

Maryland Children and Youth with Special Health Care Needs Outcome #1

Families are partners in decision making at all levels

Effective promotion of health and health services for children and youth with special health care needs (CYSHCN) requires a system of care that is integrated, comprehensive, coordinated, family centered and consistent across the life course (or lifespan). Ideally, families of CYSHCN can easily navigate such a system, leading to positive experiences seeking care and interacting with service providers. Advancing integrated care systems for CYSHCN and their families is a national mandate under Public Law 101-239 as well as a priority reflected in the Healthy People goals set forth by the U.S. Department of Health and Human Services from 2000 to 2020. To determine progress toward an integrated system of care for all CYSHCN, the Federal Maternal and Child Health Bureau established the following six core outcomes:

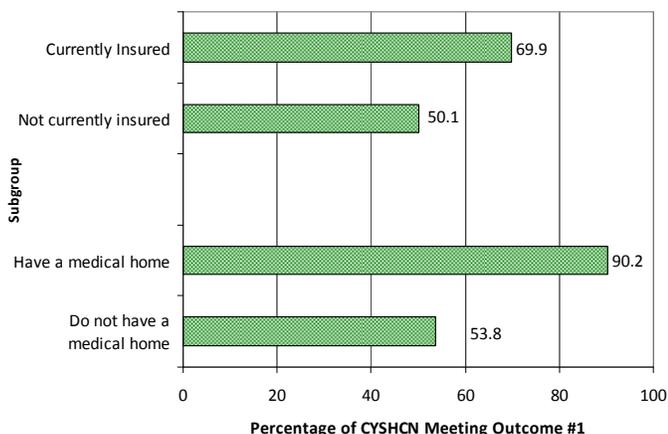
- Partners in Decision-Making
- Medical Home
- Adequate Health Insurance
- Early and Continuous Screening
- Ease of Community-Based Service Use
- Transition to Adulthood

The National Survey of Children with Special Health Care Needs (NS-CSHCN) is designed to provide information on the CYSHCN population and to assist in the measurement of these core outcomes. Since 2001, the NS-CSHCN has been conducted every four years. The NS-CSHCN measures each core outcome with low-threshold criteria. Outcome #1 is measured through questions that assess the extent to which health professionals engage families in decision-making about their child's health care. Based on data from the 2009/10 NS-CSHCN, 70.3% of CYSHCN nationwide meet Outcome #1, with states ranging from 61.8% - 77.6%. In Maryland, 69.3% of CYSHCN meet this outcome. Maryland ranks 37th in the nation. Assessment of the variation between states and within demographic or other subgroups of CYSHCN is critical to developing appropriate interventions and policy responses.

CYSHCN meet Outcome 1 when the respondent answers usually or always to all four of the following questions: We want to know about how [S.C.]'s doctors or health care providers work with you to make decisions about [his/her] health care services and treatment. During past 12 months...

1. How often did [S.C.]'s doctors or other health care providers discuss with you the range of options to consider for [his/her] care or treatment?
2. How often did they encourage you to ask questions or raise concerns?
3. How often did they make it easy for you to ask questions or raise concerns?
4. How often did they consider and respect what health care and treatment choices you thought would work best for [S.C.]?

Figure 1: 2009-10 Portion of Maryland CYSHCN Meeting Outcome #1 by Presence of a Medical Home and Insurance Status in 2009 - 10



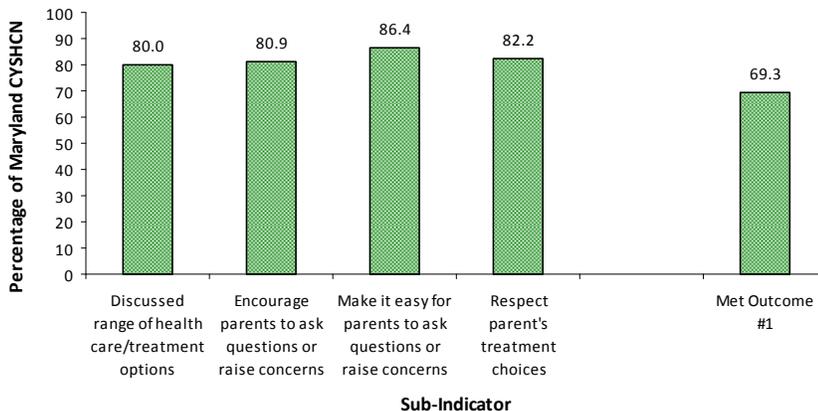
- Maryland CYSHCN with a medical home are more likely to receive care where their families are partners in decision making than are CYSHCN without a medical home.
- Maryland CYSHCN who are currently insured are more likely to meet Outcome #1 than CYSHCN who are not currently insured.



Setting the stage for optimal health trajectories.

A partnership between a child's family and their health care providers allows for an open and intentional dialogue about his or her unique health needs. This leads to individualization of care and the ability to identify factors that may negatively affect his or her health. It also gives children and their families the support they need during critical periods of development. However, only about 70% of CYSHCN meet this core outcome. Vulnerable CYSHCN, especially those with functional limitations and those living in poverty, are even less likely to receive care in which families are partners in decision making.

Figure 2: 2009-10 Percentage of Maryland CYSHCN meeting Family-Professional Partnerships Sub-Indicators



- In order to meet Core Outcome # 1, caregivers must answer “usually” or “always” to the sub-indicator questions. While over 80% of caregivers answered “usually” or “always” to individual sub-indicators, less than 70% answered “usually” or “always” to all sub-indicators. The individual sub-indicator most often met was “providers usually or always make it easy for parents to ask questions or raise concerns” (86.4%).

Taking it a Step Further:

The following are questions relating to Outcome #1 that cannot be answered by this national survey data but are important to consider when evaluating how early and continuous screening can best work to improve the health and well-being of CYSHCN:

- Current measurement is physician-focused -- are families working to encourage these critical conversations?
- Do families have the support they need to play the most positive role possible in their child's development?
- What do health care providers do to educate families on how they can best support their child's development?
- What is the family doing in the day-to-day life of their child to promote or maintain health?
- Are families involved in the policy decisions that affect them?

53.5
Hispanic CYSHCN

59.3
CYSHCN with one or more emotional, behavioral, or developmental issues

69.3
All Maryland CYSHCN

73.6
CYSHCN 12 -17 years of age

90.2
CYSHCN with a medical home

* Child and Adolescent Health Measurement Initiative (CAHMI). 2009-2010 National Survey of Children with Special Health Care Needs Indicator Data Set. Data Resource Center for Child and Adolescent Health. www.childhealthdata.org