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 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:

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Discrimination=.;
if ACE10=0 or (ACE10=1 and (ACE11 in (3,4))) then
Discrimination=0;
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else if ACE10=1 and ACE11 in (1,2) then Discrimination=1;
if (ACE10 in (6,7)) or (ACE11 in (6,7)) then Discrimination=.M;

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 experiences 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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