however, African American children are at a significantly higher risk of being exposed to tobacco smoke inside their homes than non-Hispanic White or Hispanic children[25]. In 2011, 1.9 percent of Hispanic children, 5.2 percent of White children and 9.0 percent of Black children were exposed to secondhand smoke inside the home [25]. Gilpin et al (1999) found only 24 percent of African American smokers in California reported a smoke-free home which was far lower than Hispanic (58 percent), Asian (43 percent), or non-Hispanic White (32 percent) smokers. Overall, fifty percent of African American children and more than one-third of children from low-income families in smoking households are exposed to secondhand smoke inside the home [7].

Secondhand smoke exposure in the home also varies by geographic location and age of the child. Children living in rural locations are more likely to be exposed to secondhand smoke inside the home than children living in urban areas (12.4 vs. 6.5 percent)[7]. Prevalence of exposure to secondhand smoke inside the home also increases as children get older. For example, 4.8 percent of children age 0-5 years, 7.4 percent of children age 6-11 years and 10.4 percent of children age 12-17 years are exposed to secondhand smoke inside the home [7-8].

A child who lives in household where someone smokes is also more likely to begin using tobacco products in adolescence. [9-10]. While secondhand smoke exposure has been shown to lead to adverse health consequences, a lifetime of tobacco product use has a larger impact on risk for heart disease, stroke, and cancer [11]. The cyclical nature of the exposure to both the effects of secondhand smoke and modeled behavior leads to the socioeconomic and racial disparities in tobacco use, secondhand smoke exposure, and consequently, health outcomes.

Public health impact
Prevention of child exposure to secondhand smoke in the home is in the best interest of infants, children, and adolescents as exposure has been correlated with childhood health issues, onset of diseases in adulthood, barriers to educational achievement, and onset of adolescent use of tobacco products [12]. Secondhand smoke is a contributor to some of the most costly and prevalent chronic diseases in the United States. Each year second hand smoke causes 8,000 deaths from stroke, 34,000 premature deaths from heart disease, and 7,300 lung cancer cases among U.S. nonsmokers [3]. In addition, secondhand smoke contributes to infant mortality through increasing the risk of SIDS for infants who are exposed to secondhand smoke after birth. Infants who have died from SIDS have been found to have higher levels of biological markers for secondhand smoke than infants who died of other causes [3].

Exposure to secondhand smoke has been associated with increased health service utilization and negative health consequences, including increased number of sick visits to outpatient providers [13] and increased severity of illness [14]. Asthmatic children exposed to secondhand smoke have greater risk for emergency department utilization [26]. Overall, children who are exposed to environmental secondhand smoke had a higher frequency of sick visits and to the pediatrician’s office [13]. Secondhand smoke exposure also increased a child’s need for intensive care services when diagnosed with influenza [14]. For children who were hospitalized for influenza, those who also had secondhand smoke exposure were more likely to require intensive care, intubation, and require longer stays in the hospital [14]. Reducing exposure to secondhand smoke among children should also lead to a reduction in emergency department utilization, intensive care service need, and health care costs.

Increased utilization of health services and severity of health problems can reduce individual productivity as children, including engagement in school and later as adults in the form of missed work days. Interventions for parental cessation of smoking or counseling future parents to quit smoking can have a public health impact through both a reduction in smoking rates and a reduction in child secondhand smoke exposure. Preventing individuals from starting to smoke and increasing the opportunities for successful smoking cessation are critical to reducing exposure of children and other vulnerable populations to secondhand smoke exposure.

**Leverage or realign resources**

Smoking cessation interventions for parents designed to be implemented in family homes, pediatric clinics, and hospitals can encourage and assist parents in their efforts to quit smoking [15]. These interventions were most successful when providing high levels of follow-up with the parents, as well as nicotine replacement medication to assist in the cessation process [15]. However, success rates for cessation were less than one in four parents, which indicates a need for programs with greater efficacy and stronger education components to teach parents how to keep children safe from secondhand smoke in homes with an adult who smokes tobacco products.

Pediatric outpatient clinics have the opportunity to both monitor the child as well as provide educational materials to parents. The Clinical Effort Against Secondhand Smoke Exposure (CEASSE) intervention utilizes evidence-based practices to support identification of children exposed to secondhand smoke, identification of parental stage and intent to quit, and treatment program management [16]. This program presents an opportunity to bring not only identification and education into the child health visit, but also engage the parent in behavior modification to improve child outcomes.

Another approach is to implement tobacco control policies, such as cigarette excise taxes and smoke-free home legislation [17]. The impact of cigarette excise taxes has shown that for every $1.00 increase, there is a 4 percent decrease in household tobacco use; however, no impact was shown for smoke-free home legislation. Legislation that limits smoking in work places and public places can also impact smoking cessation. A review of eleven studies found smoke-free work place policies were associated with a median 6.4 percent increase in smoking cessation among workers [28]. Through the Communities Putting Prevention to Work (CPPW) initiative, the American Lung Association worked with other national partners to develop an online curriculum on how to implement a smokefree policy in multi-unit housing properties like apartments and condominiums [35]. CDC’s Healthy Homes and Lead Poisoning Branch has produced a manual for implementing smokefree policies in multi-unit housing for use by state and local Healthy Homes programs looking to reduce exposure to secondhand smoke [36].

The Environmental Protection Agency (EPA) supports Smoke-Free Home Pledge Campaigns that encourage individuals to designate that smoking cannot occur within their home [5]. The EPA also has partnered with the Department of Health and Human Services to encourage Head Start Centers to use tools such as these pledges to help low income families
learn about secondhand smoke health consequences and commit to smoke-free homes and cars [29]. Assessment of the success of the Oregon Smoke-Free Home Pledge Campaign found that one-third of households were able to implement a household smoking ban over the two-year study. While more than 90 percent of households indicated support for a ban of smoking in households with children, greater success in implementation was found for those who quit smoking or reduced consumption [18]. The EPA also provides a free bilingual (English & Spanish) educational brochure called Secondhand Tobacco Smoke and the Health of Your Family. The brochure is available for download at [epa.gov/smokefree/](http://epa.gov/smokefree/) and is designed to educate parents on the dangers of secondhand smoke and how to protect their families [30].

**Predict an individual’s health and wellness and/or that of their offspring**

A meta-analysis of the research on effects of secondhand smoke exposure in children found correlations with SIDS, asthma, altered respiratory function, infection, cardiovascular effects, behavior problems, sleep difficulties, increased cancer risk, and a higher likelihood of smoking initiation [19]. Secondhand smoke has serious effects on children with asthma. Children regularly exposed to high levels of secondhand tobacco smoke are more likely to have moderate or severe asthma and decreased lung function than children with low levels of tobacco smoke exposure [26]. Secondhand smoke is also associated with sleep problems in asthmatic children including longer sleep-onset delay, sleep-disordered breathing parasomnias, daytime sleepiness, and overall sleep disturbance [27]. Exacerbation of asthma symptoms can lead to serious negative health effects that accompany poorly controlled asthma including weight gain, anxiety, depression, and loss of lung function [31,32]. Respiratory effects occurring later in life, including presence of chronic obstructive pulmonary disease (COPD), have also been associated with exposure to childhood secondhand smoke, even when controlling for current smoking and exposure as adults [21]. While many have considered individual smoking to be a larger factor in developing of heart and respiratory conditions in adulthood, exposure to secondhand smoke has been shown to have nearly the same impact as active smoking [22].

Children exposed to secondhand smoke in the home are more likely to have two or more neurobehavioral disorders, including learning disabilities, attention-deficit/hyperactivity disorder, behavioral and conduct disorders, and conditions requiring mental health counseling/treatment, even after controlling for sociodemographic variables [19]. Neurobehavioral conditions have been associated with higher likelihood to repeat a grade and show problem behaviors. Additionally, they have lower likelihood of being engaged in school and exhibiting positive social behaviors [20]. The presence of these adverse outcomes can cause lower educational attainment, limited earnings, substance abuse and trouble with the law.

In addition to secondhand smoke, children who are exposed to in home tobacco smoke are also exposed to thirdhand smoke. Thirdhand smoke is residual tobacco smoke contamination that lingers on skin, clothes, hair, home surfaces such as furniture and rugs, and even dust particles long after a cigarette is extinguished. While the issue of thirdhand smoke is still being researched, early findings show lingering tobacco smoke contaminants form new carcinogens (tobacco-specific nitrosamines)[33]. These carcinogens on dust particles and rugs/floors are of particular concern for young children as they spend more time in close contact with household floors than adults [34].

**Data Criteria**

**Data availability**

The National Survey of Children’s Health (NSCH), sponsored by the Maternal and Child Health Bureau of the Health Resources and Services Administration, examines the physical and emotional health of children ages zero to 17 years of age. The survey is administered using the State and Local Area Integrated Telephone Survey (SLAITS) methodology, and it is sampled and conducted in such a way that state-level estimates can be obtained for the 50 states, the District of Columbia, and the Virgin Islands. The survey has been designed to emphasize factors that may relate to the well-being of children, including medical homes, family interactions, parental health, school and after-school experiences, and safe neighborhoods. The Maternal and Child Health Bureau leads the development of the NSCH and NS-CSHCN survey and indicators, in collaboration with the National Center for Health Statistics (NCHS) and a national technical expert panel. The expert panel includes representatives from other federal agencies, state Title V leaders, family organizations, and child health researchers, and experts in all fields related to the surveys (adolescent health, family and neighborhoods, early childhood and development etc.). The most recent data set, the 2011-2012 NSCH, encompasses a sample size of more than 95,000 children with approximately 1,800 interviews completed in each of the 50 states and the District of Columbia.
MCH programs can readily gain immediate access to the data through datasets released by the National Center for Health Statistics, and on the MCHB sponsored Data Resource Center for Child and Adolescent Health website (childhealthdata.org). Data from the 2011/2012 NSCH were made available in early 2013. The survey questionnaire and raw dataset are available for download on the CDC’s NCHS website in SAS format. The Data Resource Center (DRC) website provides data nationwide, for all 50 states and the District of Columbia. Additionally, both the raw datasets and the website allow users to stratify measures by sociodemographic groups, including but not limited to age, sex, race/ethnicity, primary household language, household income, and special health care needs. Cleaned, state-specific datasets with new variables that include national and state indicators are available at no cost in SAS and SPSS formats. For information on how to order state-specific sets, contact cahmi@ohsu.edu. Local data is not searchable. The NSCH is not administered annually. Over the past decade, the NSCH has been administered four times.

Data on child exposure to secondhand smoke inside home is currently collected every four years for the 50 states and the District of Columbia. The numerator is calculated from data reported by parents on (1) whether child lives in household with someone who smokes, and (2) whether smoking occurs inside the home. Parents are asked about the “current” status of smoking in the household.

**Data quality**
The Maternal and Child Health Bureau leads the development of the NSCH and NS-CSHCN survey and indicators, in collaboration with the National Center for Health Statistics (NCHS) and a national technical expert panel. The expert panel includes representatives from other federal agencies, state Title V leaders, family organizations, and child health researchers, and experts in all fields related to the surveys (adolescent health, family and neighborhoods, early childhood and development etc.).

The main limitation of the NSCH is that the information provided is from parent recollection of screenings received and perception of child’s health and development over the past year. The survey methodology does not provide an opportunity for confirmation with medical records or physical measurements. The NSCH is weighted to represent the national population of non-institutionalized children age zero to 17 years. According to the survey documentation, missing data for income were relatively high for 2011-2012 data, and a study of nonresponse patterns indicated that excluding records with missing income could impact the representativeness of the remaining data; therefore, a data file with imputed values for income is provided to be used with the datasets.

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Previously validated questions and scales are used when available. All aspects of the survey are subjected to extensive literature and expert review. Respondents’ cognitive understanding of the survey questions is assessed during the pretest phase and revisions made as required. All final data components are verified by NCHS and DRC/CAHMI staff prior to public release. Face validity is conducted in comparing results with prior years of the survey and/or results from other implementations of items.

The measure is utilized by the federal Maternal and Child Health Bureau (MCHB) in their children’s health chartbook following the 2007 NSCH data release [1].

**Simplicity of indicator**
The level of complexity in calculating and explaining this indicator is low. The numerator and denominator are simple. Data weighting, indexing, or adjustments are not required and the statistical formula is straightforward. Reducing child exposure to secondhand smoke is a common focus area among professionals and communities and one that community members can understand. In fact, numerous government, national, and community groups have been addressing child exposure to secondhand smoke:

References


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Life Course Indicator: Hypertension

The Life Course Metrics Project

As MCH programs begin to develop new programming guided by a life course framework, measures are needed to determine the success of their approaches. In response to the need for standardized metrics for the life course approach, AMCHP launched a project designed to identify and promote a set of indicators that can be used to measure progress using the life course approach to improve maternal and child health. This project was funded with support from the W.K. Kellogg Foundation.

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In June of 2013, state teams selected 59 indicators for the final set. The indicators were put out for public comment in July 2013, and the final set was released in the Fall of 2013.

Basic Indicator Information

Name of indicator: Hypertension (LC-29)

Brief description: Percent of adults with diagnosed hypertension

Indicator category: Family Well-Being

Indicator domain: Risk/Outcome

Numerator: Total number of adults aged 18 and over who indicated a health professional told them they had high blood pressure

Denominator: Total adult population 18 and over

Potential modifiers: Age, Race/Ethnicity, Gender, Education, and Income

Data source: Behavioral Risk Factor Surveillance System (BRFSS)

Notes on calculation: Numerator: Yes to the question “Have you EVER been told by a doctor, nurse, or other health professional that you have high blood pressure?” (Excludes female told only during pregnancy). Currently, the hypertension question is only asked every other year on BRFSS. Analysts who use the raw datasets should apply the appropriate survey weights to generate the final estimates.

Similar measures in other indicator sets: Preconception Health Indicator I3; HP 2020 Focus area HDS-5; Chronic Disease Indicator
Life Course Criteria

Introduction
Hypertension, or high blood pressure, increases the risk for heart disease and stroke, which are leading causes of death in the United States [2]. Currently, nearly one in three adults (approximately 67 million) have high blood pressure and more than half do not have their blood pressure under control [2, 4]. Uncontrolled hypertension increases risk for heart attacks and strokes, heart failure, and chronic kidney disease [2,7,9-11]. According to the Centers for Disease Control and Prevention (CDC), high blood pressure (>140/90 mm Hg) increases one’s risk of having a stroke by four and the risk of heart disease by three [12]. In the United States, hypertension prevalence has risen steadily since the 1990s. In 1995, 22.2 percent (BRFSS) of adults reporting having been told they have high blood pressure. Since then, prevalence has risen to 25.6 percent in 2001, and is currently estimated at 30.9 percent (BRFSS 2011). Hypertension is significant to the life course as it accumulates with age and can have an adverse impact on everyone from adolescents to the elderly. Medical expenditures associated with hypertension and hypertension-related morbidity have been estimated as being $131 billion [12]. The economic burden of hypertension is just one dimension of the need for improved prevention and intervention of high blood pressure. Improvements in hypertension prevalence and control would ease the financial burden of this disease and lead to improved quality of life and productivity among adults living in the United States.

Implications for equity
Generally, the risk for hypertension increases with age [2, 5-7]. In 2011, rates of hypertension were only 7.2 percent among young adults (ages 18-24). Rates increase steadily with age until peaking among adults 65 years and older at 61.4 percent (BRFSS 2011). Racial/ethnic and socioeconomic disparities in hypertension prevalence in the United States have been documented for decades [2,4], with hypertension being consistently higher among blacks than among non-Hispanic whites and Hispanics. In 2011, prevalence among blacks was 39.2 percent, compared to 31.7 percent among non-Hispanic whites and only 22.4 percent among Hispanics (BRFSS 2011). Hypertension rates tend to decrease as income and educational attainment increase. In 2011, prevalence of hypertension was approximately 38 percent for the least educated and least wealthy, while it was approximately 25 percent for the most educated and most wealthy (BRFSS 2011). Research suggests that inequities in hypertension also exist by nativity, health insurance status and health status including being diabetic, obese, and/or disability status [2]. Evidence supporting inequities by gender are inconsistent [2, BRFSS 2011].

One’s social context plays an important role in their risk for hypertension. Studies have generally shown that lower neighborhood socioeconomic status is associated with hypertension after adjusting for individual socioeconomic status [52-58]. Characteristics of lower socio-economic neighborhoods such as increased air and noise pollution [59-62], lack of healthy food options and green space for exercise [63-65], low social cohesion and social capital, and elevated crime and perceived insecurity all contribute to elevations in blood pressure [66-67]. Furthermore, research has shown work environments that create job strain (the combination of high psychological job demands and low job control) put employees at increased risk for high hypertension, after adjusting for potential risk factors, such as age, body mass index, race, work physical activity, and alcohol use [68].

The ability to control hypertension is also important. Estimates from 2008 indicate that only 50 percent of individuals diagnosed with hypertension were taking appropriate measures to control their blood pressure [7]. Age-adjusted rates of hypertension control from the 2009-2010 NHANES indicate a significant difference in control between non-Hispanic whites and blacks and Hispanics. Compared to the 56.3 percent of non-Hispanic whites with hypertension control, only 40.7 percent of Hispanics and 47.9 percent of blacks had control. The same study found that men were significantly less likely than women to control their hypertension (50.4 percent compared to 57.5 percent) and that adults ages 18-39 years of age were significantly less likely than persons 40-59 years or 60 or more years of age to control their hypertension (32.8 percent, 55.7 percent, and 54.9 percent respectively) [8]. It is likely that factors contributing to increased risk for hypertension are also associated with ability to control hypertension. Social factors, neighborhood, work environment, job stress, and income all have influence over an individual’s ability to access health care or pharmacy needs, their opportunities to reduce continued exposure to risk factors (e.g. stressful environments), and ultimately the power to make healthy lifestyle choices.
Public health impact
Medical expenditures associated with hypertension and hypertension-related morbidity have been estimated at $131 billion annually [12]. The economic burden of hypertension, which includes an added $25 billion in costs from loss of productivity due to morbidity and premature mortality, is compelling evidence of the need for improved prevention and intervention of high blood pressure. Improvements in hypertension prevalence and control would ease the financial burden of this disease and lead to improved quality of life and productivity among adults living in the United States.

The Healthy People 2020 objective for hypertension is to decrease rates among U.S. adults to 26.9 percent [13]. In an analysis based on the Framingham Heart Study experience, Cook et al. concluded that a two mmHg reduction in the population average of diastolic blood pressure for white U.S. residents 35 to 64 years of age would result in a 17 percent decrease in the prevalence of hypertension, a 14 percent reduction in the risk of stroke and transient ischemic attacks, and a six percent reduction in the risk of cardiovascular heart disease [69]. Documented effective interventions of hypertension include weight loss, dietary sodium reduction, increased physical activity, moderation of alcohol consumption, potassium supplementation, and maintaining a diet that is rich in fruits and vegetables and in low fat dairy products. Interventions with uncertain, or less proven, efficacy include calcium, fish oil, and herbal (e.g. Gingko biloba extract and St. John’s wort) supplementation.

The U.S. Food and Drug Administration has proposed requirements that certain establishments whose primary objective is to sell food (e.g. restaurants, fast food chains, and vending machines) display calorie counts for their menu items [24]. Some research suggests that displaying calorie information in fast-food restaurants could be beneficial for public health, especially among young women. In several studies, women who received calorie information chose significantly lower calorie meals than did women who did not receive calorie information [48-51]. Efforts to reduce obesity, smoking, and inactivity will require continued public health attention in order to reduce hypertension. Even small reductions in these rates could make a long term impact on the prevalence of hypertension and incidence of other chronic conditions.

Leverage or realign resources
The hypertension indicator has the potential to leverage and realign resources across public and private employers, in clinical settings, and within municipal and county governments. An average reduction of just 12 to 13 mmHg in systolic blood pressure over four years of follow-up is associated with a 21 percent reduction in coronary heart disease, a 37 percent reduction in stroke, a 25 percent reduction in total cardiovascular disease deaths and a 13 percent reduction in overall death rates. U.S. adults substantially lowered their blood pressure, high cholesterol levels and other heart disease risk factors during the 1980s. As a result, U.S. costs associated with coronary heart disease declined by an estimated 9 percent – from about $240 billion in 1981 to about $220 billion in 1990 [71].

If effectively planned, implemented, evaluated, and documented, worksite wellness programs also can reduce the burden. Workplace Wellness programs can yield a $3.27 drop in medical expenses for every $1 spent on wellness programs. Taking presenteeism and absenteeism into account, the return on investment can yield up to $6 for each dollar invested [72].

Health care providers can ensure they are following clinical guidelines related to blood pressure, counsel patients on healthier eating and exercise, and refer patients to wellness programs. Municipal and county governments can act to develop and enlarge parks and green spaces, and also repair or create walking trails, all to ensure that safe places to walk are easily accessible.

The Million Hearts Initiative is one example of a comprehensive effort to leverage best practices and apply what works to a very large problem. Million Hearts has as its goal to prevent one million heart attacks and strokes by 2017 by improving access to effective care, improving the quality of care for the ABCS (Aspirin, Blood Pressure Control, Cholesterol Management, and Smoking Cessation), focusing clinical attention on the prevention of heart attack and stroke, activating the public to lead a heart-healthy lifestyle, and improving the prescription and adherence to appropriate medications for the ABCS [73]. Million Hearts includes a challenge to use electronic health records and other health IT as tools to identify patients who need support in achieving safe and swift control of the blood pressure; the challenge will help patients and care teams use health IT tools to improve their cardiovascular health [74].
Predict an individual’s health and wellness and/or that of their offspring

Contributing to nearly 1,000 deaths per day, hypertension is a major cause of mortality and morbidity in the United States [12]. Currently, nearly one in three adults (approximately 67 million) have high blood pressure and more than half do not have their blood pressure under control [2, 4]. Uncontrolled hypertension increases risk for heart attacks and strokes, heart failure, and chronic kidney disease [2,7,9-11]. According to the CDC, high blood pressure (>140/90 mm Hg) increases one’s risk of having a stroke four-fold and the risk of heart disease three-fold [12].

As we age, our risk for hypertension generally increases, making it a disease that we typically face later in the life course. Although hypertension is not common among children [27-28], only about one to five percent, it is on the rise [29]. It is clear that hypertension has the potential to begin in childhood and adolescence and that it contributes to early development of cardiovascular disease and chronic kidney disease [29-30]. Childhood risk factors for high adult blood pressure include obesity and metabolic syndrome. Researchers speculate that the propensity toward developing hypertension may begin during gestation. According to the Barker hypothesis, intrauterine growth restriction is the failure of a fetus to reach his/her biological growth potential because of a pathological slow-down in the fetal growth pace [28-29, 31-39]. Infants who have experienced compromised growth during gestation are at higher risk for neonatal mortality and morbidity, particularly when they are preterm [31,40-41]. Subsequently, infants born prematurely or small-for-gestational-age, were shown to be at elevated risk for chronic diseases in adulthood. These diseases include hypertension, coronary heart disease, stroke, diabetes and metabolic diseases. [31, 42].

Maternal determinants of premature or low birth weight are many of the same determinants for hypertension and pregnancy-induced hypertension. Infants at risk are generally born to mothers who are obese [43], gain excessive [43] or inadequate weight during pregnancy [33, 44], consume alcohol during pregnancy [34], smoke [35], experience maternal stress [45], endure gestational hypertension [46], and experience preeclampsia [47].

Data Criteria

Data availability
The Behavioral Risk Factor Surveillance System (BRFSS) is the world’s largest, ongoing telephone health survey system, tracking health conditions and risk behaviors in the United States yearly since 1984. Currently, data are collected monthly in all 50 states, the District of Columbia, Puerto Rico, the U.S. Virgin Islands, and Guam for adults 18 years of age and older. CDC provides state and national level prevalence data on their website.

The CDC develops approximately 80 questions each year. Some of these are core questions asked each year, and some are rotating core questions asked every other year. There are also CDC supported modules that address specific topics that states can use. States also may develop additional questions to supplement the core questions. Modules used by states are noted on the CDC websites.

Local level estimates for BRFSS data can be obtained using the Selected Metropolitan/Micropolitan Area Risk Trends (SMART) data. Local areas are metropolitan or micropolitan statistical areas (MMSAs) as defined by the Office of Management and Budget. SMART data is currently available for data going back to 2002 for MMSAs with 500 or more respondents.

Currently, the BRFSS has one hypertension indicator in the core module: “Adults who have been told they have hypertension.” Prevalence and trend reports are available biannually from 1995 through 2011. These reports allow users to quickly analyze prevalence of adult hypertension by state and by sociodemographic predictors including: gender, age, race, income or education. One limitation of the reports provided by the BRFSS is that they do not allow researchers to cross tabulate prevalence and trends (e.g. gender by race or gender by age) [1].

Data quality
Numerous studies have compared estimates of chronic conditions and behaviors obtained from BRFSS to other national surveys including the National Health Interview Survey and the National Health and Nutrition Examination Survey; while there are some differences, findings on overall health status and certain chronic conditions tended to be similar despite declining response rates for BRFSS.
Since some questions on the BRFSS address sensitive health conditions and behaviors, there is intermittent missing data throughout the dataset. However, refusal to answer generally accounts for a small proportion of responses for most data elements. The notable exception is income, where refusals accounted for more than 23 percent of the data in one state in 2010; the median percent missing across BRFSS for income in 2010 was 14 percent.

Quality control computer programs are used to check the raw data for values out of range. CDC performs quality checks for core questions, and each state has its own protocol for checking state-specific questions. Interviewers are monitored during the annual questionnaire pilot period and intermittently during the data collection period to determine whether any interviewer bias exists and to correct any bias that might be found. On an ongoing basis, 10 percent of interview calls are verified.

Prior to 2011, the sampling for BRFSS represented only adults living in a private residence with a landline telephone, but starting in 2011, the sample also included data from respondents living in cell phone-only households. Weighted response rates are presented by state. For 2011, the median weighted response rate for the combined cell phone and landline was 49.72 percent.

The survey adjusts for non-response to reduce the known differences between respondents and non-respondents. Although participants interviewed may not represent a state in terms of age, sex and race distribution, it is believed that weighting the data corrects for this potential bias. As with other health surveys, estimates are based on self-report data and they may over- or underestimate the actual prevalence of a particular risk factor in the population. Despite some oversampling in states by geography, the annual sample size is too small to compute precise estimates at the county level.

A study testing the reliability of BRFSS chronic disease measures found the Cohen Kappa reliability statistic for hypertension to be 0.82 [48]. Kappa statistics greater than 0.75 represent excellent agreement, suggesting that BRFSS indicators for chronic conditions are generally reliable.

**Simplicity of indicator**
The level of complexity in calculating this indicator is very low. The BRFSS provides pre-calculated rates for every state, as well as several counties and cities, by gender, age, race, income, and education. Data weighting and adjustments are calculated by state health departments and the CDC prior to their release on the CDC website. Additionally, many states conduct county-level surveys every two or three years. These data contribute richer detail on county health status and facilitate county health assessment and tracking. The indicator is simple to explain and conceptually easy to understand.

**References**


Life Course Indicator: Hypertension (LC-29)


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Life Course Indicator: Illicit Drug Use

The Life Course Metrics Project

As MCH programs begin to develop new programming guided by a life course framework, measures are needed to determine the success of their approaches. In response to the need for standardized metrics for the life course approach, AMCHP launched a project designed to identify and promote a set of indicators that can be used to measure progress using the life course approach to improve maternal and child health. This project was funded with support from the W.K. Kellogg Foundation.

Using an RFA process, AMCHP selected seven state teams, Florida, Iowa, Louisiana, Massachusetts, Michigan, Nebraska and North Carolina, to propose, screen, select and develop potential life course indicators across four domains: Capacity, Outcomes, Services, and Risk. The first round of indicators, proposed both by the teams and members of the public included 413 indicators for consideration. The teams distilled the 413 proposed indicators down to 104 indicators that were written up according to three data and five life course criteria for final selection.

In June of 2013, state teams selected 59 indicators for the final set. The indicators were put out for public comment in July 2013, and the final set was released in the Fall of 2013.

Basic Indicator Information

Name of indicator: Illicit Drug Use (LC-30)

Brief description: Prevalence of illicit drug use in the past month among population 12 years and older.

Indicator category: Family Well-being

Indicator domain: Risk / Outcome

Numerator: Reported illicit drug use in the past month for those 12 and older

Denominator: Total population aged 12 and older

Potential modifiers: Race/ethnicity, sex, parental drug use

Data source: National Survey on Drug Use and Health (NSDUH), Substance Abuse and Mental Health Services Administration (SAMHSA)

Notes on calculation: None

Similar measures in other indicator sets: HP 2020 Focus area SA-13, SA-2.4, SA-13.3; Maternal, Infant, and Early Childhood Home Visiting (MIECHV) Benchmark Area Improved Maternal and Newborn Health: Parental use of alcohol, tobacco or illicit drugs
Life Course Criteria

Introduction
Although this indicator includes adults, the focus of the evidence presented here is on adolescence because illicit drug use among adolescents is associated with harmful behaviors that can lead to many negative short- and long-term health outcomes throughout an individual’s life span. In addition, substance and illicit drug use in the United States places huge burdens on the health care, justice, education and social service systems [2]. Adolescence is a particularly concerning time for drug use, as the developing brain is more susceptible to addiction and risk-taking, impulsive behavior. Additionally, addictive substances physically alter an adolescent’s brain structure and function faster and more intensely than that of an adult [3]. One of the most common, and most dangerous risky adolescent behaviors is using illicit drugs, which includes marijuana/hashish, cocaine (including crack), heroin, hallucinogens, inhalants, or psychotherapeutic medications not taken under a health provider’s supervision [4].

According to the National Survey on Drug Use and Health (NSDUH), 2.2 million adolescents between the ages 12-17 were illicit drug users. Recent studies indicate that by the 12th grade, about half of adolescents have abused an illicit drug at least once. Furthermore, 90 percent of Americans with a substance abuse problem started smoking, drinking or using other drugs before age 18 [2,5]. Because of the large impact this indicator has on adolescent health in the short term and into adulthood, improvements in this area and prevention of adolescent illicit drug use have significant potential to improve the life course trajectory and long-term health throughout adulthood.

Implications for equity
Adolescent drug use is a concern in the United States. According to the Child Health USA 2011 report, 10 percent of adolescents aged 12 to 17 years reported illicit drug use in the past month, a significant increase from past years. According to the NSDUH (reporting a two-year average of data from 2010 and 2011), teenagers are the most likely age group to use illicit drugs while pregnant, with an estimated prevalence of 20.9 percent among pregnant teens aged 15 to 17 years. Further, based on NSDUH data from 2011, illicit drug use varies by age, with 3.3 percent of youth aged 12 to 13 years reporting drug use in the past month, compared to 9.2 percent of youth aged 14 to 15 years and 17.2 percent of youth aged 16 to 17 years. On average, the prevalence of illicit drug use among male adolescents is higher than among female adolescents. There is also variation by race/ethnicity, with rates ranging from 5.5 percent among non-Hispanic Asian youth to 14.6 percent among non-Hispanic American Indian/Alaska Native youth. Rates for non-Hispanic White, non-Hispanic Black, and Hispanic youth were 9.6 percent, 10.8 percent, and 11.4 percent, respectively.

Other factors shown to be associated with adolescent illicit drug use include family structure, such as parental educational attainment and parental substance use, and other social and environmental factors that include family and social networks, poverty and peer groups [6].

Public health impact
Illicit drug use during adolescence is a strong predictor of normative use of these substances in adulthood that can influence community and society at large. Further, adolescents who persistently use these substances are observed to have academic difficulties, mental health problems, lower social and peer relations and an increased involvement in criminal behaviors [7]. Use of any illicit drug among adolescents aged 12 to 17 years is associated with increased emergency visits because of unintentional injuries caused by drug overdose or illicit drug use [7].

Engaging in sexual behaviors that increase the risk of contracting sexually transmitted diseases (such as HIV and hepatitis) is associated with adolescent use of substances [8]. Though rates of AIDS diagnoses are currently relatively low among teenagers compared with most other age groups, this could be due to long latency period of the virus where many young adults with AIDS were actually infected with HIV as adolescents [7].

Economic and societal costs of adolescent drug use include an estimated $14.4 billion in substance-related juvenile justice programs each year. Total costs to federal, state and local governments of substance use (including alcohol) are estimated at $468 billion per year, and included costs associated with substance use-related accidents, diseases, crimes, child neglect and abuse, unplanned pregnancies, homelessness, unemployment, and other health conditions. The majority of these costs are driven by individuals who began substance use as adolescents [2]. Reducing the illicit drug use among adolescents age 12 to 17 years will reduce the burden of emergency visits, as well as reduce lifelong social and...
economic costs. This includes reducing the familial and societal burden of supporting adolescents who are not self-sufficient, the additional burden on the medical system for long-term and lifelong care of such individuals, and the financial loss to the community due to crime connected with substance abuse [7].

**Leverage or realign resources**

Family-centered interventions are critical for improvement in this indicator. Well-integrated programs that address entire families and not only parents or adolescents alone are more successful in improving this indicator [9, 10]. Other factors in the social environment like peer pressure and community norms need to be addressed through community programs [9, 11]. Media campaigns can be successful to bring about social changes, and policy and regulations have been successful in restricting access to alcohol, tobacco, or other drugs. For example, the Partnership for a Drug-Free America’s Above the Influence campaign has shown evidence in reducing initiation and use of illicit drugs in adolescents. Effectiveness of such campaigns is increased when combined with school-based prevention programs. School-based programs that focus on increasing protective factors, increasing awareness and education, and fostering life skills, have show significant effectiveness in reducing drug use among adolescents [15-17]. Similar programs that occur outside the classroom, such as in a community or after-school settings, also show effectiveness in decreasing drug use and promoting protective factors and positive peer-influences, especially when efforts are aligned [9,13]. There are several federal investments in research on understanding drug use and providing resources and grants for states and communities to reduce and prevent illicit drug use, such as through the National Institute on Drug Abuse and Substance Abuse and Mental Health Services Administration. Overall, when all of the interventions targeting changes in individual level behaviors are accompanied by community and policy level changes, greater impact on the use of alcohol or illicit drugs in adolescent is shown [12].

**Predict an individual’s health and wellness and/or that of their offspring**

Adolescent illicit drug use is a leading cause of mortality and morbidity among this age group, particularly because it leads to accidental injuries. The leading causes of death among adolescents are unintentional injuries, homicide and suicide. While there is not exact data on the proportional of these death that are attributable to illicit drug use, research suggests that substance use or abuse is a key contributing factor to each of the leading causes [2]. Among adolescents aged 12 to 17 years, visits to hospital emergency rooms are correlated with the use of illicit drugs and resulting accidental injuries [7]. In addition, drug overdose increases the risk of other serious health problems by damaging the functionality of vital organs like the liver, kidneys and heart, and causing long-term disability in some instances. Adolescents who use illicit drugs are also more likely to engage in high risk sexual behaviors and are more likely to expose themselves to and contract sexually transmitted diseases, such as HIV and hepatitis [14]. While there is not explicit data to link illicit drug use and unintended pregnancies in adolescents, the more addictive substances an adolescent uses throughout his/her life decreases the likelihood of reporting condom use, and substance use is correlated with “doing more” sexual activity under the influence compared to planned activity while sober [2,14]. Further, adolescents who persistently use these substances are observed to have academic difficulties, mental health problems, poorer social and peer relations and increased involvement in criminal behaviors. A recent report stated that up to 67 percent of youth involved in the juvenile justice system have a substance use problem [9]. Thus, this indicator predicts the individual health of adolescents in the short and long term [12, 13].

**Data Criteria**

**Data availability**

Data on adolescents using any illicit drugs during the past 30 days is captured through the administration of the NSDUH funded by SAMHSA, an agency of the U.S. Department of Health and Human Services (HHS). The NSDUH is a nationwide survey administered annually since 1971 and involves interviews with randomly selected individuals aged 12 and older across all 50 states in the United States and District of Columbia. The indicator is based on whether the survey respondent used any illicit drug “within the past 30 days” as one of the response options. The NSDUH obtains information on nine categories of illicit drug use: marijuana, cocaine, heroin, hallucinogens, and inhalants, as well as the nonmedical use of prescription-type pain relievers, tranquilizers, stimulants, and sedatives. The NSDUH uses multistage area probability sampling for each of the 50 states and the District of Columbia and oversamples youth and young adults who represent three major age groups of 12 to 17 years, 18 to 25 years, and 26 years or older. The NSDUH data is available for download through the SAMHSA Substance Abuse and
Mental Health Data Archive (SAMHDA) (samhsa.gov/data/) and is readily available to any MCH program in the country. This website provides links to the public-use data files as well as restricted-use data files that list information on use of some illicit drugs. The SAMHDA website also allows users to generate quick tables for the target age group of 12-17 years and allows for required variable searches across the different years of data.

**Data quality**
A reliability study was conducted for NSDUH in 2006 by the Office of Applied Studies of SAMHSA, based on a directive of the Office of Management and Budget to evaluate the quality of federally funded surveys. The reliability study was conducted on a subsample of the main study by administering a second interview in addition to the interview conducted for the main study. A total of 3,136 interviews were completed and they were done five to 15 days after the initial interview for the main study. The interview for the reliability study followed the same procedure for data collection as the main study. The study found perfect reliability for indicators that measure lifetime substance use, as well as substantial reliability for substance dependence and abuse indicators.

NSDUH is the primary source of statistical information on the use of illegal drugs by the U.S. population. Prior to 2002, the NSDUH was called the National Household Survey on Drug Abuse (NHSDA) with the first round of surveys being conducted in early 1970s with 3,000 respondents. As the data collected through this survey gained importance, the Office of National Drug Control Policy advocated for expansion of the sample in the early 1980s for tracking data about illicit drug use. Also, a series of studies were conducted to evaluate the survey methods and questionnaire that lead to the redesign of the survey in 1994. Following this redesign of the survey, SAMHSA pursued the use of a newly emerging data collection technology, audio computer-assisted self-interviewing (ACASI), simultaneously with new sampling design to produce state-level estimates from survey responses. Since this initial redesign, there has been routine evaluation of the survey methodology and periodic improvements of the survey design and implementation.

**Simplicity of indicator**
The indicator is widely used by many federal and state agencies and other organizations interested in the use of tobacco, alcohol, illicit drugs (including non-medical use of prescription drugs) and mental health in the United States. The indicator is used by HHS, Health Resources and Services Administration, and the Maternal and Child Health Bureau for their Child Health USA report [1]. The data for the indicator are readily available, and the numerator and denominator for this indicator are simple. Adolescent use of illicit drugs is a common focus area among professionals and communities and one that community members can understand.

Numerous government, national, and community groups use this indicator for advocacy or improving public health programs. The White House Office of National Drug Control Policy uses NSDUH data to track progress toward goals in the National Drug Control Strategy. SAMHSA prepares statistical reports on substance use patterns and trends and uses the data to identify populations and geographic areas with particular substance abuse problems so federal resources can be used efficiently for prevention and treatment programs. The Partnership for a Drug-Free America uses NSDUH data to design media advertising campaigns for the prevention of substance use and abuse. Based on the trends and patterns of substance use evident in the data, the National Institute on Drug Abuse develops research programs targeted toward populations and types of drug use problems where the need is greatest. University-based researchers use NSDUH data to conduct research on important substance use issues, such as the risk and protective factors associated with substance use, personal and societal consequences of substance use, and the impact of policy decisions for dealing with the substance abuse problem. Substance abuse agencies at the state and local levels use NSDUH data to assess the potential need for treatment services and to design programs that fit the needs of populations served. State and local health departments use NSDUH data to assess area substance use problems and to develop appropriate funding strategies and prevention measures. The U.S. Department of Education uses the data to inform drug use prevention and education programs and provide educational materials for teachers and administrators. The U.S. Department of Transportation uses NSDUH data on driving after alcohol and illicit drug use to develop prevention programs and materials on impaired driving.

**References**
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Life Course Indicator: Intimate Partner Violence, Injury, Physical or Sexual Abuse

Basic Indicator Information

Name of indicator: Intimate Partner Violence, Injury, Physical or Sexual Abuse (LC-31)

Brief description: Number of intimate partner victimizations per 1,000 persons age 18 and older

Indicator category: Family Well-being

Indicator domain: Risk/Outcome

Numerator: Number of persons aged 18 years or older who reported intimate partner violence

Denominator: Number of persons aged 18 and older per 1,000

Potential modifiers: Age, race/ethnicity, gender, household construct, socioeconomic status

Data source: Behavioral Risk Factor Surveillance System (BRFSS)

Notes on calculation: The Centers for Disease Control and Prevention (CDC) offers two optional modules to the BRFSS, an eight-question module on sexual violence and a seven-question module on intimate partner violence (IPV). The numerator can be calculated by including anyone who answered “yes” to any of the seven questions on the IPV module, or yes to any of the sexual violence questions if the answer to the question, “Think about the time of the most recent incident involving a person who had sex with you—or- attempted to have sex with you after you said or showed that you didn’t want to or without your consent? What was that person’s relationship to you?” was an intimate partner (answers options one through seven are intimate partners). Theses modules are optional, and no state has included the Intimate Partner Violence module since 2007; however, if this indicator is of interest, the modules could be added. Other data sources for IPV may have more timely data, but either do not include state-level estimates (National Crime Victimization Survey) or include state estimates that should be compared with extreme caution (National Intimate Partner and Sexual Violence Survey). Analysts who use the raw datasets should apply the appropriate survey.
weights to generate the final estimates.

**Similar measures in other indicator sets:** Preconception Health Indicator H1; HP 2020 Focus area IVP-39

## Life Course Criteria

### Introduction

Intimate Partner Violence (IPV) is defined as the physical, sexual, or psychological harm by a current or former partner or spouse. This harm can take numerous forms, and has historically been defined through four different types: 1) physical violence, 2) sexual violence, 3) threats of physical or sexual violence and 4) psychological/emotional violence caused by acts, threats of acts, or coercive tactics, including stalking [21]. The occurrence of IPV is complex, multifaceted, and increasingly gaining public attention. It is inclusive of rape, domestic violence, sexual assault, and reproductive coercion, and has deep relevance for programs serving the maternal and child health population, including but not limited to home visiting, family planning, injury and mortality surveillance, and direct services, as well as law enforcement and schools, colleges, and universities. Programs addressing IPV must focus not only on the primary prevention of violent acts, injury, and death, but also assessment and intervention, including the removal from danger, and mediation of the lifelong consequences of exposure to IPV. These lifelong consequences relate not just to the victim but also the victim’s family, including children that may have directly or indirectly witnessed the IPV.

In the United States, the estimated annual rate of IPV of persons aged 12 and older has declined by 64 percent from 1994 to 2010, 9.8 to 3.6 victimizations per 1,000 persons respectively. However, this decline has slowed in recent years from 3.8 per 1,000 in 2005 to 3.6 per 1,000 in 2010 [10], and recent reports indicate that every minute, 20 individuals become victims of physical violence by an intimate partner. The complexity of reducing the prevalence of IPV originates in part from the abuse being hidden from public view, its consequences silent within its victims, and its ‘syndemic’ association with other public health challenges, including depression and psychological disorders, substance abuse, and sexually transmitted infections. However this interrelatedness also points to multiple touch-points with community members, teachers and professors, health professionals, and public servants, who can interrupt the cycle.

The prevalence of IPV among the U.S. population differs based both on the measurement or surveillance system used and the type of IPV (physical, sexual, threats, or psychological/emotional violence). To provide the most recent data possible, this narrative utilizes data from the National Crime Victimization Survey and recent results from the National Intimate Partner and Sexual Violence Survey (NIPSVS).

### Implications for equity

Experiences of IPV and sexual violence vary by gender, race/ethnicity, and socioeconomic status. Nearly one in 10 women in the United States has been raped by an intimate partner in her lifetime. A comparable statistic is not available for men, due to too few men reporting rape by an intimate partner to produce a reliable estimate. Women are more than two times more likely to have experienced sexual violence other than rape by an intimate partner as compared to men (16.9 percent versus 8.0 percent) and have a lifetime prevalence of stalking by an intimate partner more than five times greater than men (10.7 percent versus 2.1 percent). Women also have a significantly higher prevalence of other experiences of IPV, including severe physical violence by an intimate partner. However, certain types of IPV do affect men as much or more than women. Nearly half of both men and women have experienced at least one psychologically aggressive behavior by an intimate partner during their lifetime, and of individuals that report IPV, men are more likely than women (92.1 percent versus 56.8 percent) to experience physical violence only. All of these data must be considered within the context of disclosure of victimization, however: it is estimated that 84.2 percent of female victims, compared to 60.9 percent of male victims, disclose their own experiences with IPV. However, the high prevalence of experiences of IPV among women above that of men underscore the significance of IPV as not just a public health issue, but a gender justice issue as well.

Variations in experiences of IPV by race/ethnicity and socioeconomic status point to other important inequities. Black, non-Hispanic women (43.7 percent) and multiracial non-Hispanic women (53.8 percent) have a higher lifetime prevalence of rape, physical violence, or stalking by an intimate partner compared to White non-Hispanic women (34.6 percent) and Asian or Pacific-Islander non-Hispanic women (19.6 percent). Similar disparities exist among men, however, American
Indian or Alaska Native non-Hispanic men have the highest lifetime prevalence (45.3 percent). With regard to poverty and socioeconomic status, while there is a significantly higher prevalence of IPV among men and women who experienced food insecurity in the past 12 months, the difference is most pronounced among women and men who experience housing insecurity: Women who experienced housing insecurity in the past twelve months were more than four times more likely to experience rape, physical violence, or stalking by an intimate partner, and for men, they are more than two times more likely to experience these episodes of violence [25].

The relationship between socioeconomic factors and IPV is complex. The CDC and World Health Organization (WHO) list low income, economic stress, and poverty as risk factors for IPV [6,7]. It has also been found that as socioeconomic status increases, the risk for IPV decreases by as much as 72 percent [12]. There also is evidence to suggest that as parental educational level increases, the risk for IPV decreases [11]. IPV has proven to vary based on household composition [11, 10], with females living in households comprised of one female adult raising multiple children experiencing IPV at a rate of ten times that of their peers living in a household with two married adults and multiple children [10]. Some research models suggest that the association between socioeconomic status and IPV is in part due to the stressors associated with poverty but also power, including maternal economic dependency and gender beliefs. A recent study by Golden and colleagues found that women were at higher risk for one or more types of IPV when these risk factors were present [26]. For example, the odds of a woman experiencing emotional abuse or coercion who did not have control over household finances were more than two times greater than women who did have control over the finances, and traditional gender beliefs were associated with a seven-fold increased risk for physical assault.

**Public health impact**

According to the National Intimate Partner and Sexual Violence Survey implemented in 2010 [25], millions of Americans are victims of IPV, sexual violence, and stalking every year. In fact, every minute, 20 individuals become victims of physical violence by an intimate partner. The most comprehensive resource available on the societal costs of IPV is a CDC study from 2003 [27]. In the report, the team details how the millions of injuries, both seen and unseen, from IPV result in a loss of nearly eighty million days of paid work, or the equivalent of 32,000 full-time jobs, and nearly 5.6 million days of household productivity. Using cost estimates from 1995, the research team estimated the cost of IPV, in 1995, to exceed $5.8 billion, which included $4.1 billion for direct medical and mental health care services, $0.9 billion for lost productive from paid work and household chores, and $0.9 billion in lifetime earnings lost by victims. When updated to 2003 dollars, this value exceeded $8.3 billion. Brown and colleagues more recently attempted to measure the health care costs attributable to IPV, and identified a medical cost burden within the first 12 months after victimization ranging from $2.3-7.0 billion alone [29]. These numbers most likely underestimate the true cost of IPV. For example, victims of IPV often need services outside of the medical field such as the need for housing, victim advocacy, and legal services, which can be costly [13].

For the individual, the effects of experiences of IPV are far-reaching and difficult to quantify. For example, Fishman and colleagues found that women who experience IPV not only have higher health care costs, but these health care costs remain high for more than three years after the cessation of the violence [28]. As may be expected, health care costs and utilization are also higher for children of mothers who experienced IPV, both if the IPV occurred before the child was born and if the child was directly exposed to it [30].

**Leverage or realign resources**

The violence prevention arm of the CDC has implemented funds from the Violence Against Women Act (VAWA) to help reduce societal costs associated with the victimization of women, sexual assault, rape and IPV. Given the significant public health impact of IPV, in 2013, Congress passed and President Obama signed VAWA into law, a renewal of the previous legislation passed in 1994. Areas of focus of the law include justice and safety specifically for Native American women and lesbian, gay, bisexual, and transgender (LGBT) survivors of violence, safe housing, protections for immigrants, justice on campuses, and the maintenance of previous VAWA grant programs.

Based on researchers cost benefit analysis, the net benefit of VAWA is estimated at $16.4 billion [15]. Approximately $14.8 billion in victimization costs are averted due to VAWA, which only costs $1.6 billion to implement. At the individual level, VAWA is estimated to cost $15.50 per woman, yet saves $159 per U.S. women in averted victimization costs, suggesting VAWA to be a fiscally efficient program. Actions taken through VAWA have championed interventions that focus on IPV prevention in addition to treatment for victims.
The CDC Division of Violence Prevention has outlined objectives and prevention strategies that focus on preventing IPV before it occurs [16]. These include reducing factors that put people at risk for IPV perpetration as well increasing factors that protect against victimization. Strategies to achieve this include instruction on non-violent conflict resolution, effective communication skills, negotiation and adjustment to stress, and building healthy relationships through the belief in partner autonomy [16]. These priorities outlined by the CDC are synergistic with a number of maternal and child health efforts seeking to reduce IPV.

For example, the Affordable Care Act (ACA) authorized the creation of the Maternal, Infant, and Early Childhood Home Visiting Program (MIECHV) under a new section of Title V of the Social Security Act. It provides $1.5 billion over five years to states, tribes, and territories to develop and implement one or more evidence based home visitation models. One of the six benchmark areas against which states are being measured is the reduction of crime, including domestic violence. Many of the evidence-based home visiting models include a domestic violence assessment, with the goal of connecting the family to needed supports. With services being delivered in the context of the home, home visitors are in a unique position to break the cycle of intergenerational violence, domestic violence, child maltreatment, and adverse childhood experiences. The Family Violence Prevention Fund published a guide for policymakers to this end, underscoring the importance of collaborating with state home visiting programs in the implementation of a unified approach to reduce IPV [31].

In addition to the implementation of MIECHV, state MCH programs can bring together diverse partnerships to impact IPV prevalence. Collaborations may include working with schools and universities on risk factors for violence and outreach and services for potential victims and survivors, implementation of prevention curricula with students, and appropriate responses to suspected or confirmed events; collaborating with and training first responders in their encounters with domestic violence; and developing community-based programs and social marketing strategies that address gender norms and healthy relationships, beginning at a young age.

In recent years, prevention interventions utilizing these strategies have grown in support and are beginning to develop an evidence base. For example the prevention program “Safe Dates” and others like it have gone through rigorous testing to prove their efficacy in preventing IPV [17,18].

**Predict an individual’s health and wellness and/or that of their offspring**

The impact of IPV on an individual, family and community cannot be considered within a vacuum; multiple forms of violence co-occur in communities, and the impact of IPV on an individual is an amalgamation of the effects of this context [32]. The physical and mental impact of current and previous exposure to IPV is profound, with consequences of victimization leading to hospitalization, disability or death [4,8,14]. Victims of IPV can experience physical injuries such as cuts, bruises, broken bones and internal injuries [13]. The chronic stress brought on by IPV can also have a negative impact on the cardiovascular, gastrointestinal, endocrine and immune systems [14]. IPV victims are at an increased risk for contracting sexually transmitted infections (STIs), including HIV/AIDS [13]. Female victims of IPV can experience issues related to their reproductive health, including; gynecological disorders, unwanted pregnancy, and unsafe abortion [6].

Along with physical health, victims of IPV often suffer negative mental health consequences like depression, anxiety, low self-esteem, posttraumatic stress disorder (PTSD) symptoms, inability to trust, sleep disturbances, and suicidal thoughts or actions [14, 25]. Those who experience IPV are more likely to display behaviors that present further health risks compared to those who have not. These negative health behaviors include; engaging in high-risk sexual behavior like engaging in unprotected sex and choosing unhealthy sexual partners, using harmful substances like illicit drugs, as well as unhealthy dieting behaviors like fasting, vomiting and overeating [14]. Novel research approaches currently point to ‘syndemic’ or synergistic effects of health issues associated with IPV, where the negative impacts associated with IPV are intensified and co-occur frequently with other health issues, including HIV/AIDS and substance use [33]. Approximately 324,000 pregnant women experience some form of IPV each year in the United States [8], which can have negative effects on the pregnancy, and may result in premature labor and preterm birth. As previously described, children of a parent or caregiver that has experienced IPV are more likely to have higher health care costs, and by nature of living in the same home as the mother, be exposed to violence at a young age, having lifelong developmental impacts. Children who are witnesses to IPV amongst parents or caregivers are at-risk for physical and emotional trauma such as injury.
related to trying to intervene, PTSD, and difficulties forming emotional attachment [20]. These experiences have the potential to adversely affect development and health over the life course, and an individual’s own attitudes and perspective toward violence and healthy relationships.

**Data Criteria**

**Data availability**
The BRFSS is the world’s largest, on-going telephone health survey system, tracking health conditions and risk behaviors in the United States annually since 1984. Currently, data are collected monthly in all 50 states, the District of Columbia, Puerto Rico, the U.S. Virgin Islands, and Guam for adults 18 years and older. CDC provides state and national level prevalence data on their website.

The CDC develops approximately 80 questions each year. Some of these are core questions asked each year, and some are rotating core questions asked every other year. There are also CDC supported modules that address specific topics that states can use. States may also develop additional questions to supplement the core questions. Modules used by states are noted on the CDC websites. BRFSS has not included the Intimate Partner Violence module since 2007; that year, three states utilized the module: Hawaii, Virginia and West Virginia. CDC offers two optional modules to the BRFSS associated with intimate partner violence: an eight-question module on sexual violence and a seven-question module on intimate partner violence.

In 2007, the last year the modules were available, the questions in the modules included the following [22]:

**Module 17: Sexual Violence**
1. In the past 12 months, has anyone touched sexual parts of your body after you said or showed that you didn’t want them to, or without your consent (for example being groped or fondled)?
2. In the past 12 months, has anyone exposed you to unwanted sexual situations that did not involve physical touching? Examples include things like sexual harassment, someone exposing sexual parts of their body to you, being seen by a peeping Tom, or someone making you look at sexual photos or movies?
3. Has anyone EVER had sex with you after you said or showed that you didn’t want them to or without your consent?
4. Has this happened in the past 12 months?
5. Has anyone EVER ATTEMPTED to have sex with you after you said or showed that you didn’t want to or without your consent, BUT SEX DID NOT OCCUR?
6. Has this happened in the past 12 months?
7. Think about the time of the most recent incident involving a person who had sex with you — or attempted to have sex with you after you said or showed that you didn’t want to or without your consent. What was that person’s relationship to you?
8. Was the person who did this male or female?

**Module 18: Intimate Partner Violence**
1. Has an intimate partner EVER THREATENED you with physical violence? This includes threatening to hit, slap, push, kick, or hurt you in any way.
2. Has an intimate partner EVER ATTEMPTED physical violence against you? This includes times when they tried to hit, slap, push, kick, or otherwise hurt you, BUT THEY WERE NOT ABLE TO.
3. Has an intimate partner EVER hit, slapped, pushed, kicked, or hurt you in any way?
4. Have you EVER experienced any unwanted sex by a current or former intimate partner?
5. In the past 12 months, have you experienced any physical violence or had unwanted sex with an intimate partner?
6. In the past 12 months, have you had any physical injuries, such as bruises, cuts, scrapes, black eyes, vaginal or anal tears, or broken bones, as a result of this physical violence or unwanted sex?
7. At the time of the most recent incident involving an intimate part who was physically violent — or — had unwanted sex with you, what was that person’s relationship to you?

Local level estimates for BRFSS data can be obtained using the Selected Metropolitan/Micropolitan Area Risk Trends (SMART) data. Local areas are metropolitan or micropolitan statistical areas (MMSAs) as defined by the Office of
Management and Budget. SMART data is currently available for data going back to 2002 for MMSAs with 500 or more respondents.

It is important to note that the BRFSS modules do not contain questions specific to all four categories or types of IPV, specifically, psychological and emotional violence caused by acts, threats of acts, or coercive tactics, including stalking. States wishing to measure these variables on an ongoing basis should visit the following CDC online resource to identify additional data sources, including the recent (beginning in 2010) National Intimate Partner and Sexual Violence Survey developed in partnership between CDC, the National Institutes of Justice, and the Department of Defense: cdc.gov/violenceprevention/sexualviolence/datasources.html

Data quality
Numerous studies have compared estimates of chronic conditions and behaviors obtained from BRFSS to other national surveys including the National Health Interview Survey and the National Health and Nutrition Examination Survey; while there are some differences, findings on overall health status and certain chronic conditions tended to be similar despite declining response rates for BRFSS.

Since some questions on the BRFSS address sensitive health conditions and behaviors, there is intermittent missing data throughout the dataset. However, refusal to answer generally accounts for a small proportion of responses for most data elements. The notable exception is income, where refusals accounted for over 23 percent of the data in one state in 2010; the median percent missing across BRFSS for income in 2010 was 14 percent.

Quality control computer programs are used to check the raw data for values out of range. CDC performs quality checks for core questions, and each state has its own protocol for checking state-specific questions. Interviewers are monitored during the annual questionnaire pilot period and intermittently during the data collection period to determine whether any interviewer bias exists and to correct any bias that might be found. On an ongoing basis, 10 percent of interview calls are verified.

Specifically regarding refusal to answer and sensitive health conditions, some researchers have sought to better characterize the data quality for responses to the IPV and sexual violence modules. In particular, before a surveyor asks the questions in each module to the participant, he or she asks the question, “Are you in a safe place to answer these questions?” Ranney et al. investigated correlations between responding “not safe” to the screener for the IPV module. These respondents were found to have lower income, lower education levels, and were older than other respondents, and when compared to respondents that responded with experiences of some form of IPV, those that answered “not safe” were more likely to be male. This initial screener for asking the IPV and sexual violence questionnaires points to both the validity of IPV and sexual violence estimates derived from BRFSS and the necessity to further explore validity, reliability and comprehensibility of the safety screener [23].

While not specific to IPV, Potter and Laflamme assessed state level sexual assault prevalence estimates, comparing three surveys: BRFSS, the National Violence Against Women Survey (NVAWS) extrapolations, and state replications of NVAWS. They found significant differences between the prevalence estimates for the three surveys. For example, states that conduct their own sexual violence studies, in general, report higher prevalence rates for both sexual and physical violence. The BRFSS measure was described as reliable since states use the same measure regularly and it produces consistent results. However, the authors cited concerns with the lower level of BRFSS specificity [24].

Prior to 2011, the sampling for BRFSS represented only adults living in a private residence with a landline telephone, but starting in 2011, the sample also included data from respondents living in cell phone-only households. Weighted response rates are presented by state. For 2011, the median weighted response rate for the combined cell phone and landline was 49.7 percent.

The survey adjusts for non-response to reduce the known differences between respondents and non-respondents. Although participants interviewed may not represent a state in terms of age, sex and race distribution, it is believed that weighting the data corrects for this potential bias. As with other health surveys, estimates are based on self-report data and they may over- or underestimate the actual prevalence of a particular risk factor in the population. Despite some
oversampling in states by geography, the annual sample size is too small to compute precise estimates at the county level.

**Simplicity of indicator**

Data weighting and adjustments are applied to the numerator. The level of complexity in calculating and explaining the indicator is simple to moderate. The numerator captures the number of self-reported instances of IPV as indicated by BRFSS per 1,000 individuals. Of importance, the BRFSS module measures behavioral components of IPV (the actions or acts associated with IPV) and does not rely on the respondent to interpret terminology associated with IPV. It also does not measure the impact of IPV (e.g. does the respondent feel in control of his or her own life). With growing national attention on intimate partner violence in the media, in politics (e.g. passage and maintenance of the Violence Against Women Act of 1994), and by national and international leaders, explaining intimate partner violence and its public health impact is not overly complex.

**References**


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Life Course Indicator: Obesity

The Life Course Metrics Project

As MCH programs begin to develop new programming guided by a life course framework, measures are needed to determine the success of their approaches. In response to the need for standardized metrics for the life course approach, AMCHP launched a project designed to identify and promote a set of indicators that can be used to measure progress using the life course approach to improve maternal and child health. This project was funded with support from the W.K. Kellogg Foundation.

Using an RFA process, AMCHP selected seven state teams, Florida, Iowa, Louisiana, Massachusetts, Michigan, Nebraska and North Carolina, to propose, screen, select and develop potential life course indicators across four domains: Capacity, Outcomes, Services, and Risk. The first round of indicators, proposed both by the teams and members of the public included 413 indicators for consideration. The teams distilled the 413 proposed indicators down to 104 indicators that were written up according to three data and five life course criteria for final selection.

In June of 2013, state teams selected 59 indicators for the final set. The indicators were put out for public comment in July 2013, and the final set was released in the Fall of 2013.

Basic Indicator Information

Name of indicator: Obesity (LC-32 A/B)

Brief description: Percent of children and percent of adults who are currently overweight or obese

Indicator category: Family Well-being

Indicator domain: Risk/Outcome

Numerator:

a. Number of children 10-17 who are currently overweight or obese, based on Body Mass Index for age (BMI-for-age): overweight OR obese (85th percentile or above)
b. Number of adults who are currently overweight or obese based on Body Mass Index (BMI): overweight OR obese (with a BMI of 25 or above)

Denominator:

a. Total number of children 10-17 with height and weight data
b. Total number of adults with height and weight data

Potential modifiers: Age, race/ethnicity, gender, education level, income level

Data source:

a. For children: National Survey of Children’s Health (NSCH)
b. For adults: Behavioral Risk Factor Surveillance System (BRFSS)

Notes on calculation: The concept of obesity was considered to be important for tracking across the life span. To operationalize this, the indicator proposed is actually broken into separate indicators by age because different age groups are assessed using different data sources. These are NOT intended to be summed, averaged, or combined in any other way. They should be treated as separate indicators.

BMI for age is pre-calculated by the National Survey of Children’s Health and is available as a four-category variable called BMICLASS.
in the 2011/2012 dataset. Categories three and four can be combined to obtain the percent of children 10-17 in the 85th percentile or above. BMI for adults pre-calculated by the Behavioral Risk Factor Surveillance System and is available both as a four-category variable and binary variable (SAS variable names_BMI5CAT and _RFBMI5) for the 2012 dataset. Analysts who use the raw datasets should apply the appropriate survey weights to generate the final estimates.

Similar measures in other indicator sets:

a. HP 2020 Focus area NWS-10; CDC Winnable Battle (Reduce the proportion of children and adolescents age 2-19 who are obese by 5 percent); Title V Performance Measure #14; Chronic Disease Indicator
b. Preconception Health Indicator F-2; HP 2020 Focus area NWS-9 (Leading Health Indicator); Title V Performance Measure #14; Chronic Disease Indicators; United Health Rankings Core Measure

Life Course Criteria

Introduction
Over the past 30 years, obesity prevalence has more than doubled among children and adults and tripled among adolescents. The alarming rates of obesity cause concern because of the associated health consequences. Obesity increases the risk of many chronic diseases and conditions including diabetes, heart disease, hypertension, depression, stroke, arthritis, and some cancers. Overweight children are likely to become overweight or obese adults. A range of complex economic, environmental, social and cultural factors all have a part to play in the rise of obesity as a health problem, and the differential exposure to these factors by different populations has contributed to disparities in overweight and obesity by socioeconomic status, racial/ethnic origins, geographic location, gender and having a physical or mental disability.

Obesity in childhood, particularly in adolescence, is a key predictor for obesity in adulthood. Whitaker et al. found that the risk of adult obesity was greater in both obese and non-obese children if at least one parent was overweight. This effect was most pronounced in children that were <10 years old; over the age of 10 years, the child’s own overweight/obesity status was a better predictor than having an obese parent. Improvements in this indicator have significant potential to improve health throughout the life course, as well as potential to improve associated health conditions and quality of life. Recently documented improvements in childhood obesity among two to five year olds indicate that as a nation we are beginning to move in the right direction with addressing obesity. To have an impact over the long term, these improvements will need to be expanded, accelerated, and sustained.

Implications for equity
A range of complex economic, environmental, social and cultural factors all have a part to play in the rise of obesity as a health problem. These factors have implications for health equity in terms of disparities in obesity prevalence by socioeconomic status, racial/ethnic origins, geographic location, gender and having a physical or mental disability. Obesity is also associated with inequities in unemployment, poverty and well-being of adults and children. Psychosocial and psychological influences are also tied to increased risk for obesity and can often be influenced by environmental stressors or conditions.

Considerable evidence suggests that people with low socioeconomic status (SES) are at greater risk of becoming overweight and obese than people with high SES. SES measures (parental education, occupation, income, marital status, single-parent); home-related factors (parental divorce, parental support in education); school-related factors (learning experience, delinquency, early menarche), and health behavior factors (tobacco use, alcohol consumption, physical inactivity, and screen time) may all contribute to disparities in obesity, which translate to health and social inequities. Further, access to safe places to play, sidewalks allowing safe routes to school, and other factors comprising a healthy “built environment” are associated with the socioeconomic status of the census block group in which a person lives, which is in turn associated with physical activity and prevalence of overweight and obesity. Multiple adverse circumstances experienced from adolescence to young adulthood in the context of their family and environment have a cumulative impact on risk for obesity.
Underlying pathways to social inequity in overweight differ between men and women.\textsuperscript{9} Between the NHANES I and NHANES III surveys (a period of 20 years) prevalence for overweight and obesity in young girls increased more than twofold, whereas that of boys increased less (approximately 25 percent). However, in children older than six years of age, and particularly in adolescence, there has been an approximate doubling of obesity prevalence in boys as well as in girls in the United States in the same time. Racial and ethnic differences also are apparent. For boys and girls, overweight is highest in Mexican American children, intermediate among non-Hispanic black children, and lowest in non-Hispanic white children. In examining what can be defined as the overweight group in childhood (i.e., above the 85th percentile cutoff), nearly 22 percent of pre-school children in the United States can be defined as overweight and 10 percent as obese.\textsuperscript{10,11,12,13}

Emerging data suggest associations between the influence of maternal and fetal factors during intrauterine growth and growth during the first year of life on risk of later development of adult obesity and its comorbidities. In addition, recent data suggest that varying biological responses in different racial/ethnic groups differently contribute to overweight, obesity, and their comorbidities, placing some children at greater risk – African-American, Latino, Native American, Asian American and Pacific Islander children living in low-income communities.\textsuperscript{14,15,16,17}

Additionally, children and adults that have a physical disability that limits mobility, or an intellectual or learning disability are at an increased risk of obesity.\textsuperscript{18,19} For example, 20 percent of children ages 10 through 17 years who have special health care needs are obese compared with 15 percent of children the same ages without special health care needs.\textsuperscript{20}

Recent research shows that children and adults living in rural communities may also have an increased risk for obesity and require focused prevention efforts as well. Research published in Obesity and The Journal of Rural Health reinforces that children living in rural areas should be recognized as a high-risk population for childhood obesity, who warrant additional attention and assistance. According to the studies, 16.5 percent of rural children and 20.4 percent of rural adults are obese, compared with 14.4 percent of urban children and 17.8 percent of urban adults.\textsuperscript{21,22} The studies also show that in addition to being at increased risk for obesity and overweight, rural children also are at increased risk of poverty, are less likely to have health insurance, are less likely to have accessed preventive care in the past year, and have lower levels of physical activity. Overall, children living in rural areas are about 25 percent more likely to be overweight or obese than children living in metropolitan areas.\textsuperscript{23,24} This represents a change from the past when children from metropolitan areas were at greater risk for being overweight than rural children.

A person’s risk of developing obesity is often heavily influenced by psychological factors. Boredom, depression, anxiety, stress, trauma (whether as an adult or child), and feelings of low self-esteem are examples of psychological factors that could result in an individual’s overeating and under-exercising. Identifying the psychological problems can help an individual greatly in his or her understanding of the basis of overeating. Psychosocial factors associated with the incidence of obesity in ethnic minorities include inadequate social support, cultural barriers to communication, racism and discrimination, stress and lack of knowledge. Psychological factors also influence eating habits and obesity. Many people eat in response to negative emotions such as boredom, sadness, or anger.\textsuperscript{25,26}

**Public health impact**

Obesity is a public health problem as it is a risk factor for several chronic diseases and can lead to higher rates of morbidity. According to the NCHS, 66 percent of adults age 20 years and over are overweight or obese.\textsuperscript{27} Despite moderate declines among two to five year olds, over the past 30 years, obesity prevalence has more than doubled among children and adults and tripled among adolescents.\textsuperscript{28,29} The alarming rates of obesity cause concern because of the associated health consequences. Obesity increases the risk of many chronic diseases and conditions including diabetes, heart disease, hypertension, depression, stroke, arthritis, and some cancers.\textsuperscript{30} Overweight children are likely to become overweight or obese adults.\textsuperscript{31,32,33} Further, experts posit that obesity is beginning to have an impact on life expectancy; if the trends in obesity continue unchecked, the increases in fatal and non-fatal chronic conditions could impact life expectancy such that children may live shorter and unhealthier lives then their parents.\textsuperscript{34}

The economic costs of obesity are staggering. The total cost of obesity and physical inactivity in 2000 was estimated to be $117 billion. The treatment of obesity related conditions has been linked to a 36 percent increase in health care spending.\textsuperscript{35} The proportion of pediatric hospital discharges with obesity-related diagnoses has increased dramatically in the past 20 years. Wang and Dietz analyzed the economic burden of obesity in youths six to 17 years of age and found
that obesity-related annual hospital costs (based on 2002 constant dollar value) increased more than three-fold over the
two decades between 1979-81 and 1997-99; from $35 million to $127 million. During that period, discharges of obesity-
related diabetes nearly doubled (1.43 to 2.36 percent); obesity-related gallbladder disease tripled (0.36 to 1.06 percent);
and obesity-related sleep apnea increased five-fold (0.14 to 0.75 percent). Asthma and certain mental disorders were the
most common primary diagnoses when obesity was listed as the secondary diagnosis. Thus, the increasing prevalence
and severity of obesity among children and adolescents has resulted in significant economic costs. 36

Recent studies have documented the impact that obesity has on annual medical expenditures among adults. Sturm found
that obese adults (18 to 65 years of age) have 36 percent higher average annual medical expenditures compared with
those of normal weight. 37 Finkelstein et al. found that aggregate obesity-attributable medical expenditures account for 5.3
percent of adult medical expenditures in the United States and that roughly 50 percent of these expenditures are financed
by Medicare and Medicaid. 38

Leverage or realign resources
With the strong evidence that a life course perspective is important in obesity development and its consequences,
consideration must be focused on preventing obesity in women of child-bearing age, preventing excessive weight gain
during pregnancy, and encouraging breastfeeding in infants. Family behavior patterns, diet after weaning, adequate
physical activity and the use of new methods of information dissemination can help reduce the impact of childhood obesity
worldwide. 39,40 Public health programs can work with providers and other community organizations that provide care and
services to pregnant women to include messaging and resources around healthy weight.

Other potential approaches to fighting the obesity epidemic beginning in childhood include leveraging and readjusting
resources to ensure that children, particularly those who are disadvantaged, have access to and benefit from a
comprehensive, effective, community-based health and mental health care system. It will be necessary to work with non-
health partners to integrate childhood obesity priorities with initiatives such as environmental design and sustainability,
food systems, food marketing, disabilities, or economics. 41 Strategies such as those implemented by the New York City
local government, including requirements to post nutrition information on menus, the banning of trans fats, and limiting the
size of single serving beverage cups, are all regulatory policy changes that aim to make the healthy choices easier;
whether or not these strategies will ultimately influence personal choice and impact health outcomes remains to be seen,
but early studies show that consumer awareness of nutrition has increased since labeling requirements went into effect. 42

A key aspect of capacity building involves establishing collaborative relationships with partners from state and local
governments and the private sector. It is crucial for the maternal and child health (MCH) programs and other key partners
at the state and local level (e.g., department of transportation, parks and recreation, local health departments) to build
numerous partnerships with health care organizations (e.g. the American Academy of Family Physicians), volunteer
agencies (e.g., the YMCA, the American Heart Association), universities, organizations that address health disparities
(e.g., the Indian Health Service), private companies (e.g., sporting goods companies), and other types of organizations
(e.g., the National Guard). 43 The potential partners that can improve the health of the community is not limited to those
listed above; schools, planning commissions, restaurants, and farmers are all stakeholders in this effort. Through
partnerships and collaborations, organizations can align efforts, policies and resources to promote healthy behaviors, and
ensure communities have access to healthy foods and environments that promote physical activity and healthy lifestyles.

Predict an individual’s health and wellness and/or that of their offspring
Overweight and obesity are independent risk factors for increased morbidity and mortality throughout the lifecycle. For
example, overweight and obesity in women are predictors of gestational diabetes during pregnancy and newborns with
excessive birth weight. High birth weight is a predictor of overweight and obesity in adulthood and in cofactors associated
with insulin resistance. 44,45,46,47 Overweight and obese individuals are more likely to develop conditions such as
hypertension, diabetes, some cancers, sleep apnea and stroke.

Data from a number of studies provide strong evidence that higher levels of BMI during childhood can predict overweight
later in life. This was recently summarized in a review by Goran. 48 Data from four longitudinal studies were reviewed and
showed that the probability of overweight at 35 years of age for children with BMI in the 85th to 95th percentiles increased
with increasing age. The prediction for adult weight was most accurate for BMI at 18 years of age with accuracy
decreasing for BMI below 13 years of age. Goran concluded that the "persistence of pediatric obesity into adulthood increases according to the age at which obesity is initially present.\textsuperscript{49}

Maternal obesity during pregnancy carries an increased risk of birth defects, including neural tube defects, orofacial clefts, and congenital heart defects (CHDs).\textsuperscript{50,51} As maternal obesity becomes more common, the potential for children to be born with CHDs is anticipated to increase; CHDs and other birth defects contribute significantly to infant morbidity and mortality, adding to the overall health consequences of obesity.\textsuperscript{52}

Comorbidities associated with obesity and overweight are similar in children as in the adult population. Elevated blood pressure, dyslipidemia, and a higher prevalence of factors associated with insulin resistance and type 2 diabetes appear as frequent comorbidities in the overweight and obese pediatric population; the obesity-dependence of type 2 diabetes has led to the use of the term "diabesity" to describe the co-morbidity.\textsuperscript{53} In some populations, type 2 diabetes is now the dominant form of diabetes in children and adolescents.\textsuperscript{14,54} Thus, being overweight during childhood brings comorbidities that will increase the duration of comorbidities in an individual by one to two decades, a factor that can increase the impact of a number of risk factors on adult diseases and overall health.\textsuperscript{50,61} Obese children and adolescents also have a greater risk of social and psychological problems, such as discrimination and poor self-esteem, which can continue into adulthood.\textsuperscript{55}

Data Criteria

Data availability
Data tracking population obesity measures are compiled and collected from multiple data sources. To capture the child and adult populations two surveys must be used; one for children under 17 years of age, and one for adults 18+ years of age.

Childhood/Adolescent Obesity Data
The National Survey of Children’s Health (NSCH), sponsored by the Maternal and Child Health Bureau (MCHB) of the Health Resources and Services Administration, examines the physical and emotional health of children ages zero to 17 years of age. The survey is administered using the State and Local Area Integrated Telephone Survey (SLAITS) methodology, and it is sampled and conducted in such a way that state-level estimates can be obtained for the 50 states, the District of Columbia, and the Virgin Islands. The survey has been designed to emphasize factors that may relate to the well-being of children, including medical homes, family interactions, parental health, school and after-school experiences, and safe neighborhoods. The MCHB leads the development of the NSCH and NS-CSHCN survey and indicators, in collaboration with the National Center for Health Statistics (NCHS) and a national technical expert panel. The expert panel includes representatives from other federal agencies, state Title V leaders, family organizations, child health researchers, and experts in all fields related to the surveys (adolescent health, family and neighborhoods, early childhood and development etc.). The most recent data set, the 2011-2012 NSCH, encompasses a sample size of more than 95,000 children with approximately 1,800 interviews completed in each of the 50 states and the District of Columbia.

MCH programs can readily gain immediate access to the data through datasets released by the NCHS, and on the MCHB sponsored Data Resource Center for Child and Adolescent Health Website (www.childhealthdata.org). Data from the 2011/2012 NSCH were made available in early 2013. The survey questionnaire and raw dataset are available for download on the CDC’s NCHS website in SAS format. The Data Resource Center (DRC) website provides data nationwide, for all 50 states and the District of Columbia. Additionally, both the raw datasets and the website allow users to stratify measures by sociodemographic groups, including but not limited to age, sex, race/ethnicity, primary household language, household income, and special health care needs. Cleaned, state-specific datasets with new variables that include national and state indicators are available at no cost in SAS and SPSS formats. For information on how to order state-specific sets, contact cahmi@ohsu.edu. Local data is not searchable. The NSCH is not administered annually. Over the past decade, the NSCH has been administered four times.

In the NSCH, BMI-for-age is based on parents' recollection of the selected child's height and weight. Data are available for children age 10-17 years only and are grouped into three categories: Underweight (less than 5th percentile); healthy weight (5th to 84th percentile); overweight OR obese (85th percentile or above).
In children and teens, body mass index percentile is used to assess underweight, overweight, and obesity. Children's body fat composition and volume change over the years as they grow. Also, girls and boys differ in their body fat composition and volume as they mature. This is why BMI for children, also referred to as BMI-for-age, is gender- and age-specific. For more information, including how BMI-for-age is calculated for children and teens, go to: www.cdc.gov/healthyweight/assessing/bmi/childrens_bmi/about_childrens_bmi.html.

Adult Obesity Data
The Behavioral Risk Factor Surveillance System (BRFSS) is the world's largest, on-going telephone health survey system, tracking health conditions and risk behaviors in the United States yearly since 1984. Currently, data are collected monthly in all 50 states, the District of Columbia, Puerto Rico, the U.S. Virgin Islands, and Guam. The Centers for Disease Control and Prevention (CDC) provides state and national level prevalence data on their web site.

The CDC develops approximately 80 BRFSS questions each year. Some of these are core questions asked each year, and some are rotating core questions asked every other year. There are also CDC supported modules that address specific topics that states can use on an optional basis. States can also develop additional questions to supplement the core questions.

Due to changes in the weighting methodology and the addition of the cell phone sampling frame, the BRFSS 2011 data should be considered a baseline year for data analysis and is not directly comparable to previous years of BRFSS data. This indicator is calculated from self-reported weight and heights from survey respondents. BMI is computed as weight in kilograms divided by height in meters squared (kg/m$^2$). BMI is an intermediate variable used in defining overweight and obesity. BMI categories for adults are: Underweight=BMI less than 18.5, Recommended Range=BMI 18.5 to 24.9, Overweight=BMI 25.0 to 29.9 and Obese=BMI 30 or greater. Respondents who answer that they do not know their height and weight or refuse to answer these questions are not included in the analysis.

Data quality

Childhood/Adolescent Obesity Data
The main limitation of the NSCH is that the information provided is from parent recollection of screenings received and perception of child's health and development over the past year. The survey methodology does not provide an opportunity for confirmation with medical records or physical measurements. Although literature regarding parental reporting as a proxy measure is contradictory, research supports the use of parents as proxy measures when obtaining child health information.

The NSCH is weighted to represent the national population of non-institutionalized children age 0-17 years. According to the survey documentation, missing data for income were relatively high for 2011-2012 data, and a study of nonresponse patterns indicated that excluding records with missing income could impact the representativeness of the remaining data; therefore, a data file with imputed values for income is provided to be used with the datasets.

The NSCH documentation presents both response rates and completion rates. For 2011-2012 data, the combined national response rate for both landline and cell phone samples was 23 percent. The completion rate, which is calculated as the proportion of households known to include children that completed all sections up to and including Section 6 (for children less than 6 years of age) or Section 7 (for children 6 to 17 years of age), was 54.1 percent for the landline sample and 41.2 percent for the cell-phone sample.

Qualitative testing of the entire 2007 NSCH was conducted by the National Center for Health Statistics. They conducted cognitive interviews with the 2007 NSCH Computer-Assisted Telephone Interview (CATI) to make sure the entire survey instrument was functioning properly. N=640 interviews were completed over three days in December 2006. The questionnaire was then revised and finalized based on feedback from participants in these interviews.

Previously validated questions and scales are used when available. All aspects of the survey are subjected to extensive literature and expert review. Respondents’ cognitive understanding of the survey questions is assessed during the pretest phase and revisions made as required. All final data components are verified by NCHS and DRC/CAHMI staff prior to public release. Face validity is conducted in comparing results with prior years of the survey and/or results from other implementations of items.
NSCH survey collects data on childhood obesity, including state reports of childhood obesity. The sample sizes are sufficient for state-level analyses in every state. Responses to questions K2Q02 (child’s height) and K2Q03 (child’s weight) from NSCH were not independently verified (e.g., measurement, health records, etc.). A study comparing parent-reported height and weight estimates from the 2003 NSCH with results of physical measurement from the National Health and Nutrition Examination Survey revealed that parents typically overestimate height and underestimate weight of children younger than 10 years of age. Therefore, BMI for children under 10 years of age are not reported or included as part of this indicator. Additionally, calculation of BMI-for-age is usually based on the age of the child in months. Because age was only reported in years for this survey, children were assumed to be at the midpoint of the age-year for purposes of calculating BMI-for-age.

Items K2Q02 and K2Q03 and calculation of BMI-for-age were not changed since 2003. However, changes in CDC’s labeling of the 2 highest BMI-for-age categories are reflected in DRC label changes for the 2007 NSCH. The 85th to 94th percentile range was changed from "At risk of overweight" to "Overweight." The 95th and higher percentile range was changed from "Overweight" to "Obese."^59

**Adult Obesity Data**

Numerous studies have compared estimates of chronic conditions and behaviors obtained from BRFSS to other national surveys including the National Health Interview Survey and the National Health and Nutrition Examination Survey; while there are some differences, findings on overall health status and certain chronic conditions tended to be similar despite declining response rates for BRFSS.

Since some questions on the BRFSS address sensitive health conditions and behaviors, there is intermittent missing data throughout the dataset. However, refusal to answer generally accounts for a small proportion of responses for most data elements. The notable exception is income, where refusals accounted for more than 23 percent of the data in one state in 2010; the median percent missing across BRFSS for income in 2010 was 14 percent.

Quality control computer programs are used to check the raw data for values out of range. CDC performs quality checks for core questions, and each state has its own protocol for checking state-specific questions. Interviewers are monitored during the annual questionnaire pilot period and intermittently during the data collection period to determine whether any interviewer bias exists and to correct any bias that might be found. On an ongoing basis, 10 percent of interview calls are verified.

Prior to 2011, the sampling for BRFSS represented only adults living in a private residence with a landline telephone, but starting in 2011, the sample also included data from respondents living in cell phone-only households. In 2012, the BRFSS sample expanded to include adults who live in college housing. Weighted response rates are presented by state. For 2011, the median weighted response rate for the combined cell phone and landline was 49.72 percent.

The survey adjusts for non-response to reduce the known differences between respondents and non-respondents. Although participants interviewed may not represent a state in terms of age, sex and race distribution, it is believed that weighting the data corrects for this potential bias. As with other health surveys, estimates are based on self-report data and they may over- or underestimate the actual prevalence of a particular risk factor in the population. Despite some oversampling in states by geography, the annual sample size is too small to compute precise estimates at the county level. The child prevalence data are reliant on proxy report from the adult respondent to the BRFSS and may be subject to misclassification related to this method.

The majority of BRFSS health indicators are at least moderately reliable and valid, with many being of high reliability and validity. The BMI measures used for this indicator were found to be of high reliability and validity.^60

Estimates of overweight and obesity obtained from the BRFSS are based on sound methods for conducting surveys and performing statistical analyses; however, respondents tend to overestimate their height and underestimate their weight leading to underestimation of BMI and the prevalence of obesity.

**Simplicity of indicator**

BMI is calculated using weight in kilograms divided by height in meters squared. It is a measure to determine overweight and obesity. BMI does not measure body fat directly, but it is a reasonable indicator of body fat composition and volume...
for most children and teens. A child’s weight status is determined using an age- and sex-specific percentile for BMI rather than the BMI categories used for adults because children’s body composition varies as they age and varies between boys and girls.

CDC Growth Charts are used to determine the corresponding BMI-for-age and sex percentile. For children and adolescents (aged two to 19 years):

- Overweight is defined as a BMI at or above the 85th percentile and lower than the 95th percentile for children of the same age and sex
- Obesity is defined as a BMI at or above the 95th percentile for children of the same age and sex

Despite this moderate complexity explaining how BMI is calculated in children, the data required for calculation of the indicator from the NSCH are not difficult to obtain, nor is the indicator difficult to calculate.

For adults, overweight and obesity ranges are determined by using weight and height to calculate a number called the “body mass index” (BMI). BMI is used because, for most people, it correlates with their amount of body fat.

- An adult who has a BMI between 25 and 29.9 is considered overweight
- An adult who has a BMI of 30 or higher is considered obese

Data required for calculation of the indicator for adults from the BRFSS are not difficult to obtain, nor is the indicator difficult to calculate.

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Life Course Indicator: Obesity (LC-32 A/B)
Life Course Indicator: Physical Activity Among High School Students

The Life Course Metrics Project

As MCH programs begin to develop new programming guided by a life course framework, measures are needed to determine the success of their approaches. In response to the need for standardized metrics for the life course approach, AMCHP launched a project designed to identify and promote a set of indicators that can be used to measure progress using the life course approach to improve maternal and child health. This project was funded with support from the W.K. Kellogg Foundation.

Using an RFA process, AMCHP selected seven state teams, Florida, Iowa, Louisiana, Massachusetts, Michigan, Nebraska and North Carolina, to propose, screen, select and develop potential life course indicators across four domains: Capacity, Outcomes, Services, and Risk. The first round of indicators, proposed both by the teams and members of the public included 413 indicators for consideration. The teams distilled the 413 proposed indicators down to 104 indicators that were written up according to three data and five life course criteria for final selection.

In June of 2013, state teams selected 59 indicators for the final set. The indicators were put out for public comment in July 2013, and the final set was released in the Fall of 2013.

Basic Indicator Information

Name of indicator: Physical Activity Among High School Students (LC-33)

Brief description: Proportion of high school students who are physically active for at least 60 minutes per day on five or more of the past seven days.

Indicator category: Family Well-being

Indicator domain: Risk/Outcome

Numerator: Number of high school students who report being active for at least 60 minutes per day on five or more of the past seven days.

Denominator: All high school students

Potential modifiers: race, Hispanic ethnicity, gender, high school grade (9-12), state, urban school district

Data source: Youth Risk Behavior Surveillance System (YRBSS)

Notes on calculation: Analysts who use the raw datasets should apply the appropriate survey weights to generate the final estimates.

Similar measures in other indicator sets: HP 2020 Focus area PA-3; NQF measure 1348; Chronic Disease Indicator
Life Course Criteria

Introduction
The Centers for Disease Control and Prevention (CDC) recommends children and adolescents should participate in 60 minutes or more of physical activity each day. Most of this activity should come in the form of moderate- or vigorous-intensity aerobic activity, which is defined as activity that increases heart rate and makes you breathe hard for some of the time. Moderate physical activity is activity such as brisk walking, while vigorous physical activity is an activity that involves mostly running. Two other types of physical activity include muscle strengthening (gymnastics, pushups, sit-ups, etc.) and bone strengthening (jumping, hopping, jump roping). The majority of adults and adolescents in the United States do not achieve CDC recommended activity levels. According to YRBSS, only 49.5 percent of high school students reach recommended physical activity levels nationally and these percentages drop for racial/ethnic minorities as well as females. Intervention is needed to improve this indicator overall and within specific populations in order to improve health and equity.

Regular physical activity decreases the risk of the leading causes of morbidity and mortality in the United States including high blood pressure, heart disease, diabetes, obesity, and certain types of cancer. An active lifestyle during early childhood and youth increases the chances that an individual will remain active in adulthood, making intervention in youth particularly important. Physical activity has the ability to improve intergenerational health as well as individual health. Healthy weight prior to pregnancy can improve birth outcomes and lowers risk for maternal morbidity and mortality. Regular physical activity throughout pregnancy can help women control their weight, make labor more comfortable, and reduce their risk of pregnancy complications and postpartum depression. In addition, parents that maintain a healthy weight by modeling a healthy lifestyle are setting good examples for their children to follow to maintain better health outcomes as adults.

Implications for equity
National data from the 2011 YRBSS shows Black, Asian, and Hispanic high school students are less likely to achieve at least 60 minutes of physical activity on five or more days of the last week compared to White high school students. Children of low socioeconomic status (SES) also achieve fewer minutes per day of moderate to vigorous physical activity than high SES children. Racial/ethnic minority and low SES youth living in urban, low-resource communities have barriers to adequate physical activity in school and outside of school. Access to school sports facilities and equipment storage space increase recreational opportunities among youth, which is associated with increased levels of physical activity. Low-income schools suffer from limitations in providing these and other resources, which is likely a contributor to the inverse relationship that has been observed between a school’s median household income and average body mass index. Outside of school, low SES, urban neighborhoods may lack infrastructure necessary for activity such as sidewalks, or may not be safe enough for outdoor activity. A study examining data from the National Longitudinal Study of Adolescent Health found low SES adolescents were more likely to live in an area without a physical activity or recreation facility and these adolescents were at a greater risk for not achieving adequate moderate to vigorous physical activity levels. Even when there are recreation facilities available in low-income communities, the quality of those facilities is typically not on par with facilities in high-income communities.

Disparities in attaining recommended physical activity levels also exist by gender. Girls are less active than boys at all ages, and many females experience a transition away from sport and physical activity in early adolescence that leads to a sedentary lifestyle in later adolescence. Nationally, only 38.5 percent of female high school students achieve 60 minutes of physical activity on five or more days per week compared with 59.9 percent of high school males. Racial/ethnic minority females fare even worse with only 31.9 percent of Black, 33 percent of Hispanic, and 24.7 percent of Asian high school females reaching recommended activity levels. Limited involvement in physical activity by high school age females may be due to social constraints. Girls in a study by Youngbult, Schinke, and McGannon (2011) listed numerous social reasons such as judgment for not being good enough, not having other active friends, or lack of peer support in sports as reasons for limited participation in physical activity.

Public health impact
Physical inactivity is a contributing factor to some of the most prevalent and costly public health issues in the U.S. Sedentary lifestyle is highly correlated with overweight and obesity, which are risk factors for heart disease, stroke, type II diabetes and certain types of cancer. Health care and lost productivity costs associated with obesity are $147 billion
annually in the United States and are expected to increase by $48 billion annually by 2030.\textsuperscript{17} Much of these costs fall on government funded health care as estimates for the percentage of health care costs that are financed through Medicaid and Medicare are as high as 50 percent.\textsuperscript{18} Economic models show if just 10 percent of U.S. adults began a regular walking program, approximately $5.6 billion in heart disease costs could be eliminated, yet, 56 percent of adults report they do not engage in any vigorous activity at all.\textsuperscript{19}

Randomized control trials have found increasing physical activity results in weight loss and decreases in body fat composition, indicating increasing physical activity is an effective intervention against obesity.\textsuperscript{16} Adequate physical activity also has a role in chronic disease prevention that is independent from overweight or obesity. Research suggests inactivity and low cardiorespiratory fitness are independently equal predictors of mortality as overweight and obesity.\textsuperscript{16} Developing physically active habits in youth is critical to successfully achieving a rise in physical activity among the U.S. population as tracking physical activity levels has shown moderate to high stability throughout life periods.\textsuperscript{7}

In addition to affecting important physical health outcomes in both adolescence and adulthood, increasing physical activity in youth could help to achieve improved academic outcomes.\textsuperscript{20} Studies have found positive associations between school-based physical education, recess, classroom physical activity, and extracurricular physical activity with academic performance indicators such as grades and standardized test scores as well as improved cognitive skills and attitudes.\textsuperscript{20}

**Leverage or realign resources**
The health care sector currently has emerging opportunities for engagement in increasing physical activity for high school students through prevention provisions in the Affordable Care Act (ACA). Children under the age of 21 are eligible for preventive and comprehensive health services under the Medicaid Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) benefit.\textsuperscript{21} The screening component of EPSDT entitles children to periodic physical examinations as well as health education, which enables discussions surrounding health concerns between children, their parents, and a health care provider. These discussions present an opportunity for health care providers and parents to discuss increasing physical activity in children who are not meeting recommended levels. Additionally, section 4108 of the ACA authorizes grants to states to provide initiatives or programs to Medicaid enrollees to accomplish a number of chronic disease prevention goals that are related to physical inactivity including lowering blood pressure, avoiding the onset of diabetes, and controlling or reducing weight.\textsuperscript{21} These initiatives may be geared toward youth as Medicaid beneficiaries of all ages are eligible to be the target of these programs.

The education sector is an equally important partner in improving the high school students' physical activity indicator. More than 49.8 million students can be impacted by working with public schools, and 14.9 million of these are in grades nine through 12.\textsuperscript{22} Schools have an added stake in the issue of students' sedentary lifestyle as educational outcomes have been tied to physical activity in a number of studies.\textsuperscript{20} Physical education (PE), recess activity plans, improved recess space design, and classroom activity breaks have all produced increases in the amount of moderate to vigorous physical activity in students, with classroom activity breaks also yielding improvements in students’ on-task behavior.\textsuperscript{22} Quality PE is key in developing activity patterns throughout the life course and schools need proper resources, trained PE staff, and time to achieve national and state standards. The following six content standards for PE are listed by the National Association of Sport and Physical Education (NASPE):

1. Demonstrates competency in motor skills and movement patterns needed to perform a variety of physical activities
2. Demonstrates understanding of movement concepts, principles, strategies, and tactics as they apply to the learning and performance of physical activities
3. Participates regularly in physical activity
4. Achieves and maintains a health-enhancing level of physical fitness
5. Exhibits responsible personal and social behavior that respects self and others in physical activity settings
6. Values physical activity for health, enjoyment, challenge, self-expression\textsuperscript{23}
Low budgets for school PE programs have become commonplace in the U.S. In 2010, the NASPE conducted the Physical Education Trends in Our Nation’s Schools: A Survey of Practicing K-12 Physical Education Teachers and found the median PE budget for schools in the U.S. is only $764 per school year. Schools often reduce PE programs in order to increase classroom time, assuming that this will improve academic performance measures, however, the data on physical fitness, physical activity, PE, and academic performance measures indicate this may be counterproductive. Studies in California and Texas have shown positive relationships between physical fitness and standardized test scores. Research and analysis by the CDC found only positive correlations or no correlations between PE, recess, classroom physical activity, and extracurricular physical activity with academic achievement measures. The Alliance for a Healthier Generation’s Healthy School Program provides a framework for promoting healthier school environments through best practices related to physical activity, healthy eating, and wellness. Schools can enroll in the program at no cost and gain access to customized action plans and other online resources. Funding for implementing PE and health programs identified through the Healthy School Program can be found through the SPARK Grant-Finder Tool, which locates grants for PE and health-related programs. In South Carolina, the Healthy Schools Program provides tools and resources for physical activity and health education at 330 schools to over 160,000 students and is funded completely through a grant from the Robert Wood Johnson Foundation. In Florida, improvements have been made in time spent in physical and health education through the Healthy Schools Program with funding from multiple organizations and grants. Another resource for improving PE in schools is the Presidential Youth Fitness Program, which provides a model to enhance school PE programs. Funding is currently available for eligible schools to implement the Presidential Youth Fitness Program through the year 2017. The grant covers professional development for physical educators, fitness assessment resources and software, and awards for students who meet fitness standards through the program. Targeted interventions toward young females may be necessary to create equally healthy physical activity patterns among males and females. The Trial of Activity for Adolescent Girls (TAAG) was a large national study on increasing physical activity opportunities for girls and was conducted in 36 middle schools in conjunction with local universities. The TAAG intervention provided physical education, health education with physical activity homework challenges, partnerships between universities, communities, and schools to promote physical activity, and social marketing promoting an active lifestyle. Results of evaluation of TAAG indicated an increase in physical activity programs for girls at participating schools, increased collaborations with community agencies to promote physical activity in girls, and that as girls’ enjoyment of physical activity levels increased so did their perceived benefits of physical activity and self-efficacy for physical activity outside of school. Access to recreation facilities and community physical activity programming is positively associated with physical activity in young people. Low-income groups typically have less access to community physical activity programming and quality, safe parks. Efforts to increase community physical activity programming and the quality of recreation facilities, such as parks and community centers, in low-income neighborhoods may increase physical activity levels in the youth of these communities. The President’s Challenge is an online resource that can be used by families and communities to boost physical activity levels. The program was originally designed for youth but now has resources, activity tools, and award recognition for people of all ages. The goal of the President’s Challenge is to help “people of all ages and abilities increase their physical activity and improve their fitness through research-based information, easy-to-use tools, and friendly motivation.” The challenge website (www.presidentschallenge.org) provides free resources such as youth fitness programs, fitness challenges, activity trackers, and recognition for reaching fitness milestones. Since the conception of the President’s Challenge, over 50 million youth have been recognized for reaching fitness achievements with the help of the program.

**Predict an individual’s health and wellness and/or that of their offspring**

Physical inactivity has been identified by the World Health Organization as the fourth leading risk factor for global mortality. People who do not engage in at least 30 minutes of moderate intensity physical activity are at a 20 to 30 percent increased risk of death than people who do achieve this level of activity. Research has shown that physical activity levels impact an individual’s risk for overweight/obesity, cardiovascular disease, type II diabetes, certain cancers, and many other health conditions. Regular physical activity helps maintain health through improved muscular and cardio-respiratory fitness, improved bone and functional health, reduction in risk of chronic disease, and a reduction in risk of falls and fractures. Increased physical activity has been shown to improve patients’ quality of life and nutrition, reduce inflammation and depression, and decrease treatment costs and the need for hospitalization.
Studies tracking physical activity from childhood through youth and into adulthood have found rates of physical activity in early life correlate with physical activity rates in adulthood. In order to increase the chances that an individual will remain physically active over the life course and receive the health benefits of physical activity in each life stage, it is crucial to instill activity habits in youth. Increasing activity before a person reaches high school should help them remain active throughout their life course.

**Data Criteria**

**Data availability**
The Youth Risk Behavior Surveillance System (YRBSS) monitors priority health-risk behaviors and the prevalence of obesity and asthma among youth and young adults. The YRBSS includes a national school-based survey conducted by the CDC, state, territorial, and local education and health agencies and tribal governments.

YRBSS monitors six categories of priority health-risk behaviors among youth and young adults, including behaviors that contribute to unintentional injuries and violence; sexual behaviors that contribute to unintended pregnancy and sexually transmitted diseases, including HIV infection; alcohol and other drug use; tobacco use; unhealthy dietary behaviors; and inadequate physical activity. In addition, YRBSS monitors the prevalence of obesity and asthma.

The YRBSS is administered every other year (odd years), generally in the spring semester in schools via a pencil and paper mode. The YRBSS survey contains no skip patterns. In the even-numbered years, CDC leads a process of examining and revising the questionnaire, using both expert opinion and votes from the YRBS coordinators in states. The final result is a standard questionnaire that can be modified by states to meet their needs, but modifications must be within certain parameters: 1) the modified questionnaire must contain at least two-thirds of the original standard questionnaire, 2) questions that are added are limited to eight mutually exclusive response options, 3) the questionnaire may not have skip patterns or fill in the blanks, and 4) the questionnaire may not exceed 99 questions, and the state must retain the height and weight questions. The 2011 YRBSS included a national school-based survey conducted by CDC and 47 state surveys, six territory surveys, two tribal government surveys, and 22 local surveys conducted among students in grades nine through 12 during October 2010-February 2012. Data collected by CDC represent both public and private schools with students in grades nine through 12; data collected by states, territories, tribes, and localities represents primarily public school students.

The relevant survey question for this indicator is: “During the past seven days, on how many days were you physically active for a total of at least 60 minutes per day? (Add up all the time you spend in any kind of physical activity that increases your heart rate and makes you breathe hard some of the time.)” which is a part of the standard questionnaire.

**Data quality**
From the available YRBSS documentation, the 2011 national YRBS school response rate was 81 percent; the student response rate was 87 percent; and the overall response rate was 71 percent. Comparisons between estimates for states and districts from the national data collection effort and the surveys collected by states, territories, tribes, and localities can be found on the CDC YRBSS website. Each jurisdiction reached a minimum site response rate of 60 percent and therefore had weighted data for that year. Weighted data allows a jurisdiction to make statements from the data that generalize to all high school students in that jurisdiction.

Studies by CDC and others indicate that data about risk behaviors can be gathered as credibly from adolescents as from adults. YRBSS performs internal reliability checks to help identify the small percentage of students who falsify their answers. To obtain truthful answers, students must perceive the survey as important and know procedures have been developed to protect their privacy and allow for anonymous participation.

A test-retest study of the 1999 version of the questionnaire found that 47 percent of items had at least “substantial” reliability, with kappa statistics of agreement of 61 percent or greater, and 93 percent of items had at least “moderate” reliability, with kappas of 41 percent or greater. The study found no differences in reliability by gender, grade, or race/ethnicity. The study found that items related to tobacco use, alcohol and other drug use, and sexual behavior had the highest reliability. By comparison, items asking about dietary behaviors, physical activity, and other health-related topics were less reliable. A study of mode and setting using the YRBSS questions determined that students were more likely to report risk behaviors when they took the survey at school compared with taking the survey at home.
Simplicity of indicator

The numerator and denominator are simple to calculate. This indicator is easy to explain and can be understood by all stakeholders.

References


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Life Course Indicator: Cervical Cancer Screening

Basic Indicator Information

Name of indicator: Cervical Cancer Screening (LC-34)

Brief description: The proportion of women who receive the appropriate evidence-based clinical preventive services (pap smear) for cervical cancer screening

Indicator category: Health care access and quality

Indicator domain: Service/Capacity

Numerator: Women ages 21 to 65 who received a pap smear within the last three years

Denominator: Total women ages 21 to 65

Potential modifiers: Age, race/ethnicity, sex, health insurance status

Data source: Behavioral Risk Factor Surveillance System (BRFSS)

Notes on calculation: Percent of females responding "Within past year", "Within past two years" or "Within past three years" to question: How long has it been since you had your last Pap test? Analysts who use the raw datasets should apply the appropriate survey weights to generate the final estimates.

Similar measures in other indicator sets: HP 2020 Focus area C-15; NQF measure 0032; Chronic Disease Indicator

The Life Course Metrics Project

As MCH programs begin to develop new programming guided by a life course framework, measures are needed to determine the success of their approaches. In response to the need for standardized metrics for the life course approach, AMCHP launched a project designed to identify and promote a set of indicators that can be used to measure progress using the life course approach to improve maternal and child health. This project was funded with support from the W.K. Kellogg Foundation.

Using an RFA process, AMCHP selected seven state teams, Florida, Iowa, Louisiana, Massachusetts, Michigan, Nebraska and North Carolina, to propose, screen, select and develop potential life course indicators across four domains: Capacity, Outcomes, Services, and Risk. The first round of indicators, proposed both by the teams and members of the public included 413 indicators for consideration. The teams distilled the 413 proposed indicators down to 104 indicators that were written up according to three data and five life course criteria for final selection.

In June of 2013, state teams selected 59 indicators for the final set. The indicators were put out for public comment in July 2013, and the final set was released in the Fall of 2013.
Life Course Criteria

Introduction
Cervical cancer is a slow growing cancer that is often asymptomatic. It is almost always caused by the Human Papillomavirus (HPV), which is the most common sexually transmitted infection in the United States; more than 70 percent of cervical cancer cases are caused by two strains of HPV, types 16 and 18, which constitute high risk HPV infection. Worldwide, High-risk HPV infection accounts for approximately 5 percent of all cancers (National Cancer Institute 2012). Men and women can protect themselves from HPV through vaccination when given in the recommended age groups.

Cervical cancer also can be detected through regular screening tests known as Papanicolaou tests or pap smears. Pap smears are recommended for all women between the ages of 21 and 65. This evidence-based, clinical preventive service is included in the well-woman exam, and is covered by private insurance, Medicare, Medicaid, and the Patient Protection and Affordable Care Act (ACA). Additionally, persons that do not have health insurance may be able to get a free or low-cost pap smear test through the National Breast and Cervical Cancer Early Detection Program.

While the cancer usually occurs later in life, the combination of the HPV vaccine and regular screening through pap smears, is an effective way to prevent, or increase early detection of cervical cancer, which can lead to successful treatment. Many women around the world, and in the United States, are affected by cervical cancer. In 2012 there were an estimated 12,170 new invasive cervical cancer cases and over 4,200 cancer-related deaths in the United States, making cervical cancer the third most common form of female-related malignancy (del Carmen & Avila-Wallace, 2013). With regular screening tests beginning in early adulthood and follow up, cervical cancer is a gynecological cancer that is easily preventable.

Implications for equity
The United States has seen significant improvements in the incidence and mortality rates due to cervical cancer, yet large disparities still exist between populations groups of women. These disparities exist not only in terms of incidence and mortality rates, but also in terms of screening utilization and prevention (del Carmen, & Avila-Wallace, 2013). African-American women have higher rates of cervical cancer morbidity and mortality compared to their White counterparts (Jemal, Thun, Ries et al, 2008); and Latina women also experience higher incidence compared to non-Hispanic White women (Watson, Saraiya, Benard, et al, 2008). In addition to race and ethnicity, socioeconomic status also has been linked with cervical cancer mortality and late stage diagnosis. It has been suggested that almost three-quarters of the cervical cancer-related deaths that occurred in 2007 might have been avoided through the elimination of socioeconomic disparities. (Simard, Fedewa, Ma, Siegel, & Jemal, 2012).

While poverty and minority racial/ethnic status have been linked to lower rates of pap smear utilization (American Cancer Society, 2011), other factors such as perception of pain and personal experiences of discomfort have also been identified as barriers to screening utilization (Hoyo, Yarnall, Skinner, et al, 2005; Jennings-Dozier, 1999). A literature review found that women who were uninsured, obese, homeless, older, experiencing language barriers, had low education, and who have sex with women, were least likely to utilize pap smear screening (Brankovic, Verdonik, and Klinge 2013).

Adolescents are a prime audience to engage about awareness and early intervention for cervical cancer screening. Despite recommendations for routine HPV vaccinations among adolescents starting at age 11 or 12, only 50 percent of women, and less than 2 percent of men in the United States are fully vaccinated (Etter, Zimet, & Rickert, 2012). Monitoring and evaluating HPV uptake and completion rates, which are tracked in the life course indicator LC-36 A/B “HPV Immunization,” will provide another opportunity to discern possible disparities affecting women and men of different racial/ethnic groups, and income levels. A study by Niccolai, Mehta, & Hadler (2011) suggested that non-Hispanic African-American and Hispanic teens between the ages of 13 and 17, who received at least one dose of HPV vaccine, were significantly less likely to complete their HPV vaccine series, than non-Hispanic White teens. Additionally, lower income adolescents and young women were at higher risk of not initiating or completing their vaccination series (Niccolai, Mehta, and Hadler, 2011; Wei, Moore, & Green, 2013). Furthermore, despite HPV vaccination being covered by Medicaid, provider-based studies have shown lower rates of HPV vaccine uptake among young female patients covered by Medicaid (Vadaparampil, Staras, Malo, Eddleton, Christie, Rodriguez, Giuliano, & Shenkman, 2013). Another significant factor associated with low initiation rates is not having a regular provider and not having received childhood immunizations.
Reducing socioeconomic disparities would significantly impact disparities in pap smear utilization rates (Simard, Fedewa, Ma, Siegel, & Jemal, 2012). Additionally, it has been suggested that culturally competent and integrated outreach efforts to increase knowledge and improve attitudes toward the HPV vaccine and pap smear screening should be implemented in order to bridge the knowledge divide affecting those with differential access to more traditional means of communication such as the Internet or a regular health care provider (Kontos, Emmons, Puleo, & Viswanath, 2012; Daley, 2011). Providers can play an important role in reducing inequalities in HPV vaccine initiation, series completion, and pap smear utilization (Vadaparampil, Staras, Malo, et al., 2013; Daley, Vamos, Buhi, et al, 2010).

**Public health impact**

Cervical cancer still affects a large proportion of women worldwide and in the United States. In 2012 alone in the United States, there were an estimated 12,170 new invasive cervical cancer cases and over 4,200 cancer-related deaths, making cervical cancer the third most common form of female-related malignancy (del Carmen & Avila-Wallace, 2013). Additionally, it is estimated that as many as 80 percent of females and 50 percent of males in the United States will contract HPV throughout their lives (Alexander, Daley, Dempsey, 2012). Several studies have documented the efficacy and safety of both pap smears and HPV vaccine to prevent and increase early detection of cervical cancer (Etter, Zimet, & Rickert, 2012). While the HPV vaccine is an effective way to prevent cervical cancer, pap smears are still needed in addition to the vaccine as the vaccine alone does not cover all strains of HPV. Additionally, regular screening through pap smears, are an effective means to increase early detection of cervical cancer, which can be important for persons whom are not vaccinated or are incompletely vaccinated for HPV.

The incidence of HPV infections in the United States is highest among teens and young adults (Alexander, Daley & Dempsey, 2012), with development of cervical cancer usually occurring later, and most commonly in the premenopausal stage (median age at diagnosis, 47 years) (CDC, 2011). By monitoring the effectiveness of prevention and screening prior to and during young adulthood, intervention will be more effective well in advance of cancer development.

**Leverage or realign resources**

This indicator presents opportunities for leveraging and realigning resources in numerous sectors including health care providers such as pediatricians, primary care physicians, and OB/gyns; public health practitioners working on education and awareness campaigns related to preconception health; education professionals working to educate students and their parents about available immunizations with a focus on complete health for boys and girls; and navigators and insurance providers who can educate families about coverage options related to women’s health with private insurers, Medicaid, Medicare, and the ACA.

Extensive studies have shown that universal utilization of HPV vaccine among indicated at-risk populations, as well as the use of pap smears to detect early stage cervical lesions and abnormalities, does not only result in health gains, but also in health care cost savings associated with cervical cancer treatment (Tully, Anonychuk, Sanchez, Galvani, & Bauch, 2012; Westra, Rozenbaum, Rogoza, et al, 2011). Additionally, a link between HPV infection and other types of cancer such as oral and anal malignancies has been suggested (Hu & Goldie, 2008; Meyers, 2008).

Given this, education and awareness campaigns that encourage age-appropriate HPV vaccines for men and women, and promote cervical cancer screening through pap smears, can serve to promote and protect the health of all men and women. This is very much a focus among health care professionals (including pediatricians, primary care providers and gynecologists), insurers, communities, government groups, employers, hospitals and others.

Furthermore, pap smears are covered by private insurance, Medicare, Medicaid and also the ACA. Through the ACA, women’s preventive health care services, such as mammograms, screenings for cervical cancer, and other services, are already covered with no cost sharing under some health plans (HRSA 2013). Therefore, health insurance providers who
cover women at highest risk of cervical cancer, as well as other cancer researchers, are likely to be interested in the preventive interventions available.

**Predict an individual’s health and wellness and/or that of their offspring**

HPV has been identified as a necessary causal factor in the development of cervical cancer (Daley, 1998; Crosbie, Kitchener, 2012; MMWR, 2012). While most HPV infections clear the body within the first two years, some will progress and develop into cancer several years later (MMWR, 2012). The median age of cervical cancer diagnosis is 48 years; however, women in their child-bearing years are still susceptible to cervical cancer (CDC, 2011). The widespread use of safe and effective HPV vaccines and pap smears for early detection is a significant determinant of lifelong health for women who may be at risk of developing cervical cancer. Additionally, early detection and treatment also can be critical in preserving fertility for women who wish to become pregnant and have children.

**Data Criteria**

**Data availability**

The National Health Interview Survey (NHIS) is a cross-sectional household interview survey that has been in use in the United States since 1957. Sampling and interviewing are continuous throughout each year. Data are collected in-person by U.S. Census Bureau interviewers (CDC, 2012). The National Cancer Institute (NCI) chose the NHIS to periodically identify trends in cancer-related health behaviors in the U.S. population, by adding the Cancer Control Supplement (CCS), which has been administered every five years since 2000 (National Cancer Institute, 2011). As part of this survey, pap smear data among women 18 years and older are collected and reported with stratification by selected demographic characteristics such as race/ethnicity, age, and insurance status. Specifically as it relates to pap smear utilization, the survey asks if the woman has ever had a pap smear, and if so, the age of her first pap smear, the number of pap smears in the last six years, and when the most recent pap smear occurred. Given that HPV is the most sensitive indicator of cervical cancer, data related to the HPV vaccination among 18 to 26 year olds is also collected. The NHIS includes an HPV vaccine section for children that can estimate HPV vaccination for the nine to 17 year old U.S. population. The variables included in the adult and child modules measure whether a child in the household has ever received an HPV vaccination, the number of HPV shots received, and the age at which the first shot was received.

**Data quality**

The sampling plan follows a multistage area probability design that allows for representative sampling of households and non-institutionalized group quarters. The NHIS sample is drawn from each State and the District of Columbia. The current NHIS sample design features oversampling of African Americans, Hispanics and Asian/Pacific Islanders. Survey participation is voluntary and confidential. The annual response rate of NHIS is approximately 90 percent of the eligible households in the sample. The NHIS sample may be too small to provide State level data with acceptable precision for each state. Therefore, states should combine years to obtain selected estimates. This may be a drawback as the Cancer Control Supplement is implemented every five years. If this time frame is too long, BRFSS could be used as a data source for both measures.

The BRFSS is the world’s largest, on-going telephone health survey system, tracking health conditions and risk behaviors in the United States yearly since 1984. Currently, data are collected monthly in all 50 states, the District of Columbia, Puerto Rico, the U.S. Virgin Islands, and Guam for adults 18 years and older. CDC provides state and national level prevalence data on their website. The CDC develops approximately 80 questions each year. Some of these are core questions asked each year, and some are rotating core questions asked every other year. There are also CDC supported modules that address specific topics that states can use. States may also develop additional questions to supplement the core questions. Modules used by states are noted on the CDC website: [cdc.gov/brfss/publications/mvr.htm](http://cdc.gov/brfss/publications/mvr.htm).

Both the BRFSS and the NHIS surveys are administered post-vaccination and post-pap smear so that responses may be subject to recall bias. The issue of recall bias is not just pertaining to participants’ responses about their own experiences with HPV vaccines and pap smears, but in the case of minors, participants are reporting on their children’s experiences, which may differentially impact reporting accuracy.
**Simplicity of indicator**

Though this indicator is relatively simple, the indicator could include a layer of complexity if researchers choose to include incomplete HPV vaccine series in addition to completion of HPV vaccine series to measure uptake. Additionally, this indicator is a composite measure of both screening (pap smears) and HPV vaccination. The purpose of this indicator is to measure preventive services among women of reproductive age, and combining pap smears and HPV vaccination captures this group of women and provides a good sentinel indicator for preventive services.

**References**


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Life Course Indicator: Children Receiving Age Appropriate Immunizations

The Life Course Metrics Project

As MCH programs begin to develop new programming guided by a life course framework, measures are needed to determine the success of their approaches. In response to the need for standardized metrics for the life course approach, AMCHP launched a project designed to identify and promote a set of indicators that can be used to measure progress using the life course approach to improve maternal and child health. This project was funded with support from the W.K. Kellogg Foundation.

Using an RFA process, AMCHP selected seven state teams, Florida, Iowa, Louisiana, Massachusetts, Michigan, Nebraska and North Carolina, to propose, screen, select and develop potential life course indicators across four domains: Capacity, Outcomes, Services, and Risk. The first round of indicators, proposed both by the teams and members of the public included 413 indicators for consideration. The teams distilled the 413 proposed indicators down to 104 indicators that were written up according to three data and five life course criteria for final selection.

In June of 2013, state teams selected 59 indicators for the final set. The indicators were put out for public comment in July 2013, and the final set was released in the Fall of 2013.

Basic Indicator Information

Name of indicator: Children receiving age-appropriate immunizations (LC-35)

Brief description: Percent of children ages 19-35 months receiving age-appropriate immunizations according to the Advisory Committee for Immunization Practices (ACIP) guidelines and HP 2020 Goal.

Indicator category: Health Care Access and Quality

Indicator domain: Service/Capacity

Numerator: Number of children surveyed who received ≥ four doses of DTaP/DT/DTP (Diphtheria/Tetanus/Acellular pertussis), ≥ three doses of poliovirus vaccine, ≥ one dose of measles-containing vaccine, full series of Hib (Haemophilus influenza - three or four doses, depending on product type), ≥ three doses of HepB (Hepatitis B), ≥ one dose of varicella vaccine, and >= four PCV (Pneumococcal) doses.

Denominator: Number of children age 19-35 months

Potential modifiers: The following modifiers are available at the state level for the National Immunization Survey: Milestone Age; Poverty Status (at or above the federal poverty level vs. below the federal poverty level); Urbanicity (living in a Metropolitan Statistical Area [MSA] central city vs. MSA non central city vs. non-MSA central city); race (non-Hispanic White, non-Hispanic Black, Hispanic, non-Hispanic American Indian (AI) or Alaska Native (AN), non-Hispanic Asian, non-Hispanic Native Hawaiian or other Pacific Islander, and non-Hispanic Multiple Race); Provider Facility Type (Public, Private, Mixed, or Other); and Vaccines for Children Facility Participation (yes or no).

Data source: National Immunization Survey (NIS)

Notes on calculation: The numerator is the 4:3:1:3:3:1:4 vaccine series as reported by the NIS. The survey data are weighted to represent the U.S. population of children age 19-35 months.
**Life Course Indicator: Children Receiving Age-appropriate Immunizations (LC-35)**

**Introduction**

The prevention of disease and its spread is critical to ensuring the public’s health. Vaccine-preventable diseases have a costly impact, including medical visits, hospitalizations, long-term disability or adverse health outcomes, and possible death. Early vaccinations against serious and crippling diseases, administered when children are most vulnerable, can protect children against illness, lifetime adverse health effects, and even early death. In the past century, life expectancy has increased by more than 30 years and mortality for most childhood vaccine-preventable diseases has decreased by 99 percent. Furthermore, immunizing individual children can help protect the health of communities at large, including children who are too young to be vaccinated. Vaccinations can also improve health outcomes for future generations by limiting the spread of disease and potentially ending serious side effects of certain diseases.

Properly immunizing infants and children against serious infectious diseases helps both the individual child (critical and sensitive period) and future generations (over time), which is consistent with life course science. With regard to communication and explanation of the indicator, in general, vaccines are accepted as a safe and effective way to protect the health of young children. However, in recent years there has been an increase in the number of parents refusing to vaccinate their children, citing fears of the adverse effects of vaccination (in many cases based upon faulty science) and questioning its value, given the reduction and elimination of vaccine-preventable diseases in the United States. While the number of parents refusing vaccines is quite small, it poses a threat to communities, and communicating and upholding the value of vaccination will remain a public health challenge in the years to come.

**Implications for equity**

Disparities in childhood immunizations have been found among those populations affected by poverty and low socioeconomic status. The NIS allows for comparison of childhood immunization rates by race/ethnicity and by poverty status (at or above the federal poverty level or below the federal poverty level). In the most recent survey results (2011), immunization coverage, or estimates of the number of people who have received particular vaccines, differs by poverty level. The Vaccines For Children program was created to provide vaccinations to financially vulnerable children and has helped eliminate differences for particular vaccines; however, immunization coverage rates among children living below poverty are still lower than those for children living at or above the poverty level for newer vaccines (e.g., pneumococcal conjugate vaccine and rotavirus vaccine) and vaccines that require four doses to complete the series.

Additionally, there is some evidence that race and ethnicity may have implications for equity in childhood immunizations. The recent NIS data indicate that American Indian/Alaska Native (AI/AN) children have lower immunization coverage compared with white children for many vaccines. Immunization coverage among AI/AN children decreased from 81.8 percent in 2010 to 72.7 percent in 2011 for ≥ four doses of DTaP, and from 85.3 percent to 75.3 percent for ≥ four doses of PCV (Pneumococcal conjugate vaccine). While immunization coverage rates vary among other racial and ethnic groups, few differences were observed after adjusting for poverty status. For example, differences in immunization coverage between white and black children could be explained by a higher prevalence of poverty among black children. Immunization coverage among children in all other racial/ethnic groups was similar to or higher than immunization coverage among white children for most vaccines after adjusting for poverty.

**Public health impact**

Vaccines have been shown to be one of the most cost-effective clinical preventive services, and childhood immunization programs provide a very high return on investment. Per Healthy People 2020, *for each birth cohort vaccinated with the routine immunization schedule (this includes DTap, Td (Tetanus-Diphtheria), Hib, Polio, MMR (Measles/Mumps/Rubella), Hep B, and varicella vaccines), society:*

- Saves 33,000 lives.
- Prevents 14 million cases of disease.
- Reduces direct health care costs by $9.9 billion.
Immunizations help protect the health of a community, especially those people who cannot be immunized such as children who are too young for particular vaccines (e.g., measles vaccine cannot be given to a child less than one year), cannot be immunized for medical reasons (e.g., children with leukemia), or cannot make an appropriate immune response to the vaccine. Medical and religious exemptions to school immunization requirements are allowed in most states (medical in all states, and religious in most states), thus making it important for health departments and schools to work together to maintain high immunization coverage rates. While the incidence of most vaccine-preventable diseases remains at historically low levels in the United States, recent outbreaks, such as measles and pertussis, highlight the public health costs and need to maintain high rates of immunization.

Vaccine-preventable diseases also can have additional social and economic costs, including missed school days for children and lost work time for parents; medical costs from doctor’s visits, medications and hospitalizations; and premature death. The return on investment and maintenance of herd immunity signifies that an increase in the indicator of age-appropriate immunizations is vitally important for the continued preservation and protection of childhood, family, and community health.

**Leverage or realign resources**

To maintain high immunization coverage rates, the Centers for Disease Control and Prevention (CDC) encourages the use of evidence-based methods, which include the following components:

- parent and provider reminders
- reducing out-of-pocket costs
- standing orders
- home visits to vulnerable populations
- vaccination requirements for child care centers
- use of immunization information systems
- vaccination programs in child care centers and Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) settings

These components lend themselves to traditional public health partnerships (e.g., among providers, immunization programs, WIC programs, and home visiting programs), but also suggest collaborations among new partners such as child care centers and community organizations.

Under the Affordable Care Act (ACA), health plans are required to cover recommended immunizations without cost to the enrollee when administered by an in-network provider. ACA also reauthorizes the Section 317 Immunization Grant Program, which provides availability of federally purchased vaccines and grants to all 50 states, the District of Columbia, five large urban areas, and territories and protectorates to provide immunization services to priority populations.

**Predict an individual’s health and wellness and/or that of their offspring**

Vaccination is one of the best ways parents can protect infants, children, and teens from 16 potentially harmful and contagious diseases. Vaccine-preventable diseases can be very serious, may require hospitalization, cause long-lasting health complications, or even be deadly – especially in infants and young children.

In addition to protecting an individual child’s health, specific immunizations also can protect future generations. For example, once a female infant or child has been fully immunized against Hepatitis B, she also is protecting any future children she may have from the possibility of perinatal transmission. In some cases, specifically children of refugees from countries where Hepatitis B is endemic, the Hepatitis B vaccine provides the opportunity to break the cycle of maternal to child transmission which may not be present in the country of origin.

While this particular indicator pertains to childhood immunizations, it should be noted that immunizations are recommended throughout a person’s life. The CDC sets recommended adolescent and adult immunization schedules along with the infant and childhood schedules. Adolescents need to be immunized because vaccine protection from some childhood vaccines wears off over time and boosters are needed, and also because some vaccines, like HPV, are given...
only during the preteen years. Adults need booster vaccinations for some childhood vaccines, but also may need vaccines against diseases such as influenza and pneumococcal pneumonia.

**Data Criteria**

**Data availability**
The NIS is a list-assisted random-digit-dial telephone survey followed by a mailed survey to children’s immunization providers. Parent/guardian respondents provide vaccination and sociodemographic information on children or adolescents in their care. The NIS began data collection in April 1994 to monitor childhood immunization coverage. The survey is conducted jointly by the National Center for Immunizations and Respiratory Diseases and the National Center for Health Statistics, CDC.

The study collects data by interviewing households in all 50 States, the District of Columbia and selected large urban areas. The target population for the NIS is children between the ages of 19 and 35 months living in the United States at the time of the interview. Vaccinations included in the survey are: diphtheria and tetanus toxoids and acellular pertussis vaccine (DTaP); poliovirus vaccine (polio); measles-containing vaccine (MCV); Haemophilus influenzae type b vaccine (Hib); hepatitis B vaccine (Hep B); varicella zoster vaccine (chicken pox), pneumococcal conjugate vaccine (PCV), hepatitis A vaccine (Hep A), and influenza vaccine (FLU). Survey data are used to calculate vaccine coverage rates based on the recommended number of doses to be up to date, as recommended by the Advisory Committee on Immunization Practices (ACIP). Estimates are produced for the nation and non-overlapping geographic areas consisting of the 50 states, the District of Columbia, and selected large urban areas. Data files for the NIS are available starting with 1995.

State-level data on immunization coverage from NIS for the series included in this indicator are published annually through the CDC Morbidity and Mortality Weekly Report (in September for the previous year’s data). State level data from 2011 is currently available on the CDC website (users can download the dataset and SAS and R input statements from the CDC website at cdc.gov/nchs/nis/data_files.htm). Data users should note that the 2011 data includes a modified series where Hib was not analyzed, due to a shortage of vaccines.

**Data quality**
For both the NIS and the NIS-Teen, parents and guardians are asked for consent for a second phase of the study in which the child or adolescent’s pediatrician is contacted. The provider receives an immunization history questionnaire to fill out for the selected child; this information is used to ensure the accuracy and precision of the immunization coverage estimates. CDC publishes a NIS “Guide to Quality Control Procedures” that describes the procedures used to ensure the quality of the data through all phases of the sampling, data collection, and processing.

The data are weighted to reduce potential biases from non-response and non-coverage. In addition to households with an eligible child that do not respond to the survey, an additional source of potential error is a household that responds but does not have complete provider information. Item non-response for the NIS is typically very low. However, for data elements used in weighting, the hot-deck method of imputation is used. Although in one year a total of about 14,000 data elements are imputed, these account for only 0.08 percent of all data items in the file.

The findings in the NIS are subject to at least four limitations. First, 2011 was the first year that the NIS used a dual-frame sampling scheme that included landline and cell phones for households, thus estimates might not be comparable with those from previous years when surveys were conducted using landline phones only. Although differences between national landline and dual-frame estimates for specific vaccines in the 2011 NIS were small, (absolute magnitude <1 percent), larger variations were observed for state-specific coverage estimates. Comparisons of 2011 estimates with those of previous years at the state level should be interpreted with caution. Second, immunization coverage might have been underestimated because of the exclusive use of provider-reported vaccination records. Completeness of these records is unknown, and estimates might have been biased upwards or downwards if immunization coverage among children without provider records differed from immunization coverage among children with provider data. Third, although survey results are weighted, bias could still remain because of non-response and exclusion of households without telephone service. Finally, although national immunization coverage estimates are precise, confidence intervals are much wider for state estimates, thus the point estimates should be interpreted with caution.
Simplicity of indicator
This indicator is complex for several reasons. Immunization coverage rates are available for individual vaccinations and also several different vaccination series. These immunization coverage rates also are available for all the modifiers listed above. Determining an accurate cross walk for vaccine alone versus vaccine series and against multiple modifiers could be difficult due to comparability issues. Further, while the point estimates of an area’s immunization coverage rate are available and useful for certain advocacy activities, care must be taken to include a discussion of the 95 percent confidence intervals around the immunization coverage estimates and to compare this data over time.²

References


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Life Course Indicator: Children Receiving Age-appropriate Immunizations (LC-35)
The Life Course Metrics Project

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Using an RFA process, AMCHP selected seven state teams, Florida, Iowa, Louisiana, Massachusetts, Michigan, Nebraska and North Carolina, to propose, screen, select and develop potential life course indicators across four domains: Capacity, Outcomes, Services, and Risk. The first round of indicators, proposed both by the teams and members of the public included 413 indicators for consideration. The teams distilled the 413 proposed indicators down to 104 indicators that were written up according to three data and five life course criteria for final selection.

In June of 2013, state teams selected 59 indicators for the final set. The indicators were put out for public comment in July 2013, and the final set was released in the Fall of 2013.

**Basic Indicator Information**

**Name of indicator:** Human Papillomavirus (HPV) Immunization (LC-36 A/B)

**Brief description:** The proportion of adolescents ages 13-17 and the proportion of young adults ages 18-26 who receive the evidence-based clinical preventive service HPV vaccine

**Indicator category:** Health care access and quality

**Indicator domain:** Service/Capacity

**Numerator:**

a. 13-17 year olds (males and females) who received the complete series of HPV vaccine
b. 18-26 year olds (males and females) who received the complete series of HPV vaccine

**Denominator:**

a. Total 13-17 year old children
b. Total 18-26 year old adults

**Potential modifiers:** age, sex, race/ethnicity, poverty status, urbanicity, health insurance status

**Data source:**

a. National Immunization Survey-Teen (NIS-Teen)
b. National Health Interview Survey (NHIS)

**Notes on calculation:** The numerator from the NIS-Teen is the number of 13-17 year olds (males and females) who received the complete series of HPV vaccine, three doses of vaccine. The numerator from the NHIS is the number of 18-26 year olds (males and females) who received the complete series of HPV vaccine, three doses of vaccine. Analysts who use the raw datasets should apply the appropriate survey weights to generate the final estimates.

**Similar measures in other indicator sets:**

a. HP 2020 Focus area IID-11.4; NQF measure 1959
b. None
Life Course Criteria

Introduction
Most cases of invasive cervical cancer are caused by persistent human papillomavirus (HPV) infection, a common virus transmitted from one individual to another during sexual activity. These cases are highly preventable if the patient has access to regular screening tests and follow-up and vaccination to protect against HPV. The Advisory Committee for Immunization Practices (ACIP) recommends that all girls and boys who are 11 or 12 years old get three doses of HPV vaccine (Gardasil or Cervarix, the two FDA-approved HPV vaccines), and HPV vaccines are recommended for all teen girls and women through age 26 and all teen boys and men through age 21 who did not get the vaccine when they were younger (catch-up vaccines)(CDC, 2013). Today, it is estimated that 79 million persons in the United States are infected with HPV, and approximately 14 million will become newly infected each year (Satterwhite et al., 2013). In addition to the morbidity and mortality associated with persistent HPV infection causing cervical cancer, HPV infection is associated with significant detriments in health-related quality of life, and the economic burden of this sexually transmitted virus is second only to human immunodeficiency virus. The median age of cervical cancer diagnosis is 48 years of age. Adherence to the ACIP guidelines for early HPV vaccination for adolescent girls and boys is a simple, cost-effective preventive measure to reduce the lifetime risk of cervical cancer morbidity and mortality. Increasing vaccination coverage rates will require a multi-level approach of physician education and parent engagement, and interventions from the policy level (e.g. school vaccine requirements) through to innovative partnerships with community organizations, including schools.

Implications for equity
While significant improvements have been made in the United States with regard to the decreasing incidence and mortality rates of cervical cancer (CDC, 2012), large disparities still exist between different groups of women, not only in incidence and mortality but also in screening and prevention (del Carmen, & Avila-Wallace, 2013). HPV-associated cervical cancer incidence rates are higher among black women (9.9 per 100,000) as compared to white women (7.4 per 100,000); and women of Hispanic ethnicity have cervical cancer incidence rates of approximately 11.3 per 100,000, compared to 7.4 per 100,000 for non-Hispanic women (Watson, Saraiya, Benard, et al, 2008; Jemal, Thun, Ries et al, 2008).

Despite recommendations for routine HPV vaccinations among adolescents, only 49 percent of adolescent girls aged 13 through 17, and less than two percent of adolescent boys in the United States have received one or more doses of the HPV vaccine (Etter, Zimet, & Rickert, 2012). Monitoring and evaluating HPV vaccine uptake and completion rates as part of this indicator will provide an opportunity to discern possible disparities affecting women and men of different racial/ethnic groups and income levels. A study by Niccolai, Mehta, & Hadler (2011) suggested that non-Hispanic black and Hispanic teens between the ages of 13 and 17, who received at least one dose of HPV vaccine, were significantly less likely to complete their HPV vaccine series, than non-Hispanic white teens. Additionally, lower income adolescents and young women were at higher risk of not initiating or completing their vaccination series (Niccolai, Mehta, and Hadler, 2011; Wei, Moore, & Green, 2013). Despite HPV vaccination being covered by Medicaid, provider-based studies have shown lower rates of HPV vaccine uptake among young female patients covered by Medicaid (Vadaparampil et al., 2013). Other factors associated with low initiation rates are not having a regular provider and not having received childhood immunizations (Wei et al, 2013; Kessels, Marshall, Watson, et al., 2012). Despite the widespread availability of the HPV vaccine, knowledge of, and clinician recommendation for the HPV vaccine is lower among lower income and racial minority women. (Polonijo, Carpiano, 2013; Mehta, Julian, Meek, Sosa, Bilinski, Hariri, Markowitz, Hadler, & Niccolai, 2012).

Researchers identify reduced access to screening or follow up care as part of the explanation for the disparity in cervical cancer incidence as well as vaccine initiation and other preventive measures (Benard et al, 2005). Socioeconomic position also has been linked with cervical cancer mortality and late stage diagnosis. By evaluating temporal trends in age-adjusted cervical cancer mortality rates by individual education level between 1993 and 2007, Simard and colleagues (2012) found that the decreases in cervical cancer mortality rates were smaller for women with lower versus higher levels of education, in turn leading to a widening of the disparity in mortality by socioeconomic status. The team suggested that 74 percent of all cervical cancer deaths in 2007 would have been averted if no educational disparities existed. These data suggest inequity in both access to and utilization of HPV vaccination as well as outcomes from cervical cancer.
Public health impact
In 2012, there were an estimated 12,170 new invasive cervical cancer cases and over 4,200 cancer-related deaths in the United States, making cervical cancer the third most common form of female-related malignancy (del Carmen & Avila-Wallace, 2013). It is estimated that as many as 80 percent of females and 50 percent of males in the United States will contract HPV throughout their lives (Alexander, Daley, Dempsey, 2012), with 79 million persons in the United States infected with HPV today and approximately 14 million becoming newly infected each year (Satterwhite et al., 2013).

A July 2013 Morbidity and Mortality Weekly Report (MMWR) posited that while decades may be required for the impact of HPV vaccination to be well documented, short-term outcomes can be measured. For example, despite low uptake of the vaccine, Markowitz and colleagues found that within four years of the introduction of the HPV vaccine (the period of 2007-2010), prevalence of HPV types targeted by the vaccine decreased over 50 percent (from 11.5 percent to 5.1 percent) for females aged 14 to 19 years (2013). These short-term findings are promising, given the economic and health-related quality of life burden of cervical HPV disease. Fleurence and colleagues conducted a systematic review and found that the annual health care costs of HPV-related conditions in the United States range from $2.25-$4.6 billion (2005 dollars) and the annual burden of cervical cancer ranges from $181.5-$393 million (2005 dollars), making the economic burden of this sexually transmitted virus second only to human immunodeficiency virus. Furthermore, the authors looked at a range of health-related quality of life outcomes and their association with three factors: abnormal Pap smear test, HPV infection, and cervical cancer. The authors found studies suggesting associations across a range of outcomes related to emotional function (e.g. anxiety/worry, depression), body image or self-esteem (e.g. desirability, self-confidence), sexual function (e.g. reduced sexual contact, relationship with partner), and physical function (e.g. role limitations). The most recurrent themes were anxiety, distress, and detriment in sexual functioning (2007). Given this information, the potential public health impact of increasing HPV vaccination rates can be significant, both in terms of reduced morbidity and mortality from cervical cancer but also reducing the disease’s economic burden and detriments to quality of life.

Leverage or realign resources
Extensive studies indicate that universal utilization of HPV vaccine among indicated at-risk populations does not only result in health gains, but also in health care cost savings associated with cervical cancer treatment (Tully, Anonychuk, Sanchez, Galvani, & Bauch, 2012; Westra, Rozenbaum, Rogoza, et al, 2011). Several studies have documented the efficacy and safety of both Pap Smears and HPV vaccine to prevent and increase early detection of cervical cancer (Etter, Zimet, & Rickert, 2012). It has been suggested that culturally-competent and integrated outreach efforts to increase knowledge and improve attitudes towards the HPV vaccine should be implemented in order to bridge the knowledge divide affecting those with differential access to educational resources or a regular health care provider (Kontos, Emmons, Puleo, & Viswanath, 2012; Daley, 2011). Researchers also have indicated the need to address providers themselves as a means to reduce inequalities in HPV vaccine initiation and series completion (Vadaparambil, Staras, Malo, et al., 2013; Daley, Vamos, Buhí, et al, 2010), recognizing tremendous missed opportunities in the doctor’s office for raising awareness of the HPV vaccine and messaging the importance of receiving all doses.

The responsibility for improving vaccine coverage rates does not lie solely among health care professionals. Parents have been identified as a preferred source of information about HPV vaccination by adolescent girls (Mullins et al., 2013), indicating that parent discussions with their children about HPV and the benefits of vaccination are critical to improve series initiation and completion. Other key partners in improving vaccine coverage rates may include the following:

- **Legislators:** According to the National Council of State Legislatures, in 2007, at least 24 states and the District of Columbia introduced legislation to specifically mandate the HPV vaccine for school, and as of June 13, 2013, 8 states had proposed HPV-related legislation for the 2013-2014 sessions. A table of state action is currently available at the following location: ncsl.org/issues-research/health/hpv-vaccine-state-legislation-and-statutes.aspx.

- **School-based health centers:** Research indicates that school-based health centers can be effective in administering the complete series of HPV vaccines to adolescents, compared to community health centers, despite serving a primarily uninsured or underinsured population (Frederico et al., 2010).

- **Schools and Extramural Programs (e.g. after-school programs and other school-sponsored activities):** Hayes and colleagues (2013) investigated lessons learned from extramural programs across the United States that partnered with schools to increase HPV vaccination rates (among other immunizations). These efforts are based on the notion that school-located programs are a valuable complement to clinical care because of the infrequency with which adolescents visit their physicians. Funding for such programs remains a challenge, as these programs
often don't have adequate mechanisms for billing private insurers and Medicaid, and thus rely upon grant funds and other sources with limited sustainability. McRee and colleagues (2013) investigated the acceptability of alternative settings for HPV vaccine delivery among parents and adolescent males, and found that comfort with these settings correlated with parent perception of greater barriers to HPV vaccination, if the parent or son had not recently visited their health care providers or had previously received vaccines at school, and if sons perceived that their peers were more accepting of the HPV vaccine.

*Predict an individual's health and wellness and/or that of their offspring*

HPV has been identified as a necessary causal factor in the development of cervical cancer (Daley, 1998; Crosbie, Kitchener, 2012; MMWR, 2012). It is a sexually transmitted infection associated with sexual health practices, including the effective use of condoms during every sex act, and has implications for individual health (and partner sexual health) at the outset of sexual activity. While most HPV infections clear the body within the first two years, some will progress and develop into cancer several years later (MMWR, 2012). The median age of cervical cancer diagnosis is 48 years of age (CDC, 2011). The widespread use of safe and effective HPV vaccines is a significant determinant of lifelong health for women who may be at risk of developing the third most common malignancy among women. Additionally, a link between HPV infection and other types of cancer has been suggested, including vulvar, vaginal, penile, anal, and oropharyngeal cancers (Hu & Goldie, 2008; Meyers, 2008; CDC, 2012). These cancers affect the health trajectories of both men and women.

**Data Criteria**

*Data availability*

**NIS and NIS-Teen**

The National Immunization Survey (NIS) and National Immunization Survey-Teen (NIS-Teen) are both part of a study in which data are collected by interviewing households in all 50 States, the District of Columbia, and selected areas for oversampling, to determine vaccine coverage rates among children 19-35 months of age (NIS) and adolescents aged 13-17 years (NIS-Teen). The interviews are conducted by telephone (previously landline telephone numbers only, with cell phone numbers added in 2011) with households selected at random, followed by a mailed survey to immunization providers. Parent/guardian respondents provide vaccination and sociodemographic information on children or adolescents in their care. Teen data files are available starting with 2008. The NIS and NIS-Teen are conducted jointly by the National Center for Immunizations and Respiratory Diseases and the National Center for Health Statistics, Centers for Disease Control and Prevention (CDC).

The NIS-Teen includes meningococcal conjugate vaccine (MCV4), tetanus, diphtheria, acellular pertussis (Tdap), and human papillomavirus (HPV). Survey data are used to calculate vaccine coverage rates based on the recommended number of doses to be up to date, as recommended by the Advisory Committee on Immunization Practices (ACIP). Data on vaccination coverage from NIS-Teen are published annually through the CDC Morbidity and Mortality Weekly Report. State level data from 2011 is currently available (users can download the dataset and SAS and R input statements from the CDC website at [cdc.gov/nchs/nis/data_files_teen.htm](http://cdc.gov/nchs/nis/data_files_teen.htm)), and 2012 data on HPV vaccination in adolescent girls was published in July 2013 (CDC, 2013).

**NHIS**

The National Health Interview Survey (NHIS) is a cross-sectional household interview survey that has been in use in the United States since 1957. Sampling and interviewing are continuous throughout each year. Data are collected in-person by U.S. Census Bureau interviewers (CDC, 2012). The National Cancer Institute (NCI) chose the NHIS to periodically identify trends in cancer-related health behaviors in the U.S. population, by adding the Cancer Control Supplement (CCS), which has been administered every five years since 2000 (National Cancer Institute, 2011). Additionally, the National Center for Immunizations and Respiratory Diseases at CDC sponsors an immunization supplement that includes HPV vaccination coverage (currently included in the Adults Health Care Access and Utilization Section) and is collected annually. NHIS includes data related to HPV vaccination among 18-26 year olds, including whether an individual in the household has ever received an HPV vaccination, the number of HPV vaccinations received, and the age at which the first vaccination was received. NHIS data files through 2012 and SAS, SPSS, Stata input statements are available online at [cdc.gov/nchs/nhis/nhis_2012_data_release.htm](http://cdc.gov/nchs/nhis/nhis_2012_data_release.htm).
Data quality
For both the NIS and the NIS-Teen, parents and guardians are asked for consent for a second phase of the study in which the child or adolescent’s pediatrician is contacted. The provider receives an immunization history questionnaire to fill out for the selected child; this information is used to ensure the accuracy and precision of the vaccination coverage estimates. CDC publishes a NIS “Guide to Quality Control Procedures” that describes the procedures used to ensure the quality of the data through all phases of the sampling, data collection, and processing. The data are weighted to reduce potential biases from non-response and non-coverage. In addition to households with an eligible child that do not respond to the survey, an additional source of potential error is a household that responds but does not have complete provider information. Item non-response for the NIS is typically very low. However, for data elements used in weighting, the hot-deck method of imputation is used. Although in one year a total of about 14,000 data elements are imputed, these account for only 0.08 percent of all data items in the file. Dorell and colleagues assessed the validity of parent-reported adolescent vaccination histories by analyzing data from the 2008 NIS-Teen. Of all vaccines, the net reporting bias between parent-reported estimates and provider-reported estimates was lowest for at least one dose of HPV4 or at least three doses of HPV4, with kappa statistics of 0.920 and 0.865 respectively (the highest kappa values compared with the other adolescent-administered vaccines) (Dorell et al., 2011).

For the NHIS, the sampling plan follows a multistage area probability design that allows for representative sampling of households and non-institutionalized group quarters. The NHIS sample is drawn from each State and the District of Columbia. The current NHIS sample design features oversampling of Blacks, Hispanics and Asians. Survey participation is voluntary and confidential. The annual response rate of NHIS is approximately 90 percent of the eligible households in the sample. The NHIS sample may be too small to provide State level data with acceptable precision for each State. Therefore, states should combine years to obtain selected estimates. Information specific to the validity of the HPV measure in the NHIS is not available at this time, however a previous assessment of the validity of estimates of vaccine coverage for children aged 19-35 months showed that both the NIS and NHIS produce similar results, despite one being conducted in-person and another via telephone (Bartlett et al., 2001). If the delay for combining multiple years of data from the NHIS is too long, BRFSS could be used as a data source. BRFSS is considered a valid and reliable resource. Researchers can find a list of studies that have examined the validity and reliability of BRFSS on the CDC BRFSS website at: cdc.gov/brfss/publications/mvr.htm. Both surveys are administered post-vaccination so that responses may be subject to recall bias.

Simplicity of indicator
This indicator is relatively simple to explain and understand. State coverage estimates (for both ≥ one dose and ≥ three doses) are made available through the supporting agency, and data files for subgroup analyses are readily available on the agency websites. The indicator aligns with the Healthy People 2020 goal of increasing the vaccination coverage level of three doses of human papillomavirus (HPV) vaccine for females age 13 to 15 years to a target of 80 percent, easing challenges associated with justifying the public health need for such an indicator.

References


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Life Course Indicator: Medical Home

The Life Course Metrics Project

As MCH programs begin to develop new programming guided by a life course framework, measures are needed to determine the success of their approaches. In response to the need for standardized metrics for the life course approach, AMCHP launched a project designed to identify and promote a set of indicators that can be used to measure progress using the life course approach to improve maternal and child health. This project was funded with support from the W.K. Kellogg Foundation.

Using an RFA process, AMCHP selected seven state teams, Florida, Iowa, Louisiana, Massachusetts, Michigan, Nebraska and North Carolina, to propose, screen, select and develop potential life course indicators across four domains: Capacity, Outcomes, Services, and Risk. The first round of indicators, proposed both by the teams and members of the public included 413 indicators for consideration. The teams distilled the 413 proposed indicators down to 104 indicators that were written up according to three data and five life course criteria for final selection.

In June of 2013, state teams selected 59 indicators for the final set. The indicators were put out for public comment in July 2013, and the final set was released in the Fall of 2013.

Basic Indicator Information

Name of indicator: Medical Home (LC-37)

Brief description: Proportion of families who report their child received services in a Medical Home

Indicator category: Health care Access and Quality

Indicator domain: Service/Capacity

Numerator: Children whose health care meets Medical Home criteria

Denominator: Children age zero to 17 years

Potential modifiers: race/ethnicity, income, geography, rural vs. urban

Data source: National Survey of Children’s Health

Notes on calculation: Analysts who use the raw datasets should apply the appropriate survey weights to generate the final estimates.

Similar measures in other indicator sets: HP 2020 Focus area MICH-30; Title V Performance Measure #03 (For CSHCN); Maternal, Infant, and Early Childhood Home Visiting (MIECHV) Benchmark Area Improved Maternal and Newborn Health: Well-Child Visits

Life Course Indicator: Medical Home (LC-37)
Life Course Criteria

Introduction
A medical home is an approach to providing comprehensive primary care that was originally developed in the 1960s for children with special health care needs (CSHCN) but has since been widely recognized as an ideal model of care for all children (American Academy of Pediatrics, 2014). The American Academy of Pediatrics (AAP) defines the medical home as primary care that is, “accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective” (AAP, 2014). Life course provides a framework for the medical home to promote health and wellness over time, provide support to families, and create the opportunity to develop long-term relationships between providers and families offering the families consistency, safety and support. Children of families receiving the high-quality, coordinated care of a medical home have more knowledge about their health, are better equipped to identify resources to facilitate healthy behaviors, and are more likely to share this information with their family and with their community (Homer, 2008). Both CSHCN and children without special health care needs experience improvements in health measures such as emergency department (ED) visits when accessing care within a medical home (Homer et al, 2008, Long et al, 2012), highlighting the importance of extending this model of health care to all populations in order to maximize health and development in childhood that will carry over into adulthood.

Implications for equity
The medical home has the potential to act as a powerful tool in increasing health equity among all populations. When individuals receive care within a medical home, racial/ethnic disparities in receiving timely, needed care as well as preventive care disappear (Beal et al, 2007). However, multiple populations in the United States struggle to receive high-quality, comprehensive health care that classifies as a medical home. Data from the National Survey of Children’s Health (NSCH) continue to indicate disparities in access to a medical home by race/ethnicity, income level, special health care needs, and health insurance status (Zickafoose & Davis, 2013).

Although the concept of the medical home was originally developed to provide adequate care for CSHCN, only 46.8 percent of CSHCN receive care from a medical home compared to 56.3 percent of non-CSHCN (NSCH, 2012). Effective care coordination is the medical home component that is most difficult for CSHCN to attain. Only 56.4 percent of CSHCN received coordinated care when needed compared to 71.4 percent of non-CSHCN (NSCH, 2012). CSHCN also are more likely to have problems getting referrals for specialty care when needed than non-CSHCN (24.5 percent vs. 18.5 percent, respectively) (NSCH, 2012).

Insurance status and insurance type also are predictors of receiving care qualifying as a medical home. Only 27.8 percent of uninsured children receive care meeting medical home criteria compared to 64 percent of privately insured children (NSCH, 2012). Barriers to the medical home also are evident in publicly insured children as more than half (56 percent) of children with public insurance such as Medicaid or SCHIP do not receive health care qualifying as a medical home (NSCH, 2012). Community health centers and public clinics, which often serve uninsured and low-income families, are less likely to provide medical home care than private medical practices (Beal et al, 2007).

Racial and ethnic minorities and low-income children are disproportionately affected by lack of access to adequate medical care resulting in disparities in care qualifying as a medical home. Only 36.4 percent of children below 100 percent federal poverty level (FPL) had care qualifying as a medical home while nearly 68 percent of children at or above 400 percent FPL had care that met medical home requirements (NSCH, 2012). Children living below 100 percent FPL are less likely to receive each of the five criteria of a medical home (having a personal doctor or nurse, having a usual source of sick care, receiving family-centered care, ability to get referrals when needed, and help with coordinating care) than children living at or above 400 percent FPL (NSCH, 2012). Hispanic children (37.2 percent) and Black non-Hispanic children (44.7 percent) are much less likely to receive care in a medical home than non-Hispanic White children (65.7 percent) (NSCH, 2012). As with low-income children, Hispanic and non-Hispanic Black children are less likely to receive every care component of a medical home than non-Hispanic White children (NSCH, 2012).

Historically, the cost of health care has been a burden for low-income families because they have been unable to afford out-of-pocket expenses or adequate health insurance (Davidoff, 2004). The Affordable Care Act (ACA) will assist families with obtaining adequate health insurance, but the medical home offers an effective intervention to reduce health care
disparities that go beyond insurance status. When children have access to care within a medical home, they are more likely to have better health outcomes, fewer emergency room visits, better sustained health and experience fewer high-risk behaviors (Bachrach et al., 2011; Beal et al., 2007). These benefits have the potential to increase overall health equity if disparities in obtaining care within a medical home were reduced.

**Public health impact**

High-quality care obtained through a medical home from infancy through adolescence reduces health disparities, lowers hospitalization rates, ED visits and costs, and promotes healthy behaviors, physical activity, and avoidance of risk behaviors (Cooley et al., 2009; Long et al, 2012, Beal et al, 2007). Addressing health care and overall health issues such as high ED visits or youth risk behaviors through the medical home can reduce costs and poor outcomes to public health programs, communities and tax payers (Benedict, 2008).

Liptak et al. (1998) found that after implementation of coordinated care programs, adjusted hospital inpatient charges for chronic conditions fell from $28.1 million in 1989 to $14.6 million in 1995. Hospitals that have strong primary care medical homes are less likely to hospitalize children with common chronic conditions, and the high quality care provided in these medical homes reduce visits to the ED, indicating improved chronic disease management on the part of families (Cooley et al., 2009). Due to better health management, parents of children with chronic conditions with a medical home miss fewer days of work due to child illness, which can lead to increased productivity (Palfrey et al, 2004).

Nationally, nearly 31 million children are covered by Medicaid (CMS, 2014). Utilization of the ED by Medicaid beneficiaries is nearly two-fold higher than privately insured individuals (USDHHS, CMS, 2014). The medical home has the potential to reduce both urgent and non-urgent ED visits by Medicaid beneficiaries through the provision of non-urgent care in appropriate settings and a focus on prevention, disease management, and wellness that reduces incidence and severity of chronic diseases and other illnesses (USDHHS, CMS, 2014, Cooley et al, 2009). The disparity that exists between publicly insured and privately insured children in obtaining medical home care indicates potential for improvement in this indicator among Medicaid beneficiaries that could result in significant cost-savings.

The ACA required the U.S. Department of Health and Human Services (HHS) to establish the National Strategy for Quality Improvement in Health Care (National Quality Strategy), which aims to “improve the delivery of health care services, patient health outcomes, and population health” (HHS, 2012). In the HHS 2012 Annual Progress Report to Congress on the National Quality Strategy, several health care priorities were established that are in line with the medical home. These priorities include ensuring individuals and families are engaged as partners in care, promoting effective communication and coordination of care, and promoting the most effective prevention and treatment practices for leading mortality causes (HHS, 2012). The medical home is an intervention that is capable of aiding in achieving the priorities outlined by HHS in the National Quality Strategy.

**Leverage or realign resources**

The National Center for Medical Home Implementation (NCMHI), which is a cooperative agreement between AAP and the Maternal and Child Health Bureau (MCHB) aims to ensure “all children and youth, including children with special needs, have a medical home where health care services are accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally competent” (AAP, 2014). The NCMHI website (medicalhomeinfo.org) offers general medical home information, ways to implement a medical home, training resources to help medical practices build a medical home, national resources and initiatives, and state resources and initiatives.

Public and private health insurers are stakeholders who are already partnering with health care providers to reduce costs and improve quality of medical care by promoting and implementing medical homes. A variety of models of care, payment mechanisms and incentives are in place between insurers, physician groups, and organizations to implement the medical home. Research showed that patients of physicians who attended a seminar on developing a medical home with their asthma patients’ families had fewer hospitalizations than other physicians who did not attend a seminar (Clark et al., 1998; Clark et al., 2000). Although these studies examined the association between medical home and asthma, similar outcomes would likely be seen in other chronic conditions. Insurers are interested in reduced hospitalizations, fewer emergency department visits, and improved chronic disease management provided by the medical home as their costs will ultimately be reduced.
The ACA offers a number of opportunities, utilizing payment reform models, for community programs, health departments, and states to further realign resources to institutions, organizations and health care providers who expand and refine care delivery within a medical home (Kenney & Pelletier, 2010). Two specific provisions in the ACA supporting medical home are Section 2703 pertaining to health homes in Medicaid and Section 10333, which funds the Community-based Collaborative Care Network Program. Funds of up to $25 million are available for planning grants to develop state plans to provide health homes for Medicaid beneficiaries with chronic conditions (AMCHP, 2010). The Community-based Collaborative Care Network Program provides funding to coordinate and integrate health care services for low-income uninsured and underinsured populations through consortiums of health care providers (AMCHP, 2010). AMCHP developed a fact sheet, located at amchp.org/Policy-Advocacy/health-reform/Documents/Medical-Homes-ACA-Fact-Sheet.pdf, containing a full list of ACA provisions promoting the medical home and how state MCH programs can maximize these opportunities.

**Predict an individual’s health and wellness and/or that of their offspring**

The medical home redesigns pediatric primary care into a family-centered, coordinated system that focuses on a longitudinal view of the child’s lifespan to improve clinical outcomes, promote wellness, increase patient satisfaction, and lower care costs (Klein, 2009). Care within the medical home promotes relationships among health care providers, families and children that positively impact a host of individual health factors across the life span including prenatal care, school readiness, teen pregnancy, risk reduction, resilience, and family capacity to find resources to care for their children (Bachrach et al., 2011; Beal et al., 2007; Benedict, 2008; Kenney & Pelletier 2010). Children with a medical home are not only more likely to receive timely care in appropriate settings, but also are more likely to exhibit behaviors that aid in disease prevention and increase overall wellness (Long et al, 2012). The medical home is associated with increased preventive care visits and fewer ED and outpatient sick visits in children (Long et al, 2012). Overall wellness behaviors that may not typically be associated with health care including family reading, sufficient sleep, helmet use, and decreased television and video game use are also all more likely in children with a medical home (Long et al, 2012).

The medical home is particularly important for children as pediatric health care has a large role in maximizing a child’s developmental trajectory (Stille et al, 2010). The medical home offers increased surveillance for childhood disabilities and developmental problems, which can lead to early detection and intervention (Adams, 2013). Once a disability, developmental delay, or chronic condition is detected, medical home provides an effective approach to treatment and care management. Children without a medical home are likely to delay or forego health care, which negatively impacts child health outcomes (Strickland et al., 2004; Smaldone, Honig, & Byrne 2005). CSHCN with a medical home are less likely to have unmet need for supportive or therapeutic services (Benedict, 2008). Coordination of high quality therapeutic care for CSHCN maximizes eventual child independence, decreases family care burden, and enables the child to partake fully in their community (Benedict, 2008). Children with chronic diseases and disabilities with a medical home are less likely to be hospitalized or visit the emergency department (Cooley et al, 2009). A highly common childhood chronic condition, asthma, benefits from the coordinated chronic disease management received within a medical home (Clark et al., 1998; Clark et al., 2000), indicating opportunity to improve outcomes for other chronic conditions through managed medical home care.

**Data Criteria**

**Data availability**

The NSCH, sponsored by MCHB, examines the physical and emotional health of children ages zero to 17 years of age. The survey is administered using the State and Local Area Integrated Telephone Survey (SLAITS) methodology, and it is sampled and conducted in such a way that state-level estimates can be obtained for the 50 states, the District of Columbia, and the Virgin Islands. The survey has been designed to emphasize factors that may relate to the well-being of children, including medical homes, family interactions, parental health, school and after-school experiences, and safe neighborhoods. MCHB leads the development of the NSCH and NS-CSHCN survey and indicators, in collaboration with the National Center for Health Statistics (NCHS) and a national technical expert panel. The expert panel includes representatives from other federal agencies, state Title V leaders, family organizations, and child health researchers, and experts in all fields related to the surveys (adolescent health, family and neighborhoods, early childhood and development etc.). The most recent data set, the 2011-2012 NSCH, encompasses a sample size of more than 95,000 children with approximately 1,800 interviews completed in each of the 50 states and the District of Columbia.
MCH programs can readily gain immediate access to the data through datasets released by the National Center for Health Statistics, and on the MCHB sponsored Data Resource Center for Child and Adolescent Health website (childhealthdata.org). Data from the 2011/2012 NSCH were made available in early 2013. The survey questionnaire and raw dataset are available for download on the Centers for Disease Control and Prevention (CDC) NCHS website in SAS format. The Data Resource Center (DRC) website provides data nationwide, for all 50 states and the District of Columbia. Additionally, both the raw datasets and the website allow users to stratify measures by sociodemographic groups, including but not limited to age, sex, race/ethnicity, primary household language, household income, and special health care needs. Cleaned, state-specific datasets with new variables that include national and state indicators are available at no cost in SAS and SPSS formats. For information on how to order state-specific sets, contact caymi@ohsu.edu. Local data is not searchable. The NSCH is not administered annually. Over the past decade, the NSCH has been administered four times.

National, state and regional level results can be accessed online from the Data Resource Center website: childhealthdata.org. State and national data can be further refined to assess differences by race/ethnicity, income, special health care needs status and a variety of other important demographic and health status characteristics.

A total of 19 different survey questions are used to develop the overall composite score for having a Medical Home, which include assessment of whether children and youth:

- Have a personal doctor or nurse
- Have a usual source of care
- Receive care that is family-centered
- Receive care that is culturally sensitive
- Obtain needed specialty care referrals
- Receive help coordinating across multiple providers and types of services

**Data quality**
The main limitation of the NSCH is that the information provided is from parent recollection of screenings received and perception of child’s health and development over the past year. The survey methodology does not provide an opportunity for confirmation with medical records or physical measurements. The NSCH is weighted to represent the national population of non-institutionalized children age zero to 17 years. According to the survey documentation, missing data for income were relatively high for 2011-2012 data, and a study of nonresponse patterns indicated that excluding records with missing income could impact the representativeness of the remaining data; therefore, a data file with imputed values for income is provided to be used with the datasets.

The NSCH documentation presents both response rates and completion rates. For 2011-2012 data, the combined national response rate for both landline and cell phone samples was 23 percent. The completion rate, which is calculated as the proportion of households known to include children that completed all sections up to and including Section 6 (for children less than six years of age) or Section 7 (for children six to 17 years of age), was 54.1 percent for the landline sample and 41.2 percent for the cell-phone sample.

Qualitative testing of the entire 2007 National Survey of Children’s Health was conducted by the National Center for Health Statistics. They conducted cognitive interviews with the 2007 NSCH Computer-Assisted Telephone Interview (CATI) to make sure the entire survey instrument was functioning properly. N=640 interviews were completed over three days in December 2006. The questionnaire was then revised and finalized based on feedback from participants in these interviews.

Previously validated questions and scales are used when available. All aspects of the survey are subjected to extensive literature and expert review. Respondents’ cognitive understanding of the survey questions is assessed during the pretest phase and revisions made as required. All final data components are verified by NCHS and DRC/CAHMI staff prior to public release. Face validity is conducted in comparing results with prior years of the survey and/or results from other implementations of items.
The survey has been designed to emphasize factors that may relate to well-being of children, including Medical Homes, family interactions, parental health, school and after-school experiences, and safe neighborhoods. The main limitation of the survey is the fact it is based on parents’ recollection of screenings received and child’s health over the past year, with no opportunity for confirmation with medical records or physical measurements.

Simplicity of indicator
NSCH data have been extensively analyzed and presented graphically on the Data Resources Center website making it easy to use and explain. Professionals can run stratified analyses by subgroups of interest, while the public can see prevalence estimates with brief explanations. Data can be broken out by Medical Home component questions in order to address specific concerns.

“The American Academy of Pediatrics specifies seven qualities essential to Medical Home care: accessible, family-centered, continuous, comprehensive, coordinated, compassionate and culturally effective. Ideally, Medical Home care is delivered within the context of a trusting and collaborative relationship between the child’s family and a competent health professional who is familiar with the child and family and the child’s health history (AAP, 2002).” While the indicator itself might be easy to obtain, the Medical Home concept can be difficult to define or describe to those who are unfamiliar with it. Numerous initiatives are currently underway to promote and create Medical Homes (HHS, nd).

References


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Life Course Indicator: Asthma Emergency Department Utilization

The Life Course Metrics Project

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Basic Indicator Information

Name of indicator: Asthma Emergency Department Utilization (LC-38)

Brief description: Proportion of persons on Medicaid with asthma having an asthma emergency department (ED) visit

Indicator category: Health Care Access and Quality

Indicator domain: Risk/Outcome

Numerator: Number of Medicaid beneficiaries with asthma having one or more ED visit for asthma during the measurement year.

Denominator: Number of Medicaid beneficiaries with asthma during the measurement year.

Potential modifiers: The proportion of persons with an asthma ED visit can be stratified by age, gender, and race / ethnicity groups. In addition, the proportions may be stratified by geographic areas of interest based on available geographic indicators (e.g., zip code, county).

Data source: Medicaid Analytical eXtract (MAX) files

Notes on calculation: Numerator: Asthma ED visits. Patients with asthma who have an ED visit during the measurement year. ED visits are identified by either procedure codes 99281-99285 or revenue codes 450.xx. Either type of ED claim must have one or more of the following asthma ICD-9 diagnosis codes: 493.00, 493.01, 493.02, 4983.10, 493.11, 493.12, 493.81, 493.82, 493.90, 493.91, or 493.92 as the primary diagnosis. Dates of service must be within the measurement year. Denominator: All patients with a Medicaid claim reporting a diagnosis of asthma during the measurement period. Denominator includes beneficiaries with claims having one or more of the following asthma ICD-9 codes: 493.00, 493.01, 493.02, 493.10, 493.11, 493.12, 493.81, 493.82, 493.90, 493.91, or 493.92 (excludes 493.20, 493.21 and 493.22) as primary or secondary diagnoses.

Dates of service must be within the measurement year.

Similar measures in other indicator sets: HP 2020 Focus area RD-3; NQF measure 1381; MIECHV Benchmark Area Improvements in
Life Course Indicator: Asthma Emergency Department Utilization (LC-38)

Life Course Criteria

Introduction
Asthma is a common and costly health condition affecting 25.7 million people in the United States (Akinbami et al, 2012). Through physician guided asthma management plans, appropriate medications, and control of exposure to common asthma triggers, both adults and children with asthma should experience minor symptoms, few flare-ups, and infrequent interruptions of daily life. Emergency department (ED) visits for asthma are most often a result of uncontrolled asthma. Uncontrolled asthma has an affect on the life course of an individual as it is associated with increased mortality rates, long term health effects, comorbidities, and reduced performance in school or work due to absences and illness (O’byrne, 2013). A reduction in ED utilization for asthma symptoms should indicate an increase of control over asthma in the community, improved access to resources and services for management and improved collaboration between physicians and providers for treatment.

Implications for equity
The majority of patients visiting the ED for asthma have experienced uncontrolled or partially controlled bronchial asthma in the months leading up to the ED visit (AL-Jahadali et al, 2012). Age, race, socioeconomic status, and environmental factors all contribute to risk of uncontrolled asthma.

Asthma-related ED or urgent care center visits are significantly more prevalent annually for non-Hispanic blacks, Puerto Ricans, other Hispanics, and non-Hispanic American Indian or Alaskan Natives than for non-Hispanic whites (Law, Oraka, & Mannino, 2011). Black persons have the highest asthma ED visit and hospitalization rates per 100 persons in the United States and the highest asthma death rate per 1,000 persons in the United States with asthma (Akinbami et al, 2012). Large differences are found in asthma ED visit rates between blacks and whites, indicating disparities not just in prevalence of asthma but also asthma control. National rates for ED visits and hospitalizations are two- to three-fold higher for black Americans than white Americans (Law, Oraka, & Mannino, 2011). In the U.S. Hispanic population, Puerto Rican Hispanics had the highest ED visit rates, particularly in the national population below the Federal Poverty Level (FPL) (Law, Oraka, & Mannino, 2011). Lack of access to care and poor adherence to prescribed management in minority populations may contribute to these disparities. An analysis of state Medicaid programs showed that while Hispanics and blacks had higher asthma ED visit rates than whites, the number of filled prescriptions for inhaled corticosteroids and asthma specialist visits were higher in whites than Hispanics or blacks (Lieu et al, 2002).

Risk for asthma ED visits also varies by age. Children under four years of age have a higher rate of ED visits than any other age category (Akinbami et al, 2012). Racial disparities exist among children as well, with the rates of asthma-related ED visits among black children being approximately three times higher than those among white children (Law, Oraka, & Mannino, 2011). Although longitudinal studies of asthma morbidity across an individual’s life course are not available, evidence suggests substantial differences in asthma prevalence and ED use exist across age groups (Akinbami et al, 2012).

Children living in low-income areas have both a higher prevalence of asthma as well as higher hospital admission rates (Milton et al, 2004). Individuals with lower income and those without insurance face social and financial barriers to asthma prevention medications and consultations with specialists that would help avoid eventual ED visits. Increased exposure to household irritants in low income households may also be a contributing factor to uncontrolled asthma in this population (Milton et al, 2004).

Public health impact
Approximately 34 million people (11.5 percent) in the United States have been diagnosed with asthma during their lifetime (American Lung Association, 2007). As of 2011, 18.9 million adults (8.2 percent) (Schiller, Lucas, & Peregoy, 2011) and 7.1 million children (9.5 percent) had asthma (Bloom, Cohen, & Freeman, 2012). From 2001 to 2010, asthma prevalence increased from 7.3 percent to 8.4 percent (Akinbami et al, 2012).
Asthma is the cause of 2.1 million ED visits each year (National Hospital Ambulatory Medical Care Survey, 2009), which indicates poorly controlled asthma and increased risk for future complications (U.S. Department of Health and Human Services, 2007).

Asthma is also responsible for large direct and indirect economic costs. The annual direct health care cost of asthma in the United States has been estimated at $50.1 billion, with indirect costs due to lost productivity at $5.9 billion, totaling $56 billion (Barnett & Nurmagambetov, 2011). ED visits were estimated to cost approximately $638 million in 2006 alone (U.S. Department of Health and Human Services, 2007). Uncontrolled asthma severely impacts quality of life and limits school and work attendance. Asthma resulted in 2.3 million children missing 14.4 million days of school and adults missing 36.2 million days of work in 2008 (Lyon-Callo et al). It is estimated that more than half (59 percent) of children and one-third of adults who had an asthma attack missed school or work because of asthma (Reeves et al, 2006).

A decrease in the proportion of Medicaid beneficiaries with asthma having an ED visit in a given year would indicate improved asthma management, perhaps via access to care or medication adherence and assistance. This would result in fewer missed school or work days in a population that bears a disproportionate share of risk for asthma and poor health outcomes from asthma. Improving asthma management in youth can instill health behaviors that can carry forward through transition to adult care.

**Leverage or realign resources**

There are a number of opportunities to use health care and health research resources to improve this indicator. These opportunities include:

- Care managers/coordinators working with providers to target education and self-education
- Health care providers working with asthmatic patients or parents of asthmatic children to create an asthma management plan that includes use of preventer, reliever, and symptom controller medications as well as regular follow-up visits for assessment of asthma control
- Potential to alert primary care providers that their patient has been seen (or repeatedly seen) in the ED for asthma (capitalizing upon telehealth and/or electronic medical records)
- Ability to characterize ED utilization patterns, monitor outcomes of ED visits (repeat ED visits), identify subpopulations with high asthma burden (to target interventions) (Reeves et al 2006)
- Ability to monitor trends over time and compare rates of asthma between subgroups / geographic areas (e.g., zip code or county level). This may be beneficial in conjunction with air quality information, if available

In addition to these health care and health research resources, the American Lung Association lists outdoor air pollution, homes, schools, and workplaces as public policy categories that could be targeted with interventions to increase control of asthma in the United States in their National Asthma Public Policy Agenda (American Lung Association, 2009).

Although the Environmental Protection Agency (EPA) sets standards for six major outdoor air pollutants: ozone, particulate matter, sulfur dioxide, nitrogen oxide, lead and carbon monoxide, millions of Americans still live in communities that do not meet EPA air quality standards (American Lung Association, 2009). The air quality index is important for asthmatic individuals and parents or guardians of asthmatic children to know when planning outdoor activities. Modifying activities on days with a poor air quality index can help control asthma and avoid ED visits. Indoor asthma triggers include cigarette smoke, dust mites, molds, cockroaches, pet dander, and chemical irritants (American Lung Association, 2009). An opportunity exists in partnering with the housing sector to limit exposure to these asthmatic triggers. Policies and practices adopted by city and state housing authorities such as smokefree group housing and pest management strategies can reduce these indoor pollutants. Additionally, partnerships between housing and community health workers could enable home visiting for families of children with poorly controlled asthma to identify and remove or reduce household irritants.

Schools and workplaces are both stakeholders in asthma control as asthma is responsible for significant absenteeism from both school and work. The U.S. Department of Health and Human Services and the U.S. Department of Education partnered to create a guide for schools to use in asthma management. The guide includes developing student asthma management plans as well as school partnerships with families, physicians, and special service agencies to address family needs such as lack of insurance (U.S. Department of Health and Human Services & U.S. Department of Education, 2001).
The limitations of using Medicaid claims as a data source indicate the need for an increase in the amount of local and national data on asthma ED visits available for analysis. Workgroups partaking in the National Workshop to Eliminate Asthma Disparities recommended an increase in epidemiologic data surrounding asthma outcomes and risk factors through a regional coalitions engaging public (Medicaid) and private health plans (Weiss, 2007). For example, future data sources may include statewide or regional health information exchanges.

Additionally, through health reform and the Affordable Care Act (ACA) there are many opportunities through community and systems changes to improve chronic conditions such as asthma. For example, accountable care organizations (ACOs), some of which are supported through ACA funding, are “a group of health care providers who give coordinated care, chronic disease management, and thereby improve the quality of care patients get. The organization's payment is tied to achieving health care quality goals and outcomes that result in cost savings.” The Prevention and Public Health Fund, funded through the ACA, makes provisions for funding and investments in evidence-based prevention and public health to “improve health outcomes, and to enhance health care quality.” Further, the ACA authorized the Medicaid health home benefit to intensively coordinate the care of enrollees with chronic conditions such as diabetes, serious mental illness and asthma.

**Predict an individual’s health and wellness and/or that of their offspring**

The use of the ED for asthma is a well-recognized marker for poorly controlled asthma and the increased risk of future complications (National Asthma Education and Prevention Program, 2007). Poorly controlled asthma is associated with higher asthma morbidity and mortality for affected individuals. Both school attendance among children and work attendance among adults are reduced as a result of uncontrolled asthma (Reeves et al, 2006). Asthma related absences vary across the life course, with 2.3 million children missing 14.4 million days of school and adults missing 36.2 million days of work (Lyon-Callos et al 2008). Absenteeism and “presenteeism”, being present at work or school but working in a diminished capacity due to illness symptoms, can lead to decreased overall performance and capacity.

Control of asthma consists of minimizing day-to-day symptoms but also includes minimizing risks of future unstable asthma, experiencing loss of lung function, and medication side effects, underscoring the importance of ensuring effective asthma management in early childhood (O’byrne, 2013). Significant negative health impacts other than these most commonly associated impacts can result from poorly controlled asthma. Studies have shown asthmatic children who lack control of their disease are significantly less active and have less intensive daily activities than children whose asthma is controlled (O’byrne, 2013). Obesity has been associated with asthma and may be a result of weight gain and inactivity due to asthma symptoms (O’byrne, 2013). Other health effects of this indicator include asthma-disturbed sleep, reduced participation in social activities, and an increased risk for anxiety and depression (National Institute of Clinical Studies, 2005, Peters et al, 2006). Anxiety and depression can be significant contributors to non-adherence to asthma management plans, which creates a cycle of uncontrolled asthma complications and non-adherence to medications (Weiss, 2007).

Lastly, severe or difficult-to-manage asthma is associated with several other comorbidities such as allergic rhinitis and gastroesophageal reflux disease (GERD). Both conditions are thought to exacerbate asthma and are also found at a higher prevalence in asthmatics than the general population (Peters et al 2006).

**Data Criteria**

**Data availability**

Medicaid administrative claims data are available from the Medicaid Analytic Extract (MAX) files maintained by the Centers for Medicare & Medicaid Services (CMS) (Medicaid Analytic Extract (MAX) files, 2013). MAX files are claim-level data files that summarize Medicaid inpatient, outpatient, and pharmacy services as well as person-level eligibility files. MAX data contain individually identifiable data, and are available for research activities approved by CMS through a Data Use Agreement (DUA) with CMS. Technical assistance with MAX data and availability is provided by the Research Data Assistance Center (ResDAC) (ResDAC, 2013).

Although MAX data are available for each state, availability may vary by state and year, and the timeliness and completeness of data reporting varies by state and year. In general, there is more than a three-year time lag for MAX data.
A limitation of the data source is the inability to obtain a national comparison statistic. Also, because the data is obtained from Medicaid claims, stratification of the indicator by two main risk factors, insurance status and poverty level, is not possible.

**Data quality**

Data quality is an important consideration of Medicaid claims data, irrespective of the source of the data. Consequently, the user is required to understand how to determine whether the requisite fields are populated with valid values. Although MAX data are available for each state, the timeliness and completeness of data reporting varies by state and year. In general, there is more than a three-year time lag for MAX data release.

The respective MCH program should determine whether the data are sufficiently complete and accurate for their purposes. For example, one state may have incomplete data for Medicaid managed care members in a given year. If this is important to the MCH program, the MAX data should be sought for a different year that may be more complete, or complete Medicaid claims data may be available directly from the state’s program. ResDAC may be able to provide information regarding the degree to which data quality issues may exist with a particular state’s MAX data (Weiss, 2001). Information about the data quality of asthma ED visit as recorded in the MAX file is not available.

**Simplicity of indicator**

This indicator is used to assess the percentage of persons with an asthma diagnosis reported during the measurement year with one or more asthma-related ED visits. The indicator is patterned after the CHIPRA measure, but the proposed modifiers (age, gender, race/ethnicity, geographic areas of interest) offer additional insights into asthma ED visit dynamics in a given population. If a state does not wish to compute the stratified counts as proposed, the total overall ED visit categories (Table 1) is equivalent to the published CHIPRA measure.

The administrative claims data necessary to compute these measures relies on a limited number of data elements, including:

- Date of service
- Diagnosis code
- Procedure code
- Revenue code
- Date of birth (age)
- Gender
- Race
- Residence county
- Residence zip code (if available)

Given the measure is consistent with the CHIPRA quality measure and is well understood to be associated with quality of and access to care for a vulnerable population, MCH programs will face few challenges explaining and using the indicator as a measure of life course health. Any complexity associated with calculating the measure is centered around the desirability for stratification.

Medicaid administrative data are maintained by all states and have been used widely for asthma-related studies. Of note, the Centers for Medicare and Medicaid Services has published the initial core set of quality measures for children enrolled in Medicaid and the Children’s Health Insurance Program (CHIP). Among these measures is Measure 20: Annual Percentage of Asthma Patients with One or More Asthma-Related Emergency Room Visits, which is a Medicaid claims-based measure.
Although the CHIPRA-proposed measure is aimed at a simple rate of patients with at least one asthma ED visit, there is ample evidence to suggest that frequent ED use among asthma patients is a common problem. One study found that asthma patients with six or more ED visits accounted for 68 percent of total ED visits. High utilizers such as these are responsible for disproportionately high costs. Data from the National Medical Expenditure Survey reported that 20 percent of all asthma patients account for 80 percent of total asthma related costs (Weiss, 2001).

With that in mind, it may be desirable to enhance the CHIPRA quality measure to reflect additional information regarding the volume of asthma ED use by beneficiaries; this can be accomplished using the same data source as basic process. Such measures help distinguish whether multiple persons are using relatively low numbers of asthma ED visits, or if relatively few persons are making repeated asthma ED visits.

To reflect this, the proportion of persons with one or more asthma ED visit can be stratified to create an indicator that distinguishes those with minimal asthma ED use (e.g., those with one asthma ED visit) from those with repeated visits (e.g., five asthma ED visits). Table 1 illustrates how measures of beneficiaries with one asthma ED visit, two, three, four, or five or more visits can be separately counted to provide an indication of the degree to which ED resources are being used by repeat ED visitors in the course of a year. Each count of persons having the respective number of asthma ED visits is divided by the same population denominator to show the fraction of persons with asthma with that number of asthma ED visits. The denominator can be for the entire population of persons with asthma in the respective Medicaid jurisdiction, or for age, gender, and race subgroups. The total overall ED visit category is equivalent to the CHIPRA indicator of the proportion of persons with asthma having one or more asthma ED visit.

**Table 1: Asthma annual ED use metric summary**

<table>
<thead>
<tr>
<th>Group</th>
<th>Numerator</th>
<th>Denominator</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 asthma ED visit</td>
<td>Count of persons with 1 annual asthma ED visit</td>
<td>All persons in group (or age, gender, race, etc. subgroup)</td>
</tr>
<tr>
<td>2 asthma ED visits</td>
<td>Count of persons with 2 annual asthma ED visit</td>
<td></td>
</tr>
<tr>
<td>3 asthma ED visits</td>
<td>Count of persons with 3 annual asthma ED visit</td>
<td></td>
</tr>
<tr>
<td>4 asthma ED visits</td>
<td>Count of persons with 4 annual asthma ED visit</td>
<td></td>
</tr>
<tr>
<td>5 or more asthma ED visits</td>
<td>Count of persons with 5 annual asthma ED visit</td>
<td></td>
</tr>
<tr>
<td>All groups combined</td>
<td>Count of persons with 1 or more annual asthma ED visit</td>
<td></td>
</tr>
<tr>
<td>(e.g., persons with 1 or more</td>
<td></td>
<td></td>
</tr>
<tr>
<td>asthma ED visit)</td>
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</tbody>
</table>

Similarly, counts of asthma ED visits can be examined to determine the average number of asthma ED visits per capita over the entire eligible population or subgroups (Table 2). This measure provides a sense of the proportion of total asthma ED visit volume that is attributable to beneficiaries having one asthma ED visit, two asthma ED visits, etc. This measure is determined by computing the number of asthma ED visits for each member with asthma (identical to the measure described in Table 1), but then summing the total number of asthma ED visits over all persons in the respective categories as shown in Table 2. Each sum of asthma ED visits is divided by the total population of persons with asthma in the respective Medicaid jurisdiction. Again, these counts can be stratified in a similar manner as above to yield per capita rates by age, gender race, etc.
Table 2: Asthma annual ED volume metric summary

<table>
<thead>
<tr>
<th>Group</th>
<th>Numerator</th>
<th>Denominator</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 asthma ED visit</td>
<td>Sum of annual asthma ED visits among those with 1 visit</td>
<td></td>
</tr>
<tr>
<td>2 asthma ED visits</td>
<td>Sum of annual asthma ED visits among those with 2 visits</td>
<td></td>
</tr>
<tr>
<td>3 asthma ED visits</td>
<td>Sum of annual asthma ED visits among those with 3 visits</td>
<td></td>
</tr>
<tr>
<td>4 asthma ED visits</td>
<td>Sum of annual asthma ED visits among those with 4 visits</td>
<td></td>
</tr>
<tr>
<td>5 or more asthma ED visits</td>
<td>Sum of annual asthma ED visits among those with 5 or more visits</td>
<td></td>
</tr>
<tr>
<td>All groups combined (e.g., persons with 1 or more asthma ED visit)</td>
<td>Sum of annual asthma ED visits over all groups</td>
<td></td>
</tr>
</tbody>
</table>

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Life Course Indicator: Inability or Delay in Obtaining Necessary Medical Care or Dental Care

Basic Indicator Information

Name of indicator: Inability or delay in obtaining necessary medical care or dental care (LC-39)

Brief description: Percent of parents reporting their child was not able to obtain necessary medical care or dental care.

Indicator category: Health Care Access and Quality

Indicator domain: Service/Capacity

Numerator: Number of survey respondents that report their child (ages 0-17) was not able to obtain or had a delay in obtaining necessary medical care or dental care.

Denominator: Total child population ages 0-17

Potential modifiers: Age, race/ethnicity, family structure, primary household language, household income, health insurance status, type of health insurance, special health care needs status

Data source: National Survey of Children’s Health (NSCH)

Notes on calculation: The numerator is calculated from the question “During the past 12 months, was there any time when [child name] needed health care but it was delayed or not received? Was it medical care, dental care, mental health services, or something else?” (K4Q27) and unmet needs are grouped according to type of health care: medical (K4Q28X01), dental (K4Q28X02), vision care (K4Q28X03), mental health (K4Q28X04), or other (K4Q28X05). This indicator counts the number of children who had unmet needs in only medical and dental care. Analysts who use the raw datasets should apply the appropriate survey weights to generate the final estimates.

Similar measures in other indicator sets: HP 2020 Focus area AHS-6; Title V Performance Measure #04 (limited to CSHCN); MIECHV Benchmark Area Improvements in Family Economic Self-Sufficiency: Health insurance status of participating adults and children

The Life Course Metrics Project

As MCH programs begin to develop new programming guided by a life course framework, measures are needed to determine the success of their approaches. In response to the need for standardized metrics for the life course approach, AMCHP launched a project designed to identify and promote a set of indicators that can be used to measure progress using the life course approach to improve maternal and child health. This project was funded with support from the W.K. Kellogg Foundation.

Using an RFA process, AMCHP selected seven state teams, Florida, Iowa, Louisiana, Massachusetts, Michigan, Nebraska and North Carolina, to propose, screen, select and develop potential life course indicators across four domains: Capacity, Outcomes, Services, and Risk. The first round of indicators, proposed both by the teams and members of the public included 413 indicators for consideration. The teams distilled the 413 proposed indicators down to 104 indicators that were written up according to three data and five life course criteria for final selection.

In June of 2013, state teams selected 59 indicators for the final set. The indicators were put out for public comment in July 2013, and the final set was released in the Fall of 2013.
Life Course Criteria

Introduction
Delay in obtaining necessary health care is connected to our current scientific understanding of the life course approach to health. Existing literature supports a new understanding that health develops as a consequence of the cumulative influence of multiple risk and protective factors over time (Simpson, 1997). The exposure to unmet health care needs during critical and sensitive periods of development (i.e. early childhood and adolescence) can be extremely influential in impacting health later in life. For example delays in hearing screening can result in language impairment and other morbidities (Patel, 2011). Another example is the diagnosis of autism, which indicates need for more care to reduce delays in the child’s development. Additionally, delay in diagnosis or treatment of asthma in childhood has been associated with increased urgent care use and poorer asthma management and health outcomes (Lynch et al, 2010; Stanford et al, 2012) Associations found in literature between this indicator and poverty, race, and insurance status show how delay in care for children contributes to health inequities. Eliminating significant health risks of children by ensuring there are no delays in obtaining timely health care can have a positive impact on that individual's health and well-being as they proceed through their life course.

Implications for equity
Nationally in 2007, less than 10 percent (6.9 percent) of parents reported to the NSCH that their child was unable to obtain or was delayed in receiving health care (DRCCA, 2012). Risk of delay or inability to receive health care for children is intertwined with access to care and varies by race/ethnicity, household income level, and health insurance status. While these factors are interrelated, each one plays a role in the issue of childhood unmet health care needs.

Black (8.9 percent) and Hispanic (8.2 percent) children are more likely to have a delay in receiving care compared to non-Hispanic white (5.9 percent) children (DRCCA, 2012). Minority race is associated with other risk factors for delay in health care such as lack of insurance. However, a 2009 analysis by the Kaiser Family Foundation found that while public or private insurance improved children’s access to care across three racial categories (black, Hispanic, and non-Hispanic white), disparities remained among these groups (Lillie-Blanton, 2009).

Unmet health care needs in children also are strongly associated with poverty status. Even after controlling for insurance status and other confounders, children in families with income below the federal poverty level were four times as likely to experience unmet health care needs as children in families with incomes greater than or equal to 200 percent of the federal poverty level (Newacheck, Hughes, Hung, Wong, & Stoddard, 2000). Poor families face both financial barriers such as lack of insurance, or if insured, copayments, as well as non-financial barriers such as health care facility location, transportation, and operating hours. Misunderstanding the seriousness of a disease and delaying care for necessary conditions also is most common in low income groups, suggesting that these individuals are not well integrated into the health care system and have difficulty discerning between conditions that require care and self-limited conditions (Weissman, Stern, Fielding, & Epstein, 1991).

Insurance status has been shown to be the strongest predictor of delay of child health care. Uninsured children are more likely to have an unmet health care need than insured children (Lave, 1998; Newacheck, 1998; Stoddard, 1994; Newacheck, 2000). Inability or delay in receiving care was experienced by 17.2 percent of uninsured children compared to just 5.0 percent of consistently insured children (DRCCA, 2012). Lack of insurance causes obvious financial barriers to obtaining medical and dental care and contributes to a family’s lack of integration into the health care system.

Receiving timely and appropriate health care is an important aspect of child well-being that can affect a child’s health, development, and life chances. An unmet need for health care can adversely affect a child’s health status and functioning both short and long term (Newacheck et al, 2000). Not receiving care or delaying in receiving care can have serious consequences for both the child and their family. Disparities in access by race/ethnicity, household income level, insurance status, and others promote health inequity (Newacheck et al, 2000). Addressing this indicator and working toward decreasing the number of children who have trouble accessing care would have an impact on reducing inequities.

Public health impact
Delays in receiving medical care may result in a patient becoming more severely ill and having a worse prognosis than if they had presented at a medical facility earlier in the course of their illness. The advanced condition can lead to possible
hospitalization and higher costs than would have been required initially (Weissman et al., 1991). These additional costs can put an added strain on an already taxed health care system by increasing hospital costs as well as Medicaid costs for beneficiaries who may have delayed care. Where low income status has been associated with delay or inability in obtaining medical care even when insurance status is controlled for in analysis, Medicaid claims could be significantly negatively affected by an increase in costs associated with conditions that were worsened by a delay in care.

Untreated physical, psychological, and behavioral problems are risk factors for children to develop lifelong chronic conditions (Newacheck et al., 2000). Access to care has been theorized as a major contributor for the health status discrepancies across high, mid, and low socioeconomic status. Studies have found that when access to primary care is leveled across income strata, no significant differences are found for ambulatory care-sensitive conditions such as asthma (Andrulis, 1998). Findings such as these suggest prompt care for injury and illness in childhood has the potential to reduce the burden of disease later in life.

**Leverage or realign resources**

The ability to reduce this indicator at both the national and state level is influenced by several factors, the most important being access to health insurance. Work towards universal health insurance in the United States has great potential to affect this indicator. Several federally funded programs like Medicaid and the State Children’s Health Insurance Program are working toward providing health insurance to those who cannot afford or are ineligible for private insurance. However, there is still a large gap in coverage throughout the United States. The Affordable Care Act (ACA) was developed, in part, to address the issue of delays in obtaining timely health care. Service utilization should increase with the implementation of the ACA as uninsured individuals who would have previously delayed or not sought medical care will be insured.

Although ACA implementation and other state health reform efforts will help to reduce the number of children who are uninsured and increase integration into the health care system, barriers to accessing care remain, particularly for people of low socioeconomic status. Difficulties can arise in getting children to health care services through transportation issues, facility hours, and the ability of the parent to take time off of work. Medicaid programs in states such as Massachusetts include a non-emergency transportation service component. Including non-emergency transportation to health services in other Medicaid programs could help low income families utilize care for their children. Also essential to accessing care are more convenient hours at facilities and the ability of a parent to take time off of work. Many workers in low wage jobs do not have the benefit of paid time off, an issue that has been presented to law makers in a number of states and cities recently.

A number of national and state programs aim to increase timely health care utilization and can be partnered in efforts to decrease barriers. For example, reducing the number of individuals in the US who are delayed in receiving timely health care is one of the goals of Healthy People 2020 (USDHHS, 2013).

Schools have a vested interest in ensuring children receive timely health care services. Children with inadequate health care are more likely to have problems in school or learn at a slower pace. One example of the education system’s actions to reduce receipt of timely health care is through their screening program for early diagnosis of certain developmental disorders such as autism. Early diagnosis of autism spectrum disorders has been demonstrated to result in benefits for children and their families (Dababnah, 2011). Another example is the establishment of Early Head Start (EHS) and Head Start (HS) programs. These programs focus on language and literacy, cognition and general knowledge, physical development and health, social and emotional development, and approaches to learning (Head Start, March 2013). EHS and HS programs serve families with infants, toddlers, preschool age children, or pregnant women who live below the federal poverty level. Children that graduate from these programs are more likely to receive timely health care and perform well in school compared to their peers (Lee, 2013; Love 2013).

Early intervention (EI) programs also are an important resource to consider when looking at this indicator. EI programs focus on improving child health and development, which can help identify children who are experiencing delays in receiving timely health care. Researchers should note that these services are more effective the earlier they are received. Delays in timely health care are likely to translate to delays in EI services which can translate to decreased efficacy due to later intervention and increased costs for the education system in the form of special education. The Early Childhood Outcomes Center showed that EI services between the ages of three and five can avoid costs associated with special education and that EI participants perform at the same developmental level as their peers (2011). Early intervention also
may reduce the costs associated with morbidity from untreated dental caries, delayed vaccination, and delayed identification of autism spectrum disorders.

**Predict an individual’s health and wellness and/or that of their offspring**

Inadequate access to health care, measured by the delay in obtaining timely health care, can result in poor health outcomes for children. For example, several studies have shown the negative impacts of delays in necessary dental care. The short term health impacts of delays in timely dental care for children include increased morbidity and cost of care (Mouradian, 2000). Poor oral health and dental disease often continue into adulthood with the potential to affect speech, nutrition, economic productivity, and quality of life (Mouradian, 2000). A delay in obtaining necessary health care is associated with poor health outcomes; timely access to necessary and appropriate medical care could potentially prevent such events. For example, early diagnosis of autism spectrum disorders have been shown to benefit children and their families by helping reduce problem behaviors, improving academic achievement and school outcomes, and increasing social participation (Dababnah, 2011).

A limitation of this indicator is the availability of state level data for children (aged 0-17 years) but not for adults. The lack of state-level data for adults makes the task of monitoring the effect of delays in obtaining timely health care across the life-course more challenging. However, NSCH data capture a key risk factor during critical periods of development. Data for adults are available through the Medical Expenditure Panel Survey, but MEPS only provides national level data, and there is no evidence to support the estimation of state level data from MEPS.

**Data Criteria**

**Data availability**

The National Survey of Children’s Health, sponsored by the Maternal and Child Health Bureau (MCHB) of the Health Resources and Services Administration, examines the physical and emotional health of children ages 0-17 years of age. The survey is administered using the State and Local Area Integrated Telephone Survey (SLAITS) methodology, and it is sampled and conducted in such a way that state-level estimates can be obtained for the 50 states, the District of Columbia, and the Virgin Islands. The survey has been designed to emphasize factors that may relate to the well-being of children, including medical homes, family interactions, parental health, school and after-school experiences, and safe neighborhoods. The MCHB leads the development of the NSCH and NS-CSHCN survey and indicators, in collaboration with the National Center for Health Statistics (NCHS) and a national technical expert panel. The expert panel includes representatives from other federal agencies, state Title V leaders, family organizations, child health researchers, and experts in all fields related to the surveys (adolescent health, family and neighborhoods, early childhood and development etc.). The most recent data set, the 2011-2012 NSCH, encompasses a sample size of more than 95,000 children with approximately 1,800 interviews completed in each of the 50 states and the District of Columbia.

MCH programs can readily gain access to the data through datasets released by the NCHS, and on the MCHB sponsored National Data Resource Center for Child and Adolescent Health Website (www.childhealthdata.org). Data from the 2011/2012 NSCH were made available in early 2013. The survey questionnaire and raw dataset are available for download on the CDC’s NCHS website in SAS format. The Data Resource Center (DRC) website provides data nationwide, for all 50 states and the District of Columbia. Additionally, both the raw datasets and the website allow users to stratify measures by sociodemographic groups, including but not limited to age, sex, race/ethnicity, primary household language, household income, and special health care needs. Cleaned, state-specific datasets with new variables that include national and state indicators are available at no cost in SAS and SPSS formats. For information on how to order state-specific sets, contact cahmi@ohsu.edu. Local data is not searchable. The NSCH is not administered annually. Over the past decade, the NSCH has been administered four times.

Data from the 2011/2012 NSCH was made available in early 2013. The numerator is calculated from data reported by parents in response to the following question: “During the past 12 months, was there any time when [child name] needed health care but it was delayed or not received? Was it medical care, dental care, mental health services, or something else?” (DRCCA, 2012).
Data quality
The main limitation of the NSCH that the information provided is from parent recollection of screenings received and perception of child’s health and development over the past year. The survey methodology does not provide an opportunity for confirmation with medical records or physical measurements. The NSCH is weighted to represent the national population of non-institutionalized children age 0-17 years. According to the survey documentation, missing data for income were relatively high for 2011-2012 data, and a study of nonresponse patterns indicated that excluding records with missing income could impact the representativeness of the remaining data; therefore, a data file with imputed values for income is provided to be used with the datasets.

Data from the NSCH are standardized nationally, relevant and valid, can be stratified by subgroups, and have been collected every four years since 2003 (USDHHS, 2009). The NSCH documentation presents both response rates and completion rates. The response rate for the survey was 51.2 percent, and the interview completion rate was 66.0 percent in 2007. For 2011-2012 data, the combined national response rate for both landline and cell phone samples was 23 percent. The completion rate, which is calculated as the proportion of households known to include children that completed all sections up to and including Section 6 (for children less than six years of age) or Section 7 (for children six to 17 years of age), was 54.1 percent for the landline sample and 41.2 percent for the cell-phone sample. Therefore, researchers should be cautious when interpreting survey results at the state level.

Qualitative testing of the entire 2007 National Survey of Children’s Health was conducted by the National Center for Health Statistics. They conducted cognitive interviews with the 2007 NSCH Computer-Assisted Telephone Interview (CATI) to make sure the entire survey instrument was functioning properly. N=640 interviews were completed over three days in December 2006. The questionnaire was then revised and finalized based on feedback from participants in these interviews.

Previously validated questions and scales are used when available. All aspects of the survey are subjected to extensive literature and expert review. Respondents’ cognitive understanding of the survey questions is assessed during the pretest phase and revisions made as required. All final data components are verified by NCHS and DRC/CAHMI staff prior to public release. Face validity is conducted in comparing results with prior years of the survey and/or results from other implementations of items.

There are no specific reliability results available for this measure. Survey participants were asked what type of health care was delayed or not received. The data are reported as either no unmet need or one or more unmet need(s). Unknown values (responses of “refused to answer”, “do not know”, or system missing) are not included in prevalence estimates (DRC/CAHMI, 2012). States can further stratify the answer one or more unmet need(s) by adding the question: “What type of care was delayed or not received? Was it medical care, mental health services, or something else?” The 2011-2012 NSCH questionnaire adds “vision care” to this question. Stratifying by levels of care allows for more in-depth analysis, which may be important as delay in some types of care, like dental, are more frequently observed or result in more morbidity. Some stratified data at the state level are less reliable due to small sample sizes so states should consider combining years. If states combine years, they should consider that the survey is asked every four years and that timeframe may have implications for response comparability. The survey does not ask specifically about prescription medicines. A lack of data for this aspect of care will be a limitation of the data.

Simplicity of indicator
The level of complexity in calculating and explaining this indicator is low. The linkage of data sets is not required to calculate this indicator. The NSCH reports data in a way that does not require additional data weighing, indexing, or adjusting. The numerator and denominator are simple to calculate. Additionally, this indicator is easy to explain to professionals as well as the general public. Researchers should consider that potential modifiers might influence the results. To account for some modification, the website where users can access data allows for stratification by sociodemographic groups.
Life Course Indicator: Inability or delay in obtaining necessary medical care or dental care (LC-39)
Life Course Indicator: Inability or delay in obtaining necessary medical care or dental care (LC-39)


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Life Course Indicator: Medical Insurance for Adults

The Life Course Metrics Project

As MCH programs begin to develop new programming guided by a life course framework, measures are needed to determine the success of their approaches. In response to the need for standardized metrics for the life course approach, AMCHP launched a project designed to identify and promote a set of indicators that can be used to measure progress using the life course approach to improve maternal and child health. This project was funded with support from the W.K. Kellogg Foundation.

Using an RFA process, AMCHP selected seven state teams, Florida, Iowa, Louisiana, Massachusetts, Michigan, Nebraska and North Carolina, to propose, screen, select and develop potential life course indicators across four domains: Capacity, Outcomes, Services, and Risk. The first round of indicators, proposed both by the teams and members of the public included 413 indicators for consideration. The teams distilled the 413 proposed indicators down to 104 indicators that were written up according to three data and five life course criteria for final selection.

In June of 2013, state teams selected 59 indicators for the final set. The indicators were put out for public comment in July 2013, and the final set was released in the Fall of 2013.

Basic Indicator Information

Name of indicator: Medical Insurance for Adults (LC-40)

Brief description: The proportion of adults with medical insurance.

Indicator category: Health Care Access and Quality

Indicator domain: Service/Capacity

Numerator: Number of adults 19 years and older with medical insurance

Denominator: All adults 19 years and older

Potential modifiers: Age (19 to 64 and 65 and older), sex, race/ethnicity, marital status, household income, employment status, education


Notes on calculation: These data can be obtained from Table HI05. Health Insurance Coverage Status and Type of Coverage by State and Age for All People. Some data sources define adults as over age 18; this indicator includes all adults including those 65 and older covered by Medicare. Elder adults do not contribute much to the uninsured group; looking at age as a potential modifier is recommended. Additional data sources to examine the modifiers include the Agency for Healthcare Research and Quality Medical Expenditure Panel Survey; the Centers for Disease Control and Prevention (CDC) National Health Interview Survey, the National Health and Nutrition Examination Survey and the Behavioral Risk Factor Surveillance System; U.S. Census Bureau American Community Survey (ACS) and Survey of Income and Program Participation.

Similar measures in other indicator sets: Healthy People 2020 Access to Health Services (AHS)-1.1; Maternal, Infant, and Early Childhood Home Visiting (MIECHV) Benchmark V - Family Economic Self-Sufficiency: Construct 5.3, Health Insurance Status; Chronic Disease
Life Course Criteria

Introduction
In 2012, there were 48 million Americans, representing about 15 percent of the population, without health insurance (DeNavas-Walt, 2013). Of these uninsured Americans, more than 80 percent were 19 years of age or older, the majority had low incomes, and persons of color were disproportionately represented. There are many reasons why so many Americans have not had health insurance, although the number of uninsured persons in the United States has been decreasing since the implementation of the Patient Protection and Affordable Care Act (ACA) in 2010.

Many persons do not have access to insurance through an employer; and there have been limited affordable options to purchase insurance. For low-income families, there are public insurance options (e.g., Medicaid), but there are gaps in eligibility, and the process of securing coverage can be onerous. Additionally, Medicaid has historically been based on categorical eligibility that included pregnant women, children, and disabled and elderly persons, but not non-disabled adults. The ACA has expanded access to insurance coverage. Two of its key provisions are to close the eligibility gap for low-income persons, including non-disabled adults through Medicaid expansions, and to facilitate access to insurance coverage through the Health Insurance Exchanges.

Lack of insurance has both health and financial implications. Numerous studies have demonstrated the positive effects of Insurance coverage on both chronic and acute conditions (Institute of Medicine, 2002a; McWilliams, 2009). When uninsured persons do seek care, they can be left with medical bills that they cannot pay, often resulting in the accumulation of medical debt, which can have devastating consequences. Peoples with medical debt have been found to cancel medical appointments, delay recommended care and not fill prescriptions (Grande et al., 2013). They also are at risk of using up their savings, having damaged credit or even filing for bankruptcy (Sommers et al., 2011).

As the ACA is fully implemented, it will be important to monitor insurance coverage for the U.S. population. Health insurance is a major factor in understanding and addressing health and disease patterns, including disparities, found across populations and across the life span.

Implications for equity
The majority of the uninsured persons in the United States are low-income working families. Persons of color are disproportionately represented among the uninsured, and non-elderly adults are more likely to be uninsured than children (Kaiser Family Foundation, September, 2013). Adults with less than a high school education are more likely to be uninsured than those with more education (Ross et al., 2006).

There is well-established evidence of disparities in health insurance coverage across different racial/ethnic groups (Institute of Medicine, 2003, Kaiser Family Foundation, March 2013, DHHS, 2014). In 2012, the highest rates of non-insurance were found in Hispanic (41 percent), American Indian (32 percent), and Black (26 percent) adults. White adults had the lowest rate of non-insurance (15 percent), and Asian adults had the second lowest rate at 21 percent (Kaiser Family Foundation, March 2013). Employment may, in fact, explain some of disparities in insurance coverage among different racial/ethnic groups. Persons of color are more likely to be in low-wage jobs where insurance is either not available or unaffordable (Lillie-Blanton and Hoffman, 2005).

Public health impact
Compared to the insured, uninsured persons are less likely to receive medical care, preventive screening and treatment, and are more likely to have poor health status. When uninsured persons do receive care, it is often for conditions or events that may have been avoided with regular medical care, and the care is costly. In 2008, uninsured persons received about $86 billion dollars in uncompensated care, 75 percent of which was financed by government programs (Hadley et al., 2008). These dollars could potentially have been used for other health care services, including preventive services.

Clinical preventive services, including immunizations and disease screening, are key to preventing death and disability and improving the health of Americans. These services not only prevent disease, but also facilitate early detection, diagnosis and treatment of acute and chronic disease. There is significant research showing that uninsured adults,
compared to insured adults, have less access to preventive health services (Freeman et al. 2008, DeVoe et al., 2003, Schoen et al, 2014, Ayanian et al., 2000). Although there is some debate whether clinical preventive services save money, one analysis showed that greater use of proven preventives services could avoid two million life-years annually, and an increase in preventive services use to 90 percent could have saved almost $4 billion dollars in 2006 (Maciocek et al., 2010). Even among higher income persons who lack health insurance, being uninsured has been associated with significantly decreased utilization of recommended cancer screening, cardiovascular risk reduction and diabetes management; increased income did not mitigate the differences (Ross et al., 2006).

Uninsured adults are much more likely to have undiagnosed hypertension, and hypercholesterolemia (Ayanian et al. 2003, Fowler-Brown, 2007), as well as diabetes (Fowler-Brown, 2007). Additionally, uninsured adults with chronic conditions (asthma, cancer, chronic obstructive pulmonary disease, diabetes, heart disease or hypertension) are more likely to say they were unable to receive or had to delay receiving a needed prescription than their insured peers (Wilper et al. 2008); uninsured adults also experience more delays in follow-up care. Use of preventive services has been strongly associated with insurance and a usual provider or source of care (Devoe et al., 2003).

**Leverage or realign resources**
Providing health insurance coverage to uninsured Americans is one of the major goals of the ACA. The creation of Health Insurance Exchanges and Medicaid expansions are two of the primary vehicles to accomplish this goal. Currently, there are 27 federally facilitated health exchanges, 17 state-based health exchanges, and seven partnership exchanges. Twenty-seven states and the District of Columbia are implementing Medicaid expansions, two states are engaged in open debates about the expansion, and 21 states have decided not to move forward with Medicaid expansion at this time (Kaiser Family Foundation, September 2014). In the future, more states may opt for Medicaid expansion, thereby expanding coverage to more Americans, including non-disabled adults.

In addition to ensuring that uninsured Americans have access to health insurance coverage, it is also important that they know about their coverage options and the enrollment processes. There are many opportunities at the local, state and federal level to outreach to uninsured persons, and assist them with enrollment, as needed. Health care organizations, schools, advocacy groups, as well as state and federal agencies can pay an important role in assisting uninsured persons to access insurance.

**Predict an individual’s health and wellness and/or that of their offspring**
Research shows more positive health outcomes for insured adults, compared to uninsured adults. For example, some studies found lower mortality among the insured, compared with insured persons (Wilper, 2008; Freeman et al., 2008, Sommers et al. 2012). Uninsured stroke patients have higher levels of neurological impairment and intracerebral hemorrhage, as well as mortality (Shen and Washington 2007); and uninsured persons diagnosed with cancer have later stage diagnoses (Halpern 2008). Increases in self-reported health status, in which a person reports that their health is very good or excellent, also have been found among the insured, compared with the uninsured (Sommers et al. 2012). In a study in Oregon where a trial expansion of Medicaid allowed a randomly selected group of uninsured low-income adults to enroll in Medicaid, coverage was then associated with decreased incidence of positive screens for depression (Baicker et al., 2013).

Growing up in a household with uninsured members can also have some adverse consequences. A 2002 Institute of Medicine report concluded that the financial, physical, and emotional well-being of all members of a family may be adversely affected if any family member lacks coverage, and that, for children, these effects can last into adulthood (Institute of Medicine, 2002b).

**Data Criteria**

**Data availability**
U.S. Census Bureau data are collected through three surveys: the CPS ASEC and the ACS. This indicator sources data from the CPS ASEC and insurance status can be obtained for the nation, all 50 states, District of Columbia, and Puerto Rico. Both CPS ASEC and ACS are collected annually; those wishing to analyze the data at a geographic level more granular than the state level can access county and neighborhood census tract level data via advanced search of the American Fact Finder.
Data quality
The CPS sample is based on the civilian noninstitutional population of the United States and is located in 792 sample areas comprising 2,007 counties and independent cities with coverage in every state and in the District of Columbia (U.S. Census 2013). According to the ASEC documentation, approximately 98,100 housing units were in sample for the ASEC, including the basic CPS sample in 2013. Of the approximately 83,200 housing units that were eligible for interview, about 75,500 interviews were obtained (U.S. Department of Commerce 2013). The additional sample for the ASEC provides more reliable data for Hispanic households, non-Hispanic minority households, and non-Hispanic White households with children 18 years or younger (U.S. Department of Commerce 2013).

The final weight for the ASEC supplement, which is the product of several adjustments, is used to produce population estimates for the various items covered in the regular monthly CPS. This weight is constructed from the basic weight for each person, which represents the probability of selection for the survey, and adjusted for special sampling situations and failure to obtain interviews from eligible households (U.S. Census 2013).

Studies examining changes in insurance coverage and changes in insurance coverage for children used CPS data by analyzing the verified and unverified CPS data (Holahan & Pohl, 2002; Blewett, Davern, & Rodin, 2004). A study that used the CPS data to examine the economic conditions and health insurance coverage, stating that the CPS is the most frequent cited national survey on American health insurance (Holahan & Cook, 2005). It has been debatable about whether the CPS is measuring the uninsured for an entire year or reflect the uninsured at a point in time and whether enrollment is under or overstated for Medicaid and the uninsured (Holahan & Cook, 2005).

According to the Census Bureau, the CPS ASEC is mainly useful for examining timely estimates of the insured and uninsured population at the national level and can be used for state-level estimates, trends, and differences (through multiyear averages). The large sampling errors of state-level data limit its usefulness; when examining state level data and trends from the CPS ASEC, the Census Bureau recommends using CPS ASEC non-overlapping two-year averages for time periods that include years prior to 2008 (U.S. Department of Commerce 2013). Despite these limitations, the CPS ASEC is the most widely used source of data on health insurance coverage in the United States, with a consistent time series of estimates from 1999.

Simplicity of indicator
Measuring and explaining the indicator is straightforward. The data include the proportions of the population who are insured and uninsured by various characteristics. It is easy and simple to explain the importance of insurance coverage. Health insurance coverage is important to have throughout the course of life to allow people to access medical care for preventive services in order to reduce the rate of morbidity and mortality in infants, children, adolescents and adults. Having access to care at an early age would improve health that can expand to adulthood. Medical insurance coverage has been a common focus for professionals and communities especially with the introduction of the ACA.

References


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Life Course Indicator: Oral health preventive visit for children

The Life Course Metrics Project

As MCH programs begin to develop new programming guided by a life course framework, measures are needed to determine the success of their approaches. In response to the need for standardized metrics for the life course approach, AMCHP launched a project designed to identify and promote a set of indicators that can be used to measure progress using the life course approach to improve maternal and child health. This project was funded with support from the W.K. Kellogg Foundation.

Using an RFA process, AMCHP selected seven state teams, Florida, Iowa, Louisiana, Massachusetts, Michigan, Nebraska and North Carolina, to propose, screen, select and develop potential life course indicators across four domains: Capacity, Outcomes, Services, and Risk. The first round of indicators, proposed both by the teams and members of the public included 413 indicators for consideration. The teams distilled the 413 proposed indicators down to 104 indicators that were written up according to three data and five life course criteria for final selection.

In June of 2013, state teams selected 59 indicators for the final set. The indicators were put out for public comment in July 2013, and the final set was released in the Fall of 2013.

Basic Indicator Information

Name of indicator: Oral health preventive visit for children (LC-41)

Brief description: Percent of children who received a preventive dental visit in the past 12 months.

Indicator category: Health care access and quality

Indicator domain: Service/Capacity

Numerator: Number of children ages one to 17 surveyed who received at least one preventive dental visit in the past 12 months

Denominator: Total child population ages one to 17

Potential modifiers:

- Age groups (one to five, six to 11, 12 to 17)
- Gender
- Race/ethnicity (Hispanic, NH White, NH Black, NH Multi-racial, NH Other)
  - Primary household language (Spanish, English)
  - Household income level (zero-99 percent FPL, 100-199 percent FPL, 200-399 percent FPL, 400 percent or higher FPL)
  - Household income level SCHIP (zero-199 percent FPL, 200-299 percent FPL, 300-399 percent FPL, 400 percent FPL or higher)
  - Family structure (two parent – biological or adoptive, two parent – at least one step parent, mother only – no father present, all other family structures),
  - Special Health Care Needs status (CSHCN, non-CSHCN)
  - Special Health Care Needs type (Non-CSHCN, CSHCN – prescription medication, CSHCN – above routine services, CSHCN prescription medication and above routine services, CSHCHN – functional limitations)
  - Emotional, behavioral or developmental issues (one or more emotional, behavioral or developmental issues, no qualifying emotional, behavioral or developmental issues, non-CSHCN
  - Medical home (care does not meet all medical home criteria, medical home)
  - Type of Insurance (public insurance, private insurance, uninsured)
Life Course Indicator: Oral health preventive visit for children (LC-41)

- Consistency of health care coverage (consistently insured, currently uninsured or periods with no coverage)
- Adequacy of current insurance (adequate, inadequate)
- Rural urban commuter areas (urban core, suburban, large town, small town/rural)
- Urban/Rural residence (urban, rural)

**Data source:** National Survey of Children’s Health (NSCH)

**Notes on calculation:** Numerator: number who indicated at least once in response to the question: During the past 12 months/since [his/her] birth, how many times did [child name] see a dentist for preventive dental care such as check-ups and dental cleanings? Analysts who use the raw datasets should apply the appropriate survey weights to generate the final estimates.

**Similar measures in other indicator sets:** HP 2020 focus area OH-7 (Leading Health Indicator); NQF measure 1334, Chronic Disease Indicator; National Oral Health Surveillance System Indicator

**Life Course Criteria**

**Introduction**
The health of the mouth and surrounding structures is central to a person’s overall health and well-being. The craniofacial complex (collective dental, oral, and craniofacial tissues) allows people to speak, smile, smell, taste, chew, protect against microbial infections, and swallow. Consequently, many oral health conditions undermine self-image and self-esteem, discourage normal social interaction, or lead to chronic pain, stress and depression. These conditions can also interfere with vital functions including breathing, food selection, eating, speaking and daily living activities such as school and social interactions. Preventable oral health problems remain common in U.S. children, particularly in children of low socioeconomic status. In 2000, the Surgeon General reported that tooth decay is the most common chronic childhood disease and a silent epidemic of oral disease affecting the nation’s poor children. Persistent disparities exist in access to and use of oral health preventive visits across age, racial and ethnic groups, insurance status, insurance type, language, and others, with many of these disparities pronounced in young children. To improve the prevalence of receipt of oral health preventive services among children, numerous partnerships may be leveraged – including among payers (especially Medicaid and Children’s Health Insurance Program (CHIP)), diverse health professionals and training programs, community organizations and schools. These partnerships are critical in intervening in preventable health conditions in children and influencing an individual's engagement in oral health that may influence health across the lifespan, including in adolescence, pregnancy (influencing birth outcomes), and later life.

**Implications for equity**
Despite improvements in oral health for the overall U.S. population, oral health disparities exist by socioeconomic status, gender, age, location and racial and ethnic groups. Children from lower income families and racial/ethnic minority groups continue to be disproportionately affected by oral disease than their counterparts. Only one third of eligible children enrolled in Medicaid/CHIP were reported to have received any preventive dental services, in spite of the American Academy of Pediatric Dentistry (AAPD) recommendation of more frequent use of preventive dental measures for children at higher risk for oral disease.¹

Barriers to obtaining dental care for poor children, the elderly, and racial and ethnic minorities include lack of insurance, the inability to speak English, and lack of dentists who accept Medicaid or see children with special health care needs.² People in racial minority groups reported more difficulty in trying to obtain children’s dental care,³ with the most pronounced challenges experienced among Mexican American and African American non-Hispanic children ages two to four years and ages six to eight years.⁴

More than 108 million children and adults lack dental insurance, more than two and a half times the number of individuals who lack medical insurance.² Uninsured children have a higher burden of dental disease than their insured peers and experience substantially less access to dental services. Children from families without dental insurance are three times more likely to have dental needs than children with either public or private insurance.³
The decision of dentists to participate in Medicaid and CHIP plans impacts access to dental services, especially for children with special health care needs. In addition to the challenges in finding dentists who accept Medicaid and CHIP, parents of children with special health care needs may struggle with the high out-of-pocket cost of specialized care, which remains a barrier to regular preventive oral health visits.5

**Public health impact**

Use of dental services and maintaining good oral health habits in childhood is beneficial to both oral health and general health later in life. Several studies have linked dental caries (tooth decay) in the primary teeth to caries in the permanent teeth.6,7 Oral health care visits for children allow for the provision of preventive and educational services as well as the early identification and treatment of existing oral disease. Through early and regular oral health care visits, children can avoid complex and expensive restorative and emergency dental treatment in later years, ultimately leading to significant savings in dental expenditures.

Preventable oral health problems remain common in U.S. children, particularly in children of low socioeconomic status. In 2000, the Surgeon General reported that tooth decay is the most common chronic childhood disease and a silent epidemic of oral disease affecting the nation’s poor children.3 The prevalence of dental caries among children ages five to 11 years is 26 percent and 67 percent among children aged 12-17 years.6 The American Academy of Pediatric Dentistry (AAPD), the American Academy of Pediatrics (AAP), the American Dental Association (ADA), and the American Association of Public Health Dentistry (AAPD) all recommend establishing a dental home and the first dental visit by age one year. Adhering to these recommendations and increasing the number of children who have had a preventive dental visit in the past 12 months can decrease oral health problems, such as dental caries, in children and improve general health later in life.

**Leverage or realign resources**

Medicaid and CHIP must provide dental services, including diagnostic, preventive and related services for all eligible enrollees under the age of 12. However, obtaining dental care for children in these programs remains a challenge, as most dentists accept few or no Medicaid or CHIP patients. In 2008, less than 37 percent of children enrolled in Medicaid received any dental services.9 Dentists cite low payment rates, administrative requirements and patient issues as why they do not treat Medicaid patients.9 Partnerships with dental providers, public health dentistry professionals, and public payers are critical to overcoming these hurdles and expanding access to preventive services for this vulnerable population.

Federal efforts to improve access to dental services for children in underserved areas (such as expanding dental services in health centers, providing scholarships and loan repayment for dentists and hygienists who practice in underserved areas for three years, and funds to support new dental service sites in underserved areas) are underway but the effect is unknown.9 Increasing delivery of preventive dental services by medical care providers is an innovative practice. In 2009, 35 state Medicaid programs allowed reimbursement of medical care providers for preventive dental services for children.10 The Institute of Medicine (IOM) convened a committee to assess the current oral health care system and recommend strategies to achieve a vision to improve oral health care for vulnerable and underserved populations.11 The committee identified that the separation of oral health care from overall health care is a factor limiting access to oral health care for many Americans, and encourages the use of nondental health care professionals for screening and delivering oral health care services. The committee also suggested that oral health education and training could be integrated into health professional school curricula. Further, to increase the exposure of future dental care providers to underserved populations, the committee recommended providing students with clinical experiences in community-based settings, and expanding recruitment and support for students from underrepresented communities. Together, community-based partnerships between health professional schools and community health centers, including Federally Qualified Health Centers, could help to overcome access issues to preventive dental services.

A number of innovative partnerships also may be explored with regard to improving the oral health of children and increasing access to preventive dental visits. For example, partnerships between schools and oral health providers could focus on delivery of oral health services as well as expanding dissemination of public health messages, such as reducing intake of sugary drinks and snacks (possibly through their removal from the school).
Increasing dental services to all children, adolescents, and adults as well as closing the gap in dental service use between income strata are goals of Healthy People 2020. HP 2020 objective OH-8 is to “Increase the proportion of low-income children and adolescents who received any preventive dental service during the past year” and objective OH-7 is to “Increase the proportion of children, adolescents, and adults who used the oral health care system in the past 12 months.” The healthypeople.gov website contains evidence-based information and recommendations related to these oral health objectives.

**Predict an individual’s health and wellness and/or that of their offspring**

Preventive oral health care has a significant impact on oral diseases and conditions that affect people throughout their lifespan. Chronic oral-facial pain conditions, oral and pharyngeal cancers, oral soft tissue lesions, and birth defects such as cleft lip and palate are all conditions that can have improved outcomes through consistent oral health care visits.

Dental caries remain a common chronic disease in the United States. Left untreated, the pain and infections caused by dental caries can lead to long-term health and social problems that in many cases could be completely prevented. Ensuring use of preventive oral health services early in life may influence an individual’s perspective and engagement in oral health in the future, putting in place healthy behaviors for a lifetime. Evidence links poor oral health, especially gum disease, to several chronic diseases (diabetes, heart disease and stroke), and in pregnant women, poor oral health has been linked to premature birth and low birth weight. Additionally, many systemic diseases initially manifest orally, and preventive dental visits may lead to earlier diagnosis of these conditions. Poor oral health during critical and sensitive periods of life can alter health trajectories and have an intergenerational impact on health. Further, oral health can be improved using a life course approach similar to those applied to other chronic conditions because many of the behaviors, nutritional habits, and social determinants that influence oral health have also been linked to chronic diseases.

**Data Criteria**

**Data availability**

The National Survey of Children’s Health (NSCH), sponsored by the Maternal and Child Health Bureau of the Health Resources and Services Administration, examines the physical and emotional health of children ages zero to 17 years of age. The survey is administered using the State and Local Area Integrated Telephone Survey (SLAITS) methodology, and it is sampled and conducted in such a way that state-level estimates can be obtained for the 50 states, the District of Columbia, and the Virgin Islands. The survey has been designed to emphasize factors that may relate to the well-being of children, including medical homes, family interactions, parental health, school and after-school experiences, and safe neighborhoods. The Maternal and Child Health Bureau leads the development of the NSCH and NS-CSHCN survey and indicators, in collaboration with the National Center for Health Statistics (NCHS) and a national technical expert panel. The expert panel includes representatives from other federal agencies, state Title V leaders, family organizations, and child health researchers, and experts in all fields related to the surveys (adolescent health, family and neighborhoods, early childhood and development etc.). The most recent data set, the 2011-2012 NSCH, encompasses a sample size of more than 95,000 children with approximately 1,800 interviews completed in each of the 50 states and the District of Columbia.

MCH programs can readily gain immediate access to the data through datasets released by the National Center for Health Statistics, and on the MCHB sponsored Data Resource Center for Child and Adolescent Health Website (www.childhealthdata.org). Data from the 2011/2012 NSCH were made available in early 2013. The survey questionnaire and raw dataset are available for download on the Centers for Disease Control and Prevention (CDC) NCHS website in SAS format. The Data Resource Center (DRC) website provides data nationwide, for all 50 states and the District of Columbia. Additionally, both the raw datasets and the website allow users to stratify measures by sociodemographic groups, including but not limited to age, sex, race/ethnicity, primary household language, household income, and special health care needs. Cleaned, state-specific datasets with new variables that include national and state indicators are available at no cost in SAS and SPSS formats. For information on how to order state-specific sets, contact cahmi@ohsu.edu. Local data is not searchable. The NSCH is not administered annually. Over the past decade, the NSCH has been administered four times.

The question in the NSCH pertaining to preventive oral health visits (During the past 12 months, how many times did [CHILD’S NAME] see a dentist for preventive dental care, such as check-ups and dental cleanings) was included in the
2011-2012 and 2007 NSCH. The 2003 NSCH included a question worded differently: During the past 12 months, did [CHILD’S NAME] see a dentist for any routine preventive dental care, such as check-ups, screenings, and sealants?

Data quality
The main limitation of the NSCH is that the information provided is from parent recollection of screenings received and perception of child’s health and development over the past year. The survey methodology does not provide an opportunity for confirmation with medical records or physical measurements. The NSCH is weighted to represent the national population of non-institutionalized children ages zero to 17 years. According to the survey documentation, missing data for income were relatively high for 2011-2012 data, and a study of nonresponse patterns indicated that excluding records with missing income could impact the representativeness of the remaining data; therefore, a data file with imputed values for income is provided to be used with the datasets.

The NSCH documentation presents both response rates and completion rates. For 2011-2012 data, the combined national response rate for both landline and cell phone samples was 23 percent. The completion rate, which is calculated as the proportion of households known to include children that completed all sections up to and including Section Six (for children less than six years of age) or Section Seven (for children six to 17 years of age), was 54.1 percent for the landline sample and 41.2 percent for the cell-phone sample.

Qualitative testing of the entire 2007 National Survey of Children’s Health was conducted by the National Center for Health Statistics. They conducted cognitive interviews with the 2007 NSCH Computer-Assisted Telephone Interview (CATI) to make sure the entire survey instrument was functioning properly. N=640 interviews were completed over three days in December 2006. The questionnaire was then revised and finalized based on feedback from participants in these interviews.

Previously validated questions and scales are used when available. All aspects of the survey are subjected to extensive literature and expert review. Respondents’ cognitive understanding of the survey questions is assessed during the pretest phase and revisions made as required. All final data components are verified by NCHS and DRC/CAHMI staff prior to public release. Face validity is conducted in comparing results with prior years of the survey and/or results from other implementations of items.

Romaire and colleagues (2012) compared estimates of dental service use and delayed dental care and trends in use and delay across four surveys: the 2003 and 2007 National Survey of Children’s Health (NSCH), the 2003-2004 National Health and Nutrition Examination Survey (NHANES), the 2003 and 2007 National Health Interview Survey (NHIS), and the 2003 and 2007 Medical Expenditure Panel Survey (MEPS). The researchers found variance across the prevalence estimates due to the items and data collection procedures employed by the surveys; however this difference among estimates was less for preventive dental use as compared to dental service use. NHANES had the lowest estimate of preventive dental use in 2003 (67 percent) whereas MEPS had the highest (78 percent). The slight increase in the proportion of children with a preventive dental visit between 2003 and 2007 as found from the NSCH was also reflected in the MEPS. Across all surveys, disparities in dental services by key sociodemographic characteristics (e.g. age, race/ethnicity, insurance status, income, and children with special health care needs status) were consistent. The authors describe the differences between the prevalence estimates as related to the number of survey items used, the recall period, and use of prompts and probes (MEPS) and their influence on social desirability bias or validity and accuracy of parent reports. The authors conclude that specific research or policy questions may guide the selection of the data source, and suggest that the NSCH may best answer questions concerning state-level geographic variation or contextual factors, which the other surveys lack. ^15

Simplicity of indicator
Analysis results for the overall indicator and all sub-groups listed above are available at the NSCH Data Resource Center website. Datasets are available for download if additional analysis is desired. Survey data are weighted to be representative of the population; some sub-groups at the state level have small cells that will affect the ability to detect a significant difference. Overall this is a simple indicator to explain and use.
References


5. Association of State and Territorial Dental Directors (ASTDD), ASTDD Support for State CSHCN Oral Health Forums, Action plans and follow-up activities; Interim evaluation summary (March 2009).


The Life Course Metrics Project

As MCH programs begin to develop new programming guided by a life course framework, measures are needed to determine the success of their approaches. In response to the need for standardized metrics for the life course approach, AMCHP launched a project designed to identify and promote a set of indicators that can be used to measure progress using the life course approach to improve maternal and child health. This project was funded with support from the W.K. Kellogg Foundation.

Using an RFA process, AMCHP selected seven state teams, Florida, Iowa, Louisiana, Massachusetts, Michigan, Nebraska and North Carolina, to propose, screen, select and develop potential life course indicators across four domains: Capacity, Outcomes, Services, and Risk. The first round of indicators, proposed both by the teams and members of the public included 413 indicators for consideration. The teams distilled the 413 proposed indicators down to 104 indicators that were written up according to three data and five life course criteria for final selection.

In June of 2013, state teams selected 59 indicators for the final set. The indicators were put out for public comment in July 2013, and the final set was released in the Fall of 2013.

Basic Indicator Information

Name of indicator: Depression Among Youth (LC-42)

Brief description: Percent ninth through 12th graders who felt sad or hopeless almost every day for more than two weeks during the previous 12 months

Indicator category: Mental Health

Indicator domain: Risk/Outcome

Numerator: Number of ninth through 12th graders who felt sad or hopeless almost every day for more than two weeks during the previous 12 months

Denominator: Number of ninth through 12th graders

Potential modifiers: sex, race/ethnicity, grade level, sexual orientation, geography (including rural vs. urban school districts), reported substance abuse, reported victim of bullying, socioeconomic status, family structure

Data source: Youth Risk Behavior Surveillance System (YRBSS)

Notes on calculation: The numerator is derived from students who answered “Yes” to the question “During the past 12 months, did you ever feel so sad or hopeless almost every day for two weeks or more in a row that you stopped doing some usual activities?” Analysts who use the raw datasets should apply the appropriate survey weights to generate the final estimates.

Similar measures in other indicator sets: HP 2020 Focus area MHMD-4.1 (Leading Health Indicator)
Life Course Criteria

Introduction
Depression among youth is a costly and complex problem characterized by deep disparities across groups defined by gender, racial/ethnic, socioeconomic status (SES), and sexual orientation. This presents a substantial challenge for the U.S. health care system due to the economic cost of mental illness reaching the billions annually. The etiology of youth depression is a combination of genetic, biological, environmental, and psychosocial factors. When compared to healthy peer counterparts, adolescents who experience depression during childhood are more likely to experience severe mental illness during adulthood and suffer from comorbidities, resulting in increased risk for school drop-outs, pregnancy, substance abuse, adult depression, and suicide. Research indicates that risk for childhood and adolescent depression increases two to three times among children of depressed parents, further indicating that adolescent depression is a family-based, life course issue. A variety of traditional and non-traditional partnerships offer opportunities to reduce the proportion of adolescents experiencing depressive symptoms, including those hard to reach, and intervene in this sensitive period to reduce risks to lifelong well-being.

Implications for equity
When examining prevalence rates of adolescent depression, key disparities emerge. Research suggests gender, race/ethnicity, socioeconomic status, and sexual orientation all play a role in reported depression disparities among adolescent and young adults.

According to the 2011 national Youth Risk Behavior Surveillance System (YRBSS), female students have a higher prevalence of feeling sad or hopeless almost every day for two or more weeks in a row (35.9 percent for females vs. 21.5 percent for males). This gender disparity remained constant in every category of race/ethnicity and every grade level. The survey also indicates that state and large urban school district surveys reveal the same gender gap. Maughan et al. concluded that rates of depression rise in the teenage years, especially among females. Researchers have proposed a variety of hypotheses as to why this gender gap exists, including: ability to process stressful events and related coping styles, greater exposure/sensitivity to psychosocial stress, hormonal changes, and changes in underlying brain development.

Racial and ethnic disparities also have been linked to depression in youth. Healthy People 2010 data indicated racial and ethnic disparities among adolescents who reported experiencing major depressive episodes. Black non-Hispanic adolescents reported having the lowest proportion of major depressive episodes in the past 12 months. Non-Hispanic white, American Indian, and Alaska Native adolescents reported rates that were 23 percent to 36 percent higher when compared to Black non-Hispanic adolescents.

Socioeconomic status also contributes to inequities associated with youth depression. Although SES is not measured in the YRBSS, data measuring similar factors – lower household income and lower parental education – are both associated with higher prevalence rates of adolescent depression in the 2011 YRBSS national sample. In a study that examined SES and population attributable risk (PAR) for adolescent depression, research indicated that the adjusted PAR for lower income was 26 percent and the adjusted PAR for lower parental education was 40 percent, indicating that lower SES, most notably low parental education, is associated with an increased risk for youth depression.

A large body of research suggests depression among adolescents and young adults occurs disproportionately among youth who identify as lesbian, gay, bisexual, or transgender (LGBT), indicating a significant inequity associated with sexual orientation. Almeida et al. assessed emotional distress by analyzing data from a school-based survey (n=1,032). Results indicated that when compared to heterosexual peer counterparts, LGBT youth scored significantly higher on the scale of depressive symptomatology. Mediation analysis also revealed that this disparity could be attributable to perceived discrimination.

Moving forward, public health professionals must take gender, racial/ethnic, socioeconomic, and sexual orientation inequities into consideration when planning adolescent depression programs and policies. If programs can specifically target at-risk youth populations and determine the underlying reasons for the existence of these disparities, adolescent health and well-being could be successfully promoted by public health entities.
Public health impact
Depression among adolescents and young adults has a significant impact on the larger U.S. public health system. Although prevalence data is highly variable, most researchers suggest the lifetime prevalence rate of major depression in adolescence is 15 percent-20 percent. This translates to nearly one in five adolescents, indicating that depression is an emerging and compelling health issue for adolescents and young adults. Despite multiple efforts to identify and reduce youth depression and suicide, the prevalence of adolescents who report feeling sad or hopeless almost every day for two or more weeks in a row did not change significantly between 1999 and 2011 (28.3 percent-28.5 percent). In fact, the rate increased from 2009 to 2011 (26.1 percent and 28.5 percent respectively) according to the 2011 national YRBSS.

Extant research suggests that depression during childhood and adolescence is associated with adverse adult health outcomes, including mental illness during adulthood. This presents a substantial challenge for the U.S. health care system because the economic cost of mental illness in the United States was estimated to be approximately $300 billion in 2002 dollars. If depression during adolescence can be prevented or treated early, there is a cost-savings opportunity for public health systems. Additionally, reducing depression in adolescents is a national health priority. Healthy People 2020 includes an objective which specifically focuses on reducing the proportion of adolescents aged 12 to 17 years who experience major depressive episodes.

Recent incidences of gun violence and mass shooting such as the Aurora shooting and the Sandy Hook Elementary school shooting have forced the public health community to further examine the relationship between mental health and violence, particularly among young adults and adolescents. Although research on this topic is scant, some studies suggest a significant relationship between violence and self-rated mental health. A longitudinal study of adolescents in the United States suggests that youth who are exposed to violence (e.g., witness gun violence) experience increased risk for poor health, including symptoms associated with depression. Policy analysis also reveals a significant relationship between gun violence and suicide with some researchers even suggesting potential policy strategies to reduce gun-related suicides. Moving forward, public professionals must seek to further define the long-term consequences associated with gun violence, mental health, depression, and suicide among adolescents.

The adolescent depression indicator provides a point of intervention and reference for public health systems and programs. Research suggests that prevention programs decrease the occurrence and reoccurrence of depressive symptoms in youth. School-based selective prevention programs using cognitive behavioral therapy have shown to be beneficial to adolescents with depressive symptoms.

Leverage or realign resources
There is substantial potential to leverage and realign system resources to impact adolescent depression. Multiple entities within the system of care serving adolescents have the opportunity to intervene and address depression in adolescents. These entities include, but are not limited to: school systems, the department of labor, community employers, public and private health care systems, research institutions and federal agencies such as the National Institute for Mental Health (NIMH) and the Substance Abuse and Mental Health Services Administration (SAMHSA), social services, and non-profit organizations such as the National Alliance on Mental Illness (NAMI).

Potentially the single most important resource for preventing adolescent depression is the school system. Children and adolescents spend a large portion of their time in school, presenting school officials and teachers with an opportunity to intervene and impact adolescents’ lives. Adolescent depression is often associated with negative long-term outcomes including impairment in school and school drop-out. Many education systems are currently involved in various prevention efforts with programs in place for youth identified as at-risk for or living with depression. Such school-based programs have the potential to positively address this emerging health issue for adolescents. Maughan et al. suggests that peer conflict and bullying are risk factors highly associated with adolescent depression; therefore, schools and overlapping program entities could focus on these factors. Many non-profit organizations work in conjunction with schools to provide after-school programs such as tutoring, physical activity programs, and nutrition workshops. Such organizations could be approached for partnership possibilities regarding the prevention of adolescent depression. Sports programs within school systems also provide a visible platform for partnership, since many adolescents actively participate in school sports programs.
Adolescent depression also is associated with impairment in the workplace setting. Since many older adolescents and young adults hold part-time employment, creative partnerships are possible. The Department of Labor and local community employers known for hiring large amounts of youth could potentially provide invaluable, creative partnership opportunities.

Youth depression is associated with high medical costs. Medicaid has several vehicles to support effective community mental health services, including state plan services, managed care, waivers, and the Early Period Screening, Diagnosis and Testing Benefit. Private insurers also provide support for mental health services. Additionally, medical home and care coordination entities are potential partners as many public and private health plans move children with ongoing special health care needs, including mental health issues such as depression, into managed care programs. Given the high cost of medical expenses associated with adolescent depression and the need for clinical care, private and public health care entities are natural partners for addressing adolescent depression in states and communities.

Federal agencies also are dedicated to preventing adolescent depression and could serve as potential partners. The NIMH provides information on its website specific to depression in children and adolescents, including fact sheets and links to other organizations and information. SAMHSA has a National Registry of Evidence-based Programs and Practices for the public to view available interventions.

Lastly, it is important to note that not all adolescents and young adults can be reached via traditional mechanisms. Adolescents in the foster care system, runaway and homeless youth, and adolescents who are not connected to schools can be difficult to reach. Therefore, public health systems must creatively approach these populations by leveraging community-based partners such as homeless shelters, free counseling centers, and even law enforcement. Established partnerships with social service organizations also would allow for public systems to identify and bring in adolescents outside of the traditional system of care.

Predict an individual’s health and wellness and/or that of their offspring

Youth depression is an important indicator on the life course trajectory. The etiology of youth depression is a combination of genetic, biological, environmental, and psychosocial factors. When compared to healthy peer counterparts, adolescents who experience depression during childhood are more likely to experience severe mental illness during adulthood. Researchers also suggest disruptive disorders including Attention Deficit Hyperactivity Disorder (ADHD), Oppositional Defiant Disorder (ODD), and Conduct Disorder (CD) are co-morbidities often associated with youth depression. Research indicates that risk for childhood and adolescent depression increases two to three times among children of depressed parents, further indicating that adolescent depression is a family-based, life course issue.

As mentioned previously, depression during adolescence is significantly associated with adverse health outcomes. Untreated depression in youth is associated with increased school drop-outs, pregnancy, substance abuse, adult depression, and suicide. Given the individual negative adverse health outcomes associated with adolescent depression, public health professionals must actively seek to prevent and treat depression among youth.

Data Criteria

Data availability

The YRBSS monitors priority health-risk behaviors and the prevalence of obesity and asthma among youth and young adults. The YRBSS includes a national school-based survey conducted by the Centers for Disease Control and Protection (CDC), state, territorial, and local education and health agencies and tribal governments.

YRBSS monitors six categories of priority health-risk behaviors among youth and young adults, including behaviors that contribute to unintentional injuries and violence; sexual behaviors that contribute to unintended pregnancy and sexually transmitted diseases, including HIV infection; alcohol and other drug use; tobacco use; unhealthy dietary behaviors; and inadequate physical activity. In addition, YRBSS monitors the prevalence of obesity, asthma and symptoms of depression.
The YRBSS is administered every other year (odd years), generally in the spring semester in schools via a pencil and paper mode. The YRBSS survey contains no skip patterns. In the even-numbered years, CDC leads a process of examining and revising the questionnaire, using both expert opinion and votes from the YRBSS coordinators in states. The final result is a standard questionnaire that can be modified by states to meet their needs, but modifications must be within certain parameters.: 1) the modified questionnaire must contain at least two-thirds of the original standard questionnaire, 2) questions that are added are limited to eight mutually exclusive response options, 3) the questionnaire may not have skip patterns or fill in the blanks, and 4) the questionnaire may not exceed 99 questions, and the state must retain the height and weight questions. The 2011 YRBSS included a national school-based survey conducted by CDC and 47 state surveys, six territory surveys, two tribal government surveys, and 22 local surveys conducted among students in grades nine through 12 during October 2010-February 2012. Data collected by CDC represent both public and private schools with students in grades nine through 12; data collected by states, territories, tribes, and localities represents primarily public school students.

The National YRBSS questionnaire and datasets from each survey cycle are readily available on the CDC website via two mechanisms. Individuals can download raw YRBSS datasets in ASCII, SAS, SPSS, or Access formats. Additionally, the CDC also offers an interactive online portal entitled “Youth Online” which allows users to view results from the 2011 National YRBSS survey and filter by race/ethnicity, sex, and grade. YRBSS summaries published in the Morbidity and Mortality Weekly Report (MMWR) also are viewable and downloadable on the CDC website.

In 2011, a total of 43 states and 21 large urban school districts collected YRBSS data representative of high school students in their jurisdiction.

Sources:
About YRBSS: cdc.gov/HealthyYouth/yrbs/index.htm
CDC “Youth Online”: apps.nccd.cdc.gov/youthonline/App/Default.aspx?SID=HS

Data quality
From the available YRBSS documentation, the 2011 national YRBSS school response rate was 81 percent; the student response rate was 87 percent; and the overall response rate was 71 percent. Comparisons between estimates for states and districts from the national data collection effort and the surveys collected by states, territories, tribes, and localities can be found on the CDC YRBSS website. Each jurisdiction reached a minimum site response rate of 60 percent and therefore had weighted data for that year. Weighted data allows a jurisdiction to make statements from the data that generalize to all high school students in that jurisdiction.

Studies by CDC and others indicate that data about risk behaviors can be gathered as credibly from adolescents as from adults. YRBSS performs internal reliability checks to help identify the small percentage of students who falsify their answers. To obtain truthful answers, students must perceive the survey as important and know procedures have been developed to protect their privacy and allow for anonymous participation.

A test-retest study of the 1999 version of the questionnaire found that 47 percent of items had at least “substantial” reliability, with kappa statistics of agreement of 61 percent or greater, and 93 percent of items had at least “moderate” reliability, with kappas of 41 percent or greater. The study found no differences in reliability by gender, grade, or race/ethnicity. The study found that items related to tobacco use, alcohol and other drug use, and sexual behavior had the highest reliability. By comparison, items asking about dietary behaviors, physical activity, and other health-related topics were less reliable. A study of mode and setting using the YRBSS questions determined that students were more likely to report risk behaviors when they took the survey at school compared with taking the survey at home. The question which captured whether the ninth through 12th grader felt sad and hopeless in the past 12 months received a kappa score of 56.4 percent with a time-one prevalence of 28.2 and a time-two prevalence of 24, yielding the conclusion that the reliability of the survey question was questionable. The study reported that the question was revised in later questionnaires, but there is no documentation to determine the reliability of recent questionnaires.
YRBSS data captures the prevalence of depressive symptoms but does not truly capture the prevalence of clinical or diagnosed depression. Therefore, much of the information presented in subsequent sections on clinical depression may not be fully applicable to students who respond affirmatively to the YRBSS question of interest. Research suggests that early symptoms of mental health disorders, including depression, emerge several years before full diagnostic criteria are met.\(^3\)

In 2003, the CDC conducted an empirical literature review to examine the validity of adolescent self-reporting of risk-behaviors measured on the YRBSS and determined that neither cognitive nor situational factors impede the validity of the YRBSS self-reporting method. Lastly, it is important to note two key limitations for this data: (1) the data only applies to ninth through 12\(^{th}\) grade-aged youth attending school and (2) under- and over-reporting of behaviors cannot be determined.\(^1\)

**Simplicity of indicator**

The level of complexity in calculating and explaining the adolescent depression indicator is moderate. The YRBSS determines the prevalence rate of ninth through 12\(^{th}\) graders who felt sad or hopeless almost every day for more than two weeks by weighting the results. Weighting means that a numeric adjustment was applied to each survey record in the data set to account for the sampling design and known differences between responders and non-responders so that the results are representative of all ninth through 12\(^{th}\) graders in the United States attending public and private school. While the statistical analysis and weighting methodology used is detailed and complex, the CDC website offers information regarding weighting procedures which is simple to read and interpret. Lastly, the survey question itself may be complex for high school students to answer. Interpretation of the terms “sad”, “hopeless” and “almost every day” is subjective and could be difficult for youth to answer accurately and consistently. The indicator is, however, easy to explain to public health professionals.

Source: [cdc.gov/HealthyYouth/yrbs/faq.htm](http://cdc.gov/HealthyYouth/yrbs/faq.htm)

**References**


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The Life Course Metrics Project

As MCH programs begin to develop new programming guided by a life course framework, measures are needed to determine the success of their approaches. In response to the need for standardized metrics for the life course approach, AMCHP launched a project designed to identify and promote a set of indicators that can be used to measure progress using the life course approach to improve maternal and child health. This project was funded with support from the W.K. Kellogg Foundation.

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In June of 2013, state teams selected 59 indicators for the final set. The indicators were put out for public comment in July 2013, and the final set was released in the Fall of 2013.
Life Course Criteria

Introduction

Often the term mental health is used interchangeably with mental illness, but the two terms have been differentiated to appropriately measure the independent health conditions that can potentially harm an individual. Mental health, as defined by the Centers for Disease Control and Prevention (CDC), is “a state of well-being in which the individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community” (37). Alternatively, mental illness can be defined as “health conditions that are characterized by alterations in thinking, mood, or behavior (or some combination thereof) associated with distress and/or impaired functioning” (37). Current estimates indicate that only 17 percent of adults in the United States have optimal mental health. Mental health has historically been neglected as a priority public health issue due to traditional separations of health care and psychiatric care. There has been much current effort within public health to integrate behavioral health issues and recognize the need for improved mental health to truly achieve the overall wellness of an individual (23).

Mental health, both optimal and suboptimal, is passed on inter-generationally and within communities; individuals learn coping mechanisms, how to mediate stress, and receive support that fosters resilience, or not, through their families and communities (26, 27, 28, 29).

Implications for equity

Mental health equity can be difficult to improve because of the cyclical nature of mental health issues; poor mental health arises from and contributes to social, psychosocial, and environmental inequalities (23). Differences in mental health status exist by race/ethnicity, education, income, age, gender, marital status, weight status and sexual orientation (14, 15, 16, 17, 23). Individuals are at higher risk for poor mental health if they are unmarried, female, unemployed, young adults, without health insurance, and of low socioeconomic status (16, 23). Data from BRFSS have shown frequent mental distress is more prevalent among individuals with extremes in body weight and women of non-heterosexual orientation (15, 16). Members of racial and ethnic minority groups experience a disproportionate burden of poor mental health. BRFSS data from 2001-2002 health-related-quality-of-life (HRQOL) measures indicated frequent mental distress among American Indian/Alaska Native adults (AIANs), and increased odds for reporting frequent depressive symptoms among African American, AIAN, and Hispanic adults (14).

The built environment, the space in which people live, work, and play, also has a direct impact on mental health and can indirectly influence psychosocial consequences contributing to poor mental health. Overcrowding, noise levels, insufficient light exposure, and poor air quality are all factors of the built environment that have been associated with increased psychological distress, although they do not directly produce serious mental illness (31). Housing quality and insecurity have also been linked to poor mental health outcomes. These factors of the built environment influence psychosocial consequences like feelings of hopelessness, lack of social support, and chronic fatigue or stress, which then contribute to an increased risk of frequent mental distress (31).

Public health impact

The 2011 BRFSS data indicate the average number of poor mental health days experienced by people in the United States is 3.9 days within the last 30 days. Mental health status is a marker of quality of life and is a key component of the population’s overall health and wellness (32). Poor mental health can be a predictor for future health events, including health services utilization (33). Poor mental health is associated with chronic mental and physical health problems throughout the life course; individuals reporting a higher number of poor mental health days per month are more likely to be underweight or obese, smoke, binge drink, engage in no leisure time physical activity, have no health insurance, and rate their physical health as poor or fair. Individuals with chronic health conditions, such as diabetes, hypertension, heart disease, and cancer, are also more likely to report a higher number of poor mental health days each month (18,34). Poor mental health has been shown to decrease the ability to participate in the treatment and recovery programs necessary to overcome chronic disease or improve health. A simultaneous approach to improving the mental health and treatment of physical health conditions is therefore essential to improving overall health of populations (34).

Poor mental health is commonly reported by individuals with mental health disorders such as anxiety and depression (19,20,21,22). Extreme cases of poor mental health can also lead to suicide, which is the 10th leading cause of death among all ages in the United States (32). Approximately 46 percent of adults are expected to have a mental health...
disorder within their lifetime. Additionally, the costs of medical treatment for mental illness can total approximately $100 billion annually (32). Early diagnosis and treatment of mental health disorders is essential to decrease this burden and improve the overall well-being and quality of life of individuals and create a lasting impact on public health (34).

**Leverage or realign resources**

There are a number of opportunities to leverage or realign resources as multiple potential partners, including many non-traditional, have a vested interest in improving mental health status in the United States. These opportunities include:

- Public health agencies incorporating mental health promotion into chronic disease prevention efforts and conducting surveillance for improved knowledge and evidence based research (25)
- Mental health organizations conducting public awareness campaigns that address stigma and the barriers to seeking treatment (25)
- School health clinics including mental health services to meet a preventive need (23)
- Public and private practitioners using electronic health information that includes both physical and mental health data (23)
- Disaster and emergency responders utilizing and incorporating mental health expertise for early intervention (23)
- Homeless shelters conducting outreach that connects those experiencing homelessness to mental health benefits (35)
- Private sector organizations educating employers on the benefits of providing mental health services to employees (35)

MCH programs traditionally have focused on physical and developmental health outcomes as they pertain to the pregnant mother and her fetus, infant, or child. The inclusion of a mental health support perspective beyond perinatal depression could include collaboration with state and federal mental health programs, social services, the department of education, community and environmental planners, the private sector, and chronic disease programs. There is much opportunity to collaborate with existing chronic disease prevention efforts and the existing partnerships that would leverage resources for mental health. Other stakeholders, including private business partners, social service groups, and emergency responders, play a pivotal role in connecting individuals with the prevention or treatment services they need (23, 24, 25, 35). Improved mental health will likely lead to expanded productivity, economic development, and improved physical health that will provide tremendous benefit to all partners involved.

**Predict an individual’s health and wellness and/or that of their offspring**

Mental health has been incorporated into a great deal of life course research, which reveals that both good and poor mental health can be passed on inter-generationally and within communities, as individuals first learn ways of coping and mediating stress through their families and from others around them (26, 27, 28, 29). Poor mental health, as measured by number of poor mental health days per month, is associated with a wide variety of chronic diseases, risk factors, and risk behaviors. Individuals reporting a higher number of poor mental health days per month are more likely to have no health insurance coverage, rate their physical health as poor or fair, have a chronic health condition, experience mental illness, be obese or underweight, use tobacco and engage in substance abuse or risky sexual behavior (12). These risk factors and behaviors pose an increasingly serious threat to the health of an individual throughout their life course.

Because mental health status has serious implications for the well-being of an individual throughout their life course, prevention and promotion interventions are essential at each life stage. The stigma associated with poor mental health status can be pervasive through one’s life course. The majority of lifetime mental illnesses develop before adulthood, which validates the importance of intervention strategies targeted within childhood and adolescent years (36). Prevention efforts that reduce maternal depression for women of reproductive age also positively influence the mental health of the family. Behavioral risks such as maternal smoking can effect infant behavioral problems, attention-deficit disorders, and contribute to risk for low birth weight. Breastfeeding also is associated with improved intelligence and a decreased risk of hypertension, obesity, and diabetes, which are all factors that can influence mental health later in life (36). Mental health status is typically at its strongest in the period of an adult’s midlife. For midlife adults, the risk of depression is low and their employment and marital status are typically stable. Poor mental health becomes a risk again in the later stages of adult life initiated by role transitions, increased physical health problems, and a decreased sense of control (28).

**Data Criteria**
Data availability
The BRFSS is the world’s largest, on-going telephone health survey system, tracking health conditions and risk behaviors in the United States yearly since 1984. Currently, data are collected monthly in all 50 states, the District of Columbia, Puerto Rico, the U.S. Virgin Islands and Guam for adults 18 years and older. CDC provides state and national level prevalence data on their website.

The CDC develops approximately 80 BRFSS questions each year. Some of these are core questions asked each year, and some are rotating core questions asked every other year. There also are CDC supported modules that address specific topics that states can use on an optional basis. States can also develop additional questions to supplement the core questions (1). Modules used by states are noted on the CDC website.

Local level estimates for BRFSS data can be obtained using the Selected Metropolitan/Micropolitan Area Risk Trends (SMART) data. Local areas are metropolitan or micropolitan statistical areas (MMSAs) as defined by the Office of Management and Budget. SMART data is currently available for data going back to 2002 for MMSAs with 500 or more respondents.

The question addressing mental health is part of the Health-Related Quality of Life (HRQOL) module that is a core component of the survey; it has been included every year in all states and territories conducting the BRFSS since 1993. The CDC refers to these types of questions as Healthy Days or HRQOL measures. The mental health question is sometimes also referred to as the Frequency of Mental Distress indicator (2).

Data quality
Numerous studies have compared estimates of chronic conditions and behaviors obtained from BRFSS to other national surveys including the National Health Interview Survey and the National Health and Nutrition Examination Survey; while there are some differences, findings on overall health status and certain chronic conditions tended to be similar despite declining response rates for BRFSS.

Since some questions on the BRFSS address sensitive health conditions and behaviors, there is intermittent missing data throughout the dataset. However, refusal to answer generally accounts for a small proportion of responses for most data elements. The notable exception is income, where refusals accounted for over 23 percent of the data in one state in 2010; the median percent missing across BRFSS for income in 2010 was 14 percent.

Quality control computer programs are used to check the raw data for values out of range. CDC performs quality checks for core questions, and each state has its own protocol for checking state-specific questions. Interviewers are monitored during the annual questionnaire pilot period and intermittently during the data collection period to determine whether any interviewer bias exists and to correct any bias that might be found. On an ongoing basis, 10 percent of interview calls are verified.

Prior to 2011, the sampling for BRFSS represented only adults living in a private residence with a landline telephone, but starting in 2011, the sample also included data from respondents living in cell phone-only households. Weighted response rates are presented by state. For 2011, the median weighted response rate for the combined cell phone and landline was 49.72 percent.

The survey adjusts for non-response to reduce the known differences between respondents and non-respondents. Although participants interviewed may not represent a state in terms of age, sex and race distribution, it is believed that weighting the data corrects for this potential bias. As with other health surveys, estimates are based on self-report data and they may over- or underestimate the actual prevalence of a particular risk factor in the population. Despite some oversampling in states by geography, the annual sample size is too small to compute precise estimates at the county level. The child prevalence data are reliant on proxy report from the adult respondent to the BRFSS and may be subject to misclassification related to this method.

The HRQOL measures were developed by the CDC based on clinical guidelines. The HRQOL measures, including the mentally unhealthy days question, have been employed in a variety of federal surveys in addition to BRFSS, including the
Youth Risk Behavior Survey, the National Health and Nutrition Examination Survey, the General Social Survey and the Medicare Health Outcomes Survey. All HRQOL questions have been thoroughly tested for validity and reliability (3, 4, 5, 6, 7). A 2001 review of a wide variety of quality of life indices determined that the CDC BRFSS HRQOL index had undergone considerable reliability and validity testing and was satisfactory for measuring health-related quality of life to inform national policy (8).

Other factors that might impact the quality of the BRFSS and/or mental health days data include:

- The prevalence of poor mental health might be underestimated because BRFSS excludes persons in institutions and hospitals, who might be disproportionately likely to report poor mental health problems (2).
- This question relies on a self-reported mental health assessment. As with all self-reported data, individuals may feel uncomfortable sharing information regarding their mental health with a stranger over the phone or they may choose to give a socially desirable response. This tendency may vary by race/ethnicity, gender or age.

**Simplicity of indicator**

The BRFSS Mental Health-Related Quality of Life indicator is based on responses to the following survey question:

*Now thinking about your mental health, which includes stress, depression, and problems with emotions, for how many days during the past 30 days was your mental health not good?*

This indicator defines “poor mental health” as respondents reporting that their mental health was not good for at least 14 or more days out of the past 30 days. This is consistent with the official CDC definition of the Frequency of Mental Distress indicator. Research indicates that the 14 day minimum period is similar to the period used by clinicians as a marker for clinical depression and anxiety disorders (9). Other health indices use this same mental health indicator from the BRFSS, but instead report the average or median number of mentally unhealthy days reported (10, 11). The accompanying physical healthy days question is often combined with the mentally healthy days question to form a healthy days index (12, 13). Since this indicator is consistent with definitions of poor mental health, it should be relatively easy to calculate and explain.

**References**

Life Course Indicator: Mental Health Among Adults (LC-43)


This publication was supported by a grant from the W.K. Kellogg Foundation. Its contents are solely the responsibility of the author and do not necessarily represent the official views of the W.K. Kellogg Foundation.

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Life Course Indicator: Postpartum Depression

The Life Course Metrics Project

As MCH programs begin to develop new programming guided by a life course framework, measures are needed to determine the success of their approaches. In response to the need for standardized metrics for the life course approach, AMCHP launched a project designed to identify and promote a set of indicators that can be used to measure progress using the life course approach to improve maternal and child health. This project was funded with support from the W.K. Kellogg Foundation.

Using an RFA process, AMCHP selected seven state teams, Florida, Iowa, Louisiana, Massachusetts, Michigan, Nebraska and North Carolina, to propose, screen, select and develop potential life course indicators across four domains: Capacity, Outcomes, Services, and Risk. The first round of indicators, proposed both by the teams and members of the public included 413 indicators for consideration. The teams distilled the 413 proposed indicators down to 104 indicators that were written up according to three data and five life course criteria for final selection.

In June of 2013, state teams selected 59 indicators for the final set. The indicators were put out for public comment in July 2013, and the final set was released in the Fall of 2013.

Basic Indicator Information

Name of indicator: Postpartum Depression (LC-44)

Brief description: Percent of women who have recently given birth who reported experiencing postpartum depression following a live birth

Indicator category: Mental Health

Indicator domain: Risk/Outcome

Numerator: Number of women who experienced self-reported postpartum depression following a live birth

Denominator: Total live births to recent mothers

Potential modifiers: Race/ethnicity, education, age, nativity, household income, employment, marital status, stress, social support, personal/family history of mood disorder, number of children

Data source: Pregnancy Risk Assessment Monitoring System (PRAMS)

Notes on calculation: Three survey questions found in PRAMS assess postpartum depressive symptoms: (1) “Since your new baby was born, how often have you felt down, depressed, or sad?” (2) “Since your new baby was born, how often have you felt hopeless?” and (3) “Since your new baby was born, how often have you felt slowed down?” Women who report a response of “often” or "always" to any of these questions are defined as experiencing self-reported postpartum depression (1). Analysts who use the raw datasets should apply the appropriate survey weights to generate the final estimates.

Similar measures in other indicator sets: Preconception Health Indicator G3; MIECHV Benchmark Area Improved Maternal and Newborn Health: Screening for maternal depressive symptoms
Life Course Criteria

Introduction
Maternal mental health, which includes postpartum mood disorders like the “baby blues,” postpartum depression, and the comparatively rare postpartum psychosis, can be a challenge for families, particularly families with low income, young maternal age or unmarried parents (3). Postpartum depression, which impacts a relatively large number of women and has consequences more serious and longer in duration than the “baby blues,” has the ability to negatively affect maternal life course and the developmental trajectories of children through a number of possible avenues. Depressed mothers report higher incidences of intimate partner violence, rape, child abuse (3) and are at increased risk for future major depression or mood disorders (4,15). Postpartum depression in mothers is also associated with negative health effects in their children. Infants of mothers with postpartum depression are more likely to be abused, neglected, become hospitalized with health issues, and to be diagnosed with failure to thrive (25). The cognitive, social-emotional, and behavior development of these children can all also be negatively affected (25). Effective evidence-based interventions and practices such as providing social support or cognitive behavioral therapy exist to prevent postpartum depression or lessen the intensity of the symptoms (3). Other innovative practices currently being examined include lengthening of maternity leave and increasing father involvement in infant care. Delivering these interventions to mothers at risk for postpartum depression or currently suffering from depressive symptoms will require resources and new partnerships, but will ultimately result in better outcomes for mothers and their babies.

Implications for equity
In the United States, maternal postpartum depression occurs in 10 to 20 percent of women after birth; the timeframe for developing postpartum depression can vary from immediately after birth to up to about a year, but it most commonly occurs in the three to six months prior to birth (4). Higher estimates have been reported among socially disadvantaged groups of women. Studies of adolescent mothers have reported prevalences of postpartum depression at 53 and 56 percent (5). Among low-income women, the prevalence of postpartum depression is nearly double that of the general population (6).

In addition to young age and low socioeconomic status, single marital status (i.e. unwed or separated/divorced) and low educational attainment have been found to increase a woman’s risk for postpartum depression (4,7). A contributor to the association between single marital status and postpartum depression could be lack of sufficient father involvement during pregnancy and in parenting after birth (26,27). Mothers’ satisfaction with father involvement in parenting is associated with fewer depressive symptoms (26) and lack of paternal involvement in infant care is associated with increased intensity of maternal postpartum depression (27). A personal or family history of previous mood disorder, lack of social support, and exposure to stressful or traumatic life experiences (e.g. marital changes, domestic violence, occupational changes, unsafe residence) are also cited as risk factors (4,7).

Whether or not maternal postpartum depression varies by racial/ethnic group remains unclear. There is some evidence to suggest that minority women, particularly African-American women, are at an increased risk for depressed mood following birth (8,9,10). However, other studies on maternal postpartum depression report conflicting results (11,17). In the broad mental health literature, empirical findings often reveal that African-Americans suffer the same or lower rates of mental disorders compared to whites, despite greater physical morbidity and mortality rates (20,21). Further research on racial/ethnic disparities with regard to maternal postpartum depression is warranted. It may be that mental health patterns evident in the broad mental health literature extend to maternal postpartum depression as well.

Public health impact
Maternal postpartum depression represents a public health concern due to its prevalence, effects on health and well-being, and costs. In addition to the direct repercussions maternal postpartum depression has on the health of women and children, interpersonal relationships (e.g. family dynamics and marital harmony) and social roles are negatively affected. Additionally, maternal postpartum depression reduces the enjoyment mothers receive from their parenting role. Compared to non-depressed mothers, mothers suffering from postpartum depression exhibit reduced sensitivity and responsiveness to their infants as well as reduced healthy feeding and sleep practices (25). The effect postpartum depression has on the maternal-infant relationship may be a mechanism behind associations between maternal postpartum depression and increased health problems and behavioral and emotional issues in children. Furthermore, maternal postpartum depression contributes to increased costs of medical care and inappropriate medical care (6).
Given the repercussions of maternal postpartum depression, identification, treatment, and prevention are essential to improving outcomes for current and future generations. However, this indicator often goes undiagnosed (4,17,18) despite the existence of standard postnatal screening tools such as the Edinburgh Postnatal Depression Scale (34). Postpartum depression screening has variable sensitivity and specificity depending on the screening tool and is slowly becoming into standard practice (17). One of the best opportunities for screening is the postpartum visit, but many childbearing women miss this visit or do not see a health care practitioner regularly during the postpartum year (4). There are other opportunities for screening and diagnosis despite these potential gaps; most early childhood home visiting programs are targeted towards women and families that have higher risks for poor outcomes and screening for postpartum (or perinatal) depression is a component of most home visiting program. While women in the postpartum year may not see providers for their own health needs, most will take their child to a pediatric provider, which is another opportunity for screening and referral. The American Academy of Pediatrics Bright Futures Initiative includes three different screening tools, including the Edinburgh screening tool, in their clinical practice tool and resource kit (35). Perhaps the biggest barrier to consistent screening and follow up is an area of opportunity for public health: a healthcare workforce that is skilled and proficient in using screening tools. Public health departments can have a role in providing training for providers that see women of childbearing age, including OBs, pediatricians, and family practice physicians, on the tools available, the opportunities to screen, and the steps to follow up and refer for services using the model of home visiting.

**Leverage or realign resources**

Based on the nature of maternal postpartum depression, this indicator has moderate potential to leverage and realign resources beyond the health sector. Maternal postpartum depression threatens the health and well-being of a woman, her infant, the mother-infant bond, and the family unit. As such, family support groups, mental health service providers, and early child care programs should collaborate with health entities to promote screening, treatment, support, and follow-up for new mothers and their families.

Unfortunately, few studies examining public health interventions that can prevent or alter maternal postpartum depression and its impact currently exist (18). In a 2006 review, no clear beneficial effects of psychosocial and psychological interventions for preventing postpartum depression were found (22). Interventions that were individually based, targeted “at risk” mothers, and were initiated in the postnatal period did show promise (22). However, the ability to identify “at risk” women is hindered by the lack of a consistent, predictive, and accurate screening tool for use in the antenatal period (22). Several recommendations from clinical investigations are also in place (4,6,17). Educating families, public health officials, and health care providers about the prevalence, risk factors, and symptoms of maternal postpartum depression is warranted. Development of a proper screening program and pooling of community and medical resources are recommended.

Home visiting programs may be a valuable partner in the prevention and treatment of postpartum depression. Research has found that home visiting is not currently effectively lowering maternal postpartum depression (3). However, home visitors have access to a population with a high prevalence of maternal postpartum depression and need to overcome numerous challenges posed by depression (3). Home visiting programs may be able to boost their support for maternal mental health through innovative therapeutic practices. One method involves including a licensed social worker in home visitation to administer In-Home Cognitive Behavioral Therapy (IH-CBT), which was developed by Ammerman et al (2005) (28,29). IH-CBT was able to partially or fully relieve 84.6 percent of depressed mother’s PPD symptoms in a 2005 open trial (28). Academic partnerships with home visiting programs have trained home visiting nurses to administer simple evidence-based interventions such as problem-solving therapy (3).

Research has found longer maternity leave is associated with a decreased risk of postpartum depression (30). However, the United States policies surrounding parental leave are some of the least generous of all industrialized nations. The Family and Medical Leave Act (FMLA) currently provides employees who have worked for a minimum of 1,250 hours in the public sector or for a private employer with more than 50 employees with 12 weeks of unpaid, job protected parental leave to care for a newborn or newly adopted child (30). Many mothers are not covered by this policy, particularly low-income mothers who have been found to be at a higher risk for postpartum depression. Moreover, recent evidence indicates that the 12 weeks included in the FMLA may not be sufficient to assist mothers struggling with postpartum depressive symptoms (36). Maternity leave policies that cover all employees or are paid as opposed to unpaid would increase the amount of time many new mothers could afford to take off of work, which could reduce postpartum

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*Life Course Indicator: Postpartum Depression (LC-44)*
depressive symptoms (30). Other family friendly workplace policies, such as flexible schedules, paid sick leave, and infant at work policies have the potential to improve outcomes for mothers and infants including and beyond postpartum depression, including promotion of breastfeeding, increasing maternal-infant bonding, and reducing sick days used to care for a sick child. Women who work hourly jobs and those who cannot afford to take unpaid leave are disproportionately affected by poor maternal and infant outcomes; public and private sector workplaces need to be leaders in promoting policies that promote healthy families, ultimately resulting in a more productive workforce.

Lower levels of social support are associated with higher levels of maternal postpartum depression (31). Social support can be provided to expectant or new mothers through several interventions involving peers, family members, or even online communities. Programs connecting mothers to a peer over the phone have been found to reduce the risk of postpartum depression (33) and studies of online communities of new mothers show these networks provide key emotional, informational, and instrumental support (31). Nurses or midwives are also a useful partner in heightening awareness of a mother’s need for social support among family and friends (32). Fathers are a crucial resource for mothers who are suffering from postpartum depression as these mothers often look to their partners as a main source of support (25). Mothers experience fewer postpartum depressive symptoms when they have higher levels of satisfaction with father involvement in parenting (27). Programs aimed to increase father involvement in the life of their infant may in turn decrease prevalence or intensity of postpartum depression.

**Predict an individual’s health and wellness and/or that of their offspring**

Maternal postpartum depression can result in poor health outcomes for both women and children that can be severe and long lasting. The symptoms of maternal postpartum depression mirror those of major depression, including sadness, despair, anxiety, compulsive thoughts, insomnia, and appetite disturbances (12). In some instances, women have thoughts of suicide or self-harm (12,13). These symptoms not only disable women from performing daily activities (14), but also affect parenting behaviors and attitudes (6). In addition, studies have found that women who have experienced postpartum depression are at an increased risk for future episodes of major depression, and recurrent postpartum mood disorders in subsequent pregnancies (4,15). This often causes women to alter their reproductive plans, choosing to avoid future pregnancies (4).

Children of depressed mothers (including infants and toddlers) are also adversely affected. Research has linked maternal depression to developmental delays, insecure attachment patterns, and behavioral problems in infants (4,6). Women with postpartum depression often discontinue breastfeeding infants as well (6). Moreover, school-age children who had postnatally depressed mothers are at a higher risk for child abuse and/or neglect (4), exhibit higher rates of behavioral disturbance (4,16), and are three to five times more likely to develop psychiatric disorders as adults (6).

**Data Criteria**

**Data availability**

The Pregnancy Risk Assessment Monitoring System (PRAMS) was initiated in 1987. PRAMS is an ongoing population-based surveillance system designed to identify and monitor selected maternal experiences and behaviors that occur before and during pregnancy and during the child’s early infancy. Forty states and New York City currently participate in PRAMS, representing approximately 78 percent of all U.S. live births. Six other states previously participated. The Centers for Disease Control and Prevention (CDC) maintains a combined dataset with information from all participating PRAMS states, which represents approximately 87 percent of all live births in the United States. CPONDER is a Web-based query system created to access data collected through Pregnancy Risk Assessment Monitoring System (PRAMS) surveys.

The length of time between an event and entry into the sampling frame is typically two to six months. Because PRAMS data are weighted to the final birth file, there is a data availability lag between the close of a calendar year and access to the final PRAMS dataset. As of July 2013, the most current year of data available in CPONDER was 2008. Although the 40 states and one city that participate in PRAMS have access to their own state data, only states where the minimum response rates have been met are included in CPONDER. For 2000-2006, this required response rate was 70 percent, and for 2007-08 it was 65 percent. The required response rate may limit the availability of a “national” estimate through CPONDER, but states with PRAMS are encouraged to use their own data whenever possible.
The PRAMS survey consists of core questions that all states must include and standard, pilot-tested questions that states may choose to add. In addition, PRAMS allows states to design and add their own questions, and the state is responsible for completing question testing before the question can be included. PRAMS data is available from CDC by submitting a proposal for and data sharing agreement to CDC. Data from a single state can be requested from the state PRAMS coordinator.

Data on postpartum depressive symptoms are collected by all participating states, representing approximately 78 percent of all U.S. live births (1, 19). Six other states previously participated in PRAMS. A dataset combining information from all states that have participated in PRAMS, including the six that are not currently involved, is maintained by the CDC and represents approximately 87 percent of all U.S. live births (1). However, items that assess postpartum depression were not included in the core questionnaire prior to 2009; therefore, data on postpartum depression prior to 2009 is only available from states that included optional depression items (19).

**Data quality**

PRAMS is a mixed-mode surveillance system that combines mail and telephone surveillance. Each year's sample is weighted to represent all births that meet the inclusion criteria before reporting. Unlike many health surveys, the PRAMS project has a wealth of information from the birth certificate on those who do not respond by either mode of contact, and therefore weighting can be effective at minimizing differences between respondents and non-respondents. Since the PRAMS survey is completed retrospectively by a woman two to six months after her birth outcome, some bias may occur due to self-reporting and recall. PRAMS is sampled from live births only, so the data do not include information on other pregnancy outcomes such as abortions, miscarriages, or stillbirths; the data do include responses from women who have experienced an infant death. PRAMS is sampled among singleton, twin, and triplet births, and therefore it is not representative of higher order births.

Currently, three survey items found in PRAMS assess postpartum depressive symptoms. The combination of these three items yields 57 percent sensitivity, a high positive predictive value (PPV = 60 percent), and produces a high value of specificity (87 percent), indicating that these items are sensitive and accurate screening questions for this indicator (19). The two optional depression items included in the PRAMS survey prior to 2009 yield 63 percent sensitivity, 83 percent specificity (87 percent), indicating that these items are sensitive and accurate screening questions for this indicator (19). However, the PRAMS data relies on women's self-reports; therefore, data may over- or underestimate the prevalence of the indicator. Other biases, including recall bias, are also a possibility. In addition, only women who gave birth to a live infant are surveyed. Thus data does not capture information on stillbirths, miscarriages, or abortions. Nevertheless, data quality is generally consistent and representative of populations across time and location (1).

**Simplicity of indicator**

The level of complexity in calculating this indicator is relatively low, especially when analyzing prevalence estimates of the indicator through CPONDER. Although the PRAMS uses a complex survey design, data weighting and adjustments are conducted by the CDC prior to release on CPONDER. However, states that prefer to use the PRAMS analytic research file in place of estimates from CPONDER will have to weight data. Use of the PRAMS analytic research file also requires appropriate software that can account for the complex sampling design of the PRAMS survey (1).

Overall, the indicator is easy to understand and interpret. Estimates of maternal postpartum depression are generally reported as a percentage of women in the population who meet the criteria for depressive symptoms following birth.

**References**


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Life Course Indicator: Suicide

The Life Course Metrics Project

As MCH programs begin to develop new programming guided by a life course framework, measures are needed to determine the success of their approaches. In response to the need for standardized metrics for the life course approach, AMCHP launched a project designed to identify and promote a set of indicators that can be used to measure progress using the life course approach to improve maternal and child health. This project was funded with support from the W.K. Kellogg Foundation.

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In June of 2013, state teams selected 59 indicators for the final set. The indicators were put out for public comment in July 2013, and the final set was released in the Fall of 2013.

Basic Indicator Information

Name of indicator: Suicide (LC-45)

Brief description: Suicides per 100,000 population ages 10 and older, age-adjusted

Indicator category: Mental Health

Indicator domain: Risk/Outcome

Numerator: Number of suicides to persons ages 10 and older

Denominator: Total population ages 10 and older

Potential modifiers:
- Specific age groups (age-specific mortality rates)
- Race
- Gender
- Geographic location-state, U.S. Territory, county, census tract
- Education, occupation and other variables from the mortality file

Data source: National Vital Statistics System (NVSS) Records

Notes on calculation: The ICD-10 codes denoting suicide are X60-X84, Y87.0, and U03. In the NVSS mortality data set, the ICD-10 codes have been grouped into 39 underlying causes of death, one of which is suicide and can be used to calculate this indicator. Because the suicide rate for people under 10 is very small and the Centers for Disease Control and Prevention (CDC) WISQARS system only provides suicide mortality rates for people ages 10 and older, the numerator and denominator should be restricted to people ages 10 and older. Because of differences in population distribution by age, suicide rates should be age-adjusted when examined as a total rate. The CDC presents age-adjusted rates using the standard 2000 population; a reference for calculating age-adjusted rates using this population can be accessed here: cdc.gov/nchs/data/statnt/statnt20.pdf
Life Course Criteria

Introduction
Suicide is the 10th leading cause of death among all Americans and is among the top five leading causes of death among Americans under age 45. An average of 33,000 suicide deaths occurred each year in the United States between 2001 and 2009, which equates to more than one death every 15 minutes [2]. Suicide affects many more people than those who die from this cause. Family, friends, classmates and coworkers of the suicide victim are negatively affected through emotional suffering and social stigma that is associated with suicide. People who have been bereaved by suicide are at higher risk for suicidal thoughts and behaviors themselves. Individuals may not die by suicide, but can still suffer from suicidal behaviors or suicidal thoughts. For every death by suicide there are more than 30 attempted suicides [2]. While suicide is often thought of as strictly a mental health issue, it is actually a complete health issue requiring preventive efforts from state and local government, health care systems, physicians, businesses, educational institutions, and community organizations. The existing literature supports that the indicator, suicide, is highly connected to our current scientific understanding of life course health.

Implications for equity
Suicide is a complex human behavior, with no single determining cause. The factors that affect the likelihood of a person attempting or dying by suicide include: prior suicide attempt(s), psychiatric problems and depressive disorders, substance abuse, and access to lethal means [3]. The highest suicide rates are among Non-Hispanic Whites and American Indian/Alaska Native. Among males, Asian/Pacific Islanders have the lowest suicide rates while among females, Non-Hispanic Blacks have the lowest suicide rate [3]. Men die by suicide four times as often as women and represent 78.8 percent of all U.S. suicides. However, women attempt suicide two to three times as often as men and are more likely to have suicidal thoughts. Although most U.S. suicide deaths occur among white, middle aged men, because of the higher numbers of white, middle aged men in the U.S. population, they do not have the highest suicide rate. A particularly concerning subgroup of youth is in the American Indian/Alaska Native adolescent population where 14-27 percent have reportedly attempted suicide [2].

Suicide is strongly associated with psychiatric illness and substance abuse disorders. People with a bipolar disorder diagnosis have a rate of suicide 25 times higher than the general population [4]. Besides previous suicide attempts, severe depressive disorders and alcohol abuse are the most strongly associated risk factors for suicide. Alcohol use and depression are linked risk factors as studies have found 45-70 percent of people with substance use disorders that die by suicide also had depression [2, 4].

Lesbian, gay, bisexual and transgender (LGBT) populations have been shown in studies to have a higher risk of suicide than the general population. U.S. death certificates do not record sexual orientation or gender identity, making it difficult to discern exact estimates of suicide in this population. A meta-analysis studying suicide attempts found 12-19 percent of LGB adults reported a suicide attempt compared with less than 5 percent of all U.S. adults [2]. The same analysis also found at least 30 percent of LGB adolescents reported suicide attempts compared with 8-10 percent of all U.S. adolescents [2]. Less research has been performed in the transgender population, but limited information shows transgendered individuals also have a high risk for suicide. In the 2009 National Transgender Discrimination Survey, 41 percent of respondents reported at least one lifetime suicide attempt [2]. Higher rates of suicide attempts may be due to stress associated with experiences of discrimination, family rejection, harassment, bullying, violence, and victimization.

Public health impact
Suicide affects adults of working age resulting in large costs to the economy from lost wages and work productivity. In the United States, the economic impact of suicide is $34 billion per year. In addition to lost wages and work productivity, suicide attempts result in increased spending on medical care. In 2010, more than 650,000 hospital visits were related to intentional self-harm [5]. An estimated $3 billion dollars each year is spent on direct medical costs related to unsuccessful suicide attempts [5].
Suicide also has a strong, negative impact on the social network of the suicide victim. An estimated six “survivor-victims” result from each suicide in the United States creating 5-6 million Americans who are emotionally affected by suicide. Survivor-victims tend to experience higher levels of overall grief, guilt, shock, and confusion than people who have lost loved ones to other causes.

In addition, the impact of suicide is tied to substance abuse prevention. Based on suicide data from 16 states in the National Violent Death Reporting System in 2009, 33.3 percent of suicide decedents tested positive for alcohol abuse, 23 percent for antidepressants, and 20.8 percent for opiates, including heroin and prescription pain killers [6]. Prevention of suicide could also prevent those connected to the suicide victim from turning to substance abuse to self-medicate from complex experiences of grief and guilt.

**Leverage or realign resources**

The ability to impact suicide – intentional self-harm – among all segments of the population will need to include use of evidence-based programming and policy. It is noteworthy that there are few evidence-based programs to impact adults, including American Indian/Alaskan Natives and Non-Hispanic Whites. A public health approach to suicide prevention identifies successful programming that produces significant, sustained reductions and focuses on identifying broader patterns of suicide and suicidal behavior throughout a group or population. This is in contrast to the clinical approach that explores the history and health conditions leading to suicide in the individual. Interventions to promote emotional health and prevent mental health problems should be chosen in the context of a strategic thinking and planning process. Taking the time to define the underlying problem that needs to be addressed and clearly define goals will help to maximize success [7].


Major protective factors against suicide include effective mental health care, being socially connected (to family, friends, community and social institutions), and possessing adequate stress coping mechanisms. Mental health care, including Cognitive Behavioral Therapy and Dialectical Behavior Therapy, can reduce suicide risk [8, 9]. It is essential to ensure the use of these evidence based mental health approaches are supported by funders (Medicaid, Medicare, Private insurance, etc.) and in policy. Connectedness between individuals, family members, community organizations, and social institutions is equally important and is a main component of the CDC focus on suicide prevention [10]. Building communities that promote the use of evidence based mental health treatment in conjunction with teaching coping skills in educational settings will enhance our ability to impact the prevalence of suicide and suicide attempts.

Lastly, a major risk factor for suicide is access to lethal means. One of the most powerful risk factors for suicide deaths is the ready availability of highly lethal methods. All U.S. studies that have compared individuals who have died by suicide with matched controls (demographically similar people who did not die by suicide) have found that a gun in the home increases the risk of suicide [11]. This is true for people of all ages, but particularly for youth. It is true both for those with psychopathology and without [11]. Limiting access to lethal means needs to be addressed in policy and promoted in programs.

**Predict an individual’s health and wellness and/or that of their offspring**

The death of a person by suicide can have an impact on the emotional, mental and/or financial well-being of family, friends, coworkers and others. Individuals who are bereaved by suicide have a higher risk for suicidal thoughts. They may not seek help in coping with a death by suicide due to social stigma causing an already complex grief and grieving process to be increasingly difficult to overcome. People bereaved by suicide have also been found to be at a higher risk for substance use disorders.
Children exposed to suicide may be more likely to adopt health risk behaviors. In the initial Adverse Childhood Experiences Study (1998) over 13,000 recipients of health care received surveys to ascertain their exposure to abuse or household dysfunction. The survey questions included asking the respondents if they grew up with a household member who was depressed or mentally ill, and, if they grew up with a household member that attempted suicide [12]. The results of the study showed that there was a strong relationship between the breadth of exposure to abuse or household dysfunction during childhood and multiple risk factors for several of the leading causes of death in adults. Occurrence of adverse childhood experiences, such as exposure to suicide, may result in adult health problems that represent a long-term consequence of this adverse childhood experience [12].

Many more individuals attempt suicide than those who die by suicide. For each suicide death, there are more than 30 suicide attempts [2]. Suicidal behaviors affect the health of the individual who attempted suicide as well as their family members and social network. Most importantly, a previous suicide attempt could be indicative of underlying social connection issues or mental health problems and is a major risk factor for eventual death by suicide.

**Data Criteria**

**Data availability**
The National Vital Statistics System is an intergovernmental sharing of data whose relationships, standards, and procedures form the mechanism by which the National Center for Health Statistics (NCHS) collects and disseminates the Nation's official vital statistics. Vital event data are collected and maintained by the jurisdictions which have legal responsibility for registering vital events; these entities provide the data via contracts to NCHS. Vital events include births, deaths, marriages, divorces, and fetal deaths. In the United States, legal authority for the registration of these events resides individually with the 50 States, two cities (Washington, DC, and New York City), and five territories (Puerto Rico, the Virgin Islands, Guam, American Samoa, and the Commonwealth of the Northern Mariana Islands).

Vital Statistics data are available online in downloadable public use files, through pre-built tables in VitalStats, and through the ad-hoc query system CDC WONDER (Wide-ranging Online Data for Epidemiologic Research). Birth certificate data is available in WONDER for 1995-2010, and death certificate data by underlying cause of death (detailed mortality) is available for 1999-2010.

Suicide or intentional self-harm data (total numbers and rate) are provided for the total population, as well as at age intervals beginning at five years of age. The national estimate for suicide rate is based on the mechanism of death as determined by the following International Classification of Diseases, Tenth Revision (ICD-10) codes: U03, X60-X84, and Y87.0. The denominator, all persons in the population, is obtained from U.S. census data.

**Data quality**
Standard forms for the collection of the data and model procedures for the uniform registration of the events are developed and recommended for State use through cooperative activities of the States and NCHS. As reported in the NCHS publication U.S. Vital Statistics System, Major Activities and Developments, 1950-1995, efforts to improve the quality and usefulness of vital statistics data are ongoing. NCHS uses techniques such as testing for completeness and accuracy of data, querying incomplete or inconsistent entries on records, updating classifications, improving timeliness and usefulness of data, and keeping pace with evolving technology and changing needs for data. Work with state partners to improve the timeliness of vital event reporting is ongoing, and NCHS is working closely with National Association of Public Health Statistics and Information Systems and the Social Security Administration to modernize the processes through which vital statistics are produced in the United States, including implementation of the 2003 revised certificates.

**Simplicity of indicator**
The indicator is relatively simple to calculate and explain. The numerator is the total number of persons in the population whose cause of death was reported as intentional self-harm and are aged 10 and over. The denominator is the total number of people in the population aged 10 and over. Age-adjustment of the indicator, which corrects for population distributions that differ by age, adds a degree of complexity to the indicator but increases the utility for comparisons across states and to the nation.
References

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The Life Course Metrics Project

As MCH programs begin to develop new programming guided by a life course framework, measures are needed to determine the success of their approaches. In response to the need for standardized metrics for the life course approach, AMCHP launched a project designed to identify and promote a set of indicators that can be used to measure progress using the life course approach to improve maternal and child health. This project was funded with support from the W.K. Kellogg Foundation.

Using an RFA process, AMCHP selected seven state teams, Florida, Iowa, Louisiana, Massachusetts, Michigan, Nebraska and North Carolina, to propose, screen, select and develop potential life course indicators across four domains: Capacity, Outcomes, Services, and Risk. The first round of indicators, proposed both by the teams and members of the public included 413 indicators for consideration. The teams distilled the 413 proposed indicators down to 104 indicators that were written up according to three data and five life course criteria for final selection.

In June of 2013, state teams selected 59 indicators for the final set. The indicators were put out for public comment in July 2013, and the final set was released in the Fall of 2013.

Basic Indicator Information

Name of indicator: Capacity to Assess Lead Exposure (LC-46)

Brief description: Capacity of states to assess lead exposure

Indicator category: Organizational Measurement Capacity

Indicator domain: Service/Capacity

Numerator: State level: Yes or No to the question, does your state have an explicit requirement that blood lead test results be reported to the state health department; National level: Number of states/districts/territories with an explicit requirement that blood lead test results be reported to the state health department

Denominator: State level: no denominator; National level: Number of states, districts and territories

Potential modifiers: None

Data source: Council of State and Territorial Epidemiologists (CSTE) State Reportable Conditions Assessment (SRCA)

Notes on calculation: At the state level, this indicator will be binary (Yes/No) to the question: Does your state have an explicit requirement that blood lead test results be reported to the state health department?

Similar measures in other indicator sets: None
Life Course Criteria

Introduction
Lead exposure in early childhood, even at very low levels, has consequences for brain development, including intelligence quotients (IQ), ability to pay attention, and academic achievement (CDC 2014). Children are particularly vulnerable, not only because of the critical and sensitive periods of growth and development, but also in how their bodies handle exposure. Children absorb 40 percent of a dose of lead compared to 10 percent in adults, and retain 30 percent of lead absorbed compared to 1 percent in adults (Rosin, 2009). Major sources of lead exposure, including gasoline, paint, pipe solder, and ceramic products, have been removed from the commercial market for decades, but exposure to lead can still occur, particularly in housing built before lead paint was banned from use in 1978. A state or jurisdiction’s monitoring of childhood exposure to lead through blood lead level testing is key to preventing further exposure, remediating exposure sites, and intervening early to minimize exposure impact. Although lead poisoning is already listed as a nationally notifiable condition by CSTE, the condition is only reported to the Centers for Disease Control and Prevention (CDC) as a notifiable disease if the disease is already reportable at the state level. Therefore, a state or jurisdiction’s commitment to lead exposure prevention can be quantified to some extent by determining whether lead poisoning is reportable at a state level, which would then be transmitted to the CDC for national surveillance efforts.

Implications for equity
Although overall numbers of lead poisonings in children have declined dramatically over the past 20 years, disparities of lead poisoning have persisted (National Center for Healthy Housing, 2008). There are multiple risk factors for elevated blood lead levels (EBLs), and these have been identified through national, state, and local exposure assessments over the past half century. These risk factors include age, race, income, location and age of housing, and parental occupation (Levin et al. 2008). A recent Morbidity and Mortality Weekly Report (MMWR) article also reported persistent disparities in the geometric mean of blood lead levels (GM BLL) by factors such as race/ethnicity and income level (CDC 2013a). Non-Hispanic Black children ages one to five are twice as likely to have lead poisoning than non-Hispanic White children ages one to five (National Center for Healthy Housing, 2008). Hicken et al. (2012) found a significant interaction between blood lead levels (BLLs), blood pressure and race, concluding that “social disadvantage exacerbates the deleterious health effects of lead.” The Advisory Committee on Childhood Lead Poisoning Prevention observed that these disparities can be traced to differences in housing quality, environmental conditions, nutrition, and other factors designed to control or eliminate lead exposure (CDC 2013a). The intersection of poverty, older housing, and the impacts of racial residential segregation create a vulnerable population of low income minority families living in older housing and therefore at increased risk for childhood lead exposure and adverse health outcomes. Due to the localized and concentrated nature of elevated BLLs in these low-socioeconomic areas, statistical national prevalence could decline to a level near zero even though children are still being affected by lead poisoning (Alliance for Healthy Homes). Continued analysis of BLLs from children in high-poverty, high-risk areas are important to identify communities posing risk of elevated BLLs (Alliance for Healthy Homes).

Additionally, in documenting the substantial disparities between racial/ethnic groups in notifiable infectious diseases, the CDC also has noted substantial gaps in collection of racial/ethnic data (CDC 2005). Interventions designed to reduce children’s exposures to lead will have more impact if their results can be quantified through nationally reported data.

Public health impact
At least four million households in the United States are exposing children to high levels of lead and about a half million children one to five years of age have a BLL of five μg/dL, which is the level that the CDC recommends public health intervention (CDC 2013b). The negative health effects of lead exposure in children have been well researched and include lifelong, incurable intellectual and behavioral problems (CDC 2013a). Children are highly susceptible to lead poisoning because their bodies absorb lead more easily than adults and lead interferes with the development of their brains, organs and other systems (National Center for Healthy Housing, 2008). There is no safe level of exposure to lead (Child Trends Data Bank, 2013). Even at low levels, lead exposure causes reduced IQ and attention span, hyperactivity, impaired growth, learning disabilities, hearing loss, insomnia, and other health problems (Child Trends Data Bank, 2013). These adverse effects on a child’s neurodevelopment can persist beyond early childhood into adolescence (Child Trends Data Bank, 2013). High BLLs have severe health consequences including seizures, coma and death (Child Trends Data Bank, 2013).
Lead poisoning at low levels can occur without any observable symptoms, resulting in the condition going unrecognized (Child Trends Data Bank, 2013). In order to identify cases of lead poisoning, regular BLL testing is needed (Child Trends Data Bank, 2013). Eliminating elevated BLLs in children and reducing the mean BLL in children from 1.5 μg/dL to 1.4 μg/dL by 2020 are goals of the Healthy People 2020 initiative (Child Trends Data Bank, 2013). Activities identified to support these goals include increasing the proportion of older houses that are tested for lead, increasing the proportion of older houses found to be safe for children and families, inspecting school drinking fountains for lead, and increasing state monitoring of lead poisoning (Child Trends Data Bank, 2013).

There are economic benefits to be gained from reducing children’s exposure to lead. A 2009 cost analysis by the Economic Policy Institute in Washington, DC estimated each dollar invested in lead paint hazard control results in a return of between $17 to $221, which produces a net savings of $181 billion to $269 billion through health care savings, lifetime earnings, tax revenue, special education costs, reduction in attention deficit-hyperactivity disorder, and crime costs (Gould, 2009). Despite the cost savings potential of lead exposure reduction, the CDC Lead and Healthy Homes Program budget was cut from $29 million to $2 million in 2012 (National Center for Healthy Housing, 2013). The results of these cuts have been the elimination of grants for lead poisoning prevention to local and state health departments and a 57 percent reduction in state Childhood Lead Poisoning Prevention Program positions (National Center for Healthy Housing, 2013). Although funding was increased to $15 million in 2014, funds are still just over half of what they were in 2011. Without federal funding, crucial activities including surveillance efforts, may be eliminated (National Center for Healthy Housing, 2013).

Not all states require reporting of EBLs by health care providers or clinical laboratories. In order to determine the true prevalence of EBLs and create public health lead poisoning prevention programs, reporting of all EBLs by clinical laboratories is essential (Council of State and Territorial Epidemiologists). Including lead test results as reportable conditions under state and territorial jurisdiction may increase the likelihood of use of the data for prevention and intervention programs.

**Leverage or realign resources**

Reliable data collection and reporting on EBLs can help to focus lead poisoning prevention efforts. EBLs have been a nationally notifiable non-infectious condition since 2010; however, a disease with notifiable status is not necessarily reportable in each state (CDC 2014). Notifiable diseases are voluntarily reported to the CDC by state and territorial jurisdictions for nationwide monitoring of disease data (CDC 2014). Reportable disease cases must be reported to state and territorial jurisdictions when identified by a health provider, hospital, or laboratory (CDC 2014). CDC partners with 57 state, local, territorial and health departments to improve their National Notifiable Diseases Surveillance System (NNDSS) (CDC 2014) and also runs the Healthy Homes and Lead Poisoning Prevention Program, a goal of which is to provide funding to state and local health departments to screen for EBLs (CDC, 2013). CSTE is responsible for defining and recommending which diseases are reportable within states and which diseases should be voluntarily reported to the CDC (CDC, 2014), making CSTE and CDC relevant partners in obtaining state reportable status for EBLs.

Environmental justice or specific lead poisoning advocacy organizations have had success in helping to pass tough lead poisoning laws and regulations in the past. In 2004, the environmental justice organization, WE ACT, in New York City, helped the passage of Local Law 1, one of the toughest lead poisoning prevention laws in the United States (We Act, 2010). In New Hampshire, the New Hampshire Charitable Foundation performed an advocacy campaign to enact legislation to enhance lead paint poisoning prevention and enforcement (New Hampshire Charitable Foundation). Local environmental health or child health organizations such as these may be helpful in influencing state policy toward a system of lead poisoning as a reportable condition.

In addition to making lead poisoning a state reportable condition, partners in the housing sector can be engaged to reduce lead exposure in children and families. The U.S. Department of Housing and Urban Development (HUD) funds a Healthy Homes Initiative (HHI) to protect children from housing-related health hazards (USHUD, 2014). The HHI addresses multiple housing-related hazards, one of which is elevated lead levels (USHUD, 2014). State and local governments, nonprofits, Indian Tribes, colleges, and universities are all eligible to apply for a Healthy Homes grant for effective home hazard assessment and intervention activities (USHUD, 2014). Activities eligible for funding include development of hazard assessments and interventions, evaluation of interventions, and educating high-risk residents of lead exposure dangers (USHUD, 2014). The Environmental Protection Agency (EPA) requires firms that deal with renovation or repair
projects in homes built before 1978 are certified by EPA-approved trainers and follow lead-safe work practices (USEPA, 2014). EPA also has launched several lead outreach campaigns including Get Lead-safe, Lead-Free Kids, and observes the National Lead Poisoning Prevention Week to draw public attention to the health effects of lead exposure (USEPA, 2014).

**Predict an individual’s health and wellness and/or that of their offspring**

Childhood exposure to lead has lifelong consequences. EBLs, even at low levels, can cause intellectual, learning, and behavioral deficits, and also are associated with many other serious health conditions including asthma, high blood pressure, and degenerative diseases of the elderly (Child Trends Data Bank, Joseph et al, 2005, Zhang et al, 2012, Rosin, 2009). Lead poisoning interferes with brain development in children leading to long-lasting neurological problems (Child Trends Data Bank).

Blood lead concentration of infants is often similar to maternal blood lead concentrations, which may be due to lead’s ability to cross the placenta (American Academy of Pediatrics, 2005). Pregnancy is a critical and sensitive period in the life course for lead exposure. Toxicity from increased blood lead concentration in infancy can occur following high lead exposure in the mother during pregnancy (Rosin 2009). Mid-pregnancy EBLs have been associated with decreased three-to-seven-year IQ, regardless of post-natal exposure (Schnaas et al, 2006). Additionally, a study in Cincinnati found maternal EBLs between six and 28 weeks of gestation were associated with adolescent attention scores (Ris et al, 2004). Evidence supports the early third trimester of pregnancy is a critical period for later intellectual development in childhood and lead exposure during this period can result in long-term intellectual deficits (Schnaas et al, 2006).

The American Academy of Pediatrics has stated the best approach to lead poisoning is to prevent exposure entirely, although this is a long-term goal (American Academy of Pediatrics, 2005). Currently, state surveillance, including case finding, case management, and prevention of additional exposure, is required to identify children with excess lead exposure and intervene in that exposure (American Academy of Pediatrics, 2005). Accurate lead exposure case identification, in conjunction with public health programs that rely on this data to identify where intervention is necessary, can lead to a reduction in lead poisonings (American Academy of Pediatrics, 2005). Nationally representative data also is crucial for the national public health response to lead poisoning and improvement in state monitoring trends of blood lead test results can in turn improve collective national data reported to the CDC (American Academy of Pediatrics, 2005).

**Data Criteria**

**Data availability**

CDC funding of state level lead programs through the STELLAR program has been greatly curtailed in recent years, limiting its usefulness as a capacity indicator for lead screening. Many different programs, e.g., the Medicaid Early Periodic Screening, Diagnosis, and Treatment program, continue to emphasize blood lead testing of children. However, the results of those tests are not automatically available for public health surveillance; whether these data are readily available can serve as an indicator of a state’s ability to use its data for program planning and evaluation.

"Disease reporting in the United States is mandated by legislation or regulation at local, state, or territorial levels only. States and territories determine which conditions to include on reportable condition lists, who is required to report, what information should be reported, and how quickly disease information must be reported to public health authorities. The list of reportable conditions varies across states and from year to year.

Some reportable conditions are designated by CSTE as being nationally notifiable. CSTE recommends that all states and territories enact laws or regulations making these diseases or conditions reportable in their jurisdictions. Currently, states and territories voluntarily report data (without direct personal identifiers) about nationally notifiable conditions (NNCs) that are reportable in their respective jurisdictions to the CDC. Not all NNCs are reportable for each state or territory." (Jajosky et al., 2011). "Each state determines which conditions are reportable within its jurisdiction, including which conditions are reportable from various entities (e.g., facilities, providers, laboratories), within what time frame, to whom within the health department, by what method, and in what format” (PHIN, 2012).

CSTE added lead poisoning to the nationally notifiable conditions list in 2010, which means that if it is reportable at the state level then the information will be transmitted to CDC. When reportable, lead screening results (positive or negative)
are required to be submitted quarterly for children and twice a year for adults. The CDC gathers these data in a State Reportable Conditions Assessment (SRCA) that also tracks the reporting authority: whether the condition is mentioned by name in the jurisdiction’s laws or reportable condition list (“explicit authority”), not specifically listed as reportable but would be considered reportable under general language, e.g., “any condition of public health importance” (“implicit authority”), or not reportable. An important use of the SRCA data is clarification of NNDSS (includes both infectious and non-infectious conditions) data tables published in the CDC MMWR, allowing readers to “distinguish between when no notification of cases for reportable conditions has occurred and when no notification occurred because a condition was not reportable for a state or territory” (Jajosky 2011). The SRCA, which has a marginally intelligible query system, is thus expected to be a long-term, stable source of data.

**Data quality**

Although disease reporting is mandated by legislation or regulation at the state and local levels, state notification to CDC is voluntary. According to the national Biosurveillance Strategy for Human Health, reporting completeness of notifiable disease is highly variable and related to the condition or disease being reported. CSTE and CDC have promoted standardized data elements and case detection algorithms for identification and reporting of nationally notifiable conditions from health care entities to local and state public health. Implementation guides are being developed to enable electronic exchange of these data. This work, combined with widespread adoption of electronic health records, has the potential to improve case detection capabilities for reportable public health conditions. Further development, testing, and implementation of algorithms and data exchange standards are necessary to enhance capabilities (U.S. DHHS, 2010). SRCA staff has diligently searched for reporting and data limitations, and has worked to address those challenges as much as possible (Jajosky, 2011).

**Simplicity of indicator**

This indicator is simple to calculate and relatively easy to explain.

**References**


The Life Course Metrics Project

As MCH programs begin to develop new programming guided by a life course framework, measures are needed to determine the success of their approaches. In response to the need for standardized metrics for the life course approach, AMCHP launched a project designed to identify and promote a set of indicators that can be used to measure progress using the life course approach to improve maternal and child health. This project was funded with support from the W.K. Kellogg Foundation.

Using an RFA process, AMCHP selected seven state teams, Florida, Iowa, Louisiana, Massachusetts, Michigan, Nebraska and North Carolina, to propose, screen, select and develop potential life course indicators across four domains: Capacity, Outcomes, Services, and Risk. The first round of indicators, proposed both by the teams and members of the public included 413 indicators for consideration. The teams distilled the 413 proposed indicators down to 104 indicators that were written up according to three data and five life course criteria for final selection.

In June of 2013, state teams selected 59 indicators for the final set. The indicators were put out for public comment in July 2013, and the final set was released in the Fall of 2013.

Basic Indicator Information

Name of indicator: Data capacity to support integrated childhood research (LC-47)

Brief description: Ability of state maternal and child health (MCH) programs to support integrated, population-based childhood research (i.e., research using linked program data). For the state level, proportion of priority datasets to which the MCH program always has timely access for program or policy planning purposes. For the national level, proportion of states that always have timely access to at least five priority datasets.

Indicator category: Organizational Measurement Capacity

Indicator domain: Service/Capacity

Numerator: State level: Number of priority datasets (e.g. programs) the Title V agency always has timely access to for policy and program planning purposes (including for linkage). (score of three= Yes, the MCH agency always has this ability). Priority programs are death certificates, Medicaid, WIC, newborn screening, hospital discharge, birth defects surveillance, Pregnancy Risk Assessment Monitoring System (PRAMS) and Youth Risk Behavior Surveillance System (YRBSS). National level: Number of states that always have timely access (score of three) to at least five priority datasets.

Denominator: State level: total number of priority datasets (N=eight). National level: The number of states and the District of Columbia (jurisdictions)

Potential modifiers: None

Data source: Title V Information System (TVIS) - Health Systems Capacity Indicator #9A and #9B

Notes on calculation: At the state level, this indicator will be a percent of priority datasets, where 100 percent indicates that the MCH agency always has timely access to all priority datasets. At the national level, this indicator will be a percent of states that always have timely access to at least five priority datasets.
Similar measures in other indicator sets: Title V Health Systems Capacity Indicator #9A and B

Life Course Criteria

Introduction
The Maternal and Child Health Bureau of the Health Resources and Services Administration (HRSA) adopted life course theory as the conceptual framework for its strategic planning efforts in 2010 (17) and today, encourages state Title V agencies to adopt and integrate the approach into MCH programs and policies (18). As Title V agencies develop and refine programming guided by a life course framework, a fundamental challenge arises in measuring the success of these efforts: states vary in their capacity and methods for collecting, managing, and analyzing the breadth of data on population risk exposure and service utilization relevant to life course health. This indicator of organizational measurement capacity measures access of the MCH program to priority datasets for program planning and policy purposes. It focuses on linkage between a state’s birth certificates and priority datasets as well as a number of surveillance and survey activities; these efforts support hypothesis generation and new investigations into the relationships between risks and protective factors and emotional, social, and health outcomes across the life span for MCH populations. Linkage and data sharing are processes that create partnerships and collaboration across programs. Rosenberg et al. found that, “A more permissive data sharing environment can increase a state’s ability to accurately assess and forecast problems, determine the best interventions to address these problems, and appropriately evaluate whether interventions are making a difference” (15). Further, increasing the MCH data capacity of a state can support program and policy changes that improve output and outcome performance for public health impact (6, 7). Despite some limitations in HSCI09 as an indicator for the ability of state MCH programs to support integrated, population-based childhood research, it is the only mandatory and quantitative method for systematically assessing MCH data capacity at the state and national level.

Implications for equity
One of the earlier articles applying the life course approach to MCH is the 2003 article by Michael Lu and Neal Halfon published in the Maternal and Child Health Journal. In this article, the authors describe life course theory as a mechanism for contextually integrating longitudinal models to describe racial disparities in birth outcomes (8). Since the publication of this article and numerous others, life course theory has served as a conceptual framework for reducing inequalities in health outcomes across the field of MCH. The individual linkage projects and the survey and surveillance activities measured by HSCI09 have been used in a number of states to generate and test hypotheses about disparities with regard to care utilization and behaviors, health care costs, and health outcomes for the MCH population, among others. Examples of research studies within the scope of HSCI09 that generated such knowledge include the following:

- Missouri linked Medicaid data, birth certificates, WIC records, and NICU admissions to examine WIC prenatal participation and its relationship to newborn medical costs (9)
- North Carolina and Kentucky examined low birth weight births among Medicaid patients who obtained care in different settings (10)
- Washington state and Ohio identified differences in the use of and outcomes among fee-for-service and managed care Medicaid enrollees (11, 12)
- Florida investigated race and ethnicity as risk factors for breech presentation, utilizing Medicaid/WIC eligibility data linkage to access a socioeconomic proxy variable (13)

The focus of HSCI09 on linkage with vital statistics allows states to capitalize on the breadth of data items included in the birth certificate, which encompasses a number of social measures such as parental education and socioeconomic status in addition to specific aspects of pregnancy, labor and delivery, infant health, and maternal health factors. Further, data activities that monitor characteristics of care received, the prevalence of birth defects, and health-risk behaviors among vulnerable populations (e.g. women, adolescents, infants) allow states to identify groups at high risk for poor outcomes, to monitor changes in health status, and to measure progress towards goals in improving health. Such analyses inform program planning and policy development to make strides toward reducing disparities in health outcomes across MCH populations.

Public health impact
A question fundamental to MCH data capacity to support integrated childhood research is whether an increase in data capacity will be associated with improved public health outcomes: essentially, does data capacity matter? The question is unique to capacity indicator development, and answering it requires considering how and why capacity is assessed in public health. In their evaluation of various tools for Title V agencies to use in capacity assessment and performance measurement, Handler et al. describe capacity as, “the resources and relationships necessary to carry out the important processes of public health. These resources include the basic infrastructure of the system as well as specific program resources” (14). In their description of the Capacity Assessment for State Title V instrument (CAST-5), the authors state the following:

…In a sense, CAST-5 acts as a conceptual bridge [emphasis added] between the EPHS [Essential Public Health Services] framework and measures of program implementation and effects. As such, state MCH programs should be able to strategically link their capacity and process assessment (CAST-5) to their output and outcome performance (Title V “24”) (121).

Applying the model of the ‘conceptual bridge’ to HSCI09, the phrasing of HSCI09 is specific to whether the data are used for MCH program planning or policy purposes – essentially undergirding the performance and enhancing the impact of these initiatives. An additional example may be useful. States that participate in the Centers for Disease Control and Prevention (CDC)-HRSA MCH Epidemiology Program (MCHEP) complete the MCH Epi and Data Capacity Tool as a part of their annual self-review (16). This tool assesses state efforts in a number of linkage, survey, and surveillance activities across the strata of access, analysis, dissemination, and program/policy use (15). The uses detailed in the tool include modifying an existing program/policy, developing a new program/policy, developing a new grant for the agency, and grant reporting. Inherent in this assessment tool is that the data activities support the performance of each of these tasks. In total, a change in the indicator (the number of priority datasets the Title V agency always has timely access to for policy and program planning purposes) can support program and policy changes that improve output and outcome performance for public health impact. Further, the individual activities can have a public health impact through performance management and quality improvement when integrated as a part of a feedback mechanism for program planning.

**Leverage or realign resources**

Linkage and data sharing are processes that create partnerships and collaboration across programs. Rosenberg et al. found that enhanced MCH epidemiology functioning on an organizational level is associated with ready access to data by the MCH program and external users, as well as increasingly regular data integration (15). The authors conclude, “A more permissive data sharing environment can increase a state’s ability to accurately assess and forecast problems, determine the best interventions to address these problems, and appropriately evaluate whether interventions are making a difference.” These findings uncover an opportunity to not only improve data capacity but also MCH epidemiology functioning through explicitly encouraging cross-program collaboration and systems integration through linkage and data sharing agreements.

HSCI09 currently includes mostly ‘traditional’ MCH data sets, namely vital records, WIC eligibility, and newborn screening, as well as registries and surveys such as birth defects surveillance, PRAMS, and YRBSS. As such, it is not entirely reflective of programs, services, and policies that expand beyond the MCH focus. However, future discussions pertaining to adding or expanding linkage activities included in HSCI09 may allow for seamless inclusion of education, housing, environmental and other programs.

A number of opportunities exist to leverage and realign resources and maximize collective impact in building MCH data capacity. For example, the Health Resources and Services Administration, the Centers for Disease Control and Prevention, and the Council of State and Territorial Epidemiologists could expand upon their unique, long-term collaboration building MCH epidemiology capacity to identify additional synergies in methods by which MCH data capacity is measured at the state agency level. The data collected through the MCHEP tool is detailed and valuable, but limited to those states that participate in the program and receive a CDC assignee. While all efforts should be taken to reduce Title V agency reporting burden, it is worthwhile to consider the value of the breadth of data collected through various federal funding sources.

Further, little incentive exists for data linkages and collaboration between Title V agencies and agencies outside of MCH that collect data of value to measuring life course trajectories, including housing, environmental, and education agencies.
Given that national, state, and local MCH programs informed by the life course approach are launching with increasing urgency, MCH epidemiology stakeholders including federal leadership, learning collaboratives formed of state agencies, and others could identify a consensus list of priority linkages both inside and outside Title V agencies that demonstrate new partnerships through data access. Additionally, both public and private funders could invest in building capacity for data sharing through grants that capitalize on novel partnerships to build life course data capacity. The fundamental focus of the grants would be incentivizing collaboration through data. Federal leadership could encourage cross-program collaboration and systems integration by developing guidance for Title V agencies in executing data sharing agreements and creating permissive data sharing environments.

Finally, information systems integration remains an exciting frontier in real-time data aggregation for long-term and intergenerational health. Data and messaging standards are not uniformly adopted across states and programs, and are a major barrier to the wide scale implementation of systems integration. The MCH community is not well represented in federal advisory committees, standards developing organizations, and others leading the charge for standard setting and adoption in the application of health information technology to the field of public health. MCH representatives from CDC, HRSA, national MCH partners, and state agencies may wish to collaborate with standard-setting entities as they work to identify new methods for improving the health of MCH populations.

**Predict an individual’s health and wellness and/or that of their offspring**

The datasets included in HSCI09 pertain primarily to exposure to risks and access to services and supports during pregnancy, infancy, early childhood, and adolescence; as such, HSCI09 is consistent with MCH program access to data pertaining to critical and sensitive periods in health and development. HSCI09 measures linkage between a state’s birth certificates and priority datasets as well as a number of survey and surveillance activities; these efforts support hypothesis generation and new investigations into the relationships between risks and protective factors and emotional, social, and health outcomes across the life span for MCH populations. These activities can support integrated childhood research and alleviate challenges with research-focused primary data collection efforts, which may include a) limitation to a study sample and not the total state MCH population, b) inflexibility to add new variables based upon evolving life course science, and c) defined time horizon as determined by study funding and hypothesis generation at study outset (19). Despite some limitations in HSCI09, including its narrow scope, it is the only mandatory and quantitative method for systematically assessing MCH data capacity, and therefore remains a valuable resource.

**Data Criteria**

**Data availability**

During the Title V MCH Block Grant application and annual reporting process, agencies respond to nine Health Systems Capacity Indicators (HSCI) that are considered key indicators of the health systems and program capacity supporting MCH in a state. One of these indicators is HSCI09. Reporting on the indicators is made publicly available through TVIS. States assess their MCH data capacity by completing Form 19 for HSCI09, the purpose of which is for states “to show the State MCH data capacity and whether the MCH program has the ability to obtain timely analyses of certain data for programmatic and policy issues.” HSCI09 focuses on eight data activities:

1. Annual linkage of infant birth and infant death certificates
2. Annual linkage of birth certificates and Medicaid eligibility or paid claims files
3. Annual linkage of birth records and WIC eligibility files
4. Annual linkage of birth records and newborn screening files
5. Hospital discharge survey for at least 90 percent of in-State discharges
6. Annual birth defects surveillance system
7. Survey of recent mothers at least every two years (like PRAMS)
8. Youth Risk Behavior Surveillance System (YRBSS)

States score themselves on two criteria for each activity:

1. Does your MCH program have the ability to obtain data for program planning or policy purposes in a timely manner?  
   *Response is a score of one to three indicating no, sometimes, or yes.*
2. Does your MCH program have direct access to the electronic database for analysis?  
   *Response is yes or no.*
For the eighth data activity (YRBSS), states respond to whether their state participates and if the MCH program has direct access to the State YRBS database for analysis (responses are as above).

There are two distinct strengths of the HSCI09/TVIS data source with regard to data availability (1). First, HSCI09 is the only national indicator measuring administrative linkage and access to databases and surveys among MCH programs in all 50 states and the District of Columbia. Like other block grant measures, reporting on the indicator is consistent, mandatory, and completed on at least an annual basis. In fact, states report on (and update) this indicator twice per year, once for their Block Grant reporting and again for reporting for the State System Development Initiative program. Secondly, TVIS contains the reports on data capacity of the states for the last five years, allowing the TVIS user to observe changes in infrastructure and trends in data capacity over time. Data in TVIS are updated annually following the Title V Block Grant reviews. As of October 2013, TVIS users could access FY2013 data.

The indicator as described measures the capacity of an MCH program to conduct integrated, childhood research. Of note, HSCI09 is its limited to a set of four individual linkage projects and four survey and surveillance activities - it is not a measure of longitudinal administrative linkage. Form 19, which includes guidance to states for reporting upon the indicator, also does not give space for states to expand upon the sophistication of a linkage project; for example, if the linkage occurs more often than annually or as the result of integrated information systems, which would further enable integrated childhood research (2).

Data quality

Reporting on HSCI09 is consistent and mandatory, and in general considered of a high quality, especially with regard to the use of categorical and dichotomous variables to assess capacity.

Reporting on the indicator includes the states scoring themselves on two criteria for each linkage or survey activity (1):

1. Does your MCH program have the ability to obtain data for program planning or policy purpose in a timely manner?
2. Does your MCH program have direct access to the electronic database for analysis?

With regard to the first scoring activity, the terms ‘ability’ and ‘timely’ are subjective and open to interpretation by the respondent. For example, in response to the third linkage activity (annual linkage of birth certificates and WIC eligibility files), 21 states scored themselves at a level of two (“Yes, the MCH agency sometimes has this ability, but not on a consistent basis”) (3). One could interpret this finding to mean that 21 states are able to conduct the linkage between these datasets, however not on a consistent, annual basis (meaning that the responding state does not gain access to birth certificates and WIC eligibility data on an annual basis, but could). However, this question could also be interpreted that the state has conducted linkages between these programs, but not on an annual basis (despite always being able to gain access): of significance is that neither the first nor second of the two self-scoring questions inquire as to whether linkage for the first four activities is actually performed, but rather that the ability is present. Stated another way, it is difficult to assess how many states performed linkage between the two data files in the most recent reporting year.

Data users should take care inferring about changing data capacity over the five years available in TVIS: some states indicate an increase in the ability to ‘obtain data in a timely manner’ (moving from one to two or two to three over reporting years) whereas others indicate a decrease. Additionally direct access to data changes over the years as well, with states losing and gaining access over the five-year period (4). These changes reflect the complexity of measuring data capacity within MCH programs, which is influenced by staff turnover, funding, identified program needs, or other external factors. In summary, while there is consistency in the frequency of reporting and block grant measures are considered of high quality, the subjective nature of both the terminology used to assess the indicator and the self-ranking process, and the measurement of ability to obtain data and access it electronically as opposed to directly measuring whether linkage occurred (and therefore a linked administrative database exists as a capacity to conduct integrated childhood research) are important quality considerations.

A final note with respect to the comparison of capacity across states: 12 states still use the 1989 revision of the standard birth certificate and have yet to implement the 2003 revision, which expanded the contents of the birth certificate to 60 data items (5). While the linkage procedure itself is unaffected, the utility of the linked data was greatly improved by the new sociodemographic items (for example, race categories in the 2003 revision align with those in the U.S. Census).
Therefore the motivation to link and the outcomes of linkage projects, including the knowledge gained from the endeavor, may vary across programs.

1 As reported by states in their Title V MCH Services Block Grant FY 2011 Annual Report and FY 2013 Application; Form 19

**Simplicity of indicator**
This indicator is simple to calculate, as it is a component of the annual Title V MCH Services Block Grant reporting process, and the scores on the items are made publicly available through TVIS via a query system. The indicator does not require linkage for calculation. The indicator is less simple to explain with regard to why MCH data capacity is critical for a life course approach in MCH.

**References**


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Life Course Indicator: States with P-20W Longitudinal Data Sets

The Life Course Metrics Project

As MCH programs begin to develop new programming guided by a life course framework, measures are needed to determine the success of their approaches. In response to the need for standardized metrics for the life course approach, AMCHP launched a project designed to identify and promote a set of indicators that can be used to measure progress using the life course approach to improve maternal and child health. This project was funded with support from the W.K. Kellogg Foundation.

Using an RFA process, AMCHP selected seven state teams, Florida, Iowa, Louisiana, Massachusetts, Michigan, Nebraska and North Carolina, to propose, screen, select and develop potential life course indicators across four domains: Capacity, Outcomes, Services, and Risk. The first round of indicators, proposed both by the teams and members of the public included 413 indicators for consideration. The teams distilled the 413 proposed indicators down to 104 indicators that were written up according to three data and five life course criteria for final selection.

In June of 2013, state teams selected 59 indicators for the final set. The indicators were put out for public comment in July 2013, and the final set was released in the Fall of 2013.

Basic Indicator Information

Name of indicator: States with P-20W Longitudinal Data Sets (LC-48)

Brief description: States with P-20W longitudinal data systems. A P-20W is a data system where policies and standards are aligned to link student data for specified purposes across the education continuum, from early childhood through K12, postsecondary and the workforce.

Indicator category: Organizational Measurement Capacity

Indicator domain: Service/Capacity

Numerator: Number of states, territories, and jurisdictions that completed 8 or more essential actions of fully functional P-20/workforce longitudinal data system (P for preschool).

Denominator: Total number of states, territories, and jurisdictions

Potential modifiers: None

Data source: The Data Quality Campaign (DQC)

Notes on calculation: None

Similar measures in other indicator sets: None
Life Course Criteria

Introduction
On an individual level, education is a powerful social determinant of overall health and well-being. Educational attainment is associated with both health behaviors and health outcomes, including heart disease, cancer, stroke, diabetes, drinking, smoking, and exercise (Cutler and Lleras-Muney 2006). Education also is associated with birth outcomes; among births experiencing uncompromised fetal growth, birthweight increases with educational attainment (Gage et al 2012). Woolf et al postulate that if everyone had “the health of the educated,” the mortality averted would be eight deaths for every one death averted by medical advances (Woolf et al 2007) and concluded that spending on medical advances to the detriment of social change actually jeopardizes health. However, the ability of public health alone to bring about the type of social change needed to positively impact health is somewhat limited.

A P-20W linkage means data from early childhood, elementary, secondary, postsecondary, and workforce sources are linked in a way that is secure, useful, and appropriately accessible. There is a governance structure that allows appropriate access to data and works to build the capacity of stakeholders to use it. The issues such a linkage can explore include the educational experience a child needs to successfully pursue his or her desired career, the alignment of high school prep programs with employer needs, whether children have access to high quality early care and education programs, and whether the expectations of K-12 and postsecondary education systems are aligned (DQC fact sheets). P-20W systems link and track data at the student level and allow for tracking of teachers, schools and school districts.

While health data are not currently included in the linkage, the existence of a robust P-20W linkage in your state means there is a framework for inclusion of health data in the future, allowing health and education to work together to ensure that the children with the most need or the most risk have the opportunity to succeed.

As state public health agencies work to advance health through a life course perspective, the capacity and integration of data systems to help measure health across the life course trajectory are important measures of larger organizational and community level capacity to address health through a life course perspective. As a life course indicator, the presence of a functioning P-20W longitudinal data system is a measure of public health capacity to address life course.

Implications for equity
The establishment of a P-20W longitudinal data system will allow users to examine equity issues across the educational continuum. If health data can be included, the complex interplay between access to quality education, educational attainment, and health can be more thoroughly explored. There are disparities in key educational markers explored elsewhere in the life course indicators, including fourth grade proficiency, high school graduation rates, and maternal education when examined by race/ethnicity and economic status. These indicators of education disparities, however, are not derived from linked data systems, making them inherently cross-sectional measures of equity. With the establishment of P-20W data systems, the capacity of the education and public health systems to examine and address issues of equity will become more advanced, allowing for examination of the cumulative burden of inequity, its impacts on the education and health trajectories of students, and the design of strategies to restore equity.

When building P-20W linkages, a consideration for equity is that the systems that are built are applied equitably across the state and with cross-state linkages. Equitable application would mean that every student, educator, and school is represented in the data; a system that potentially excludes students with the most need, the least access, or the worst health will be biased and unusable.

Public health impact
The creation and use of longitudinal data systems that link across P-20W is one of three overarching “imperatives” to create a culture of effective data use. The others are ensuring data access while protecting privacy, and building capacity of all stakeholders to use data. The DQC posits that effective implementation of these “imperatives” defines a culture where state policy makers not only collect quality data but use them for informed decision making, ultimately resulting in increased student achievement. For example, the DQC (2012) provides the following examples of reports that states can produce using student-level longitudinal data, including:

- Diagnostic reports that can guide efforts by teachers and parents to provide timely and effective help to students and to make sure that the instruction challenges them appropriately;

Life Course Indicator: States with P-20W Longitudinal Data Sets (LC-48)
Early warning system reports that provide information regarding whether individual students are at risk or in need of extra assistance;
Readiness reports that can help identify whether and to what extent each elementary, middle and high school student is on track for college and career readiness by high school graduation;
Predictive reports that use information on the past performance of students to see whether students are likely to reach a particular performance goal.

As the timeliness, predictability and sophistication of reporting develops as a result of the P-20W data system, policy makers can help drive increased academic achievement. Increased academic achievement impacts individuals’ lifetime health and well-being, and may ameliorate effects of socioeconomic and familial disadvantage (Wickrama et al., 2012). Also, understanding individual-level educational trajectories will improve research on education and health.

**Leverage or realign resources**
As a societal factor, education is a powerful predictor of health, but the public health field has very little control over increasing educational attainment. However, working together with the education sector to build data capacity is one way to engage in working to improve the social determinants of health. Both the process of building these longitudinal data systems, and the resulting information from them, can be used to enhance working relationships between public health and education.

Key stakeholders for P-20W linkages include parents, educators, policymakers, system leaders, and community members (DQC Primer, 2012). Because of the connection to what the future workforce looks like (the W in P-20W), employers should be considered key stakeholders in the use of P-20W linkages. A prepared, healthy workforce may mean that employees have higher job satisfaction and take fewer sick days, resulting in increased productivity.

**Predict an individual’s health and wellness and/or that of their offspring**
Research on individual academic achievement and later health status is challenged by questions of causality and directionality. Nonetheless, it is generally accepted that higher levels of education lead to better decision-making around health and health care use (Lleras-Muney 2005; de Walque, 2007; Cutler and Lleras-Muney, 2010; Webbink et al., 2010; Wickrama et al., 2012). Thus, the extent to which the longitudinal systems are used and perform as predicted by the DQC can be considered a (partial) predictor of health status.

**Data Criteria**

**Data availability**
The Data Quality Campaign (DQC) “Promotes the development of state longitudinal data systems that collect the quality data needed to answer critical questions facing education stakeholders.” They annually survey states’ progress in building and using longitudinal data systems for education data, with the P-20W linkage system being the first of 10 key “state actions” that DQC has identified as key to both collecting quality data and increasing student achievement. The 2012 data were due from states in August of 2012 and made available in November of 2012, indicating an approximate 3 month delay in releasing the year’s data.

The 2012 state analysis is their eighth annual report. Data on each of the state actions are requested from each state’s governor’s office or their designee to respond to the survey in collaboration with stakeholders. DQC determines whether or not states receive credit for each action based on states’ responses (see document “Criteria for the 10 State Actions” at dataqualitycampaign.org/files/DFA2012_Survey_Criteria.pdf.

The ten state actions are as follows:

1. Link state K–12 data systems with early learning, postsecondary education, workforce, social services, and other critical agencies
2. Create stable, sustained support for robust state longitudinal data systems
3. Develop governance structures to guide data collection, sharing, and use
4. Build state data repositories (e.g., data warehouses) that integrate student, staff, financial and facility data
5. Implement systems to provide all stakeholders with timely access to the information they need while protecting student privacy
6. Create progress reports with individual student data that provide information educators, parents and students can use to improve student performance
7. Create reports that include longitudinal statistics on school systems and groups of students to guide school-, district- and state-level improvement efforts
8. Develop a purposeful research agenda and collaborate with universities, researchers and intermediary groups to explore the data for useful information
9. Implement policies and promote practices, including professional development and credentialing, to ensure educators know how to access, analyze, and use data appropriately
10. Promote strategies to raise awareness of available data and ensure that all key stakeholders, including state policymakers, know how to access, analyze, and use the information

The DQC tracks 52 states, territories, and jurisdictions, including the 50 states, the District of Columbia and Puerto Rico. States may access their data in summary form on the website or download their state profile. In addition, the DQC tracks the number of states that have completed each action and reports these by action, as well as a summary of how many states have completed numbers of actions (at least 1 and 8 or more). For 2012, the data are as follows:

Action 1: 14 states
Action 2: 35 states
Action 3: 40 states
Action 4: 45 states
Action 5: 5 states
Action 6: 36 states
Action 7: 42 states
Action 8: 38 states
Action 9: 6 states
Action 10: 26 states

No state has achieved all ten actions; in 2011 four states (Arkansas, Delaware, Florida and Texas) had at least eight actions. In 2012, an additional six states had at least eight actions (Indiana, Louisiana, Maine, North Carolina, Ohio and Oregon) for a total of ten states with at least eight of the ten actions.

State and national data are available on the DQC website and do not require special permission for access. Key overall findings from the 2012 survey can be found here: dataqualitycampaign.org/your-states-progress/executive-summary/

Data quality
Data are based on states’ responses to a fairly detailed set of questions (“Criteria for the 10 State Actions”). Although there does not appear to be an independent validation of state responses, the data are closely related to those that states are required to report to the U.S. Department of Education under the 2007 America COMPETES Act, which includes 12 “Required elements of a P-16 Education Data System.”

Simplicity of indicator
P-20W data systems may be unfamiliar to those who work with the usual sources of public health data. However, there is essentially no calculation necessary to determine how many actions a state has completed or to determine how many states have completed at least 8 actions. Therefore, the indicator is relatively simple, both for calculation and explanation.

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Data Quality Campaign Fact Sheet: Postsecondary Education Data Landscape, September 2011.

Data Quality Campaign Fact Sheet: Workforce Data Landscape, September 2011.

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Life Course Indicator: Gestational Diabetes

The Life Course Metrics Project

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Basic Indicator Information

Name of indicator: Gestational Diabetes (LC-49)

Brief description: Percent of adult women with diagnosed diabetes during pregnancy, only

Indicator category: Reproductive Life Experiences

Indicator domain: Risk/Outcome

Numerator: Total women with diabetes only during pregnancy

Denominator: Total population of mothers

Potential modifiers: Age, race, pre-pregnancy weight, family history of diabetes, previous pregnancies with gestational diabetes

Data source: Pregnancy Risk Assessment Monitoring System (PRAMS)

Notes on calculation: Analysts who use the raw datasets should apply the appropriate survey weights to generate the final estimates.

Similar measures in other indicator sets: None
Life Course Criteria

Introduction
Gestational diabetes mellitus (GDM) is impaired glucose tolerance with onset during pregnancy. GDM differs from type 1 and type 2 diabetes in causes, biologic processes, affected life stages, and health implications both on the individual and intergenerational level. Issues surrounding GDM are discussed in the current narrative while a separate narrative, LC-26 “Diabetes,” discusses issues over the life course caused by type 1 and type 2 diabetes. GDM, unlike type 1 diabetes, which is caused by a lack of insulin, is caused by insulin resistance. Hormones produced during pregnancy block the body’s effective use of insulin causing insulin resistance, and subsequently, high blood sugar. GDM affects the health of women, children, and families in negative ways. Women with GDM are at a higher risk for pregnancy complications including preeclampsia and cesarean delivery. A history of GDM also puts women at higher risk for morbidity later in life through increased likelihood of type 2 diabetes, metabolic syndrome, and cardiovascular disease. Infants of mothers with GDM are at a higher risk for congenital birth defects, macrosomia, respiratory distress syndrome, and overall neonatal mortality. In childhood and adolescence, offspring of mothers with GDM are at an increased risk for both obesity and type 2 diabetes. Proposed programs and policies can help reduce GDM and prevent the morbidity and mortality women, children, and families experience due to diabetes and other health complications.

Implications for equity
In the United States, the prevalence of GDM has been measured between 4.6 percent – 9.2 percent. Prevalence of GDM is higher in Black, Hispanic, Native American, and Asian women compared to non-Hispanic White women. Only 1.5–2.0 percent of White women develop GDM, whereas Native Americans from the southwestern United States may have rates as high as 15 percent, but there is great variability across tribes in the United States. For example, Zuni Indian women have a prevalence of about 15 percent compared to Navajo Indian women with a prevalence of 10.4 percent. In Hispanic, Black, and Asian populations, the incidence is 5 percent – 8 percent. Asian/Pacific Islander women also have a high prevalence of GDM with some studies measuring prevalence in this population as high as 14 percent, which is comparable or higher than some American Indian populations. Women may experience a number of social, economic, and political barriers to accessing high-quality health care in which they will receive screening and treatment for GDM. Income, ethnicity, marital status, age, and educational attainment all affect a woman’s ability to obtain health care and many poor, minority women are left without comprehensive care coverage.

Not only are there disparities in development of GDM, but disparities also exist in negative health outcomes associated with GDM. A study of Kaiser Permanente health plan beneficiaries found while the risk of GDM was highest in Asian/Pacific Islander women, non-Hispanic Black women who developed GDM had the highest risk of any race for developing diabetes after GDM. Another study found while GDM rates were similar in non-Hispanic Black women (6.1 percent) and non-Hispanic White women (6.3 percent), non-Hispanic Black women were more likely to deliver a large for gestational age infant than non-Hispanic White women.

Janevic and colleagues (2010) assessed whether the number of healthy food outlets (e.g. supermarkets, and fruit/vegetable and natural food stores) and unhealthy food outlets (e.g. fast food, pizza, and convenience stores) in New York City communities were correlated with GDM, but did not find a significant association. While the exact reasons behind the disparities in GDM and GDM outcomes remain unclear, certain factors including race/ethnicity, previous overweight or obesity, and pre-diabetes are associated with increased risk of GDM. The disparities that exist have implications for equity due to the health consequences over the life course that exist for mothers and infants affected by GDM.

Public health impact
GDM remains a public health concern because it negatively affects the health of mothers, infants, and families and can be prevented or managed through alterations in lifestyle. An important factor in reducing the negative effects of GDM is providing preconception health care to women of childbearing age. Since overweight and obesity are risk factors for GDM, helping women maintain a healthy weight before pregnancy can reduce their chances of developing GDM. There also are opportunities for improvement in prevention, detection, and management of GDM through improving knowledge of family history of diabetes when considering having children. Family history of diabetes need not preclude having children but rather it increases the awareness of both the woman and her providers of the opportunities to improve preconception health and the potential need for control or management prenatally.

Life Course Indicator: Gestational Diabetes (LC-49)
Complications and health issues from GDM lead to avoidable health care costs for women and infants. GDM increases the likelihood of having a cesarean delivery. In 2008, the average cost per stay for a cesarean delivery with no complications was $4,700 compared to $2,900 per stay for vaginal deliveries with no complications. The costs increase drastically if complications are present. In addition to delivery costs, women who have GDM are at a higher risk for developing type 2 diabetes later in life, while offspring of women with GDM have a higher risk of developing impaired glucose tolerance and metabolic complications. Chen et al (2007) estimated pregnancy and newborn complications due to GDM increased medical costs in the United States by a total of $636 million ($596 million dollars in maternal costs and $40 million in neonatal costs) in 2007 alone. Reducing prevalence of GDM could result in significant cost savings to Medicaid as approximately 36 percent of these costs ($230 million) were paid for by government programs, mainly Medicaid. Glucose screenings are important tools for early detection and treatment. In January 2014, the U.S. Preventive Services Task Force released a statement recommending screening for GDM in all asymptomatic pregnant women after 24 weeks of gestation, concluding there was sufficient evidence for the benefits of this practice.

GDM increases a woman’s risk for developing type 2 diabetes and cardiovascular disease (CVD), which is the leading cause of death of women in the United States. Women who progress to type 2 diabetes after having GDM have a higher risk of CVD than women who had GDM that did not progress to type 2 diabetes. Metabolic syndrome, which is a group of CVD risk factors including obesity, hypertension, dyslipidemia, and insulin resistance also is more prevalent in women who have had GDM. There are opportunities to reduce risk of CVD in women through prevention of GDM and through healthy lifestyle interventions or medications that prevent development of type 2 diabetes in women who have experienced GDM.

Leverage or realign resources
There are many diabetes prevention programs on the national and state level that include community resources as well as local employers to provide services and promote healthy lifestyles. In New York, the “Creating Healthy Places to Live, Work, and Play” initiative works with communities and employers to provide safe places to be physically active to residents and workers, increase accessibility of fresh fruits and vegetables, and improve the nutritional value of foods offered at local restaurants and corner stores. Initiatives such as these could decrease risk factors for GDM or decrease the risk for progressing to type 2 diabetes after experiencing GDM. In addition, partnerships with schools could help prevent children exposed to GDM in utero from developing diabetes later on in childhood by providing health education, healthy meals, and regular exercise throughout the school year.

Medicaid would particularly benefit by addressing GDM because the program currently covers costs for 44 percent of all births in the United States. A disproportionate percentage of Medicaid insurance holders are underrepresented groups, who are at an increased risk of GDM. This is particularly true for many individuals of Native American tribes, and Medicaid is now the primary payer for Indian Health Services. Also, as Medicaid coverage is expanding under the Affordable Care Act, more women will be eligible, which will likely increase costs without better prevention and health management strategies. Prevention programs for GDM in female Medicaid beneficiaries, such as programs to help maintain healthy weight, could have additional health benefits. If overweight and obese women were able to attain a healthy weight before pregnancy, an estimated 50 percent reduction in GDM could be achieved.

Improving the GDM indicator is an important opportunity for collaboration between chronic disease (CD) programs focused on diabetes prevention and management and maternal and child health (MCH) programs focused on improving the health of women before, during, and after pregnancy and improving birth outcomes. These programs can work together to address a woman’s increased risk of developing type 2 diabetes in the future as well as the increased risk of the child developing diabetes later in life. The Centers for Disease Control and Prevention (CDC), AMCHP and the National Association of Chronic Disease Directors (NACDD) piloted this type of collaboration around GDM through support of three states in modeling effective collaboration of MCH and CD programs in developing diabetes prevention initiatives. For some participating state teams, the GDM initiative was the first time there was a formal collaboration between the MCH and CD programs, and this was an innovative way to tackle an issue that was important for both programs without being duplicative; participants cited this project as a model for future work between the programs and potentially for other areas of the health agency as well. In 2010, the Ohio Gestational Diabetes Mellitus Collaboration was founded as an effort between CD and MCH departments. The program aims to educate the public and health care providers about health complications in women with a history of GDM and promote regular screenings to prevent these
complications. The collaboration has attempted to raise awareness about GDM through radio public service announcements, social media messages, partnering with text4baby, and publishing a data book on GDM in Ohio.

**Predict an individual’s health and wellness and/or that of their offspring**

Approximately 2 – 5 percent of pregnant women will develop GDM, and type 2 diabetes may develop after pregnancy. Mothers that have GDM have a 35 percent to 60 percent chance of developing diabetes over the next 10 to 20 years. Type 2 diabetes in women with a history of GDM creates a significant risk for CVD. Women who have had GDM have been found to have a 70 percent increased risk of CVD than women who have not had GDM. Risk of CVD increases with the development of type 2 diabetes, metabolic syndrome, and obesity.

GDM affects maternal health in both the current pregnancy and future pregnancies. Once a woman has had one pregnancy with GDM, there is an increased risk that she will develop GDM in subsequent pregnancies. Also, during pregnancy a mother with GDM is at a much greater risk for developing preeclampsia, which can be life-threatening for the mother and infant. There are a few known risk factors for preeclampsia but very little can be done to prevent the condition; it is therefore important to take advantage of opportunities to reduce risk through prevention of conditions like GDM.

The health of infants is also affected by GDM. GDM is associated with higher levels of fetal death / stillbirth, especially in cases that were not treated throughout the pregnancy. GDM has been linked to some forms of congenital defects of the central nervous system. Comorbidities in the mother add increased risk of fetal health issues. Women who suffer from both obesity and GDM have a significantly higher risk of congenital birth defects than women who have only obesity or only GDM.

A frequent outcome of GDM is giving birth to infants larger than 4,000 to 4,500 g (eight pounds 13 ounces to nine pounds four ounces) which is termed macrosomia. Due to their large size, infants of mothers with GDM are much more likely to suffer trauma during birth, and mothers have an increased risk of having a cesarean delivery. Cesarean delivery increases a mother’s recovery time after birth and can delay initiation of breastfeeding.

GDM is a major risk factor for neonatal respiratory distress syndrome (RDS). RDS ranges from mild to severe cases and occurs in 25 to 38 percent of infants born to mothers with GDM. The precise reasons for increased risk of respiratory problems in infants born to mothers with GDM are not known for sure, but the higher risk may be related to a number of complex biologic processes resulting from hyperinsulinemia. Offspring born to mothers with GDM also have an elevated risk for obesity and developing type 2 diabetes during childhood or adolescence. The increased risk for becoming obese and developing diabetes at a young age means many female children of mothers with GDM will already suffer from diabetes or obesity by their childbearing years, which fuels a cycle of intergenerational health issues.

**Data Criteria**

**Data availability**

PRAMS, initiated in 1987, is an ongoing population-based surveillance system designed to identify and monitor selected maternal experiences and behaviors that occur before and during pregnancy and during the child’s early infancy. Forty states and New York City currently participate in PRAMS, representing approximately 78 percent of all U.S. live births. Six other states previously participated. The CDC maintains a combined dataset with information from all participating PRAMS states, which represents approximately 87 percent of all live births in the United States. The CDC PRAMS Online Data for Epidemiologic Research (CPONDER) is a Web-based query system created to access data collected through PRAMS surveys.

The length of time between an event and entry into the sampling frame is typically two to six months. Because PRAMS data are weighted to the final birth file, there is a data availability lag between the close of a calendar year and access to the final PRAMS dataset. As of July 2013, the most current year of data available in CPONDER was 2008.

Although the 40 states and one city that participate in PRAMS have access to their own state data, only states where the minimum response rates have been met are included in CPONDER. For 2000-2006, this required response rate was 70 percent, and for 2007-08 it was 65 percent. The required response rate may limit the availability of a “national” estimate through CPONDER, but states with PRAMS are encouraged to use their own data whenever possible.
The PRAMS survey consists of core questions that all states must include and standard, pilot-tested questions that states may choose to add. In addition, PRAMS allows states to design and add their own questions, and the state is responsible for completing question testing before the question can be included. PRAMS data is available from CDC by submitting a proposal for and data sharing agreement to CDC. Data from a single state can be requested from the state PRAMS coordinator.

The number of women with diabetes only during pregnancy is derived from self-reported PRAMS survey information in which women are asked “During your most recent pregnancy, were you told by a doctor, nurse, or other health care worker that you had gestational diabetes (diabetes that started during this pregnancy)?” and the denominator (total number of mothers) is calculated from Vital Statistics Data, which are supplied annually. For those states without PRAMS, data from birth certificates, inpatient records, county health department records, or the Behavioral Risk Factor Surveillance System (BRFSS) data may be considered for use for this indicator, but with limitations. Prevalence estimates from BRFSS would likely be lower than estimates from PRAMS because BRFSS data is derived from the general U.S. population and the question asks about whether the woman has “ever” had diabetes diagnosed only during pregnancy.

**Data quality**

PRAMS is a mixed-mode surveillance system that combines mail and telephone surveillance. Each year’s sample is weighted to represent all births that meet the inclusion criteria before reporting. Unlike many health surveys, the PRAMS project has a wealth of information from the birth certificate on those who do not respond by either mode of contact, and therefore weighting can be effective at minimizing differences between respondents and non-respondents.

Since the PRAMS survey is completed retrospectively by a woman two to six months after her birth outcome, some bias may occur due to self-reporting and recall. PRAMS is sampled from live births only, so the data do not include information on other pregnancy outcomes such as abortions, miscarriages, or stillbirths; the data do include responses from women who have experienced an infant death. PRAMS is sampled among singleton, twin, and triplet births, and therefore it is not representative of higher order births.

This indicator may be subject to recall bias because mothers are being asked about GDM after their pregnancies. However, studies of PRAMS data quality have found a high agreement (93.8 percent) between birth certificates and self-reports of GDM on PRAMS. The Kappa was only 0.53 but the Prevalence-Adjusted Bias-Adjusted Kappa (PABAK), which adjusts the kappa for imbalances caused by differences in the prevalence and bias, was 0.88, which indicates a high level of agreement.

**Simplicity of indicator**

The GDM indicator is easy to calculate and straightforward, especially when acquiring the weighted and adjusted data from CPONDER. The indicator is calculated by dividing the number of pregnant women with gestational diabetes over the total number of pregnant women. This indicator is easy to understand and explain to stakeholders.

**References**


References


Life Course Indicator: Gestational Diabetes (LC-49)


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Life Course Indicator: Early Sexual Intercourse

The Life Course Metrics Project

As MCH programs begin to develop new programming guided by a life course framework, measures are needed to determine the success of their approaches. In response to the need for standardized metrics for the life course approach, AMCHP launched a project designed to identify and promote a set of indicators that can be used to measure progress using the life course approach to improve maternal and child health. This project was funded with support from the W.K. Kellogg Foundation.

Using an RFA process, AMCHP selected seven state teams, Florida, Iowa, Louisiana, Massachusetts, Michigan, Nebraska and North Carolina, to propose, screen, select and develop potential life course indicators across four domains: Capacity, Outcomes, Services, and Risk. The first round of indicators, proposed both by the teams and members of the public included 413 indicators for consideration. The teams distilled the 413 proposed indicators down to 104 indicators that were written up according to three data and five life course criteria for final selection.

In June of 2013, state teams selected 59 indicators for the final set. The indicators were put out for public comment in July 2013, and the final set was released in the Fall of 2013.

Basic Indicator Information

Name of indicator: Early Sexual Intercourse (LC-50)

Brief description: Initiation of sexual intercourse before age 13 years.

Indicator category: Reproductive life experiences

Indicator domain: Risk/Outcome

Numerator: Number of ninth through 12th grade students who report initiating sexual intercourse before age 13 years.

Denominator: Number of ninth through 12th grade students

Potential modifiers: Sex, race/ethnicity, grade, geographic location - state, local (large urban school districts), U.S. territory, and other populations (Navajo and Nez Perce Tribal Governments)

Data source: Youth Risk Behavior Surveillance System (YRBSS)

Notes on calculation: Analysts who use the raw datasets should apply the appropriate survey weights to generate the final estimates.

Similar measures in other indicator sets: HP 2020 Focus area FP-9
Life Course Criteria

Introduction
Transition to sexual activity is an important event in the life stage of adolescence; however, youth in early adolescence have not yet made the physical, mental, and emotional developments necessary to make sensible decisions surrounding sexual activity (26). According to YRBS 2013 data, 5.6 percent of United States ninth through 12th graders initiated sexual intercourse prior to age 13. Early sexual debut has multiple short- and long-term physical and mental health implications. Adolescents who start having sex before age 13 have an increased likelihood for risky sexual behaviors and associated outcomes such as sexually transmitted infections (STIs) (22,24). In addition to sexual-related outcomes, early sexual intercourse also is associated with other unhealthy behaviors including alcohol use, delinquency and violence (25). Early sexual intercourse also affects intergenerational health through an association with unintended pregnancies. Children who are born to adolescent mothers have a higher risk for a number of negative physical and emotional health outcomes (14). These associations suggest an opportunity for prevention of important negative health outcomes, including teen pregnancy, sexually transmitted infections (STIs), and problem alcohol use, in adolescents and young adults. Early sexual education for youth is important, however, successful interventions to delay age of sexual intercourse also need to incorporate positive youth development to empower them to make informed decisions about sexual activity (25).

Implications for equity
Early sexual intercourse varies by a number of demographic factors. According to 2013 YRBS national data, 8.3 percent of male ninth through 12th graders reported they had sexual intercourse for the first time before age 13 years, compared with 3.1 percent of female respondents (5). Further, there are differences in early sexual debut among racial-ethnic groups; 14 percent of Black adolescents, 9.6 percent of American Indian/Alaskan Native adolescents, and 6.4 percent of Hispanic adolescents reported they had sexual intercourse for the first time before age 13, compared with 3.3 percent of White adolescents and an overall prevalence of 6.2 percent. The YRBS data are supported by numerous studies that found both boys and Black adolescents are at an increased risk for early sexual intercourse (6, 7, 8).

Beyond sex and race/ethnicity, household income also is a risk factor associated with early sexual intercourse. Compared with adolescents living in more affluent households, those living in low-income households are at an increased risk of engaging in early sexual intercourse. When comparing samples of low-income adolescents in the Three-City Study, Jordahl and Lohman found that low-income adolescent girls report a nearly 4 percent increase in early sexual debut when compared with the national average, while low-income adolescent boys reported rates of early sexual debut more than double that of the national average for boys (32 percent vs 15 percent) (9).

Public health impact
When comparing the results from the biennially administered national YRBSS, the percent of ninth through 12th grade respondents who report having sexual intercourse before age 13 years decreased from 1991 to 2005 (10). However, since 2005, this change has stagnated and results from the YRBSS have shown no change in this indicator (10). Early sexual intercourse initiation by youth under 13 years of age has a range of negative public health consequences. Early initiation of sexual intercourse is associated with increased risky sexual behaviors including unprotected sex and sex with multiple partners, which puts youth at risk for HIV infection and other STIs, unintended pregnancy, and other negative social and psychological outcomes (22, 24). One of the strongest predictors of STIs among adolescents and young adults is early age of sexual intercourse, which indicates an important opportunity to prevent STIs in this population by delaying age of sexual intercourse (23). The relationship between early sexual debut and STIs may be mediated not only by sexual risk behaviors but also by the link between early age of intercourse initiation and multiple other high-risk behaviors (23). Other risk behaviors and adverse outcomes that are linked with early sexual intercourse are alcohol and drug use, depression, suicidal thoughts and rape (25). Compared with peers who delay sex, adolescents with early sexual debut are more likely to use alcohol and exhibit problem use of alcohol (23).

Teenage pregnancies have negative consequences for both the teenage mothers and their offspring. A pregnancy during a woman's teenage years can be a barrier to future education and employment (28). Children of adolescent mothers may also be at higher risk for negative outcomes related to physical, social, and emotional health and well-being, indicating that the public health impact of improvement in this indicator could move beyond the individual engaging/abstaining in early sexual intercourse and extend into the next generation of children (14).
While early sexual education for adolescents can help to impact this indicator (9), social and family environments of youth also need to be addressed (27, 9). Family factors such as maternal-child relationships, living in a single parent home, and low parental education attainment are associated with early sexual debut (27). Creating stable family environments and decreasing other risk behaviors in adolescents such as drug and alcohol use to increase good judgment and decision making in adolescents also is important to delaying age of sexual intercourse initiation (9, 27).

Leverage or realign resources
From a holistic, positive youth development perspective, decreasing early sexual intercourse requires attention to factors broader than those related to sexual activity. The more developmental assets youth demonstrate, the less likely they are to engage in sexual intercourse. Developmental assets are supports, strengths, and non-cognitive skills they experience in themselves, their families, their schools, and their communities (21).

There is national support for both abstinence only and comprehensive sex education that target higher risk youth with the goal of encouraging abstinence and/or educating youth about behaviors that protect against STIs and unplanned pregnancy (3, 4). Where delaying the age of sexual debut beyond early adolescence is tied to the issue of teen pregnancy, there are multiple national teen pregnancy initiatives to engage as partners. The National Campaign to Prevent Teen and Unplanned Pregnancy aims to achieve a 20 percent reduction in the national teen pregnancy rate (28). The National Campaign engages teens directly and has had more than three million young people participate in their online National Day to Prevent Teen Pregnancy (28). They also provide a series of sexual education resources on The National Campaign website (28). Teen pregnancy also is a Centers for Disease Control and Prevention (CDC) winnable battle and one of the key actions outlined to reduce teen pregnancy is “promote the delay of sexual initiation through evidence-based programs and social norm changes (29).” Delaying sexual initiation through social norm changes acknowledges the need to not just educate adolescents about sexual intercourse but also create environments in which adolescents are able to make healthy sexual decisions. Lastly, opportunity to impact this indicator exists within the Patient Protection and Affordable Care Act of 2010, which amended Title V of the Social Security Act to include:

- Authorization and funding of the Title V State Abstinence Education Grant Program (AEGP), which provides funding to the states and territories to promote abstinence education to higher risk youth (3)
- The Personal Responsibility Education Program (PREP), which supports state agencies in providing both abstinence and contraception education (4)

Research on the disproportionate impact of this indicator on certain populations illustrates the need for timely, well-tailored, and wide-ranging resources, policies, and education to combat early sexual intercourse and associated negative effects on health (9). Higher rates of early sexual intercourse among lower income populations suggest that in addition to cultivating developmental assets, sexual education needs to be introduced at earlier ages, especially among higher-risk youth (9). In order to delay age of sexual debut, sexual education programming is needed by the fifth or sixth grade (31). A number of partners, including pediatricians, community leaders, schools and parents can be engaged to create sexual education programming for youth at earlier ages. As gender differences in rates of early sexual intercourse are clear, further tailoring of programs to appeal to and connect with higher risk populations is important.

Sexual education can be a sensitive topic in some communities. As noted above, another avenue for delaying onset of sexual intercourse in adolescents is through positive youth development. A similar tactic is cited by the CDC to assist in youth HIV prevention through increasing skills and assets of youth to help them avoid health risks such as sexual risk behaviors (30). Positive youth development is advantageous because it also has the ability to address more than one health risk behavior at one time (30). Programs can be run through schools or as extracurricular activities and teach youth problem solving skills, how to communicate with others, and help develop positive family and community relationships (30). Increasing other protective factors against early sexual debut in youth and families also is an important consideration. Maternal education is a notable protective factor against early sexual activity, and it is possible that an increase in social capital and education of young women could potentially decrease the likelihood of early sexual activity among the adolescent children of these women (9). Further, CDC research has shown the clear cost benefit of addressing
early sexual initiation and adolescent sexual activity; for every dollar spent in evidence-based school-based HIV, STI, and pregnancy prevention programs, $2.65 was saved in medical costs and lost productivity (15).

**Predict an individual’s health and wellness and/or that of their offspring**

Early initiation of sexual intercourse is associated with a number of behaviors risky to health and wellness including decreased likelihood of regular condom use during intercourse, an overall higher lifetime number of sexual partners, and increased substance abuse (11, 12, 13). Additionally, early initiation puts a person at higher risk for diseases and conditions such as STIs, adolescent pregnancy, poorer self-reports of health, and cervical neoplasia in females (11, 12, 13). Earlier sexual intercourse may be associated with poorer self-report of life satisfaction, demonstrating that the effects of this early sexual intercourse in adolescence can ripple into multiple realms of health and well-being (18).

It is critical to recognize the impact of early sexual intercourse beyond that on the health of the individual. Children of adolescent mothers are at a higher risk for negative physical, emotional and social outcomes (14). These negative outcomes include higher risk of substance abuse in adolescence, joining gangs, running away from home, being less prepared for kindergarten, dropping out of school, becoming incarcerated at some point in their lives, and to become pregnant in adolescence themselves (14, 29).

**Data Criteria**

**Data availability**

The YRBSS monitors priority health-risk behaviors and the prevalence of obesity and asthma among youth and young adults. The YRBSS includes a national school-based survey conducted by the CDC, state, territorial, and local education and health agencies and tribal governments. YRBSS monitors six categories of priority health-risk behaviors among youth and young adults, including behaviors that contribute to unintentional injuries and violence; sexual behaviors that contribute to unintended pregnancy and sexually transmitted diseases, including HIV infection; alcohol and other drug use; tobacco use; unhealthy dietary behaviors; and inadequate physical activity. In addition, YRBSS monitors the prevalence of obesity and asthma.

The YRBSS is administered every other year (odd years), generally in the spring semester in schools via a pencil and paper mode. The YRBSS survey contains no skip patterns. In the even-numbered years, CDC leads a process of examining and revising the questionnaire, using both expert opinion and votes from the YRBSS coordinators in states. The final result is a standard questionnaire that can be modified by states to meet their needs, but modifications must be within certain parameters.: 1) the modified questionnaire must contain at least two-thirds of the original standard questionnaire, 2) questions that are added are limited to eight mutually exclusive response options, 3) the questionnaire may not have skip patterns or fill in the blanks, and 4) the questionnaire may not exceed 99 questions, and the state must retain the height and weight questions. The 2011 YRBSS included a national school-based survey conducted by CDC and 47 state surveys, six territory surveys, two tribal government surveys, and 22 local surveys conducted among students in grades nine through 12 during October 2010 to February 2012. Data collected by CDC represent both public and private schools with students in grades nine through 12; data collected by states, territories, tribes, and localities represents primarily public school students.

Data on early sexual intercourse are currently collected every two years through the YRBSS. The YRBSS surveys a sample of high school, and in some cases middle school, students that is representative at the national, state, tribal, and large urban school district levels. Youth Risk Behavior Surveys (YRBS) have been conducted biennially since 1991. In 2011, 47 states and the District of Columbia conducted the YRBS, as did six United States territories, two tribal governments, and 21 other large urban school districts (1). As three states (Minnesota, Oregon and Washington) did not conduct surveys, state-level data are not available for all 50 states.

Early sexual intercourse before age 13 is included on the national, state, territorial, tribal and large urban school district versions of the survey. The formula for measurement is the same on all surveys for this indicator. The numerator is calculated from data reported by ninth to 12th grade respondents on whether or not they have had sexual intercourse before the age of 13 years.
The CDC creates reports for each participating site. Further, CDC maintains a publicly accessible website with detailed information about the YRBSS and results, including “Youth Online,” a data-query application that allows users to view detailed survey results. YRBS data available on “Youth Online” includes all weighted national, states, territorial, tribal and local results from 1991-2011. Also available through the CDC website are data files and documentation for all national surveys conducted since 1991, which allows individuals to conduct their own analysis of national data. YRBSS data tables and fact sheets are available on apps.nccd.cdc.gov/youthonline/App/Default.aspx.

Data quality
From the available YRBSS documentation, the 2011 national YRBS school response rate was 81 percent; the student response rate was 87 percent; and the overall response rate was 71 percent. Comparisons between estimates for states and districts from the national data collection effort and the surveys collected by states, territories, tribes, and localities can be found on the CDC YRBSS website. Each jurisdiction reached a minimum site response rate of 60 percent and therefore had weighted data for that year. Weighted data allows a jurisdiction to make statements from the data that generalize to all high school students in that jurisdiction.

Studies by CDC and others indicate that data about risk behaviors can be gathered as credibly from adolescents as from adults. YRBSS performs internal reliability checks to help identify the small percentage of students who falsify their answers. To obtain truthful answers, students must perceive the survey as important and know procedures have been developed to protect their privacy and allow for anonymous participation.

A test-retest study of the 1999 version of the questionnaire (1) found that 47 percent of items had at least “substantial” reliability, with kappa statistics of agreement of 61 percent or greater, and 93 percent of items had at least “moderate” reliability, with kappas of 41 percent or greater. The study found no differences in reliability by gender, grade, or race/ethnicity. The study found that items related to tobacco use, alcohol and other drug use, and sexual behavior had the highest reliability. By comparison, items asking about dietary behaviors, physical activity, and other health-related topics were less reliable. A study of mode and setting using the YRBSS questions (20) determined that students were more likely to report risk behaviors when they took the survey at school compared with taking the survey at home.

Simplicity of indicator
The level of complexity in calculating and explaining this indicator is low. The denominator captures how many youth responded ‘yes’ to ever having sexual intercourse on the YRBS. The numerator captures a segment of those who reported ever having sexual intercourse who also report ever having sexual intercourse before age 13 years. While this is a fairly simple measure, it relies on self-report, which can result in misclassification problems (2). Early sexual intercourse is a measure that can be readily and simply explained, and addressing this issue has garnered much attention in programming and policy.

References


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Life Course Indicator: HIV Prevalence

Basic Indicator Information

Name of indicator: HIV Prevalence (LC-51)

Brief description: HIV rate (diagnosed cases) per 100,000 total population

Indicator category: Reproductive Life Experiences

Indicator domain: Risk/Outcome

Numerator: Total diagnosed HIV cases in the population

Denominator: Total population

Potential modifiers: Race/ethnicity, sex, age, social economic status, geography, rural vs. urban, sexual behaviors, drug use

Data source: The Centers for Disease Control and Prevention (CDC) National Center for HIV/AIDS, Viral Hepatitis, STD and TB Prevention (NCHHSTP) Atlas

Notes on calculation: Multiply by 100,000 for rate

Similar measures in other indicator sets: HP 2020 Focus areas HIV-1, HIV-2, and HIV-3; CDC Winnable Battle (Reduce the number of new HIV infections by 25 percent)

The Life Course Metrics Project

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Life Course Criteria

Introduction
The CDC estimates that human immunodeficiency virus (HIV) prevalence increases about 4 percent each year (10). Since the 1990s HIV prevalence has been increasing, while estimated incidence has remained constant, at around 50,000 cases per year. In 2010, the prevalence of diagnosed HIV cases in the United States was an estimated 872,990 (11). When estimated undiagnosed HIV cases are included, around 1.1 million people are living in the United States with HIV. HIV directly affects individual health through the destruction of the host immune system leading to the development of acquired immune deficiency syndrome (AIDS) and subsequently, death. AIDS develops, on average, 10 years after HIV infection without treatment (42). Although treatment with antiretroviral drugs can delay onset of symptomatic HIV as well as the development of AIDS, people with HIV infection still experience emotional stress, depression, employment barriers, and medication side effects (25, 27, 31, 38, 40). Certain subpopulations are at higher risk for HIV infection than others including African Americans, Hispanics, men who have sex with men (MSM), lower socioeconomic groups, and injection drug users (IDU) (2, 15). A range of complex social and economic factors place certain subpopulations at higher risk of HIV infection including high rates of HIV within sexual networks, poverty, discrimination and stigma, incarceration rates, language barriers, and poor access to health care (44). HIV infection has a cyclical relationship with various social determinants of health. For example, low socioeconomic status is a risk factor for HIV infection, and HIV infection hinders socioeconomic advancement through employment barriers (15, 34, 38). HIV can be transmitted from mother-to-child (MTC) during delivery, although MTC transmission is nearly entirely preventable when antiretroviral therapy (ART) is given to mothers and newborns (14). Unfortunately, not only does MTC transmission still occur in the United States, large disparities exist for racial/ethnic subpopulations (14). A number of national resources and initiatives exist to lower the rate of new HIV infections and to provide care for those who are already HIV-positive. Many governmental, national and community groups have supported and promoted education and prevention activities that have contributed to the flattening of HIV incidence in recent years. While new infections contribute to the rising prevalence of HIV, it is important to note advances in treatment options have positively impacted the life span of people with HIV, also contributing to the rising HIV prevalence (10).

Implications for equity
Many disparities exist in prevalence rates of HIV across variables such as race/ethnicity, gender, sexual activity, and socioeconomic status. African American males and females have the highest prevalence rates of HIV in comparison to other racial groups (12). Although the African American population only accounts for 12 percent of the total U.S. population, African Americans are estimated to account for 44 percent of adults and adolescents living with HIV (2). The CDC estimates that one in 32 African American women will be diagnosed with an HIV infection during their lifetime, in comparison to only one in 526 White women (2). New studies are reporting that sexual networks are separated by race. Therefore increased risk of HIV could be perpetuated by the increased prevalence of HIV within different races (44). Research also indicates that increased prevalence of HIV in African American women is not due to high-risk sexual behaviors but rather the higher prevalence of HIV in the population (10). African Americans do not only have an increased prevalence of HIV, but also other sexually transmitted infections (STIs) such as gonorrhea and syphilis, which are associated with an increased likelihood of HIV transmission (46). Furthermore, the increased risk of HIV in African American males is linked with the high percentage of males in prison; 12 percent of African American males age 25-29 are presently incarcerated in jail or prison (46).

Hispanics also are disproportionately affected by HIV and account for 16 percent of people in the United States (2). While Hispanics represented only 16 percent of the U.S. population in 2009, they accounted for 21 percent of the new infections recorded in 2009 (2). Behavioral and cultural factors are hypothesized to contribute to the increased risk (59). Undocumented Hispanic immigrants also have limited access to HIV prevention services, including care and testing which adds to the burden of HIV in Hispanic communities (59). Increased prevalence of HIV in African American and Hispanic women contributes to the disparity in perinatal HIV infections (14). Between 2004 and 2007, 69 percent of perinatal HIV cases were among African American women (45). These statistics are disturbing because theoretically perinatal transmission could be eliminated due to the available intervention in the United States. (14).

Men who have sex with men of any race or ethnicity are the group most affected by HIV in the United States (2). Contributing to the sustained high prevalence rate in MSM populations is a continued high risk of infection. Although MSM represent only an estimated 4 percent of the U.S. male population, they account for nearly 78 percent of all estimated new
HIV infections (2). In looking at prevalence data, by the end of 2011, 52 percent of all U.S. HIV cases were among MSM (2). The largest number of new HIV infections occurred in White MSM (11,200) while 10,600 occurred in African American MSM (2). When stratified by age, young African American MSM aged 13-24 were at highest risk of infection(2).

Low socioeconomic status (SES) is a social factor highly associated with HIV prevalence rates. In some low SES urban areas HIV prevalence is as high as 2.1 percent; these rates are comparable to developing countries such as Haiti, Ethiopia and Angola (15). In 2007, 81.6 percent of the newly diagnosed HIV cases lived in urban areas with populations over 500,000 (10). Some investigators argue that low SES is positively correlated with the practice of riskier health behaviors, such as earlier sexual debut in comparison to higher SES groups (18). Other research suggests that unstable housing is positively correlated with risky behaviors, such as unsafe sexual behaviors and drug use (17). Not only does low SES increase the risk of HIV infection, it also can impede HIV treatment, which in turn increases risk of transmission. In comparison to higher SES individuals, treatment and testing is delayed, which decreases survival rates (18). Furthermore, the lack of health insurance of many low-SES HIV-positive individuals creates disparities between survival rates of high-SES and low-SES HIV positive individuals (19).

Public health impact
Since 1981, an estimated 1.8 million people have been infected with HIV in the United States, more than 650,000 of whom have died, leaving approximately 1.1 million U.S. residents currently living with HIV (47). HIV-related mortality rates have declined since the 1980s due to treatment advances and stabilized infection rates; however, in 2010, HIV was still the seventh leading cause of death among people ages 25-44, individuals who should otherwise be in the prime of their lives (47).

The economic burden of HIV is high. Individually, the annual cost of HIV treatment is $20,000, and in 2012 it was estimated that the U.S. government spent $15 billion on HIV care and medication (21). The lifetime cost for just one person who receives an early HIV diagnosis (CD4 count above 500 cells per microliter) and subsequently enters into treatment is an estimated $402,000 (37). Early entry into treatment is costly but necessary as people who enter into care with a CD4 count above 500 cells per microliter lose 44 percent fewer quality adjusted life years (QALYs) of illness, gain additional life expectancy, and transmit almost 50 percent fewer HIV infections than people who receive a late diagnosis (37). Not only does HIV impact the United States financially by direct medical cost, but other costs are involved such as lost productivity (23). Persons living with HIV/AIDS experience multiple perceived barriers to employment including health insurance availability, physical ability, health concerns related to the work environment, and current job skills (38). These barriers impede short- and long-term financial independence and emotional well-being of persons living with HIV/AIDS.

Lowering the prevalence of HIV in the U.S. population is in line with multiple national initiatives. In 2010, the National HIV/AIDS Strategy (NHAS) proposed goals such as lowering the annual number of new infections by 25 percent, decreasing the proportion of HIV-positive individuals who are unaware of their status to 10 percent, and increasing the proportion of HIV-diagnosed MSM with undetectable viral load by 20 percent (48). The CDC plans to meet these goals by maximizing limited resources and prioritization of highest risk sub-populations. Presently the CDC is focusing on using a High-Impact Prevention approach to reducing the transmission of HIV (24). The approach consists of a proven and cost-effective intervention focused on high-risk populations (African Americans, Latinos, MSM, transgender and injection drug users), for the largest impact on HIV transmission (24).

MTC HIV transmission is preventable, and part of the strategy for reducing MTC transmission is reducing the incidence of HIV in women and girls of childbearing age, specifically among African American and Hispanic women (14). Adherence to highly active ART of HIV positive women during pregnancy is important in preventing perinatal transmission, but identifying all HIV positive pregnant women during pregnancy can be a challenge as most jurisdictions in the United States lack resources and the framework to identify these women during their pregnancy (14). HIV also affects breastfeeding as it is strongly recommended that HIV positive women do not breastfeed due to the increased risk of MTC transmission. The HIV transmission rate can increase by as much as 30 to 45 percent when breastfeeding is prolonged (25).

Leverage or realign resources
Current science points to the possible success of a “treatment as prevention” approach to HIV (49). Proper adherence to ART medications can create an undetectable viral load, which vastly reduces the chances of transmission (49). In sero-
Researchers do not know the exact mechanism in which HIV injures the central nervous system, studies show that HIV has been noted to cause many mental and cognitive problems. Many states have serious side effects including liver damage, bone loss, kidney problems, diabetes, nerve problems, and cardiovascular problems (39). Patients who meet the clinical criteria for AIDS have worse physical functioning (40). Medications taken to delay the onset of AIDS can have serious side effects including liver damage, bone loss, kidney problems, diabetes, nerve problems, and cardiovascular problems (39).

Opportunities for funding programs to improve care of HIV-positive individuals exist through the Ryan White Comprehensive AIDS Resources Emergency Care (CARE) Act, which has become a critical part of health care delivery to HIV-positive individuals (51). More than half a million people with HIV are provided with care services through city and state programs and local community-based organizations funded by the Ryan White CARE Act (52). While a number of Ryan White CARE Act clients will now be eligible for health insurance after implementation of the Affordable Care Act, the Ryan White CARE Act will remain crucial in filling coverage gaps, assisting with copayments, and supporting HIV-positive individuals through each stage of the HIV treatment cascade (51). Medicaid is also a crucial partner in delivery of care to people with HIV. Half of all HIV positive people in the United States are insured through Medicaid (26), and this percentage may increase due to Medicaid expansion (53). Costs of HIV treatment may begin to decrease as a number of patents for HIV medications are set to expire between 2010 and 2017. Generic treatments for HIV are only slightly less effective than the current treatments, and this small decrease in effectiveness would be overshadowed by the overall improved care for people with HIV (22). As drug patents expire, generic versions of the drugs will become available, hopefully resulting in lower treatment costs and an increased proportion of individuals treated for HIV (22).

MTC transmission is almost entirely preventable through testing during pregnancy and maintaining ART adherence through birth (14). In New York State the Maternal-Pediatric HIV Prevention and Care Program (MPHPCP) has been successful in reducing MTC HIV transmission (54). Main components of the program include prenatal HIV counseling and testing, ART medication for HIV-positive pregnant women, routine HIV screening for newborns, and rapid HIV tests if a mother’s HIV status is unknown at delivery(54). As a result, the New York State Department of Health found prenatal HIV testing has risen to 95 percent to 96 percent in 2010 from 64 percent in 1997 and the number of cases of MTC transmission has fallen from 97 cases in 1999 to 3 cases in 2010 (54).

Partnering with educational systems such as middle schools and high schools can help to increase prevention efforts, testing, linkage to care in young populations. Adolescents need to be informed about HIV and other STIs to increase the probability of being tested and safe sexual practices (27). The CDC Division of Adolescent and School Health (DASH) provides a network of nationwide HIV prevention leaders that include state and local health departments as well as state education agencies and school districts. DASH provides funding and technical assistance to school based HIV prevention programs in 49 states and the District of Columbia (55).

**Predict an individual’s health and wellness and/or that of their offspring**

While multiple effective treatments exist, there is still no known cure for HIV/AIDS. Without treatment, HIV generally stays clinically latent (asymptomatic) for a period of eight to 10 years (47). Development of AIDS is marked by severe deterioration of the immune system and a decline in the body’s ability to fight infection, creating susceptibility to opportunistic infections that eventually lead to death (47). Compared with adults who have other chronic conditions (epilepsy, clinically localized prostate cancer, depression, or diabetes), persons living with symptomatic HIV or those who meet the clinical criteria for AIDS have worse physical functioning (40). Medications taken to delay the onset of AIDS can have serious side effects including liver damage, bone loss, kidney problems, diabetes, nerve problems, and cardiovascular problems (39).

HIV has been noted to cause many mental and cognitive problems. Research has shown that HIV increases the risk of anxiety and depression (29). HIV-positive persons can also be affected with a loss in cognitive ability, although researchers do not know the exact mechanism in which HIV injures the central nervous system, studies show that HIV...
can cause HIV-associated dementia (29). The depression and poor cognitive and physical function, resulting from HIV or treatment, only increases with age (30).

Risk of comorbidities in an HIV-positive person increases with age, smoking, duration of antiretroviral use, and previous immunodeficiency (43). Among HIV-positive IDUs, 80 percent are also co-infected with hepatitis C (57). HIV-positive women are at an increased risk for contraction of human papillomavirus (HPV), which can result in cervical cancer and severe pelvic inflammatory disease (56). HIV greatly increases the risk of latent TB infection to become active TB disease, which is noteworthy as TB is an AIDS-defining condition and one of the worldwide leading causes of death among HIV-positive people (58). HIV-positive individuals are also at an increased risk of heart attack and certain types of cancer (29).

HIV also can impact intergenerational health. Presently, there is less than a 2 percent chance that an HIV-positive woman will deliver an HIV-positive baby if she is treated early and takes her medication properly (14). Unfortunately, not all pregnant HIV-positive women receive treatment, which increases the risk to 25 percent that the woman will deliver an HIV-positive baby (31). Studies have also shown that HIV-related stressors on parents have the ability to negatively affect the psychological adjustment of children (32). Furthermore, a study following HIV positive parents with children reported that 50 percent of the children at one point in the two year study were not living with their HIV positive parent (33). Disruption of living arrangement can lead to negative health outcomes especially when it involves the child entering into foster care (33).

SES and HIV status can be considered to have a cyclic relationship. Low SES can increase the risk for HIV; also HIV can negatively affect SES. Many studies argue that positive HIV status negatively affects SES, because it decreases the individual’s productivity. For example, one study showed that 45 percent of HIV positive individuals were unemployed (34). As mentioned above, HIV can negatively impact cognitive ability and create barriers to employment; this loss in cognitive ability directly leads to loss of productivity in the workforce (36). It has been argued that cognitive ability of HIV positive children is even more affected by deficiencies, which decreases their earning potential and learning ability throughout life (23).

**Data Criteria**

**Data availability**

HIV is a reportable disease. Data is sent to the CDC from all 50 states and the District of Columbia and does not require the linkage of datasets for complete information (1). The CDC HIV/AIDS surveillance provides data on the national prevalence and incidence rates of the HIV/AIDS epidemic, as well as data on major metropolitan areas annually. The numerator for the prevalence of HIV is the total diagnosed HIV cases during the given calendar year (2). While an estimate of undiagnosed cases would be of value in examining HIV prevalence, only statistics on diagnosed HIV cases are available through the CDC National Center for HIV/AIDS, Viral Hepatitis, STD and TB Prevention (NCHHSTP) Atlas. CDC uses a back calculation to estimate the number of undiagnosed HIV cases in the adult population (over age 13) and provides these statistics on the CDC HIV Statistics web site (http://www.cdc.gov/hiv/statistics/basics/index.html).

However, undiagnosed HIV prevalence is not readily available for each state or for the national adult and child population. For data availability reasons, the numerator of this indicator is total diagnosed HIV cases during the given calendar year. The denominator is the population from the U.S. Census Projections. MCH programs can easily gain access to diagnosed HIV prevalence data annually. NCHHSTP Atlas provides annual data at http://www.cdc.gov/nchhstp/atlas/. The CDC also releases HIV prevalence and incidence data across demographic information and states.

**Data quality**

Since 1998, the CDC has recommended the use of confidential name-based reporting for all HIV surveillance programs (3). With confidential name-based reporting, the state health departments receive names of HIV and AIDS cases; then the data is forwarded to federal health agencies with an alphanumeric code replacing the name (4). The CDC believes that confidential name-based HIV reporting provides the most efficient and effective surveillance; thus improving the monitoring of the epidemic (5). The CDC also suggests that name-based reporting improves the efficiency of the allocation of funds for treatment and prevention programs, and the targeting of high risk populations (6). In 2008 confidential name-based reporting became the standard used to collect HIV data in all 50 states and the District of Columbia (7). The 2011 HIV Surveillance Report was the first year that name-based reporting data from all 50 states were used to estimate the rates of HIV diagnoses and prevalence in the United States (2). The regulation of data collection
means that data accuracy has been improving over the past few years. It is important to note that new diagnoses do not equate to incidence, as diagnosis can occur at different points in the course of disease (2). The data validity should continue to improve in the future as all states have been using name-based reporting for the last four years. The CDC also notes that it is important to assess the validity and reliability of the data when it is collected, managed and analyzed to guarantee the accuracy of the data (6). Furthermore, as of 2010, 25 states have funded population-based HIV incidence data collection by using serologic testing that allows HIV surveillance programs to identify how recently the HIV infection occurred and improve incidence data (2).

There are several ways to calculate prevalence of HIV including analyzing data from national probability-based surveys, antenatal clinic surveys, back-calculation and cohort studies. The CDC uses back calculation and serologic testing data information to calculate prevalence and incidence; with the regulation of name-based reporting, back-calculation is becoming more accurate. Also with the increase of serologic testing, incidence rates will become more accurate as well. Consequently, this will help to improve the accuracy of prevalence estimations from the data collected and analyzed by the CDC.

**Simplicity of indicator**

HIV prevalence, as defined as diagnosed cases of HIV in the U.S. population, is easy to explain and calculate. This indicator is already calculated and available through the NCHHSTP Atlas. Reducing new HIV infections is a common focus among many governmental, national and community groups that have supported and promoted education and prevention. These groups include:

- Greater Than AIDS aims to increase knowledge about HIV/AIDS particularly among black Americans and gay and bisexual men, and is a collaboration between the Black AIDS Institute (founding partner), CDC, the Kaiser Family Foundation, the Ford Foundation, Elton John AIDS Foundation and MAC AIDS (9).
- Magic Johnson Foundation, develops and support community-based organizations in urban communities (10)
- The Act Against AIDS Leadership Initiative (AAALI) is a coalition of predominantly African American organizations that aim to intensify HIV prevention efforts in African American, Latino and MSM communities (10)
- CDC (10)
- The Kaiser Family Foundation(10)
- The Ford Foundation(10)
- Elton John AIDS Foundation(10)
- MAC AIDS(10)

Of note, while the incidence of HIV has remained constant, the prevalence of HIV has been increasing since the 1990s partly due to longer survival rates (as a result of improvements to HIV treatment) and improved data collection and assessments.

**References**


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The Life Course Metrics Project

As MCH programs begin to develop new programming guided by a life course framework, measures are needed to determine the success of their approaches. In response to the need for standardized metrics for the life course approach, AMCHP launched a project designed to identify and promote a set of indicators that can be used to measure progress using the life course approach to improve maternal and child health. This project was funded with support from the W.K. Kellogg Foundation.

Using an RFA process, AMCHP selected seven state teams, Florida, Iowa, Louisiana, Massachusetts, Michigan, Nebraska and North Carolina, to propose, screen, select and develop potential life course indicators across four domains: Capacity, Outcomes, Services, and Risk. The first round of indicators, proposed both by the teams and members of the public included 413 indicators for consideration. The teams distilled the 413 proposed indicators down to 104 indicators that were written up according to three data and five life course criteria for final selection.

In June of 2013, state teams selected 59 indicators for the final set. The indicators were put out for public comment in July 2013, and the final set was released in the Fall of 2013.

Basic Indicator Information

Name of indicator: Postpartum Contraception (LC-52)

Brief description: Proportion of women using birth control postpartum

Indicator category: Reproductive life experiences

Indicator domain: Service/Capacity

Numerator: Respondents (women having a live birth) who reported that they or their husbands or partners were currently doing something to keep from getting pregnant

Denominator: All respondents (women having a live birth)

Potential modifiers: race, age, education, marital status, parity, health insurance status, Medicaid/non-Medicaid, poverty (e.g. annual household income), pregnancy intention of most recent pregnancy, prenatal care in most recent pregnancy, mode of delivery of most recent birth, outcome of most recent birth, postpartum visit after most recent birth, amenorrhea, breastfeeding status

Data source: Pregnancy Risk Assessment Monitoring System (PRAMS)

Notes on calculation: This question is asked of women sampled for PRAMS-eligibility at two months postpartum. By this time, there are no restrictions on the recommendations for use of contraceptives except for breastfeeding women, who are encouraged to use progestin-only contraceptives rather than combined hormone contraception. Analysts who use the raw datasets should apply the appropriate survey weights to generate the final estimates.

Similar measures in other indicator sets: Preconception Health Indicator D7; Maternal, Infant, and Early Childhood Home Visiting (MIECHV) Benchmark Area Improved Maternal and Newborn Health: Inter-birth Intervals
Life Course Criteria

Introduction
The postpartum period is a brief yet critical opportunity to impact health outcomes for a new mother and any subsequent pregnancies she may have through the mechanism of optimal birth spacing. Failure to prevent unwanted pregnancies during the postpartum time period can have long-lasting health implications for children and psychosocial implications for children, women and families. Implementation of health reform offers a window of opportunity to impact access to postpartum contraception through expanded insurance coverage. However, insurance coverage does not guarantee that women have access to preferred and effective contraceptive methods, and increased access does not always translate to increased appropriate use. Public health, primary care and other stakeholders must address many challenges to achieve increased utilization of postpartum contraception in order to reap the benefits of planned, well-timed pregnancies.

Implications for equity
Access to contraception can be mediated by income. Low-income women have difficulty accessing higher-cost contraceptive methods, such as sterilization (Potter et al., 2012). When women are offered no-cost access to any contraceptive method, many women choose long-acting methods with higher continuation rates and lower failure rates (Secura et al., 2010). Therefore, as an indicator postpartum contraception may in part show the impact of unequal access to effective contraceptive methods of choice through differences in income. However, the implementation of the Patient Protection and Affordable Care Act (ACA) includes both expansion of health insurance coverage to populations previously ineligible or unable to afford health insurance as well as requirements for coverage of all Food and Drug Administration (FDA)-approved contraceptive methods without cost-sharing as part of the essential health benefits package for women (Healthcare.gov 2014). These changes are intended to help women access contraception at any income level; it remains to be seen whether these changes will have the desired effect, but research from Massachusetts indicates that low-income women report relatively easy access to contraception several years after health reform was implemented in that state (Dennis et al., 2012).

Rapid repeat pregnancy (a possible consequence of lack of access to postpartum contraception) is associated with negative consequences for educational attainment and employment, among adolescents (Polit and Khan, 1986; Furstenberg et al., 1987). Lack of access to education and employment, especially in early life, are important predictors of poverty. Other research has demonstrated a relationship between income inequality and short interpregnancy intervals in women of all ages (Gold et al. 2004). Therefore, access to postpartum contraception could potentially have significant implications for income inequity through a relationship with educational attainment and access to employment.

Public health impact
Access to and use of effective postpartum contraception reduces births with short preceding interpregnancy intervals as well as unwanted or mistimed pregnancies. Short interpregnancy interval has been shown to be associated with preterm delivery, infants who are small for gestational age, early infant death, and congenital malformations (Grisaru-Granovsky et al., 2009; Hussaini et al., 2012; Kwon et al., 2012; Conde-Agudelo et al., 2006). There is a demonstrated J-shaped association between interpregnancy interval and outcomes such as preterm birth, where very short intervals, less than 18 months, and very long intervals, greater than five years, result in poorer outcomes. These studies suggest an optimal interval of 18 to 23 months (Zhu 2005), but it may vary for subgroups of women. Interpregnancy intervals of at least 12 months are recommended for women who had a live birth, but for women who have experienced a fetal loss, the optimal interval may depend on the timing of the loss, i.e. early miscarriage or near-term stillbirth may have different optimal intervals.

Additionally, some states are leveraging provisions of the ACA and collaborating with their Medicaid agencies to expand access to long-acting reversible contraceptives (LARC) within and beyond the postpartum period, and seeing significant public health impact not only in the prevalence of contraceptive method use, but in other MCH indicators. For example, in 2014, the Colorado Department of Public Health and Environment announced an unprecedented decline (40 percent) in the teen birth rate in Colorado from 2009 through 2014, with three-quarters of the overall decline being attributed to increasing access to intra-uterine devices or implants at low or no cost to low income women being served in family planning clinics (Guttmacher Institute, 2014). The Colorado Department of Public Health and Environment estimates that with increasing access to long-acting reversible contraceptives and the associated decline in teen pregnancy, the state
has saved $42.5 million in public funds in 2010 alone (CDPHE, 2014). Further, recent successes described in South Carolina, as a result of an update to its Medicaid coverage policy in 2012 have spurred great interest in the insertion of LARC immediately postpartum and during the delivery stay. The Association of State and Territorial Health Officials (ASTHO) recently launched a LARC learning community for states to explore the potential impact of Medicaid coverage policies and other reimbursement avenues to further support the insertion of LARC immediately postpartum, among other opportunities to expand access to highly effective contraceptive methods (e.g. Title X family planning clinics, private insurance reimbursement).

Postpartum counseling, as a part of the six week postpartum visit, is a recommended intervention for improving the uptake of postpartum contraception. It is important to note, however, that the content of clinical counseling is difficult to assess. The manner in which contraceptive counseling is delivered is important to women and may affect contraceptive uptake (Yee and Simon, 2011). Therefore, women’s report of counseling or clinical documentation of counseling may not adequately explore all the pertinent factors. It is for this reason among others that national experts have increasing interest in LARC insertion immediately postpartum (during the delivery stay) in contrast to the six-week postpartum visit, as well as innovative approaches to ensuring women attend a postpartum visit, including integrating the first well-child visit with postpartum care in the same facility.

Not all contraceptives work with equal efficacy; contraceptive failure rates are highest for the condom and methods such as withdrawal and fertility awareness, and lowest for injectable and oral contraceptives (Kost et al 2008). Access to both preferred and effective methods of contraception should help to reduce unintended pregnancy. Unintended pregnancy, regardless of timing with respect to previous births, is associated with a number of negative health and psychosocial outcomes, including delayed prenatal care, preterm delivery, low birth weight, increased maternal morbidity and mortality, and physical violence during pregnancy (Brown and Eisenberg, 1995; Santelli et al., 2003). Use of contraception in the postpartum period could be expected to have a significant public health impact by reducing births with short interpregnancy intervals and reducing unintended pregnancy.

**Leverage or realign resources**

PRAMS includes a question that asks women who indicate they are not using postpartum contraception for their reasons why; the responses to this question point to opportunities for education and intervention by a variety of partners. For example, women who indicate they want to become pregnant at the time of the survey (two to six months following birth), present an opportunity for education around birth spacing for programs such as the Supplemental Nutrition Program for Women, Infants, and Children (WIC) because WIC provides services to women and infants including nutrition, birth spacing, and breastfeeding practices. Women who indicate on PRAMS that they do not want to use birth control might be a group that pediatricians can engage during well-child visits. Pediatricians already engage families in discussions about breastfeeding and infant care practices; breastfeeding may be one of the reasons a woman may not want to use contraception, and pediatricians would be able to work with families to ensure they have another child when they are most ready.

As noted above, the postpartum visit is a key opportunity to engage postpartum women in discussions of their future childbearing plans and contraceptive preferences. PRAMS data from 2009 indicate that for the 16 reporting areas, the overall prevalence of receiving a postpartum visit was 88.2 percent, with a range of 84.2 percent in Texas to 94.4 percent in Massachusetts (Robbins et al 2014). Despite the relatively high overall prevalence, there is significant variation by age group and race/ethnicity, with the lowest prevalence of postpartum visits among 18 to 24 year olds (83.7 percent) and Hispanic women (80.3 percent) (Robbins et al 2014). Providers and insurers need to be engaged as partners in encouraging women to return for their postpartum visit as well as to ensure the quality and content of the visit.

Education advocates may have an interest in ensuring access to postpartum contraception and delaying subsequent birth, particularly in the case of adolescent mothers, for whom second and higher-order births during adolescence are associated with lower maternal educational attainment (Polit and Khan, 1986; Furstenberg et al, 1987). In addition, some research suggests that short interpregnancy intervals may have lifetime effects for the child, including poor educational performance for children born after a short interpregnancy interval (Hayes et al., 2006). Short interpregnancy intervals also may have implications for individual and intergenerational poverty, suggesting that antipoverty advocates could be engaged in efforts to increase access and use of contraception. Finally, since approximately half of unintended
pregnancies end in abortion (Henshaw 1998), advocates seeking to reduce the utilization of abortion services could be engaged in this work.

From a statewide policy perspective, recent successes shared by states point to collaboration opportunities with both Medicaid agencies as well as Title X family planning programs to increase access to postpartum contraception. The cost savings documented by the Colorado Department of Public Health and Environment in teen pregnancy alone are persuasive for state leadership, and MCH programs and partners continue to work expeditiously to document the return on investment of expanding access to contraceptive methods for state budgets. Furthermore, coordination of activities funded by the Title V MCH Services Block Grant and the Title X Family Planning Program in a state offers a unique opportunity to leverage and realign resources. In a case study published by AMCHP in 2014, MCH programs described how program performance measures reinforce one another; for example, efforts to reduce the rate of low birth weight and preterm births for the block grant are inherently associated with interpregnancy intervals, and point to opportunities for a comprehensive approach for preconception and interconception health. Further, some states utilize the flexibility of the block grant to support the purchase of highly effective LARC methods for the local agencies that provide the direct services (AMCHP, 2014). This level of collaboration and coordination of activities point to numerous opportunities for state MCH leaders and their partners to leverage and align resources.

**Predict an individual’s health and wellness and/or that of their offspring**

The health impact of postpartum contraceptive use is largely on family and child health. Although some research suggests a link between short interpregnancy intervals and increased maternal morbidity and mortality (Brown and Eisenberg, 1995; Santelli et al., 2003), the research on maternal health impacts of short interpregnancy intervals is somewhat contradictory. Most research in this area focuses on maternal health in the perinatal period; there is little data on long-term health impacts for women experiencing short interpregnancy intervals. Despite this lack of conclusive impact of interpregnancy intervals on maternal health, postpartum contraception has a role in promoting optimal health and recovery of the mother prior to becoming pregnant again. Major risk factors associated with maternal mortality in pregnancy alone are inherently associated with interpregnancy intervals, and point to opportunities for a comprehensive approach for preconception and interconception health. Further, some states utilize the flexibility of the block grant to support the purchase of highly effective LARC methods for the local agencies that provide the direct services (AMCHP, 2014). This level of collaboration and coordination of activities point to numerous opportunities for state MCH leaders and their partners to leverage and align resources.

However, short interpregnancy intervals have a direct impact on infant health, including preterm birth, low birth weight, and small for gestational age as noted above. Preterm birth can have long-term consequences for the infant as they grow and develop; infants born preterm are more likely to experience apnea, respiratory distress syndrome, intraventricular hemorrhage, patent ductus arteriosis, necrotizing enterocolitis, retinopathy of prematurity, jaundice, anemia, bronchopulmonary dysplasia and a number of infections due to their immature immune systems (March of Dimes, 2013). Additionally, these health conditions and features of the preterm newborn have been associated with longer-term health problems and disabilities. Long-term impacts of preterm birth on the infant include increased risk of autism, intellectual disabilities, cerebral palsy, lung problems, and vision and hearing loss. For example, de Kieviet, Zoetebier, van Elburg, Vermeulen, and Oosterlaan (2012) found that very preterm infants have a total brain volume 0.58 standard deviations lower than term infants, which has been associated with reduced cognitive functioning. Furthermore, in addition to potential respiratory distress syndrome after birth, children born extremely preterm have been found to have significant impairment of lung function, particularly in those who have had bronchopulmonary dysplasia (Bolton et al., 2012). Having one preterm birth increases the risk for subsequent preterm births and short intervals can further increase the risk, indicating that postpartum contraception and adequate birth spacing has the potential to reduce the risk both for preterm and repeat preterm birth.

Preventing rapid repeat pregnancies also has implications for individual socioeconomic well-being as described above (Politt and Khan, 1986; Furstenberg et al., 1987; Gold et al., 2004). Poverty and low educational attainment of both mothers and children can be expected to impact the health of the entire family through a variety of pathways.

**Data Criteria**

**Data availability**

PRAMS, which was initiated in 1987, is an ongoing population-based surveillance system designed to identify and monitor selected maternal experiences and behaviors that occur before and during pregnancy and during the child’s early infancy.
Forty states and New York City currently participate in PRAMS, representing approximately 78 percent of all U.S. live births. Six other states previously participated. The Centers for Disease Control and Prevention (CDC) maintains a combined dataset with information from all participating PRAMS states, which represents approximately 87 percent of all live births in the United States. CPONDER is a Web-based query system created to access data collected through PRAMS surveys.

The length of time between an event and entry into the sampling frame is typically two to six months. Because PRAMS data are weighted to the final birth file, there is a data availability lag between the close of a calendar year and access to the final PRAMS dataset. As of July 2013, the most current year of data available in CPONDER was 2008.

Although the 40 states and one city that participate in PRAMS have access to their own state data, only states where the minimum response rates have been met are included in CPONDER. For 2000-2006, this required response rate was 70 percent, and for 2007-08 it was 65 percent. The required response rate may limit the availability of a “national” estimate through CPONDER, but states with PRAMS are encouraged to use their own data whenever possible.

The PRAMS survey consists of core questions that all states must include and standard, pilot-tested questions that states may choose to add. In addition, PRAMS allows states to design and add their own questions, and the state is responsible for completing question testing before the question can be included. PRAMS data is available from CDC by submitting a proposal for and data sharing agreement to CDC. Data from a single state can be requested from the state PRAMS coordinator.

Data on postpartum contraceptive use are readily available in PRAMS (D’Angelo et al, 2007; DePineres et al., 2005; Whiteman et al., 2009; Williams et al., 2003). However, at this time only 40 states and New York City participate in PRAMS. Some states have similar surveys (e.g., California's Maternal and Infant Health Assessment (MIHA)). Data linkages are not required (although see below for some potential linkages for the collection of potential modifiers). The question “Are you or your husband or partner doing anything now to keep from getting pregnant?” is a core question in PRAMS, but a follow-up question identifying specific methods is a standard question and may not be used in all jurisdictions. Starting in 2012, the question “What kind of birth control are you or your husband or partner using now to keep from getting pregnant?” became a core question in PRAMS but data will not be available until 2014 (CDC, 2011).

With regard to potential modifiers, some may be more difficult to obtain than others. Routinely collected demographic information such as race, age, education, marital status, parity and health insurance status should be fairly easy to obtain. Pregnancy intention (Bloch et al., 2012) and prenatal care characteristics are most likely to be subject to recall bias, whereas mode of delivery and birth outcome are more proximal and more straightforward. Clinical counseling content is difficult to assess (Akers et al., 2010; Lopez et al., 2012; Tschudin et al., 2007); even matching PRAMS respondents to medical records only provides information on documentation of counseling.

**Data quality**

PRAMS is a mixed-mode surveillance system that combines mail and telephone surveillance. Each year, the sample is weighted to represent all births that meet the inclusion criteria before reporting. Unlike many health surveys, the PRAMS project has a wealth of information from the birth certificate on those who do not respond by either mode of contact, and therefore weighting can be effective at minimizing differences between respondents and non-respondents.

Since the PRAMS survey is completed retrospectively by a woman two to six months after her birth outcome, some bias may occur due to self-reporting and recall. PRAMS is sampled from live births only, so the data do not include information on other pregnancy outcomes such as abortions, miscarriages, or stillbirths; the data do include responses from women who have experienced an infant death. PRAMS is sampled among singleton, twin, and triplet births, and therefore it is not representative of higher order births.

One study standardized the 1995 National Survey of Family Growth (NSFG) data on unintended pregnancy, which provided an estimate between the GWHS and the PRAMS estimates to use (Dietz et al., 1998). Although the study examined pregnancy intention, it has implications for standardizing the NSFG for postpartum contraceptive use. However, PRAMS remains the recommended data source for postpartum contraception.
**Simplicity of indicator**

The indicator is relatively simple to measure and to understand as stated. This indicator provides an important and sensitive measure of health behavior that impacts child and intergenerational health, based on a substantial body of literature demonstrating that adequate birth spacing and prevention of unwanted or mistimed pregnancy is beneficial for child, and to a lesser extent maternal, health. However, contraceptive use throughout the reproductive years is an important indicator for women’s health, and is not adequately captured by postpartum contraception. A measure of current contraceptive use or ever contraceptive use could be obtained from the Behavioral Risk Factor Surveillance System (BRFSS) or NSFG. These surveys would capture a broader sample of women than PRAMS, including women who have never had a birth, women across a wider variety of ages, and women at different life stages. Men also could be included, which is not possible with PRAMS. These datasets do have some limitations. Although BRFSS attempts to capture all pregnancies, it only asks women about their last pregnancy within the past five years allowing for potential recall bias. Additionally, BRFSS does not query men about contraceptive use. NSFG is a good source for reproductive health information, including contraception, about American women and men. However, NSFG does not provide state-level data, limiting its use at the state and local level.

**References**


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Basic Indicator Information

Name of indicator: Repeat Teen Birth (LC-53)

Brief description: Percent of teen births that are repeat teen births

Indicator category: Reproductive Life Experiences

Indicator domain: Risk/Outcome

Numerator: Number of repeat live births to females 15-19 years (or other teenage group)

Denominator: Number of live births to females 15-19 years (or other teenage group)

Potential modifiers: Race/ethnicity, age, education, income, nativity, father acknowledgement, geography, rural/urban, residence in foster care


Notes on calculation: None

Similar measures in other indicator sets: HP 2020 Focus area FP-8; CDC Winnable Battle (Decrease teen birth rates by 20 percent)
Life Course Criteria

Introduction
The United States celebrates continued declines in its teen pregnancy rate, however disparities, especially by race and ethnicity, persist. Through the targeted promotion of effective interventions that delay initiation of early sexual activity and increase the effective use of contraceptive methods, the Centers for Disease Control and Prevention (CDC) has deemed continued declines in teen pregnancy as a “Winnable Battle” (1). However, repeat teen birth, within teen childbearing, presents unique challenges (as well as opportunities): according to the CDC, approximately one in five teen births is a repeat teen birth. Adolescents who experience a repeat teen pregnancy are more likely to have been younger at sexual debut, have lower educational expectations, be out of school or not a high school graduate, and unemployed (7,8). These risk factors are magnified by the fact that the repeat teen pregnancy reduces the teen’s ability to become self-sufficient and improve her and her children’s socioeconomic future.

National, state and community efforts to reduce teen pregnancy can have strong downstream impacts on the health of our nation’s adolescents. Programs that target high-risk communities and address the ‘whole adolescent’ through positive youth development, social empowerment and taking into account interrelated challenges and risk factors have tremendous potential. These programs can help reduce individual risk exposure while steering youth on trajectories for educational attainment and self-fulfillment. While preventing the initial pregnancy is the primary focus of teen pregnancy and repeat pregnancy prevention initiatives, teen pregnancy and parenting support services for youth as well as contraceptive methods initiated immediately postpartum hold promise for teen mothers and fathers. MCH programs and partners have numerous access points to achieve the aims of keeping teen parents on positive trajectories and preventing subsequent teen births.

Implications for equity
In the United States, repeat teen birth rates have been declining since 1990 but disparities still remain (2). According to preliminary 2011 data, the overall proportion of teen births that were repeat teen births in the nation was 18.4 percent. This proportion varied by race and Hispanic origin: 20.9 percent for non-Hispanic Black, 20.8 percent for Hispanic, 19.6 percent for American Indian or Alaska Native, 17.4 percent for Asian or Pacific Islander, and 14.8 percent for non-Hispanic White females (3). An estimated 19 percent of teen mothers (range 12 to 49 percent) experienced a subsequent pregnancy within 12 months and 38 percent (range 28 to 63 percent) experienced a subsequent pregnancy within 24 months (4,5). In 2010, repeat teen childbearing was typically lowest in the Northeast and highest in the South and Southwest (6).

A repeat teen birth is more likely to occur if the teen mother was younger at sexual debut and first birth, has lower educational expectations, intended her first birth, is living with a husband/partner, did not graduate high school after her first birth, and was unemployed or not enrolled in school after her first birth (7,8). Many of these characteristics are inherently associated with poverty and disinvested communities. Poverty has significant systematic effects on the occurrence and distribution of teen childbearing across populations. Unfavorable community and family socioeconomic influences that may result from poverty and increase the risk of teen pregnancy include exposure to single-parent homes at age 14, low educational attainment of the teen’s parent(s), having a mother who gave birth as a teenager, family disorganization, residence in disinvested communities with limited employment opportunities and availability of affordable and comprehensive health care, neighborhood physical disorder, and neighborhood-level income inequality (3,9-17).

Public health impact
In 2010, teen childbearing cost U.S taxpayers approximately $9.4 billion for increased health care, public assistance, and foster care and contributed to lost tax revenue due to lower educational attainment and income among teen mothers and fathers as well as increased incarceration rates among children of teen parents (18,19).

Repeat teen pregnancy reduces the teen’s ability to become self-sufficient and improve her and her children’s socioeconomic future (20,21). Relative to women with first teen births, women with repeat teen births are less likely to receive prenatal care, complete school, work or maintain economic self-sufficiency, and have school-ready children. Repeat teen mothers are also more likely to have a preterm delivery, receive welfare, and have children with emotional and behavioral problems (4).
Preventing initial pregnancies is critical to reducing subsequent births to teens. Few teen pregnancy prevention programs have been adequately evaluated. In general, the most successful programs that work to reduce the first pregnancy, combine sexuality education with youth development activities and are initiated for adolescents at a young age (6,22). The most successful programs that aim to prevent or delay subsequent births are those that combine services for the adolescent mother and her child and those with follow-up of young mothers for at least two years (e.g. home visits by nurses) (6, 24, 23).

The effectiveness of programs to reduce repeat teen births, directly or indirectly, depends on the type of program or policy intervention. Interventions that target sexual beliefs and behaviors at the individual level (e.g. age at first sex, number of partners, and use of contraception) have greater potential of reducing teen births than those aimed at addressing risk factors at the community (e.g. violence and other forms of community social disorganization) or family (e.g. family structure, dynamics, and education) levels (20). Evaluations of programs that target repeat births have yielded mixed results (4). Those with significant findings had little to modest impact on adolescent sexual and contraceptive behavior in entire study populations or in subgroups (4). Several shortcomings of assessing effectiveness of these programs have been noted including the inability to determine whether observed modest impacts could be sustained over long periods of time, paying little or no attention to community- and family-level socioeconomic predictors of adolescent childbearing, and having no focus on male involvement or inclusion of males in interventions (22, 27).

Greater reductions in teen childbearing are expected to occur with the implementation of health care policies including the expansion of access to Medicaid family planning services and the Patient Protection and Affordable Care Act of 2010, which aims to improve access to and quality of health care services in the United States (24,25). For example, some states are currently considering partnerships with their Medicaid offices to enable immediate insertion of postpartum long-acting reversible contraceptives after delivery. South Carolina made such an update to its Medicaid coverage policy in 2012 (26).

**Leverage or realign resources**

Efforts to reduce repeat teen births have great potential to leverage and realign resources in a variety of sectors including the education, Medicaid, home visiting, and social welfare sectors. High school dropout rates are higher among teen mothers than teenagers without children. By not having a high school diploma or equivalent, teen parents may change their life course trajectory towards unfavorable health and socioeconomic circumstances for themselves and their children. Given the strong association of early sexual intercourse with other risk-taking behaviors, schools have implemented and supported education and service programs such as positive youth development programs (e.g. sex education and workforce development programs) that foster resiliency in youth to help reduce school dropout rates and teen pregnancies (6, 27). In many instances these programs are the result of partnerships between schools, community organizations, and state or community maternal, child, and adolescent health programs.

In the United States, Medicaid covers the cost of more than 66 percent of deliveries among teenagers, which is greater than the percentage among women 20 to 24 years of age (52.8 percent) (28). To help decrease the number of unplanned pregnancies and births paid for by Medicaid, Medicaid agencies provide family planning waivers to states to enable them to serve women otherwise ineligible for Medicaid, many of whom are teenagers. As of 2013, 31 states have obtained federal approval to extend Medicaid eligibility for family planning services to individuals who would otherwise not be eligible (29).

Many detrimental socioeconomic, behavioral, and health factors that face teen mothers and their children call for important resources and services that teen mothers may not be able to afford or access. The Maternal Infant, and Early Childhood Home Visiting program, administered by the Health Resources and Services Administration (HRSA) with the Administration for Children and Families (ACF), provides services to priority populations including adolescent teenage mothers and their children to reduce the incidence of repeat pregnancy and birth and adverse health conditions (6,24,30,31). Home visiting, which is available to pregnant women, new mothers, and children (eligibility differs by home visiting program model), attempts to mitigate many consequences of teen births that adversely affect the teen mother and her child.

Children born to teen mothers are more likely to enter foster care and interact with the judicial system than other children. Further, youth who have ever lived in foster care are more likely to engage in risky behaviors that may lead to arrests and teen pregnancies than other individuals. Adolescents who age out of foster care are at increased risk of experiencing
several hardships including homelessness, unemployment, and criminal activity (12). Ongoing partnerships and efforts between the foster care and juvenile justice systems along with the National Campaign to Prevent Teen and Unplanned Pregnancy have been promoted (32).

**Predict an individual’s health and wellness and/or that of their offspring**

Teenage pregnancy and parenting are risk factors for poor medical and psychosocial outcomes for teen mothers, fathers, and their infants (6). As described previously, teen childbearing is associated with other adolescent risk-taking behaviors, calling into importance the integration of teen pregnancy prevention programs with positive youth development opportunities. Males, racial/ethnic minority groups, older teens, individuals who enter puberty early and are more physically developed, teens who abuse alcohol and drugs, and those who were sexually abused are more likely to engage in behaviors that lead to early childbearing than their counterparts (33). Furthermore, teen childbearing also is a risk-factor for further later disruptions in an individual’s life course. While many teen mothers are able to complete high school education at a later time, (26,34,35) teens who do no return to school soon after giving birth are at much greater risk of becoming pregnant again within 15 months (26). Teen childbearing also impacts the wellness of teenage fathers. Teen fatherhood is correlated with low educational attainment, limited earnings, substance abuse and trouble with the law. Many do not maintain a long-term relationship with the teenage mother or their child or frequently do not provide most of their child’s shelter, food, or clothing (26). Providing and collecting child support is a major issue that frequently involves the legal system.

Some of the mental health consequences of teen childbearing are also of great importance. Depression is a common occurrence for young women who bear children during adolescence (6). Maternal depression has been associated with negative maternal-child interactions and subsequent behavioral abnormalities, such as disruptive behavior in young children, especially young boys (3). In some children, this leads to persistent negative behavior and poor school performance (6,36-39). Children of teen mothers are also more likely to engage in sexual activity early, become teen parents themselves, and have higher than average rates of developmental delay, school failure, and substance abuse (26, 40, 41).

Infants born to teen mothers are at increased risk for adverse outcomes at birth, school age, and adolescence. The outcomes include increased risk of low birth weight (and subsequently increased risk of infant mortality), childhood behavioral problems, and risk-taking behavior during adolescence (6). Infants of adolescent mothers have an increased risk for death from intentional injury (6, 42-44). Children of adolescent mothers may also be at greater risk of unintentional injury, in part due to young mothers being less aware of potential risks or having lower maturity that may influence their perception or decision-making in the face of situations that may result in injury (6,38).

Further, the second-born children of teen mothers are at greater risk for adverse pregnancy outcomes (especially those resulting from short interpregnancy intervals), infant homicide, and poorer behavioral and educational development (as a consequence of limited time and resources) than his or her older sibling (5,45-47). Studies of interpregnancy interval, which is the time from the completion of one pregnancy to the conception of the next, suggest an optimal interval of 18 to 23 months, but it may vary for subgroups of women (48). Interpregnancy intervals of at least 12 months are recommended for women who had a live birth. Short interpregnancy interval has been shown to be associated with preterm delivery, infants who are small for gestational age, early infant death, and congenital malformations (49,50-52). Second and higher-order births during adolescence are associated with lower maternal educational attainment (53,54). In addition, some research suggests that short interpregnancy intervals may have lifetime effects for the child, including poor educational performance for children born after a short interpregnancy interval (55). Rapid repeat pregnancy (a possible consequence of lack of access to postpartum contraception) is associated with negative consequences for educational attainment and employment, among adolescents (53,54). Lack of access to education and employment, especially in early life, are important predictors of poverty. Other research has demonstrated a relationship between income inequality and short interpregnancy intervals in women of all ages (56).

**Data Criteria**

**Data availability**

Data on teenage births are collected annually for the 50 states and the District of Columbia. This data are also available at the city and county levels. The National Vital Statistics System is an intergovernmental sharing of data whose
relationships, standards, and procedures form the mechanism by which the National Center for Health Statistics (NCHS) collects and disseminates the nation's official vital statistics. Vital event data are collected and maintained by the jurisdictions that have legal responsibility for registering vital events; these entities provide the data via contracts to NCHS. Vital events include births, deaths, marriages, divorces, and fetal deaths. In the United States, legal authority for the registration of these events resides individually with the 50 states, two cities (Washington, DC, and New York City), and five territories (Puerto Rico, the Virgin Islands, Guam, American Samoa and the Commonwealth of the Northern Mariana Islands).

Vital Statistics data are available online in downloadable public use files, through pre-built tables in VitalStats, and through the ad-hoc query system CDC WONDER (Wide-ranging Online Data for Epidemiologic Research). Birth certificate data are available in WONDER for 1995-2010, and death certificate data by underlying cause of death (detailed mortality) are available for 1999-2010.

**Data quality**

Standard forms for the collection of the data and model procedures for the uniform registration of the events are developed and recommended for State use through cooperative activities of the states and NCHS. As reported in the NCHS publication U.S. Vital Statistics System, Major Activities and Developments, 1950-1995, efforts to improve the quality and usefulness of vital statistics data are ongoing. NCHS uses techniques such as testing for completeness and accuracy of data, querying incomplete or inconsistent entries on records, updating classifications, improving timeliness and usefulness of data, and keeping pace with evolving technology and changing needs for data. Work with state partners to improve the timeliness of vital event reporting is ongoing, and NCHS is working closely with National Association of Public Health Statistics and Information Systems and the Social Security Administration to modernize the processes through which vital statistics are produced in the United States, including implementation of the 2003 revised certificates.


Both the numerator (number of repeat live births to teenage females) and denominator (number of live births to teenage females) of this indicator are derived from birth certificate records. An Indiana study reported high agreeability of the number of previous live births (Kappa=0.935) and maternal age (Kappa=0.994) between birth certificates and medical records (57). For these two variables, sensitivity, specificity, and positive predictive value were noted as "not applicable." Overall, the percent of repeat teen live births is an accurate measure.

**Simplicity of indicator**

The level of complexity in calculating and explaining this indicator is low. Repeat birth estimates are more often reported as percentages of live births to females aged 15 to 19 years than as rates (i.e. number of repeat births per 1,000 females aged 15 to 19 years). Data weighting, indexing, or adjustments are not required and the statistical formula is simple. Names and formula for this indicator may vary according to agency, organization, or group. For example, the Annie E. Casey Foundation (kidscount.org) defines this indicator as "Teen births to women who were already mothers" or "Births that were second or higher order births to mothers who were under the age of 20 at the time of the birth." Other measures of repeat teen pregnancy may exist. Nonetheless, this measure can be easily explained.

**References**


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The Life Course Metrics Project

As MCH programs begin to develop new programming guided by a life course framework, measures are needed to determine the success of their approaches. In response to the need for standardized metrics for the life course approach, AMCHP launched a project designed to identify and promote a set of indicators that can be used to measure progress using the life course approach to improve maternal and child health. This project was funded with support from the W.K. Kellogg Foundation.

Using an RFA process, AMCHP selected seven state teams, Florida, Iowa, Louisiana, Massachusetts, Michigan, Nebraska and North Carolina, to propose, screen, select and develop potential life course indicators across four domains: Capacity, Outcomes, Services, and Risk. The first round of indicators, proposed both by the teams and members of the public included 413 indicators for consideration. The teams distilled the 413 proposed indicators down to 104 indicators that were written up according to three data and five life course criteria for final selection.

In June of 2013, state teams selected 59 indicators for the final set. The indicators were put out for public comment in July 2013, and the final set was released in the Fall of 2013.

Basic Indicator Information

Name of indicator: Teen Births (LC-54)

Brief description: Number of live births born to women aged 10-19 years per 1,000 women aged 10-19 years

Indicator category: Reproductive Life Experiences

Indicator domain: Risk/Outcome

Numerator: Number of live births born to women aged 10-19 years

Denominator: Number of women aged 10-19 years

Potential modifiers: Race/ethnicity, age, education, income, nativity, father acknowledgement, geography, rural vs. urban, residence in foster care

Data source: National Vital Statistics System (NVSS) Birth Records

Notes on calculation: Multiply by 1,000 for rate

Similar measures in other indicator sets: HP 2020 Focus area FP-8; CDC Winnable Battle (Decrease teen birth rates by 20 percent); Title V Performance Measure #08
Introduction
The United States celebrates continued declines in its teen pregnancy rate, however disparities, especially by race and ethnicity, persist. Through the targeted promotion of effective interventions that delay initiation of early sexual activity and increase the effective use of contraceptive methods, the Centers for Disease Control and Prevention (CDC) has deemed continued declines in teen pregnancy as a “Winnable Battle.” National, state, and community efforts to reduce teen pregnancy can have strong downstream impacts on the health of our nation’s adolescents. Programs that target high-risk communities and address the ‘whole adolescent’ through positive youth development and social empowerment and take into account interrelated challenges and risk factors have the potential to reduce individual risk exposure while steering youth on trajectories for educational attainment and self-fulfillment. MCH programs and partners have numerous access points to achieve these aims; recent successes in increasing access to contraceptive methods were responsible for reducing the teen pregnancy rate in Colorado by as much as 40 percent and saving the state millions of dollars in Medicaid and social program expenditures.

Implications for equity
In the United States, teen birth rates have been declining since 1990 but disparities still remain, and these disparities persist by race and ethnicity, age, region, and parental involvement. In 2010, the overall U.S. birth rate was 34.2 live births per 1,000 females aged 15 to 19 years. Among this age group, the number of births per 1,000 females was 55.7 for Hispanic, 51.3 for non-Hispanic Black, 38.7 for American Indian or Alaska Native, 23.5 for non-Hispanic White, and 10.9 for Asian or Pacific Islander populations. Also in 2010, primary and repeat teen childbearing were typically lowest in the Northeast and highest in the South and Southwest.

Approximately 9 percent of young men aged 12 to 16 years will become fathers before they reach 20 years of age. Teen fatherhood rates also vary considerably by race. Among 15-19 year old males, 34 per 1,000 Black males and 15 per 1,000 White males became fathers in 2006. Males, racial/ethnic minority groups, older teens, individuals who enter puberty early and are more physically developed, teens who abuse alcohol and drugs, and those who were sexually abused are more likely to engage in behaviors that lead to early childbearing than their counterparts. On the contrary, teenagers who are engaged in school and partake in sports (among girls), religious activities, and other positive activities are less likely to engage in risky behaviors.

Parent involvement has been associated with lower likelihood of teen pregnancy, potentially exposing the nearly half a million children living in foster care in the United States to greater risk of teen pregnancy. Teens in foster care are 2.5 times more likely than teens outside the foster care system to become pregnant by the age of 19. In addition to a greater likelihood of teen childbearing, children born to teen mothers are more likely to be involved with both the foster care system and the juvenile justice system.

Poverty has significant systematic effects on the occurrence and distribution of teen childbearing across different populations. Unfavorable community and family socioeconomic influences that may result from poverty and increase the risk of teen pregnancy include exposure to single-parent homes at age 14, low educational attainment of the teen’s parent(s), having a mother who gave birth as a teenager, family disorganization, residence in disadvantaged communities with limited employment opportunities, availability and access to affordable and comprehensive health care, neighborhood physical disorder, and neighborhood-level income inequality. Teens who reside in disinvested communities with high poverty or crime rates are more likely to engage in risky sexual behaviors and give birth than teens who live in more affluent communities.

Public health impact
In 2010, teen childbearing cost U.S. taxpayers approximately $9.4 billion for increased health care and foster care, increased incarceration rates among children of teen parents, cost of public assistance, and lost tax revenue due to lower educational attainment and income among teen mothers and teen fathers.

Furthermore, teen childbearing is a major contributor to high school dropout rates among teenage females. Perper and colleagues reported that by the age of 22 years, approximately 50 percent of teenage mothers receive a high school diploma compared with 90 percent of women who had not given birth before reaching 20 years of age.
Children of teen mothers are at high risk of having behavioral and chronic medical problems, living in poverty and in single-parent households, entering the child welfare system, relying on publicly funded health care, having lower school achievement, dropping out of high school, becoming teen mothers themselves, being incarcerated, and facing unemployment as young adults.  

Until recently, thorough evaluations of teen pregnancy prevention programs have been few with mixed results that depend on the type of activities targeted. In general, the most successful programs combine sexuality education with youth development activities and are initiated for adolescents at a young age. For example, Kirby (2001) states, “the Children’s Aid Society-Carrera Program, which includes both youth development and reproductive health components, has been demonstrated to substantially reduce teen pregnancy and birth rates among girls over a long period of time.”

Greater reductions in teen childbearing are expected to occur with the implementation of health care policies including the expansion of access to Medicaid family planning services and the Patient Protection and Affordable Care Act of 2010, which aims to improve access to and quality of health care services in the United States. For example, in 2014, the Colorado Department of Public Health and Environment announced an unprecedented decline (40 percent) in the teen birth rate in Colorado from 2009 through 2014, with three-quarters of the overall decline being attributed to increasing access to intra-uterine devices or implants at low or no cost to low income women being served in family planning clinics. The Colorado Department of Public Health and Environment estimates that with increasing access to long-acting reversible contraceptives and the associated decline in teen pregnancy, the state has saved $42.5 million in public funds in 2010 alone.

**Leverage or realign resources**

Efforts to reduce teen pregnancy have great potential to leverage and realign resources in a variety of sectors including the education, Medicaid, social welfare, foster care and judicial sectors. High school dropout rates are higher among teen mothers than teenagers without children. By not having a high school diploma or equivalent, teen parents may change their life course trajectory toward unfavorable health and socioeconomic circumstances for themselves and their children. Given the strong association of early sexual intercourse with other risk-taking behaviors, schools have implemented and supported education and service programs such as positive youth development programs (e.g. sex education and workforce development programs) that foster resiliency in youth to help reduce school dropout rates and teen pregnancies. Early sexual intercourse and the positive youth development approach are discussed in more detail in LC-50. In many instances these programs are the result of partnerships between schools, community organizations, and state or community maternal, child, and adolescent health programs.

In the United States, Medicaid covers the cost of more than 66 percent of deliveries among teenagers, which is greater than the percentage among women 20-24 years of age (52.8 percent). To help decrease the number of unplanned pregnancies and births paid for by Medicaid, Medicaid agencies provide family planning waivers to states to enable them to serve women otherwise ineligible for Medicaid, many of whom are teenagers. As of 2013, 31 states have obtained federal approval to extend Medicaid eligibility for family planning services to individuals who would otherwise not be eligible.

Many detrimental socioeconomic, behavioral, and health factors that face teen mothers and their children call for important resources and services that teen mothers may not be able to afford or access. The Maternal Infant, and Early Childhood Home Visiting program, administered by the Health Resources and Services Administration (HRSA) with the Administration for Children and Families (ACF), provides services to priority populations including teenage mothers and their children. Home visiting, which is available to pregnant women, new mothers, and children (eligibility differs by home visiting program model) attempts to mitigate many consequences of teen births that adversely affect the teen mother and child.

Children born to teen mothers are more likely to enter foster care and interact with the judicial system than other children. Furthermore, youth who have ever lived in foster care are more likely to engage in risky behaviors that may lead to arrests and teen pregnancies than other individuals. Adolescents who age out of foster care are at increased risk of experiencing several hardships including homelessness, unemployment, and criminal activity. Ongoing partnerships and efforts between the foster care and juvenile justice systems along with the National Campaign to Prevent Teen and Unplanned Pregnancy have been promoted.
**Predict an individual’s health and wellness and/or that of their offspring**

Teenage pregnancy and parenting are risk factors for poor medical, education, and psychosocial outcomes for teen mothers, fathers, and their infants.\(^{24}\) As described previously, teen childbearing is associated with other adolescent risk-taking behaviors, calling into importance the integration of teen pregnancy prevention programs with positive youth development opportunities. Males, racial/ethnic minority groups, older teens, individuals who enter puberty early and are more physically developed, teens who abuse alcohol and drugs, and those who were sexually abused are more likely to engage in behaviors that lead to early childbearing than their counterparts.\(^{36}\) Further, teen childbearing also is a risk-factor for later disruptions in an individual’s life course. While many teen mothers are able to complete high school education at a later time,\(^{24,37,38}\) teens who do no return to school soon after giving birth are at much greater risk of becoming pregnant again within 15 months.\(^{24}\) Teen childbearing also impacts the wellness of teenage fathers. Teen fatherhood is correlated with low educational attainment, limited earnings, substance abuse and trouble with the law. Many do not maintain a long-term relationship with the teenage mother or their child or frequently do not provide most of their child’s shelter, food, or clothing.\(^{24}\) Providing and collecting child support is a major issue that frequently involves the legal system.

Some of the mental health consequences of teen childbearing are also of great importance. Depression is a common occurrence for young women who bear children during adolescence.\(^{24}\) Maternal depression seems to be associated with negative maternal-child interactions and subsequent behavioral abnormalities in their children, such as disruptive behavior, especially in young boys.\(^{4}\) In some children, this leads to persistent negative behavior and poor school performance.\(^{24,39-42}\) Children of teen mothers are also more likely to engage in sexual activity early, become teen parents themselves, and have higher than average rates of developmental delay, school failure, and substance abuse.\(^{24,43,44}\)

Infants born to teen mothers are at increased risk for adverse outcomes at birth, school age, and adolescence. The outcomes include increased risk of low birth weight (and subsequently increased risk of infant mortality), childhood behavioral problems, and risk-taking behavior during adolescence.\(^{24}\) Infants of adolescent mothers have an increased risk for death from intentional injury.\(^{24,45-47}\) Children of adolescent mothers may also be at greater risk of unintentional injury, in part due to young mothers being less aware of potential risks or having lower maturity that may influence their perception or decision-making in the face of situations that may result in injury.\(^{24,43}\)

**Data Criteria**

**Data availability**

Data on teen births are collected annually for the 50 states and the District of Columbia. These data are also available at the city and county levels. The National Vital Statistics System is an intergovernmental sharing of data whose relationships, standards, and procedures form the mechanism by which the National Center for Health Statistics (NCHS) collects and disseminates the nation’s official vital statistics. Vital event data are collected and maintained by the jurisdictions that have legal responsibility for registering vital events; these entities provide the data via contracts to NCHS. Vital events include births, deaths, marriages, divorces, and fetal deaths. In the United States, legal authority for the registration of these events resides individually with the 50 states, two cities (Washington, DC, and New York City), and five territories (Puerto Rico, the Virgin Islands, Guam, American Samoa and the Commonwealth of the Northern Mariana Islands).

Vital Statistics data are available online in downloadable public use files, through pre-built tables in VitalStats, and through the ad-hoc query system CDC WONDER (Wide-ranging Online Data for Epidemiologic Research). Birth certificate data are available in WONDER for 1995-2010, and death certificate data by underlying cause of death (detailed mortality) are available for 1999-2010.

**Data quality**

Standard forms for the collection of the data and model procedures for the uniform registration of the events are developed and recommended for state use through cooperative activities of the States and NCHS. As reported in the NCHS publication U.S. Vital Statistics System, Major Activities and Developments, 1950-1995, efforts to improve the quality and usefulness of vital statistics data are ongoing. NCHS uses techniques such as testing for completeness and accuracy of data, querying incomplete or inconsistent entries on records, updating classifications, improving timeliness and usefulness of data, and keeping pace with evolving technology and changing needs for data. Work with state partners to improve the timeliness of vital event reporting is ongoing, and NCHS is working closely with National Association of
Public Health Statistics and Information Systems and the Social Security Administration to modernize the processes through which vital statistics are produced in the United States, including implementation of the 2003 revised certificates.


The number of teenage births as reported on the birth certificates is accurate. An Indiana study reported high agreeability between maternal age (Kappa=0.994) on birth certificates and medical records. Population projections are not completely accurate, especially in counties or cities experiencing changing population numbers and characteristics. These estimates are far more reliable over time with the American Community Survey, which allows one to not have to wait every 10 years for the census. Overall, the assessment of teenage births is accurate.

**Simplicity of indicator**

The level of complexity in calculating and explaining this indicator is fairly low. The rate is the number of live births to females 10-19 years old per 1,000 females 10-19 years old. Data weighting, indexing, or adjustments are not required and the statistical formula is straightforward. Reducing teen pregnancy is a common focus area among professionals and communities and one that community members can understand.

Names and formula for this indicator may vary according to agency, organization, or group. Nonetheless, this measure can be relatively easy to explain. The numerator is calculated from data reported on all versions of birth certificates and the denominator from the U.S. Census projections. This measure does not require the linkage of datasets.

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References


Life Course Indicator: Preterm Birth

The Life Course Metrics Project

As MCH programs begin to develop new programming guided by a life course framework, measures are needed to determine the success of their approaches. In response to the need for standardized metrics for the life course approach, AMCHP launched a project designed to identify and promote a set of indicators that can be used to measure progress using the life course approach to improve maternal and child health. This project was funded with support from the W.K. Kellogg Foundation.

Using an RFA process, AMCHP selected seven state teams, Florida, Iowa, Louisiana, Massachusetts, Michigan, Nebraska and North Carolina, to propose, screen, select and develop potential life course indicators across four domains: Capacity, Outcomes, Services, and Risk. The first round of indicators, proposed both by the teams and members of the public included 413 indicators for consideration. The teams distilled the 413 proposed indicators down to 104 indicators that were written up according to three data and five life course criteria for final selection.

In June of 2013, state teams selected 59 indicators for the final set. The indicators were put out for public comment in July 2013, and the final set was released in the Fall of 2013.

Basic Indicator Information

Name of indicator: Preterm Birth (LC-55)

Brief description: Percent of live births born < 37 weeks gestation

Indicator category: Reproductive Life Experiences

Indicator domain: Risk/Outcome

Numerator: Number of live births born prior to 37 weeks gestation

Denominator: Total number of live births

Potential modifiers: Maternal age, race/ethnicity, educational attainment, nativity, marital status, sex of infant, household income, parity, previous preterm birth, geography (urban versus rural), multiple gestation, maternal smoking, fertility treatment, early induction of labor, obesity, payer source

Data source: National Vital Statistics System (NVSS) Records

Notes on calculation: None

Similar measures in other indicator sets: HP 2020 Focus area MICH-9
Life Course Criteria

Introduction

Nearly one in eight babies are born preterm (before 37 weeks of gestation) in the United States. Preterm birth is the leading cause of infant death for babies born to non-Hispanic Black mothers and the preterm-mortality rate for Black infants is more than three-fold that of White infants, producing much of the racial and ethnic disparity in infant mortality in the nation. In addition to being one of the leading causes of death in the first year of life, preterm birth can be associated with lifelong health, emotional, economic, and social consequences for the child, mother, family, and community. Numerous national and state initiatives focus on and have a significant interest in reducing preterm births, including, to name a few, Healthy People 2020, the March of Dimes’ 39+ Weeks and Healthy Babies are Worth the Wait campaigns, the Health Resources and Services Administration (HRSA) Regional Collaborative Innovation and Improvement Networks (CoIIINs), and the Centers for Medicare and Medicaid Services Strong Start for Mothers and Newborns Initiative. A life course indicator for preterm birth unites these more national initiatives – which use different processes including quality improvement, public education, public policy, and health care financing reform – with more behaviorally focused efforts like smoking cessation programs or anti-poverty and anti-discrimination reforms in housing, nutrition, education, and the workforce to reduce exposure to stressors across the life span of women. Reducing the rate of preterm births in the United States and their associated disparities will require a multi-faceted effort. While recent advances in clinical care (17P, elimination of early elective deliveries) and reducing behavioral risk factors for preterm birth are promising, they are not sufficient to overcome the persistent and historically unexplained disparities in preterm birth. Improving women’s health across the life span and the social context and inequitable distribution of resources and services (including support systems) across race/ethnicities and class will need to guide future program and policy development.

Implications for equity

Various social, psychosocial, economic and environmental factors are associated with preterm birth, and in turn contribute to complex disparities across races and ethnicities and socioeconomic status.

Racial/ethnic and class disparities in preterm births are strong: non-Hispanic Black women have higher odds of having a preterm infant (Vanderweele et al., 2012), and nationally, the preterm birth rate for non-Hispanic Black women is 17.1 percent in comparison to 10.8 percent and 11.8 percent seen in non-Hispanic White and Hispanic women, respectively (Martin et al. 2012). Perhaps most significantly, in the United States, the number one cause of infant death for infants born to non-Hispanic White women is congenital anomalies, whereas for non-Hispanic Black women, complications associated with short gestation and low birthweight are the primary cause of infant death. This difference in preterm-related infant mortality explains much of the higher risk for infant mortality for babies born to Black mothers: the preterm-related infant mortality rate for non-Hispanic Black women in 2009 was 540 deaths per 100,000 live births, whereas for Non-Hispanic White women, the rate was 164 deaths per 100,000 live births (more than a three-fold difference) and for all races, the rate was 226 deaths per 100,000 live births (Mathews and MacDorman, 2013). Evidence suggests that the disparity in preterm birth-related infant mortality is increasing.

Inequities in preterm birth in women of lower socioeconomic status cut across race and ethnicity. Living in socioeconomically disadvantaged census tracts, like high poverty tracts, or in areas characterized by low educational attainment, high unemployment, and low proportion of managerial or professional occupation have been found to have a significant association with preterm birth (Messer et al., 2008). The effects of these factors were seen for Black as well as White women. Further, a study by Mason, Messer, Laraia, and Mendola (2009) found increased odds of preterm birth in both White and Black women if they resided in predominantly Black tracts. Vinikoor-Imler and colleagues (2011) found increased odds for preterm births in areas with high levels of physical incivilities and low levels of walkability for non-Hispanic White women, but not for non-Hispanic Black women. Additionally, high material and social deprivation has been associated with a higher risk of preterm birth (Auger, Park, Gamache, Pampalon, and Daniel, 2012).

Maternal factors such as age and chronic disease diagnosis or health status also are associated with differences in risk for preterm birth (Vanderweele, Lantos, & Lauderdale, 2012). Martin and colleagues found that preterm birth rates are highest among women aged 45-54 years at 25.9 percent, followed by 21.8 percent in teenagers younger than 15 years (2012). When women experience delayed access to care, women with diabetes and hypertension (Sibai et al., 2000) and genital tract infections (French, McGregor, & Parker, 2006) have been found to be at higher risk for preterm birth. Finally, environmental factors also are associated with higher rates of preterm births, with researchers finding that women who
have increased exposure to particulate matter (PM_{2.5}) (Kloog, Melly, Ridgway, Coull, & Schwartz, 2012) and sulfur dioxide (SO2) (Le et al., 2012) are at increased risk for delivering preterm.

Disparities in risk for preterm birth discussed thus far have focused on racial, socioeconomic, age, and health status factors, however the processes associated with stress, mental health, and well-being, and how these experiences ‘get under the skin’ remain some of the most complex and persistent sources of risk for adverse infant health outcomes. In a prospective study of Black women in Baltimore city, women who characterized themselves as ‘somewhat or not at all satisfied with their lives’ were more likely to have preterm infants, with an adjusted odds ratio of 1.6 (Orr, Orr, James, & Blazer, 2012). In another recent study, Straub and colleagues found that women with antenatal depression, as measured by those with thoughts of self-harm, had significant increases in preterm births for all categories of weeks of gestation (2012). Further, researchers have known for more than 15 years that stressful life events (Hedegaard, Henriksen, Secher, Hatch, & Sabroe, 1996) are associated with a higher likelihood of having a preterm infant and recently, higher perceived stress at 10 to 20 weeks of gestation has been found to be associated with increased preterm birth (Roy-Matton, Moutquin, Brown, Carrier, & Bell, 2011). Extreme examples of stressful life events that have been associated with preterm birth include the Sept. 11, 2001, terrorist attacks (Lipkind, Curry, Huynh, Thorpe, & Matte, 2010) and domestic violence (Shah & Shah, 2010). Given numerous associations between stress and preterm birth, a hypothesis that has been generated as a result of the effect of psychosocial factors, mental health, and chronic stress on adverse maternal and infant health outcomes and their disproportionate distribution and impact across races is the weathering hypothesis. Lu and Halfon (2003) describe how chronic social stressors and their disproportionate distribution and impact lead to weathering of the body’s allostatic systems over the years, contributing to the disparities in birth outcomes, including preterm birth. To intervene in improving the health of Black women across the life span, Lu and colleagues (2010) proposed a 12-point plan to reduce Black-White disparities in birth outcomes using a life course approach.

Public health impact
In 2010, the rate of preterm birth in the United States was 12.0 percent of live births (Martin et al. 2012), affecting approximately one in eight births. Preterm birth is associated with potentially life-threatening health problems in the first year of life, and is the primary cause of infant death for babies born to non-Hispanic Black mothers and the second leading cause of death for all infants in the United States. Poor outcomes for the baby, mother, and family have been found across the spectrum of gestational age, from babies born extremely preterm (less than 25 weeks gestation, the group for which there are the poorest outcomes for survival and lifelong disability), to very, moderately, and late preterm. Further, the group of ‘early term’ infants – babies born just a few weeks early – is receiving national attention due to troubling high rates of early elective deliveries and associations of those deliveries with increased morbidity for the mother and child.

Beyond the immediate health concerns, preterm birth is associated with tremendous economic costs for the family and society as a whole. The total economic cost for medical care (65 percent), maternal delivery (seven percent), early intervention (two percent), special education services (four percent), and lost household and labor market productivity (22 percent) was estimated to be $51,600 per preterm birth in the United States in 2005 (Behrman & Butler(Eds.), 2007), totaling $26 billion annually The Institute of Medicine report from which these figures were developed also specifies that in the first year of life, the medical costs for an infant born preterm are ten times that of an infant born at term.

Preterm birth is a birth outcome with complex causation and requiring a socioecological and life course approach to improve the preconception health of women. However, public health interventions focusing of specific risk factors (e.g. maternal smoking, age, previous preterm birth) have proven effective in particular communities. For example, pooled data from 21 trials of smoking cessation programs during pregnancy (Lumley et al., 2009) showed a significant reduction in preterm births with a relative risk of 0.86 (95 percent Confidence interval: 0.72-0.98). Smoking, as well as alcohol and illicit drug use, are risk factors that have been prime targets for behavioral interventions. Other risk factors for preterm birth include certain medical conditions. The Syracuse Healthy Start program that included screening, treatment and rescreening of women to reduce bacterial vaginosis was found to be associated with reduced preterm births (Koumans et al., 2011).

Other interventions have focused on improving social support and resources and entry into prenatal care. A Centering Pregnancy Program found that providing group prenatal care to pregnant women resulted in preterm infants being larger than those who received individual prenatal care (Ickovics et al., 2003). Such programs can address the psychological,
environmental stressors, and socio-economic factors that have been found to play a role in increased preterm births. The CenteringPregnancy group prenatal care model will receive additional funds from the W.K. Kellogg Foundation and the CMS Strong Start Initiative to expand its programs and reach, given the success of the model (CenteringHealthcare, 2013). However, these successes cannot be extended to all health education programs including those targeting preterm birth. Historically, preterm birth prevention educational programs have had little effect on reducing preterm births and may increase rates of preterm labor diagnoses (Hueston, Knox, Eilers, Pauwels, & Londoßfeld, 1995).

Recent efforts to prevent preterm births have focused on women who have had a previous preterm birth. In particular, the prenatal administration of progesterone (hydroxyprogesterone caproate injection, commonly known as 17P, or in the form of progesterone gel) has proven effective in reducing the risk of perinatal mortality, preterm birth less than 34 weeks, infant birthweight less than 2500 g, and a number of other poor infant health outcomes (Dodd et al, 2013). Questions remain regarding the cost effectiveness of the intervention and access to the intervention, especially for low income patients, given the cost of the injections.

Reducing the rate of preterm births in the United States and their associated disparities will require a multi-faceted effort. While recent advances in clinical care (17P, elimination of early elective deliveries) and reducing behavioral risk factors for preterm birth are promising, they are not sufficient to overcome the persistent and historically unexplained disparities in preterm birth. Improving women’s health across the life span and the social context and inequitable distribution of resources and services (including support systems) across race/ethnicities and class will need to guide future program and policy development.

Leverage or realign resources
Numerous and diverse partners have a stake in building programs and services to reduce preterm births and influence the health of infants, women, families and communities across the life span. An indicator for preterm birth articulated as a measure of life course health offers a unifying concept through which each organization and initiative can impact health across a continuum of services and supports. The following are key national efforts and priorities to reduce preterm births:

- One of the objectives of the Healthy People 2020–MICH-9 is to reduce preterm births. The MICH-9.1 objective is to reduce the proportion of births that are preterm to 11.4 percent. MICH-9.2 objective is to reduce late preterm or live births at 34 to 36 weeks of gestation to 8.1 percent. The MICH-9.3 objective pertains to reduction of the proportion of live births at 32 to 33 weeks of gestation to 1.4 percent and the MICH-9.4 objective is to reduce the proportion of very preterm or live births at less than 28 weeks of gestation to 1.8 percent (HealthyPeople.gov, 2012). The Institute of Medicine (IOM) report on “Preterm birth: Causes, Consequences, and Prevention” proposed a research agenda to investigate preterm birth that includes establishment of multidisciplinary research centers, improving research by better definition of the problem, investigation into the etiology, epidemiology, and clinical and health service research for preterm birth, and eventually inform public policies to reduce preterm birth rates (Behrman & Butler (Eds.), 2007).

- The Maternal and Child Health Bureau (MCHB) COLIN (Collaborative Improvement & Innovation Network) is a public-private partnership to reduce infant mortality and improve birth outcomes in 13 southern states comprising HRSA Regions IV and VI (U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau, 2013), which was recently expanded to also include Region V and with plans for a national expansion. States selecting priorities for quality improvement initiatives are focusing on outcomes like early elective deliveries to make an impact on preterm birth rates and other birth outcomes.

- The March of Dimes began a “Prematurity Research Initiative” to investigate the causes of prematurity and have declared the month of November as “Prematurity Awareness Month” to specifically focus on preterm births (March of Dimes, 2013). For decades the March of Dimes has been at the forefront of building awareness of and funding research into the causes of, and treatments for, preterm birth. Recent efforts receiving national attention include the Healthy Babies are Worth the Wait (HBWW) and the 39+ weeks campaign. The HBWW initiative is both a model of collaboration among local- and state-level clinical and public health partners and a national public awareness campaign. As a collaboration model, HBWW engages the community in efforts to achieve its goals of decreasing preterm births, implementing preventable strategies against preterm births and changing the attitudes and behaviors of providers and consumers. There are five core components (the five Ps) of the HBWW model: 1) partnerships and collaborations, 2) provider initiatives, 3) patient support, 4) public engagement, and 5) measuring progress. With regard to the 39+ weeks campaign, in response to the Joint Commission’s perinatal care core measure set that includes the number of elective deliveries performed >37 and <39 weeks, the March of Dimes and partners created a quality improvement toolkit for professionals: Elimination of Non-medically Indicated Deliveries Before 39 Weeks. The
toolkit focuses on scientific evidence, implementation efforts, data collection, and education. Both of these March of Dimes initiatives focus on collaborations between public health and clinical care, including hospitals and care institutions, and speak to the role of health care professionals in achieving public health goals.

- The Centers for Medicare and Medicaid Services launched the Strong Start for Mothers and Newborns Initiative (U.S. Department of Health and Human Services, 2013). With an overall goal to reduce the risk of significant complications and long-term health problems for both expectant mothers and newborns, the initiative utilizes two strategies - Public-Private Partnership to Reduce Early Elective Deliveries and Funding Opportunity for Testing New Approaches to Prenatal Care. The Public-Private Partnership to Reduce Early Elective Deliveries will examine ways to promote best practices and support providers in reducing early elective deliveries prior to 39 weeks. The Funding Opportunity for Testing New Approaches to Prenatal Care will fund opportunities for providers, states and other eligible applicants to test the effectiveness of three enhanced prenatal care approaches (enhanced Prenatal Care through Centering/Group Visits, at Birth Centers or Maternity Care Homes) to reduce preterm births for Medicaid covered women at risk for preterm births. Twenty-seven Strong Start awardees were announced in February 2013.

- Further investments in prematurity prevention include the efforts of the Association of State and Territorial Health Officials (ASTHO), which partnered with the March of Dimes to launch the Healthy Babies President’s Challenge to help states prevent preterm birth and infant mortality. The challenge asks state health officials to sign a pledge to: publicly announce a goal to reduce the rate of premature birth by eight percent by 2014 (measured against 2009 data); initiate and support programs and policies that reduce the premature birth rate; and build wider awareness of prematurity rates and other related maternal and child health indicators. The ASTHO challenge represents an important collaboration at the level of the state health official to raise awareness of preterm birth and to collaborate to implement prevention strategies.

A life course indicator for preterm birth unites these national initiatives – which use different processes including quality improvement, public education, public policy, and health care financing reform – with more behaviorally focused efforts like smoking cessation programs or anti-poverty and anti-discrimination reforms in housing, nutrition, education, and the workforce to reduce exposure to stressors across the life span of women. In addition to national initiatives, states can consider how different processes and approaches can work synergistically to achieve collective impact in reducing preterm births. The AMCHP Compendium, *Forging a Comprehensive Initiative to Improve Birth Outcomes and Reduce Infant Mortality: Policy and Program Options for State Planning* (2012), offers seven recommendations (and specific state case examples) for implementing state policy and programming options, many specific to reducing preterm births. These seven recommendations include the following:

1. Implement health promotion efforts
2. Ensure quality of care for all women and infants
3. Improve maternal risk screening for all women of reproductive age
4. Enhance service integration for women and infants
5. Improve access to health care for women before, during, and after pregnancy
6. Develop state data systems to understand and inform efforts
7. Promote social equity

**Predict an individual’s health and wellness and/or that of their offspring**

Preterm birth has implications for the health of the child born preterm, the mother, and the family unit.

Babies born preterm face a spectrum of health challenges that may begin shortly after birth, and are associated with how early the baby is born (extremely preterm, very preterm, or moderate to late preterm). Of greatest concern is the increased risk for mortality in the first year of life, as preterm birth is the leading cause of infant mortality in the United States (Centers for Disease Control and Prevention, 2013). Health problems preterm babies may face soon after delivery include apnea, respiratory distress syndrome, intraventricular hemorrhage, patent ductus arteriosis, necrotizing enterocolitis, retinopathy of prematurity, jaundice, anemia, bronchopulmonary dysplasia, and a number of infections due to their immature immune systems (March of Dimes, 2012). Many of these conditions require admittance to the neonatal intensive care unit (NICU) that drives up health care costs for the family and society.

Additionally, these health conditions and features of the preterm newborn have been associated with longer-term health problems and disabilities. Long-term impacts of preterm birth on the infant include increased risk of autism, intellectual disabilities, cerebral palsy, lung problems, and vision and hearing loss. For example, de Kievit, Zoetebier, van Elburg,
Vermeulen, and Oosterlaan (2012) found that very preterm infants have a total brain volume 0.58 standard deviations lower than term infants, which has been associated with reduced cognitive functioning. Furthermore, in addition to potential respiratory distress syndrome after birth, children born extremely preterm have been found to have significant impairment of lung function, particularly in those who have had bronchopulmonary dysplasia (Bolton et al., 2012). These children also were found to have an increased use of bronchodilators, inhaled corticosteroids, and leukotriene antagonists. With regard to vision loss, extremely preterm infants with severe retinopathy of prematurity were found to have significant reduction in vision, despite using prescription glasses, compared to those born without abnormal blood vessel growth in the eyes characterized by retinopathy of prematurity (Farooqi, Hagglof, Sedin, & Serenius, 2011). Additionally, preterm infants who have had necrotizing enterocolitis were found to have elevated levels of circulating IL-6 in the neonatal period that is associated with higher rates of poor growth (height, weight) and neurodevelopmental disability at 24-28 months (Lodha, Asztalos, & Moore, 2010).

Short and long term health problems associated with being born preterm are not limited to the more rare and extreme cases: infants born moderately or late preterm have been found to face a number of health and development problems. Preterm infants have increased odds of hyperactivity- impulsivity symptoms as well as inattention symptoms when assessed from 17 months to eight years (Galera et al., 2011). Late preterm infants have been found to grow up to face psychological development problems and behavioral and emotional disturbances, be less likely to attain university or post-secondary education, and have lower scores for reading and math in school (Ramachandrappa & Jain, 2009). Preterm infants are more likely to need early intervention and special education services across the life span. These deficits in learning can have ripple effects in educational attainment, future income and economic opportunity, and speak to the interrelationship between health and education.

Preterm birth also is an indicator for the individual health of the mother. Chronic adult diseases like diabetes (Rich-Edwards et al., 2005), obesity (Ravelli, Stein, & Susser, 1976), and coronary artery disease (Barker, 1997) have been found to precipitate preterm deliveries (Sibai et al., 2000). Other conditions associated with preterm birth in the mother include genital tract infections (French, McGregor, & Parker, 2006). Timely treatment of genital tract infections like bacterial vaginosis can reduce preterm births (Koumans et al., 2011). However, untreated infections is not only associated with preterm deliveries but signify potential challenges in accessing care. Maternal depression (Straub, Adams, Kim, & Silver, 2012) and stress (Hedegaard, Henriksen, Secher, Hatch, & Sabroe, 1996) also have been associated with preterm birth and are a reflection of maternal well-being, as are women who continue to smoke or use alcohol or illicit drugs during their pregnancy.

Exposure to stress, racism and discrimination, and prolonged deprivation for women and families also is associated with preterm birth, and recent research pursues these mechanisms as increasing the allostatic load and lifetime exposure to risk factors that precipitate preterm birth (Lu & Halton, 2003). Kramer, Dunlop, and Hogue (2013) recently published an innovative and persuasive study using longitudinally linked vital records to describe exposure to cumulative neighborhood deprivation as associated with preterm birth. It is in this vein that preterm birth as an indicator of life course health must be considered an indicator of the health of the infant, the mother, and the community and context in which that family lives.

Data Criteria

Data availability
Data for calculating preterm births are collected from the vital registration systems in the individual States and territories that are legally responsible for registration of vital events, including births. They are responsible for maintaining registries of vital events and for issuing copies of birth certificates (National Center for Health Statistics [NCHS], Division of Vital Statistics, 2000).

Historically, pre-term birth, or a birth prior to 37 weeks gestation, has been determined primarily through gestational age calculated from last menstrual period (LMP) and infant date of birth as reported in the birth certificate. The first standard birth certificate in the United States was developed by the Census Bureau in 1900. Since that time there have been 12 revisions of the birth certificate, with the most recent revision released in 2003 (NCHS, Division of Vital Statistics, 2000). According to the National Vital Statistics Report Births: Final Data for 2011, thirty-six states, the District of Columbia, and two territories implemented the revised birth certificate as of Jan. 1, 2011. The jurisdictions implementing the revisions represent 83 percent of all 2011 U.S. births. The revised reporting areas are: California, Colorado, Delaware, the District

Date of LMP has been collected on the birth certificate since 1968, with minor revisions to the instructions for birth attendants in calculating LMP in the years since its implementation. The 1989 revision of the birth certificate included a new field – clinical estimate of gestation - to be used as a source of information on gestational age when the LMP data item contains invalid or missing information. The 2003 revision of the birth certificate replaced ‘clinical estimate of gestation’ with the ‘obstetric estimate of gestation at delivery’ to further clarify that this estimate should not be computed from information obtained during the neonatal exam but rely primarily on perinatal factors and assessments. In 2006, instructions for birth attendants further clarified that the preferred method of determining the obstetric estimate is through ultrasound taken early in pregnancy (Weir, Pearl & Kharrazi, 2010). For the purposes of this indicator, gestational age as calculated from the clinical or obstetric estimate is recommended. This estimate is available on the birth certificate for each state.

Birth certificates from the states that have not implemented the 2003 revision of the U.S. Standard Certificates of Live Birth lack information about certain potential modifiers like multiple racial groups, smoking status of mother, principal source of payment, and the highest education attained by the mother. The certificate, however, has a checkbox for indicating the principal source of payment for the delivery including private insurance, Medicaid, self-payment and any other source to be specified which can be used as a proxy for income.

The data source, National Vital Statistics System-Natality, also gives annual county–level data for preterm birth (Health Indicators Warehouse, 2012). The National Vital Statistics System is an intergovernmental sharing of data whose relationships, standards, and procedures form the mechanism by which the National Center for Health Statistics collects and disseminates the Nation’s official vital statistics. Vital event data are collected and maintained by the jurisdictions which have legal responsibility for registering vital events; these entities provide the data via contracts to NCHS. Vital events include births, deaths, marriages, divorces, and fetal deaths. In the United States, legal authority for the registration of these events resides individually with the 50 states, two cities (Washington, DC and New York City), and five territories (Puerto Rico, the Virgin Islands, Guam, American Samoa and the Commonwealth of the Northern Mariana Islands).

Vital Statistics data are available online in downloadable public use files, through pre-built tables in VitalStats, and through the ad-hoc query system CDC WONDER (Wide-ranging Online Data for Epidemiologic Research). Birth certificate data is available in WONDER for 1995-2010, and death certificate data by underlying cause of death (detailed mortality) is available for 1999-2010.

**Data quality**

Standard forms for the collection of the data and model procedures for the uniform registration of the events are developed and recommended for state use through cooperative activities of the states and NCHS. As reported in the NCHS publication U.S. Vital Statistics System, Major Activities and Developments, 1950-1995, efforts to improve the quality and usefulness of vital statistics data are ongoing. NCHS uses techniques such as testing for completeness and accuracy of data, querying incomplete or inconsistent entries on records, updating classifications, improving timeliness and usefulness of data, and keeping pace with evolving technology and changing needs for data. Work with state partners to improve the timeliness of vital event reporting is ongoing, and NCHS is working closely with National Association of Public Health Statistics and Information Systems (NAPHSIS) and the Social Security Administration to modernize the processes through which vital statistics are produced in the United States, including implementation of the 2003 revised certificates.

In recent years, epidemiologists have begun to focus on the use of clinical or obstetric estimate as the population-based standard for gestational age, given a number of limitations associated with the accuracy of the LMP. LMP as a marker for gestational age is prone to recall bias and also fails to account for the variability in the pre-ovulatory interval. Moreover, LMP data has a higher frequency of missing data. Women tend to overestimate their LMPs when the length of recall is
more than three weeks (Wegienka & Baird, 2005); and Alexander et al. (1995) found that the LMP on birth certificates either overestimated or underestimated gestational age as compared to clinical estimate. In a study comparing LMP on birth certificates and LMP from California’s Expanded Alpha-fetoprotein Screening Program, 46 percent of gestational age discrepancies using the LMP on birth certificates were due to clerical or digit preference errors (Pearl, Wier, & Kharrazi, 2007). The majority of clerical errors were due to whole month deliveries (47.7 percent) and 10-day deviations (47.8 percent). Despite these limitations, LMP remained the standard for gestational age calculation. Parker and Schoendorf (2002) reported that the criteria by Alexander et al or Zhang et al can be used to correct for implausible gestational ages. The researchers found that if the criteria by Alexander et al is used, wherein records with implausible gestational age combinations are excluded, then less than 0.5 percent records would be excluded; whereas three times as many birth records were modified or excluded using Zhang et al criteria (for records with implausible birth weight/gestational age combinations clinical estimate of gestational age was substituted and records with implausible combinations but no clinical estimates are excluded). For preterm births less than 32 weeks, the calculation for national rate was 1.3, 1.2, and 1.6 according to Alexander and Zhang criteria and National Center for Health Statistics (NCHS), respectively.

To overcome questions raised about the accuracy of LMP as a population-based standard for assessing gestational age, Callaghan and Dietz (2010) explored how different methods of assigning gestational age in vital records data affect distributions of birth weight for gestational age. Using the 2005 public-use U.S. Natality file from NCHS, they compared four measures of gestational age: LMP, the clinical estimate, the obstetric estimate, and a gold standard they developed from a subcohort of births. This “gold standard” for gestational age measurement included those births for which the records had no more than a one week difference in LMP and either clinical or obstetric estimate, no record of a congenital anomaly, and the mother began prenatal care in the third month of pregnancy or earlier. The research team found that both clinical and obstetric estimates of gestational age resulted in birth weight distributions virtually identical to the gold standard, whereas the distribution derived from LMP was substantially different. It is for this reason the authors concluded that clinical or obstetric estimates may be preferable for establishing population-based size-for-gestational age norms. Additionally, researchers have found that clinical estimate tends to be more highly correlated with birthweight than LMP, and fewer birthweight-inconsistent gestational age values exist within birth files (Alexander et al., 1995; Mustafa & David, 2001).

Despite the aforementioned potential advantages, clinical assessments of gestational age may be inaccurate in instances in which postnatal measures are used or in instances where size-based gestational age estimates are used (fundal height, ultrasound measures, or maturity-focused assessments that use clinical sign, such as quickening) and that can’t take into account different rates of growth or maturation or different characteristics of the mother or the maternal environment (smoking, obesity, etc.). Such inaccuracies are hoped to be reduced with the transition to obstetric estimate. In an Indiana study (Zollinger, Przybylski, & Gamache, 2006) that compared birth certificates with hospital birth records, the measure of agreement between the clinical estimate of gestation in the birth certificate and hospital birth records was “moderate,” at a kappa of 0.660, better than the measure of agreement for date last normal menses began (0.630).

Recently, clinical or obstetric estimate as the standard for gestational age calculation has been utilized by States in designing interventions to improve maternal and infant health outcomes, including the Hawaii Department of Health, among others (Hayes et al., 2013).

**Simplicity of indicator**

The complexity of calculating preterm birth is associated with the selection of a standard method for gestational age estimate. The use of clinical or obstetric estimate as the method for estimating gestational age is a new, though believed to be improved, method from the use of LMP (clinical or obstetric estimate has been used in instances in which LMP is missing, implausible, or believed to inaccurate). Moreover, the method for calculating the indicator is substantially easier. Hall, Folger and Kelly (2013) evaluated the impact of three methods of gestational age estimate (LMP, obstetric estimate, and a combined measure using obstetric estimate if LMP is missing or inconsistent) on the calculation of the preterm birth rate in Ohio and found that disagreement in gestational age led to a 1.8 percentage point difference in preterm birth calculations (11.0 percent using obstetric and 12.8 percent using combined estimates). The findings of the study underscore the importance of clarity and consistency when describing gestational age and its use in calculating preterm birth rates, including for subcategories.
Upon selection of the gestational age estimate method, a data cleaning procedure must be implemented for instances in which a clinical or obstetric estimate is missing or implausible. In the Ohio study mentioned above, over the four year study period, the LMP variable had the greatest number of missing values, with 18.2 percent of records missing an estimate of LMP-based gestational age. For obstetrical estimate, only 0.3 percent of records were missing an obstetrical estimate of gestational age. In the event clinical or obstetrical estimate data is missing or implausible, data users may implement an algorithm to determine the record’s exclusion, substitution for LMP, or substitution using an estimate based on sociodemographic characteristics.

With a clear and consistent method for estimating gestational age and a validated cleaning procedure, preterm birth is simple to calculate and does not involve any complex formula, data weighting, or data indexing. The numerator, number of live births born prior to 37 weeks of gestation, as calculated by clinical or obstetric estimate, and the denominator, number of live births, are easy to understand and explain.

References


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The Life Course Metrics Project

As MCH programs begin to develop new programming guided by a life course framework, measures are needed to determine the success of their approaches. In response to the need for standardized metrics for the life course approach, AMCHP launched a project designed to identify and promote a set of indicators that can be used to measure progress using the life course approach to improve maternal and child health. This project was funded with support from the W.K. Kellogg Foundation.

Using an RFA process, AMCHP selected seven state teams, Florida, Iowa, Louisiana, Massachusetts, Michigan, Nebraska and North Carolina, to propose, screen, select and develop potential life course indicators across four domains: Capacity, Outcomes, Services, and Risk. The first round of indicators, proposed both by the teams and members of the public included 413 indicators for consideration. The teams distilled the 413 proposed indicators down to 104 indicators that were written up according to three data and five life course criteria for final selection.

In June of 2013, state teams selected 59 indicators for the final set. The indicators were put out for public comment in July 2013, and the final set was released in the Fall of 2013.

### Basic Indicator Information

**Name of indicator:** Stressors During Pregnancy (LC-56)

**Brief description:** Proportion of women reporting two or more stressors during pregnancy.

**Indicator category:** Reproductive Life Experiences

**Indicator domain:** Risk/Outcome

**Numerator:** Respondents (women having a live birth) who reported two or more stressors during most recent pregnancy

**Denominator:** All respondents (women having a live birth)

**Potential modifiers:** Race, age, income, insurance status, English proficiency, zip code

**Data source:** Pregnancy Risk Assessment Monitoring System (PRAMS)

**Notes on calculation:** The numerator is composed of women who reported experiencing two or more stressors in the 12 months before the birth of their most recent infant. The Phase five and six core PRAMS items list the following 13 stressful life events:

1. A close family member was very sick and had to go into the hospital
2. I got separated or divorced from my husband or partner
3. I moved to a new address
4. I was homeless
5. My husband or partner lost his job
6. I lost my job even though I wanted to go on working
7. I argued with my husband or partner more than usual
8. My husband or partner said he didn’t want me to be pregnant
9. I had a lot of bills I couldn’t pay
10. I was in a physical fight
11. My husband or partner or I went to jail
12. Someone very close to me had a problem with drinking or drugs
13. Someone very close to me died
Analysts who use the raw datasets should apply the appropriate survey weights to generate the final estimates.

Similar measures in other indicator sets: None

Life Course Criteria

Introduction
Defined broadly, “stress” experienced during pregnancy is a prime example of the life course health development model posited by Lu and Halfon (2003) which combines the concepts of early life programming and cumulative wear and tear on the body’s allostatic system; the stress experienced by a pregnant woman becomes a fetal exposure that contributes to early life programming, impacting the trajectory of her offspring, while the stress she experiences contributes to her overall allostatic load and impacts her future reproductive and health potential.

The experience of stress ultimately impacts pregnancy outcomes through both direct and indirect mechanisms. Physical stress, such as standing for long periods of time during work, impacts direct biological functions like reducing blood flow to the uterus; psychosocial stress, including items in the PRAMS stressful life events scale, impact pregnancy outcomes indirectly by eliciting hormonal and immune stress responses that prepare the fetus for early delivery and survival (Hobel and Culhane 2003). Researchers have demonstrated impacts from stress on fetal growth, preterm labor and complications of labor and delivery (Tambyrajia and Mongelli 2000). Maternal stress in pregnancy also has been linked to elevated cortisol in utero (Coussons-Read, Lobel, & Carey et al., 2012). Additionally, elevated levels of depression and anxiety during pregnancy have been associated with obstetric complications, preterm labor and use of pain relief under labor (Adler et al 2007).

There is evidence that the experience of stress during pregnancy impacts not only a woman’s health and her birth outcomes, but also birth outcomes across generations. Studies focused primarily on birth weight have demonstrated that a mother who was born low birth weight is more likely to have a child born low birth weight, that the fetal environment (including the experience of stress by the mother during pregnancy) impacts the health of that adult, including coronary artery disease and hypertension risk, and that the impact of maternal weight on the weight of her offspring is independent of factors such as receipt of adequate prenatal care (Emmanuel 1986, Barker et al 1993, Coutinho et al 1997, Collins et al 2003).

Implications for equity
Pregnancy is a critical and sensitive period in the life course of a woman; her life experiences prior to and during pregnancy have the potential to directly impact the health of her children and her children’s children, as well as the overall health and well-being of her family. Despite decades of work to reduce disparities in birth outcomes, two- and three-fold differences in infant mortality, low birth weight, preterm birth, and other health outcomes persist. As proposed by Lu and Halfon (2003), if the persistent disparity in outcomes is at least in part attributable to the impact of racism experienced by African Americans over generations, it is essential to monitor women’s experiences of discrimination and the experiences of stressful life events, particularly those experienced immediately before and during pregnancy.

While an examination of stressful life events could not explain the racial/ethnic disparities in preterm birth (Lu and Chen 2004), this study did find significant disparities in the experience of stressful life events between women in minority racial/ethnic groups, with Black and American Indian/Alaska Native women reporting the highest number of stressful life events in the 12 months before delivery. Another study reported that women with low socioeconomic status were more likely to experience stressful life events than other women (Whitehead et al 2005). A report from Michigan PRAMS found that the prevalence of low numbers of stressful life events (zero, one or two events) in the twelve months before delivery increased with increasing age, educational attainment, and socioeconomic status (Michigan Department of Community Health 2004). The impact of stress on pregnancy health is dependent upon the severity and duration of the stress, the maternal perception of the severity, and coping mechanisms available to mitigate the stressful event(s). Hamilton and Lobel describe different types of coping strategies for pregnancy stress and note that avoidance coping was associated with high state anxiety (anxiety in response to a perceived dangerous or threatening situation) and pregnancy-specific distress while spiritual and planning coping mechanisms were associated with optimism (2008).
Public health impact
The experience of stressful life events in the 12 months before delivery, as measured through the PRAMS survey, has been associated with poor birth outcomes, such as preterm birth (Whitehead et al 2002) and other risk factors and outcomes such as physical abuse (Martin et al 2001) and postpartum depression (Herrick 2000). Poor birth outcomes, such as preterm birth and low birth weight, impact children, families, and communities emotionally, developmentally, and economically. For a premature infant, the normal patterns of interaction for both parent and child are disrupted, making it difficult for bonding to occur (Goldberg 1979). Among children born extremely low birth weight (401–1000 g), those that survived to 18 months were at increased risk for neurologic abnormalities, developmental delays, and functional delays (Vohr et al 2000). The total economic cost for medical care, early intervention, and special education services, and for lost household and labor market productivity was estimated to be $51,600 per preterm birth in the United States in 2005 (Behrman & Butler (Eds.), 2007). The reduction of stressful life events could result in improvement in women’s health overall and in birth outcomes such as preterm birth and low birth weight, and also could potentially result in improving the overall health and development of children in the United States, with implications for education and health care costs in addition to public health.

Leverage or realign resources
Because the nature of “stress” before and during pregnancy is so varied, there are many partners that can be engaged in promoting healthy pregnancies. Healthy pregnancies start before conception, and the National Initiative on Preconception Health and Health Care (PCHHC) has a vision for improving preconception health and pregnancy outcomes that includes opportunities to address stress and identify mental health issues prior to pregnancy (CDC 2012). The PCHHC goals include improving the knowledge, attitudes, and behaviors of men and women related to preconception health, creating health equity and eliminating disparities in adverse maternal, fetal, and infant outcomes, ensuring that all women of childbearing age in the United States receive preconception care services—screening, health promotion, and interventions—that will enable them to achieve high levels of wellness, minimize risks, and enter any pregnancy they might have in optimal health, and reducing risks among women who have had a prior adverse maternal, fetal, or infant outcome through interventions during the postpartum and interconception period.

The Office of Adolescent Health (OAH) provides Pregnancy Assistance Fund grantees with training and technical assistance around a variety of topics, including building partnerships. The grantees are implementing programs to assist pregnant and parenting teens, and the OAH encourages them to consider engaging non-traditional community partners for their endeavors, including everything from grocery stores to law enforcement in addition to “legacy” partners such as social services.

The impacts of poor birth outcomes for children and families continue throughout the life span; infants born preterm and/or low birth weight and survive may face lifelong health and developmental challenges. Education partners are instrumental in ensuring that children reach their fullest developmental potential, and would be a unique partner to engage when thinking about how to reduce stress and promote resiliency.

Although the types of stressful events noted in the PRAMS question and the physiologic responses to those stressors occur mainly on an individual level, Hogue and colleagues endeavor to explain the mixed results of studies examining the relationship between stress and birth outcomes such as prematurity, and posit that the use of the host-environment-agent conceptual framework helps to explain how context is important (Hogue et al 2001). The framework integrates the strength of the agent (stress) with the characteristics of the host, including the host’s susceptibility to stress, coping ability, and environment or context in which that host lives. This framework provides guideposts for intervention at key points along the life course, including the need to promote healthy communities that support resiliency in the face of unanticipated stressors, the need to create supportive work environments that allow preconception, pregnant, and parenting women flexibility to handle stressful events, and the need to develop strategies that promote resilience and healthy coping across the life span. Such efforts may complement partnerships to reduce exposure to stressors for women across the life course and especially during pregnancy, including the promotion of developing and sustaining healthy relationships, access to family and social support systems (e.g. the CenteringPregnancy model of group prenatal care) as well as resources to reduce financial hardships (partnerships with housing and homeless services agencies or financial counselors), and expedited entry into maternal mental health services.
Home visiting services have been designed to support pregnant women and families and improve a variety of outcomes; the Home Visiting Evidence of Effectiveness review (HomVEE) found that, among programs that met inclusion criteria, home visiting is a promising strategy to engage high risk families that may need more supportive services (Avellar and Suplee 2013). Home visiting programs have the potential to mitigate maternal adversity and allow mothers to develop strong relationships with their children, thereby reducing the risk that children are exposed to toxic stress (Garner 2013).

**Predict an individual’s health and wellness and/or that of their offspring**

In addition to impacts on pregnancy, stress contributes to other behaviors that have negative impacts on pregnancy outcomes: women who were not able to quit smoking during pregnancy experienced significantly higher stress levels due to financial, family, and domestic violence problems when compared with women who were able to quit smoking (Bullock et al 2001). Women with multiple stressors tend to report more self-coping “risky behaviors”, such as smoking, alcohol and substance use (Ahluwalia, Mack, & Mokdad, 2004). Additionally, stress experienced in the first trimester by low-income women was associated with poor diet quality; this is a sensitive period for fetal development (Fowles, et al 2012).

The impact of experiencing stressful life events, anxiety, and depression immediately prior to and during pregnancy extends beyond birth outcomes such as low birth weight and preterm birth; studies have demonstrated that the health and development of infants is impacted in the first year of life and beyond. Experience of prenatal stress, as measured both by maternal self-report and cortisol measurements, was shown to be associated with infant health including general, respiratory, and skin illnesses as well as antibiotic use (Beijers et al 2010). Laplante and colleagues found that exposure to stress prenatally in the form of a natural disaster event was associated with lower cognitive and language ability when assessed at age five and a half years (2008).

**Data Criteria**

**Data availability**

The Pregnancy Risk Assessment Monitoring System (PRAMS) was initiated in 1987. PRAMS is an ongoing population-based surveillance system designed to identify and monitor selected maternal experiences and behaviors that occur before and during pregnancy and during the child’s early infancy. Forty states and New York City currently participate in PRAMS, representing approximately 78 percent of all U.S. live births. Six other states previously participated. The Centers for Disease Control and Prevention (CDC) maintains a combined dataset with information from all participating PRAMS states, which represents approximately 87 percent of all live births in the United States. CPONDER is a Web-based query system created to access data collected through Pregnancy Risk Assessment Monitoring System (PRAMS) surveys.

The length of time between an event and entry into the sampling frame is typically two to six months. Because PRAMS data are weighted to the final birth file, there is a data availability lag between the close of a calendar year and access to the final PRAMS dataset. As of July 2013, the most current year of data available in CPONDER was 2008.

Although the 40 states and one city that participate in PRAMS have access to their own state data, only states where the minimum response rates have been met are included in CPONDER. For 2000-2006, this required response rate was 70 percent, and for 2007-08 it was 65 percent. The required response rate may limit the availability of a “national” estimate through CPONDER, but states with PRAMS are encouraged to use their own data whenever possible.

The PRAMS survey consists of core questions that all states must include and standard, pilot-tested questions that states may choose to add. In addition, PRAMS allows states to design and add their own questions, and the state is responsible for completing question testing before the question can be included. PRAMS data is available from CDC by submitting a proposal for and data sharing agreement to CDC. Data from a single state can be requested from the state’s PRAMS coordinator.

The questions used for this indicator are core questions on the PRAMS module, meaning they are used in every state (40 states, plus New York City) conducting PRAMS. However, not all states are participating in PRAMS.

**Data quality**
Life Course Indicator: Stressors During Pregnancy (LC-56)

PRAMS is a mixed-mode surveillance system that combines mail and telephone surveillance. Each year’s sample is weighted to represent all births that meet the inclusion criteria before reporting. Unlike many health surveys, the PRAMS project has a wealth of information from the birth certificate on those who do not respond by either mode of contact, and therefore weighting can be effective at minimizing differences between respondents and non-respondents.

Since the PRAMS survey is completed retrospectively by a woman two to six months after her birth outcome, some bias may occur due to self-reporting and recall. PRAMS is sampled from live births only, so the data do not include information on other pregnancy outcomes such as abortions, miscarriages, or stillbirths; the data do include responses from women who have experienced an infant death. PRAMS is sampled among singleton, twin, and triplet births, and therefore it is not representative of higher order births.

Most states oversample for low birth weight, and stratification by mother’s race or ethnicity also is possible. Typically, the annual sample is large enough for estimating statewide risk factor proportions within 3.5 percent at 95 percent confidence. Estimated proportions within strata are slightly less precise (typically, they are estimated within five percent at 95 percent confidence).

PRAMS has a minimum overall response rate threshold policy for the release of data. For years 2006 and earlier, this threshold was 70 percent. Beginning in 2007, the threshold changed to 65 percent. For any given year, the majority, but not all states meet the threshold. For this reason the number of states with data available may vary from year to year.

There is no standard definition of preconception counseling provided and no specific time parameters on the question. To date, there is no specific information available about the quality of data from the PRAMS stressful life events scale.

Simplicity of indicator

States participating in PRAMS should have the capacity to calculate this indicator and technical assistance would be available from CDC. The indicator should be easy to describe to the public and professionals as it can be described as a percentage or a number of women per 100 women. Comparisons with extracted birth certificate data can be presented in graph or chart form. A limitation in interpretation of analyses using the list of 13 stressors is whether all of the listed life events are equally stressful; these are all life events that are disruptive, particularly during pregnancy, and there is evidence that there are threshold effects for some outcomes (Whitehead et al 2002). The list of stressors can be grouped into four categories, including partner-related stressors, financial stressors, emotional stressors, and traumatic stressors. Analyses by these groupings are available on CPONDER.

References


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Life Course Indicator: 4th Grade Proficiency

Basic Indicator Information

Name of indicator: Fourth Grade Proficiency (LC-57)

Brief description: Percent of fourth graders scoring proficient or above on math and reading

Indicator category: Social Capital

Indicator domain: Risk/Outcome

Numerator:
   a. Number of fourth graders scoring proficient or above on math
   b. Number of fourth graders scoring proficient or above on reading

Denominator: a. and b. Total enrolled fourth graders in public schools

Potential modifiers: Age, Developmental Capacity, Gender, race/ethnicity

Data source: National Assessment of Educational Progress (NAEP)

Notes on calculation: There is currently no composite score for fourth grade proficiency on math and reading available. This indicator should be calculated in two parts: a. the number of fourth graders scoring proficient or above on math over the total number of enrolled fourth graders in public schools, and b. the number of fourth graders scoring proficient or above on reading over the total number of enrolled fourth graders in public schools.

Similar measures in other indicator sets: HP 2020 Focus area AH-5.3.1; MIECHV Benchmark Area Improvements in School Readiness and Achievement: Child’s general cognitive skills

The Life Course Metrics Project

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Using an RFA process, AMCHP selected seven state teams, Florida, Iowa, Louisiana, Massachusetts, Michigan, Nebraska and North Carolina, to propose, screen, select and develop potential life course indicators across four domains: Capacity, Outcomes, Services, and Risk. The first round of indicators, proposed both by the teams and members of the public included 413 indicators for consideration. The teams distilled the 413 proposed indicators down to 104 indicators that were written up according to three data and five life course criteria for final selection.

In June of 2013, state teams selected 59 indicators for the final set. The indicators were put out for public comment in July 2013, and the final set was released in the Fall of 2013.
Life Course Criteria

Introduction
Growing evidence suggests that social environments impact health. Research on this relationship focuses on aspects of support and cohesion within the social environment, often discussed as ‘social capital’ across populations. Social capital is the collection of features of social organization – such as civic participation, norms of reciprocity, and trust in others – that help facilitate cooperation for mutual benefit (Putnam, 2000). As such, social capital is a collective resource that benefits communities and can be distinguished from the individual health effects of social networks and support (Lochner et al., 1999).

Social capital is a hard concept to measure. The contemporary use of the term evolved from the context of the importance of education (Hanifan 1916). Research indicates that social capital is not only a critical input for the success of educational systems but also one of its valuable byproducts (Heyneman 1998). Strong education systems and educational attainment across populations also fosters social capital-rich networks. The World Bank summarizes the fundamental ways social capital is produced through education as:

- development and practice of social capacity skills such as participation and reciprocity
- provisions of forums for community activity
- delivery of civil education to learn how to participate responsibly in society
- contribute or promote overall societal cohesion and strengthened citizenship when children of all socio-economic backgrounds are enrolled in the public education system (World Bank 2013)

In addition to being a marker of educational attainment and an indicator of larger social capital, there is a large and persistent association between education and health (Vinciullo & Bradley, 2009; Wei, 2012; Eide & Showalter, 2011). The connection between education and health has been well documented and spans almost all health conditions including general health status and particular acute, chronic, or disabling health conditions. Educational attainment also is a strong predictor of overall life expectancy (Ross 1995) (Molla et al 2004; Lleras-Muney 2005).

In addition to the predictive value on individual trajectories, fourth grade proficiency marks a critical point in time where future academic performance can be projected but time is still available to intervene through policy or systems interventions (Koretz, 1991). Overall, fourth grade proficiency is a life course measure because the indicator reflects current academic progress, has the potential to predict future individual and intergenerational health and social outcomes, and reflects larger social capital characteristics of a community or population.

Implications for equity
As a measure of academic performance, fourth grade proficiency has strong implications for social equity across populations. Different populations across the United States experience different rates of fourth grade proficiency. The National Assessment of Educational Progress (NAEP) characterizes the following targets for reading and math in the fourth grade: Reading Basic = 208, Proficient = 238, and Advanced = 268; Math Basic = 214, Proficient = 249, and Advanced = 282. Trend analysis from the past forty years of national fourth grade proficiency assessments in reading and math show overall population improvements, but lower average scores for racial and ethnic minorities. In 2004, the national average reading proficiency score of White students was 224 whereas the national average reading proficiency score of Black students was 197 and Hispanic students was 199. Similarly, disparities are reflected in national math proficiency scores. In 2004, the national average math proficiency score of White students was 245 whereas the national average math proficiency score of Black students was 221 and Hispanic students was 229. (NAEP 2013)

As a community level implication for equity, fourth grade proficiency also is reflective of the resources within a community surrounding a specific school. Schools located in low socioeconomic status (SES) communities are more likely to experience high levels of unemployment, teacher migration, and poor academic achievement (Muijs et al., 2009).

Finally, fourth grade proficiency also has implications for equitable distribution of resources. Under the No Child Left Behind Act of 2001 schools were encouraged to pay more attention to adequate yearly progress indicators (AYP). Strong attention to AYP creates an unintended incentive for schools to focus resources on children that fall below the proficiency threshold rather than to provide services that would improve resources for all students (Wei, 2012). As one of the
nationally reported indicators, fourth grade proficiency has implications for meeting state AYP and corrective measures that are likely to affect schools that serve predominantly low-income communities and racially diverse communities.

**Public health impact**

The benefits of investments in education are shared not only by individual students but also by the societies of which they are a part. Education, measured as academic performance, has been shown to affect employment options and health choices later in life (Harper & Lynch, 2007; NCHS, 2011; Vernez, Krop, Rydell, 1999). Individuals who perform better academically are more likely to have a higher SES, make healthier choices in their daily lives, and have knowledge of and access to quality health care. When the proportion of individuals who perform well academically increases in a community, the community’s standard of living improves. Interventions that improve academic performance within a given community, measured as fourth grade proficiency levels, have the potential to make a lasting public health impact.

Health also is causally associated with education, predominantly due to attendance rates and nutrition (Carlson et al., 2008; Spriggs & Halpern, 2008; Srabstein & Piazza, 2008). Chronically ill students, frequently due to poor nutrition or underlying health problems, are more likely to miss school, which can cause them to fall behind and perform poorly academically. Additionally, health-risk behaviors such as physical inactivity and violence can lead to poor academic performance (Dunkle & Nash, 1991). Poor academic performance reduces the probability of attaining a well-paying job or affording adequate health care to treat chronic illness. This widely influences resources for the school (those who perform well receive more), neighborhood income levels, health care utilization, and intergenerational academic performance.

From another angle, there also is potential for public health impact through wider social capital improvements. Increased social capital has been linked to various health outcomes, including self-rated health (Blakely 2001; Kawachi et al., 1999; Hyyppä and Mäki, 2001; Subramanian et al., 2002; Helliwell, 2003; Poortinga, 2006a and Poortinga, 2006b), cardiovascular and cancer mortality rates (Kawachi et al., 1997), suicide rates (Helliwell, 2003), and child mental health (Caughey et al., 2003).

**Leverage or realign resources**

As a societal factor, education is a powerful predictor of health, but the public health field has very little control over increasing educational performance. This indicator has the potential to leverage or realign resources as multiple potential partners, including many non-traditional public health partners, have a vested interest in students testing as proficient during the fourth grade. Some examples of potential new or strengthened partnerships include:

- New or strengthened partnerships with public school systems as proficiency rates are national performance measures for schools
- New or strengthened partnerships with business, commerce and union associations as employers need employees who are well trained
- New or strengthened partnerships with justice system stakeholders as there is a strong correlation between education and involvement in the justice system, and this indicator could open new avenues for collaborative public policy and strategies

Additionally, fourth grade proficiency, as measured by the NAEP, is an appropriate measure to determine the time for intervention since, as mentioned in Implications for Equity, fourth grade proficiency is a national AYP. As a performance measure, fourth grade proficiency can leverage or realign resources because primary school is an opportune time to intervene on poor academic performance and reduce the probability of the intergenerational effect of poor academic performance. As noted above, however, strong political attention to AYP can create unintended incentives for schools to focus or realign resources on children that fall just below the proficiency threshold rather than all students. In addition, many schools may use strategies such as re-assigning student enrollment to specific sub-groups given special consideration under AYP guidance, such as students with disabilities and English language learners which allows for more focus on the students who have the potential to pass the NAEP exam. Re-assignment strategies have both negative and positive side-effects. These strategies may produce better overall assessment scores for schools while masking true rates of struggling or underperforming students. However, these strategies may also result in the provision of more resources to specific individuals who may genuinely require additional academic assistance. Finally, moving these students to special education classes provides academic and developmental resources that may be influential in identifying special health care and academic needs. (Wei, 2012)
Predict an individual's health and wellness and/or that of their offspring

Generally, there is a large and persistent association between education and health. The connection between education and health has been well documented and spans almost all health conditions (Ross 1995). There is a positive association between education and health behaviors, health status, and particular acute, chronic, or disabling health conditions. Educational attainment also is a strong predictor of overall life expectancy. In addition to these positive associations, the effect of education increases with increasing years of education (Molla et al. 2004; Lleras-Muney 2005).

In addition, educational attainment also is a predictive factor for the health and wellness of an individual’s offspring. Students who fail to perform at the proficient level or above are at risk for unemployment, criminal behavior, developing risky health behaviors such as smoking, poor health, and inadequate health insurance coverage. One or more of these outcomes has the potential to lock individuals into a cycle of poor academic performance, poor health, and poor employment. Studies show living in resource-poor communities affects future generations (Brooks-Gunn, Duncan, & Maritato, 1997). In addition, multiple individual research studies as well as meta-analyses have shown the very strong predictive nature of level of parent’s education on educational achievement and thus future health and well-being for children (Klebanov et al. 1994; Haveman & Wolfe 1995; Smith et al. 1997) In particular, mother’s education level has a large, positive association on the health of her children. That relationship, observed in many small studies in rich countries, turns out to be true everywhere on the globe. A recent meta-analysis of global data illustrates half the reduction in child mortality over the past 40 years can be attributed to the better education of women, or for every one-year increase in the average education of reproductive-age women, a country experienced a 9.5 percent decrease in the child deaths (Gakidou 2010).

Specific predictability, however, may be limited by the data set. The NAEP data suggested for measuring fourth grade proficiency as a life course indicator is a tool that measures an individual's ability to decipher vocabulary meaning, make simple inferences, and find relevant information, which are necessary skills to perform well in school (DCKC, 2013). Scoring at least a “proficient” on the NAEP would indicate at least average performance. An individual who shows average or above average performance in school early on is more likely to attend college, achieve gainful employment, and experience positive health outcomes (described generally above). Conversely, the literature also has found that health can have a causal effect on schooling, which is primarily the result of poor attendance rates due to illness (Eide & Showalter, 2011). Although the NAEP does not provide scores for individual students or schools and these reports are not associated with individual health outcomes, they do provide strong indication of a child’s level of education achieved (Buckendahl et al., 2009). As such, the indicator, fourth grade proficiency, is a predictor of early childhood education performance which has been shown to be predictive of future academic achievement (NAEP, 2012, fourth Grade Reading; Buckendahl et al., 2009; Noell, 2009). Fourth grade proficiency as measured on the NAEP has not been used as an independent predictor of health outcomes in the past, but could certainly be used to examine correlations between education and health in conjunction with another valid indicator for health (Eide & Showalter, 2011).

Data Criteria

Data availability

State and national level data for this indicator can be downloaded from the National Assessment of Educational Progress (NAEP) website: nces.ed.gov/nationsreportcard/naepdata/. NAEP only provides results on subject-matter achievement, instructional experiences, and school environment for populations of students and groups within them. NAEP does not provide scores for individual students or schools, although state NAEP can report results by selected large urban districts (Buckendahl et al., 2009).

Data users may access the NAEP website to view proficiency with respect to subject (e.g. geography, mathematics, writing, reading) and sub-scales and achievement levels in those subjects for grades four, eight, and 12. In most instances, data are available for at least 2007, 2009, and 2011 assessments in both reading and math. The 2011 assessment was conducted early in the year, and data for all 50 states were made available in November 2011, with data from the Trial Urban District Assessment (voluntary assessment of public school students at the school district level) available in December 2011.

Data quality
The NAEP is the largest nationally representative and continuing assessment of the capacities of America's students on exams in several subject areas. The assessments, which are uniform throughout the nation, are administered to a representative sample of students in fourth, eighth, and 12th grade in each state every two years (NAEP, 2012, fourth Grade Reading; Buckendahl et al., 2009). The assessments also stay relatively unchanged from year to year to maintain consistency and allow for examination of student academic progress over time (Buckendahl et al., 2009). However, the degrees to which cut points are set for scoring standards have been heavily criticized (Buckendahl et al., 2009; Sireci et al., 2009). Nationally, there also are issues associated with the inferences made from the NAEP results and how the scores are interpreted by each state (Sireci et al., 2009).

Key data quality features:
- NAEP results are based on a representative sample of students in fourth, eighth and 12th grade for its main assessments (NAEP, 2013). It is the only available metric that allows for strict comparisons both across states and across years in student achievement (KPI, 2010).
- Beginning with the 2003 assessment, results from the NAEP reading and math assessments are released six months after their administration except when based on a new framework. Results from other assessments are released one year after administration (NAEP, 2012, FAQ).
- States that do not have enough students in the specified demographic cohort to meet reporting standards are scored and ranked 999 (KPI, 2010).
- Spending Per-Pupil is based on 2009 data reported by the Census Bureau (most recent available data) for current spending and excludes Capital and Debt (KPI, 2010).

Limitations
- The extent to which NAEP student achievement scores are systematically related to state implementations following policies around No Child Left Behind (NCLB) have yet to be rigorously examined in the literature (Buckendahl et al., 2009; Lee & Reeves, 2012).
- NAEP achievement levels do not appear to have a strong measure of external validity as measured by other educational assessments of students in the United States according to a report conducted by the U.S. Department of Education in 2009 (Buckendahl et al., 2009).

The 2009 U.S. Department of Education Evaluation also found that although more evidence on external validity is needed for NAEP achievement levels, the procedures used for setting achievement levels are consistent with current standards (Noell, 2009).

Simplicity of indicator
Fourth grade proficiency is moderately easy to explain. NAEP is recognized as a standard of literacy in the broader literacy community (Hock & Mellard, 2005). Scoring proficient or above on reading would indicate fourth grade level literacy or above. Some studies have utilized NAEP data as a proxy for school achievement, finding that school achievement, measured as fourth grade proficiency, is associated with positive health and occupation outcomes (Vinciullo & Bradley, 2009).

Fourth grade proficiency, however, is moderately difficult to calculate. This indicator is actually two scores, one for reading and one for math with varied levels of proficiency (proficient, advanced) since no standard composite score is available. NAEP proficiency scores for fourth grade are reported as percentage of fourth graders scoring proficient or above on math and reading (separately) over total enrolled fourth graders in public schools (NAEP, 2012, fourth Grade Reading). Additionally, researchers should be aware of certain data reporting practices that could influence the calculation of this indicator. In order to receive federal Title I funding, each state is mandated to test its students from grade three to eight each year to establish measurable objectives, or adequate yearly progress (AYP) for math and reading (Wei, 2012). While all states are required to participate in the NAEP test, states may choose whether to use a confidence interval or margin of error to determine if their entire population or a smaller subset of the school has met the AYP standards (Wei, 2012). Although most states choose to set their confidence levels at 95 percent, there has been a trend in some states to select 99 percent confidence and the wider confidence level allows for an increase in the percentage of students that have met AYP (Wei, 2012).
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Life Course Indicator: Incarceration Rate

The Life Course Metrics Project

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Basic Indicator Information

Name of indicator: Incarceration Rate (LC-58 A/B)

Brief description: Prevalence of juveniles ages 13-17 male or female, detained in residential placement and prevalence of adults incarcerated

Indicator category: Social Capital

Indicator domain: Risk/Outcome

Numerator:

a. Number of youth ages 13-17 imprisoned
b. Number of adults age 18 or over imprisoned

Denominator:

a. Total population of youth ages 13-17
b. Total population of adults age 18 or over

Potential modifiers: Race, ethnicity, sex, age, geographic location

Data source:


Notes on calculation: Multiply by 100,000 for rate

Similar measures in other indicator sets: MIECHV Benchmark Area Reduction in Crime or Domestic Violence: Convictions
Life Course Criteria

Introduction
Growing evidence suggests the social environment has an impact on health. Research on this relationship focuses on aspects of support and cohesion within the social environment, often discussed as ‘social capital’ across populations. Social capital is the collection of features of social organization – such as civic participation, norms of reciprocity, and trust in others – that help facilitate cooperation for mutual benefit (Putnam, 2000). In an attempt to clarify social capital and to assess its importance to social policy, Forrest and Kearns (2001) identify eight domains of social capital. Social capital, they argue, is composed of the following: empowerment; participation; associational activity and common purposes; supporting networks and reciprocity; collective norms and values; trust; safety; and belonging. Incarceration has implications for all of the domains of social capital.

Incarceration is a complex issue; it simultaneously touches individual offenders, their families, including their children, and the neighborhoods within which they live. For incarcerated individuals, there are impacts over a person’s life course that delay or change trajectories for health, education, and career. Incarcerated youth face a number of difficulties and barriers to a successful adulthood. Youth who have been detained in correctional facilities go on to have higher rates of adult criminality and lower rates of academic achievement and employment. Incarcerated men delay marriage, finding a job, and finishing school. Ex-offenders have lower earnings potential, struggle with unemployment, are less likely to get married or cohabitate, and may carry a stigma of incarceration.

On a neighborhood or community level, the theoretical framework for how incarceration rate impacts factors such as employment, concentrated disadvantage, and social control is well developed (Rose and Clear 2002). These factors also translate back to the broader domains of social capital through the additional stress and overall family experience when a member of the family is incarcerated, as well as through the challenges of community reentry when a person who has been incarcerated is released. Community reentry is multidimensional and involves financial, identity and relationship challenges.

Incarceration rate as a life course measure provides an important indicator for both individual level health effects and overall social capital within and across populations. In many instances, it is thought that a high incarceration rate is the result of a community feature (e.g., concentrated disadvantage) and that a high incarceration rate will exacerbate that same community feature, leading to a vicious cycle. In the United States, incarceration rate also may be a marker for institutionalized racism; though there are many challenges to impacting this indicator, incarceration may be more amenable to intervention than other institutional racism markers (e.g., racial residential segregation).

Implications for equity
Incarceration rate has well-established implications for equity because incarceration is experienced differentially across populations in the United States. Pettit looked at the life course of incarcerated individuals and notes that due to the epidemic of incarceration among certain demographic groups, this change in life course will be common among many in the recent birth cohorts of non-college educated, black men. (Pettit and Western 2004, Huebner 2005). Overall, incarceration rates are highly spatially clustered with a small number of neighborhoods representing a large proportion of incarcerations (Lynch and Sabol 2004). The most common demographic characteristics of the incarcerated population are: male, black, young (usually less than 30 years old), and low educational attainment (Pettit and Western 2004, Lynch and Sabol 2004, Western and Pettit 2010). Neighborhoods with high rates of incarceration are more likely to have high rates of unemployment and female headed households (Pettit and Western 2004). High rates of unemployment are thought to stem from the stigma associated with high incarceration rate communities, resulting in businesses not hiring members of these communities and not locating their businesses in these communities (Fagan et al 2002).

Incarcerated youth are also most likely to be black males. African-American youth are almost five times more likely to be incarcerated than white youth, while Latino and American Indian youth are between two and three times more likely to be incarcerated than white youth (Annie E. Casey Foundation 2013). Youth released from incarceration face difficulty reintegrating into their communities due to stigma, fragmented and inferior educations, and stunted psychosocial maturation.
There is also evidence that neighborhoods with high rates of incarceration have less social resiliency as measured through impacts on community solidarity, social control, social capital, and concentrated disadvantage and more income inequality (Pettit and Western 2004) (Clear et al 2003) (Sampson and Loeffler 2010, Fagan et al 2002, Arvanties and Asher 1998). The relationship between incarceration rate and these community characteristics is what Sampson calls a “mutually reinforcing social process.” (Sampson and Loeffler 2010) In the case of concentrated disadvantage, neighborhoods with high concentrated disadvantage are more likely to develop high rates of incarceration than communities with similar crime rates, and this high rate of incarceration then predicts additional disadvantage. Studying neighborhoods in Chicago, Sampson and Loeffler (2010) observed that concentrated disadvantage and the crime rate work together to drive up incarceration rates in neighborhoods.

The relationship between incarceration rate and crime rate is complex. It is most commonly thought that the relationship is curvilinear in nature, where areas with moderate levels of incarceration lead to decreases in crime rate whereas areas with high incarceration will still have high crime rates (Renauer 2006). This is thought to occur because of the large disruption in social networks due to the removal of a high proportion of residents, which is thought to lead to an increased vulnerability to crime (Fagan et al 2004). Additionally, these communities typically have the highest rates of unemployment, which may drive up the crime rate (Fagan et al 2002). Neighborhoods with high incarceration also have higher levels of police presence, which increases the re-incarceration rate (Fagan et al 2004).

Overall incarceration rate is a well-researched measure of inequity and is strongly spatially clustered. Lowering incarceration rates will not only contribute to health equity, but also broader social equity across communities.

**Public health impact**

The evidence for causal links between incarceration and health has not been well established. Many factors associated with incarceration rate are not typically directly health risks or outcomes; rather they are economic and social factors that impact health. In addition, there is differing evidence on the influence of change in incarceration on social outcomes. There is evidence that high rates of incarceration do not decrease the crime rate more so than moderate levels of incarceration and may even result in increased crime rates (Renauer et al 2006). Therefore, decreasing incarceration rates from high to moderate may have a positive impact in employment and neighborhood social networks and organization without having a negative effect on the crime rates. These positive effects are upstream of health outcomes; however improving a neighborhood’s economic and social environment will likely have a positive influence on health.

In the case of youth, incarceration has been an ineffective strategy for reforming juveniles. Studies have shown youth released from residential corrections programs have high rates of re-arrest, new convictions, and recidivism (Mendel 2011). Long-term studies in New York found more than 80 percent of youth released from juvenile correctional facilities went on to be arrested as adults (Mendel 2011). Furthermore, these youth are often well behind their peers in academic capabilities and have difficulty integrating into the employment market (Lambie and Randell 2013).

Similarly, since incarceration rate has been shown to be associated with concentrated disadvantage (Sampson and Loeffler 2010), if concentrated disadvantage is associated with health outcomes, then decreasing the incarceration rate potentially could decrease disadvantage which will lead to better health outcomes. The effects of incarceration working through disadvantage to affect health have not been thoroughly investigated in the literature.

One specific piece of evidence related to incarceration rate and public health outcomes is sexually transmitted infections (STIs). Researchers have found a correlation between STI rate and incarceration rate, indicating that a decrease in incarceration rate would lead to a decrease in STI rate, assuming causality (Thomas et al 2008, Thomas and Sampson 2005, Thomas et al 2010, Thomas and Torrone 2008). Rates of STIs, particularly chlamydia and gonorrhea are also high for incarcerated youth compared with their peers (Moser 2011). It is hypothesized that the mechanism by which incarceration rate affects STI rates is through changes in neighborhood social characteristics, increased social disorganization and decreased collective efficacy. In other words, communities that experience high rates of incarceration tend to struggle with engagement of community members in a shared set of norms and values and the ability to work together towards a common goal because many community members have been removed through incarceration and those left behind are struggling with other factors like unemployment, and poverty (Thomas et al 2008, Thomas and Sampson 2005, Thomas et al 2010).
As a broader indicator of social capital, there are potential public health impacts from increased social capital within and across populations. Social capital has been linked to various health outcomes, among which self-rated health (Blakely 2001, Kawachi et al., 1999, Hyypä and Mäki, 2001, Subramanian et al., 2002, Helliwell, 2003, Poortinga, 2006a and Poortinga, 2006b), cardiovascular and cancer mortality rates (Kawachi et al., 1997), suicide rates (Helliwell, 2003), and child mental health (Caughey et al., 2003) are included.

**Leverage or realign resources**
Removing violent and criminally active people from neighborhoods has multiple benefits for community safety and cohesion; however, the literature consistently shows that over-incarceration has negative effects. Current penal policy places an emphasis on incarceration over other forms of punishment or rehabilitation, which is to the detriment of the most affected neighborhoods (Clear et al 2003). The two most commonly cited stakeholders are the criminal justice system and the communities most affected by high incarceration rates. A third stakeholder, mostly in regards to lowering the youth incarceration rate, is the education system.

Given the evidence that high rates of incarceration do not yield significant additional gains in crime rate reduction over moderate levels of incarceration, the amount of tax payer money spent prosecuting and incarcerating people would likely be better spent on other crime-reducing activities (Stemen 2006). Factors that have been shown to be associated with a decrease in crime rate are: increased number of police per capita, reduction in unemployment, increases in wages, and education (Stemen 2006). Realigning resources to these factors instead of incarceration may lead to a further reduction in crime and have positive effects on the neighborhoods most affected by incarceration.

Community programs focusing on mentoring, education, alternative career tracks, and crime and violence prevention have been particularly effective with youth offenders (Mendel 2011). Focusing on programs such as these as an alternative to secure detention may in turn lower the adult incarceration rate through more effective youth reform. Partnering with early education facilities and schools to lower the risk of youth becoming an offender is another strategy. A longitudinal study performed in Chicago found low income children who participated in an early intervention program offering comprehensive education, family-support, and health services along with half-day preschool at ages three to four years were more likely to graduate high school and less likely to have a juvenile arrest or a violent arrest, emphasizing that opportunities to prevent adult outcomes have their roots in early childhood (Reynolds, Temple, Robertson, & Mann 2001).

Alternatives to the traditional punishment of incarceration, particularly for non-violent offenders, include: drug courts, community courts, gun courts, domestic violence courts, and reentry programs (Freudenberg 2001). These programs focus on public safety and restorative justice (a concept that focuses on involving all stakeholders to repair harm caused by criminal behavior) and may have positive effects on the community in addition to decreasing incarceration as punishment (Freudenberg 2001). For these programs to be successful, buy-in and resources from the criminal justice system are needed, in addition to support from local communities. By engaging community stakeholders and members, neighborhood-based justice strategies could increase community collective efficacy and community capacity (Clear et al 2003). This would decrease the incarceration rate and have positive effects for the community.

Since the incarcerated population is predominantly composed of minority men, national civil rights organizations like the American Civil Liberties Union (ACLU) and the National Association for the Advancement of Colored People (NAACP) have an interest in reducing incarceration rates among those most at risk. In addition to policies related to alternatives to incarceration, it is important to note that those who are incarcerated are (in most cases) eventually released and return to their community. This places the offender back in the environment in which they committed a crime. To change the environment and prevent recidivism, policies are needed that target common problems with reentry (Sampson and Loeffler 2010). Unemployment is a common problem in neighborhoods with high incarceration rates and among newly released people. Methods to address unemployment include incentivizing businesses to relocate to areas with high incarceration rates in conjunction with hiring ex-offenders and leveraging resources from the criminal justice system to provide job training and education to offenders.

**Predict an individual’s health and wellness and/or that of their offspring**
It has been thoroughly established that incarceration rate is correlated with the population rate of bacterial STIs, notably chlamydia and gonorrhea. Thomas and colleagues have found this association to be consistent in numerous studies using
data from North Carolina and Chicago (Thomas et al 2008, Thomas and Sampson 2005, Thomas et al 2010). Reasons cited for this association are: change in partners when one partner becomes incarcerated, first time men having sex with men experiences in prison, and having multiple partners upon re-entry into the community (Thomas 2008). The imbalance in male to female sex ratios caused by the incarceration of predominantly men has also been hypothesized as a reason for the correlation between STI rates and incarceration rates. A study by Green and colleagues found that living in areas with low sex ratios increased the risk of having unprotected sex with a risky partner among black men and women (Green et al 2012). High incarceration rates have also been associated with having more than one sex partner among men (Green et al 2012, Pouget et al 2010). The poor sexual health of detained adolescents is also well documented and is likely related to their higher risk of drug use, depressive symptoms, gang involvement, and exposure to violence and sexual abuse (Moser 2011). In addition to its association with increased STI rates, the incarceration rate has also been found to increase the risk of teen pregnancy after adjustment for age, race, and poverty distributions by county (Thomas et al 2008).

While it is well established that incarcerated people are at a higher risk for certain health outcomes, it is less well researched whether an area’s incarceration rate affects areas of health in addition to STIs. One study found that individuals who reported knowing an incarcerated person were more likely to report worse mental and physical health than those who did not know an incarcerated prisoner (Kruger and De Loney 2009). This relationship persisted after adjustment for demographic and health behaviors.

Incarcerated individuals are more likely to have substance abuse disorders, mental health problems, and a variety of infectious diseases including HIV, Hepatitis C, and STIs (Freudenberg 2001). Mental health issues prevalent in incarcerated youth, including depression and suicidal behavior, may be exacerbated by their detained environment through isolation, bullying, victimization, boredom, lack of proper treatment, and other stressors (Lambie and Randell 2013).

There has been substantial research on the effects of the incarceration of a parent on the economic well-being of children and their mothers; however there has been little research on the effects of incarceration rate on the health of mothers and children. While men represent the majority of the incarcerated population, the rate of increase in incarceration of women has been higher and the disparities are similar; a black women has much greater risk of incarceration, almost seven times that of a white woman (Freudenberg 2002). Freudenberg notes that incarcerated women, in comparison with other low-income women, have higher rates of sexually transmitted infections, mental health problems, and substance abuse. Of the literature that exists exploring outcomes for children of incarcerated parents, these children are at increased risk for homelessness, placement into foster care, and infant mortality (Wildeman and Western 2010, Geller et al 2009). There is some evidence of poor developmental outcomes including attachment disruption, academic difficulties, and increases in risky behaviors (Dallaire 2007), but existing studies consistently call for further examination of the longer term social and health impacts of parental incarceration on families.

**Data Criteria**

**Data availability**
The National Prisoner Statistics Program (NPS) produces annual and semiannual national and state-level data on the number of adult prisoners in state and federal prison facilities. Aggregate data are collected on age, race, and sex, inmates held in private facilities and local jails, system capacity, and noncitizens. Findings are released in the Prisoners series. Data are from the 50 state departments of correction and from the District of Columbia (until 2001, when the District ceased operating a prison system). Source: [bjs.ojp.usdoj.gov/index.cfm?ty=pbdetail&iid=4559](https://bjs.ojp.usdoj.gov/index.cfm?ty=pbdetail&iid=4559)

The vast majority of incarcerated persons under the age of 18 are under the jurisdiction of juvenile corrections programs and are not included in the National Prisoners Statistics Program. The Office of Juvenile Justice and Delinquency Prevention (www.ojjdp.gov) provides easy access to national and state level data from the Census of Juveniles in Residential Placement (CJRP). Data from 1997-2011 is currently available by sex, race/ethnicity, age, offense characteristics, placement status and type of placement facility.

The denominator for youth, the total population of youth ages 13-17, can be obtained from the Juvenile Justice and Delinquency Prevention statistics web site as they provide information on the entire youth population. Total population of youth ages 13-17 and total population of adults ages 18 and over can be obtained from the Current Population Survey.

*Life Course Indicator: Incarceration Rate (LC-58 A/B)*

Data quality
National Prisoner Statistics (NPS) program collects data on the number of state and federal prisoners at midyear and yearend. The Bureau of Justice Statistics relies on the voluntary participation by state departments of corrections and the Federal Bureau of Prisons for NPS data, therefore selection bias may be an issue. In addition, reliability/validity varies by area. Sensitivity, specificity, predictive value positive and reliability will vary depending on the outcome.

The Census of Juveniles in Residential Placement (CJRP) is performed by the Census Bureau each year in late September. The Census Bureau mails out CJRP surveys to nearly 4,000 public and private residential juvenile facilities. The most recent data from 2011 had a facility response rate of 95 percent. A caution regarding CJRP data is that juveniles held in adult prisons or jails, drug treatment centers, or mental health facilities are not included in the counts.

Simplicity of indicator
The adult incarceration rate is calculated by the Bureau of Justice Statistics and is simple and straightforward. Calculation does not involve weighting, indexing or adjustment. It is simple to calculate. Data are presented by total prisoners, age and total population in a tabular format. It is easy to communicate and easily understood by general audiences.

Youth incarceration rate is also simple and straightforward to calculate. Youth incarceration counts and total youth population counts are easily available from the Office of Juvenile Justice and Delinquency. In order to obtain the rate per 100,000, after dividing the number of incarcerated youth (13-17) by the total population of youth (13-17), you must multiply by 100,000.

References


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The Life Course Metrics Project

As MCH programs begin to develop new programming guided by a life course framework, measures are needed to determine the success of their approaches. In response to the need for standardized metrics for the life course approach, AMCHP launched a project designed to identify and promote a set of indicators that can be used to measure progress using the life course approach to improve maternal and child health. This project was funded with support from the W.K. Kellogg Foundation.

Using an RFA process, AMCHP selected seven state teams, Florida, Iowa, Louisiana, Massachusetts, Michigan, Nebraska and North Carolina, to propose, screen, select and develop potential life course indicators across four domains: Capacity, Outcomes, Services, and Risk. The first round of indicators, proposed both by the teams and members of the public included 413 indicators for consideration. The teams distilled the 413 proposed indicators down to 104 indicators that were written up according to three data and five life course criteria for final selection.

In June of 2013, state teams selected 59 indicators for the final set. The indicators were put out for public comment in July 2013, and the final set was released in the Fall of 2013.

Basic Indicator Information

Name of indicator: Voter Registration (LC-59)

Brief description: Voter registration

Indicator category: Social Capital

Indicator domain: Service/Capacity

Numerator: Number of adults registered to vote

Denominator: Total eligible population

Potential modifiers: Age, race/ethnicity and gender

Data source: Current Population Survey (CPS)

Notes on calculation: Voter registration is derived from the answers to two questions, asked of voting age citizens: "In any election some people are not able to vote because they are sick or busy, or have some other reason, and others do not want to vote. Did (this person) vote in the election held on November (date varies)?" (if yes, counted in the numerator, and if no, asked the follow-up question) and "Was (this person) registered to vote in the November (date varies) election?" (if yes, counted in the numerator).

Similar measures in other indicator sets: None
Life Course Criteria

Introduction
Growing evidence suggests that social environments have an impact on health. Research on this relationship is focused on aspects of support and cohesion within the social environment. These concepts are often discussed as ‘social capital’ across populations. Social capital is the collection of features of social organization – such as civic participation, norms of reciprocity, and trust in others – that help facilitate cooperation for mutual benefit (Putnam, 2000). As such, social capital is a collective resource that benefits communities and can be distinguished from the individual health effects of social networks and support (Lochner et al., 1999). Social capital has been linked to various health outcomes, including self-rated health (Blakely 2001; Kawachi et al., 1999; Hyppä and Mäki, 2001; Subramanian et al., 2002; Helliwell, 2003; Poortinga, 2006a and Poortinga, 2006b), cardiovascular and cancer mortality rates (Kawachi et al., 1997), suicide rates (Helliwell, 2003), and child mental health (Caughy et al., 2003).

Social capital is a hard concept to measure. Measures of civic engagement help as proxy measures that quantify levels of social capital within and across populations. Voter registration is a conventional proxy for measures of civic engagement (Mercyhurst Center, 2011). As a life course measure, voter registration will be an indicator of social capital within and across populations.

Implications for equity
Regular voters, and therefore registered voters, are more likely to be White, older, and have a higher education than non-voters. The largest positive changes in registrations, and thus conceivably actual voting and increasing social capital, are likely to be from increasing enrollment of those who are traditionally not registered. Common characteristics of non-registered populations include: younger populations (most specifically those between the ages of 18-29), persons from minority ethnic groups, and persons with a high school level education or less. (Pew Research Center, 2006)

An important equity consideration when using voter registration data is voter eligibility. Some people are not permitted to vote because they are not citizens, have been committed to the penal system, mental hospitals, or other institutions, or because they fail to meet state and local resident requirements for various reasons. The eligibility to register is governed by state laws that differ from one another in many respects. Aside from non-citizens, those not eligible to vote are more likely to be non-White and male (Purtle, 2013). This bias will not be reflected in the indicator, which is based on registration by eligibility. However, the bias of how one becomes eligible should be considered when interpreting and presenting data on this indicator.

Public health impact
The public health impact of increased voter registration, and concomitant increased voting, will have a long-term effect on policies that affect health and development. In the short term, it would most likely be detectable on very specific, high impact legislation and policies. Fujiwara found that increased enfranchisement of Brazil’s “less educated” resulted in a shift of “government spending towards health care, which is particularly beneficial to the poor” (Fujiwara, 2010). It is important to realize that an individual’s decision whether or not to vote is made at each election, and thus participation rates are inherently fluid.

In addition to policy changes resulting from election and voting outcomes, there are many potential public health impacts from increased social capital within and across populations. As summarized above, social capital has been linked to various health outcomes, including self-rated health (Blakely 2001; Kawachi et al., 1999; Hyppä and Mäki, 2001; Subramanian et al., 2002; Helliwell, 2003; Poortinga, 2006a and Poortinga, 2006b), cardiovascular and cancer mortality rates (Kawachi et al., 1997), suicide rates (Helliwell, 2003), and child mental health (Caughy et al., 2003).

Leverage or realign resources
Similar to the explanation of public health impact (above), increases in voter registration that result in increased voting may have short term impacts on very specific legislation and policies. Specific legislation does have the potential to impact long-term realignment of resources and is determined at specific voting events, which may be influenced by voter registration.
As a MCH life course indicator, voter registration can attract new partnerships into public health practice, including community organizers, social justice groups, civic groups such as the League of Women Voters, and civil rights advocates who are the traditional champions of voter registration initiatives. These new partners may have more human than financial resources, but are likely to welcome the involvement of new partnerships with public health. Another interesting opportunity for leveraging partnerships that can be acted on in relation to this indicator involves the new rules of the Affordable Care Act that require health exchanges to adhere to National Voter Registration Act and provide information on voter registration (Sink, 2013). Voter registration information integrated into exchange enrollment provides a new opportunity to increase civic engagement and empower community members.

Predict an individual’s health and wellness and/or that of their offspring

Effects at the individual level are likely to be fairly limited and impossible to measure. Being registered to vote, however, implies a certain level of an individual’s locus-of-control, aside from not being in a voting-ineligible group (Purtle, 2013; Sanders, 2001). In addition, the relationship between voting and social capital suggests associated links to individual health outcomes.

Data Criteria

Data availability

Information on voting is collected by the Current Population Survey (CPS) in November of Congressional and Presidential election years. The CPS is a monthly survey of about 50,000 households conducted by the Bureau of the Census for the Bureau of Labor Statistics. The survey has been conducted for more than 50 years, is the primary source of information on the labor force characteristics of the U.S. population, and provides data on a wide range of issues relating to employment and earnings. The sample is scientifically selected to represent the civilian non-institutionalized population. The sample provides estimates for the nation as a whole and serves as part of model-based estimates for individual states and other geographic areas. The CPS data provide reliable estimates at the state level and for 12 of the largest metropolitan statistical areas. The sample size does not allow reliable estimates to be obtained at the county level. The Basic CPS monthly microdata file is usually made available to the public 30-45 days after data collection is complete. Data files for supplemental information are available anywhere from six to 18 months after data collection (U.S. Census Bureau, 2012).

Voting and Registration data have been collected biennially in the CPS since 1964. Over the years, changes have been made to the Voting and Registration supplement. The only constant is that in all iterations of the survey a separate question has been included regarding both voting and registration, which compensates for differences in registration eligibility across states. Results are weighted to “agree with independently derived population estimates of the civilian noninstitutionalized population of the United States and each state (including the District of Columbia)”, controlling for age, race and sex (U.S. Census Bureau, 2011; further methodological details at census.gov/hhes/www/socdemo/voting/about/index.html).

In recent years, voter-participation data were derived from replies to the following questions. Voting age citizens were asked:

“In any election some people are not able to vote because they are sick or busy, or have some other reason, and others do not want to vote. Did (this person) vote in the election held on November (date varies)?”

Respondents were classified as either "voted" or "did not vote." In most tables, this "did not vote" category includes those who reported "did not vote" or "do not know," as well as noncitizens and non-respondents. The data on registration were obtained by asking the following question to those who reported they “did not vote”:

"Was (this person) registered to vote in the November (date varies) election?”

Longitudinal data on state-level voting and registration rates are available at census.gov/hhes/www/socdemo/voting/publications/historical/index.html, while updates to the biennial data are at census.gov/hhes/www/socdemo/voting/.

Data are available on the U.S. Census Bureau website and do not require special permission to access.
Data quality
The CPS is administered by the Census Bureau using a probability selected sample of occupied households annually. The CPS is a highly rigorous survey that uses extensive sampling schemes and weights to ensure accuracy (U.S. Census Bureau, 2006). The CPS has one of the highest response rates among government household surveys, consistently ranging from 91 to 93 percent (U.S. Census Bureau, 2012). To be eligible to participate in the CPS, individuals must be 15 years of age or over and not in the Armed Forces. People in institutions, such as prisons, long-term care hospitals, and nursing homes are ineligible to be interviewed in the CPS. Information on the quality of data specific to voting and registration is not available.

People who are not U.S. citizens are not eligible to vote. The voting-age population also includes a considerable number of people who cannot register to vote despite meeting citizen and age requirements. Some people are not permitted to vote because they have been committed to the penal system, mental hospitals, or other institutions, or because they fail to meet state and local resident requirements for various reasons. The eligibility to register is governed by state laws that differ from one another in many respects.

Registration is the act of qualifying to vote by formally enrolling on an official list of voters. People who have moved to another election district must take steps to have their names placed on the voting rolls in their new place of residence. The state of North Dakota has no formal registration requirement – voters merely present themselves at the polling place on election day with proof that they are of age and have met the appropriate residence requirements. Therefore, in North Dakota, people who are citizens and of voting age (and who meet the residence requirement), are automatically considered registered. census.gov/cps/files/Source%20and%20Accuracy.pdf.

Simplicity of indicator
This indicator is simple to both calculate and to explain to various stakeholders. It does not require special data linkage on the part of the data user. However, describing the relationship between voter registration, social capital, and the life course approach is conceptually difficult to describe and understand.

References


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