Life Course Indicator:
Inability or Delay in Obtaining Necessary Medical Care or Dental Care

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: 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

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

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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 (DRCCA, 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.

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