

Life Course Indicator:

Children and Youth with Special Health Care Needs

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.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.

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