MARYLAND OFFICE FOR GENETICS AND CHILDREN WITH SPECIAL HEALTH CARE NEEDS

fha.dhmh.maryland.gov/genetics
Toll-free: 1-800-638-8864

Maryland Children and Youth with Special Health Care Needs Outcome #2

Coordinated, ongoing, comprehensive care within a medical home

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:

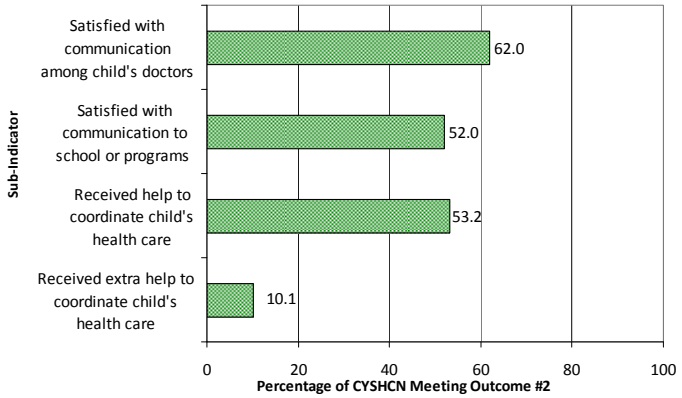
- Partners in Decision-Making
- Medical Home
- Adequate Health Insurance
- Early and Continuous Screening
- Ease of Community-Based Service Use
- Transition to Adulthood

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 #2 assesses if CYSHCN receive care within a medical home, a key American Academy of Pediatrics priority. Nationally, 43.0% of CYSHCN meet this outcome, with states ranging from 34.2% - 50.7%, as measured in the 2009/10 NS-CSHCN. In Maryland, 44.2% of CYSHCN meet this outcome. Maryland ranks 28th 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 2 when the respondent answers that heir child:

1. Has at least one personal doctor or nurse
2. Received family-centered care in the previous 12 months
   - `Health providers usually or always spend enough time with them, listen well, are sensitive to family values and customs, provide needed information and make family feel like a partner in care
3. Has no problems getting referrals when needed
4. Has usual source or sources of sick and well care
5. Receives effective care coordination
   - Saw at least 2 medical providers and usually or always got all needed help coordinating care AND, if applicable, was very satisfied with the communication between providers and school/daycare and/or between primary provider and other medical providers

Figure 1: Percentage of Maryland CYSHCN who needed Care Coordination and received it by Sub-Component in 2009-10



- Sixty-two percent of Maryland CYSHCN who needed care coordination are satisfied with communication among child's doctors; Fifty-two percent of Maryland CYSHCN who needed care coordination are satisfied with communication to school or programs
- Fifty-three percent of Maryland CYSHCN received help to coordinate child's health care when needed while ten percent of Maryland CYSHCN usually or always received extra help when needed.

* 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

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Supporting whole-person development through integration and stability.

The medical home ensures that children have easy and timely access to appropriate, individualized and comprehensive health care. It means families are given the information and framework to be actively engaged in their child's care. It also gives children support and consistency throughout childhood's diverse developmental stages. Medical homes provide youth with appropriate preventive care with a focus on integrated services and positive long-term outcomes. However, less than half of all CYSHCN have a medical home. Children with more complicated needs are substantially less likely to have a medical home, although they have great potential to benefit from one.

Figure 2: Percentage of Maryland CYSHCN Meeting Medical Home Sub-Components in 2005-06 and 2009-10

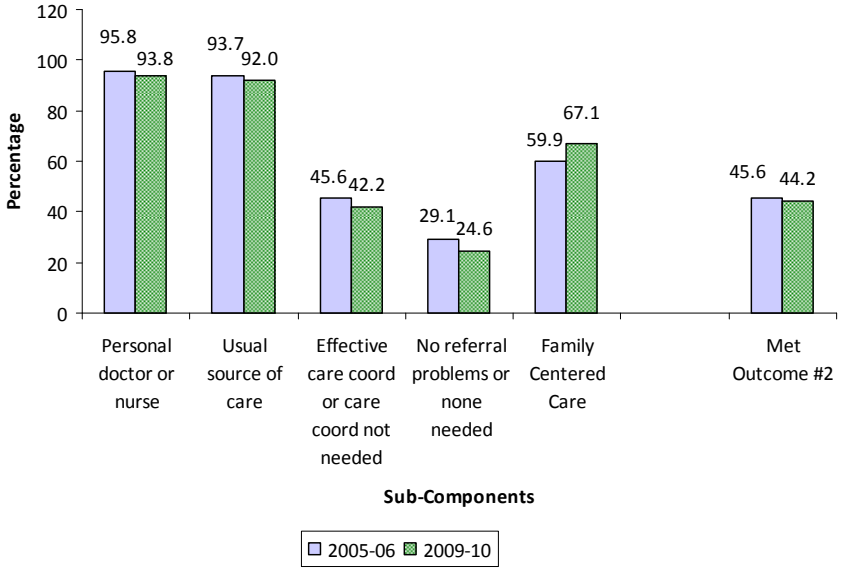
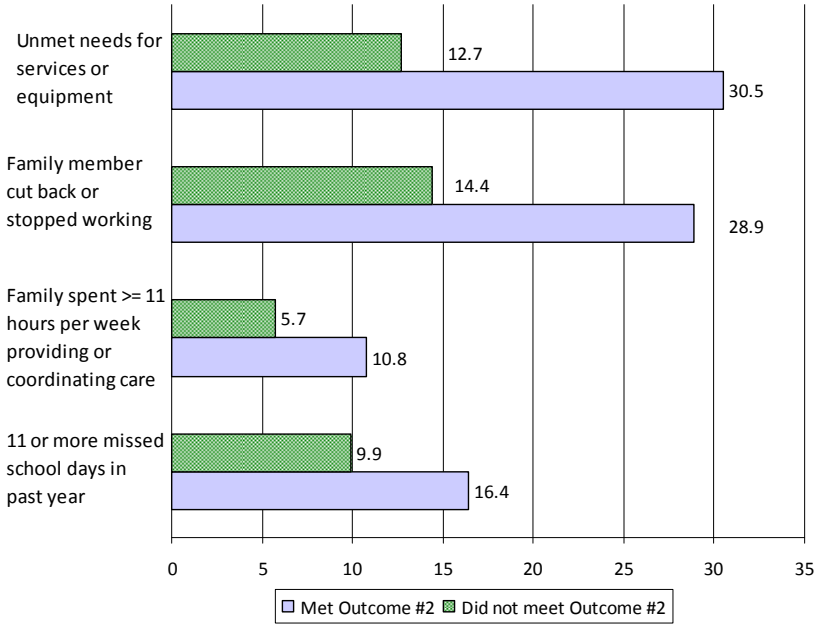


Figure 3: Experience with care, impact on the family and missed school for CYSHCN with and without a medical home



28.4 CYSHCN with inadequate insurance	**33.8 Hispanic CYSHCN**	**44.2 All Maryland CYSHCN**	46.5 White non-Hispanic CYSHCN	55.1 CYSHCN with adequate insurance

* 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