

Outcome #2

Coordinated, ongoing, comprehensive care within a medical home

Effective promotion of health and health services for children with special health care needs (CSHCN) requires a system of care that is integrated, comprehensive, coordinated, family centered and consistent across the life course (or lifespan). Ideally, families of CSHCN can easily navigate such a system, leading to positive experiences seeking care and interacting with service providers. Advancing integrated care systems for CSHCN 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 CSHCN, the Federal Maternal and Child Health Bureau established the following six core outcomes:

1. Partners in Decision-Making
2. Medical Home
3. Adequate Health Insurance
4. Early and Continuous Screening
5. Ease of Community-Based Service Use
6. Transition to Adulthood

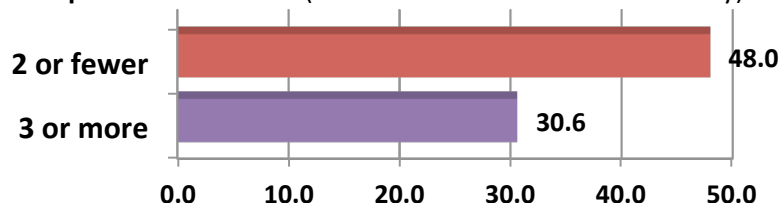
The National Survey of Children with Special Health Care Needs (NS-CSHCN) is designed to provide information on the CSHCN population and to assist in the measurement of these core outcomes. Since 2001, the NS-CSHCN has been conducted every four years. The NS-CSHCN measures each core outcome with low-threshold criteria. Outcome #2 assesses if CSHCN receive care within a medical home, a key American Academy of Pediatrics priority. Nationally, 43.0% of CSHCN meet this outcome, with states ranging from 34.2-50.7%, as measured in the 2009/10 NS-CSHCN. Assessment of the variation between states and within demographic or other subgroups of CSHCN is critical to developing appropriate interventions and policy responses.

Measurement

CSHCN meet Outcome 2 when the respondent answers that their child:

1. Has at least one personal doctor or nurse (PDN, C4Q02A)
2. Received family-centered care in the previous 12 months (C6Q01-C6Q06)
 - 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 (C5Q11, C4Q07)
4. Has usual source or sources of sick and well care (C4Q01-D, C4Q01-2)
5. Receives effective care coordination (C5Q05-06, C5Q09-10, C5Q12-17)
 - 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

Percent of CSHCN with a Medical Home by Number of Reported Conditions⁺ (of Those Asked About in the Survey)



• CSHCN with more reported conditions have a lower probability of having a medical home than those with fewer reported conditions.

⁺As measured in the 2009/10 NS-CSHCN, 70.9% of CSHCN have 2 or fewer and 29.1% of CSHCN have 3 or more of the conditions asked about in the survey

24.2%

Uninsured CSHCN

28.8%

CSHCN with one or more EBD* issues

34.6%

CSHCN with more complex needs

43.0%
All CSHCN

51.2%

Privately insured CSHCN

*Emotional, behavioral or developmental

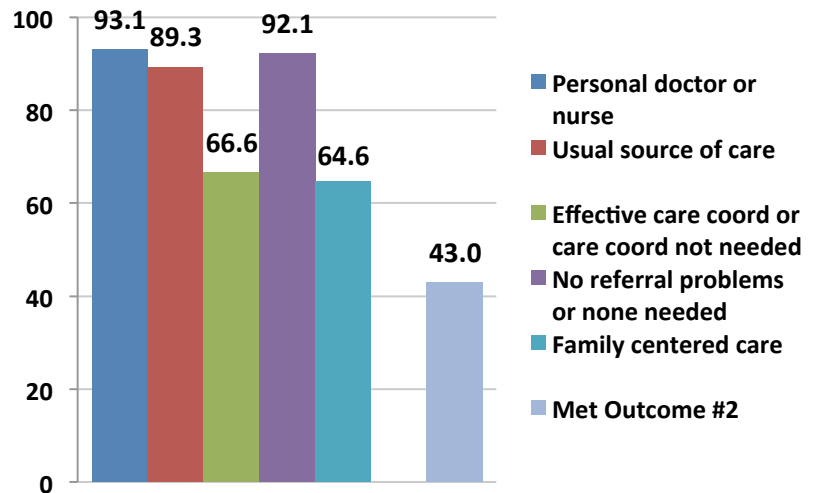
National and state-level prevalence of all outcomes by demographics & subgroups are available online at childhealthdata.org

shared ownership
 culturally acceptable
continuity well-being
 family-centered collaboration
 shared decision-making
 lasting relationships
OUTCOME 2: MEDICAL HOME
 improve health outcomes
 care coordination
personalized
 usual source of care
 preventive visits
 affordable, accessible
integrated

Supporting whole-person development through integration and stability.

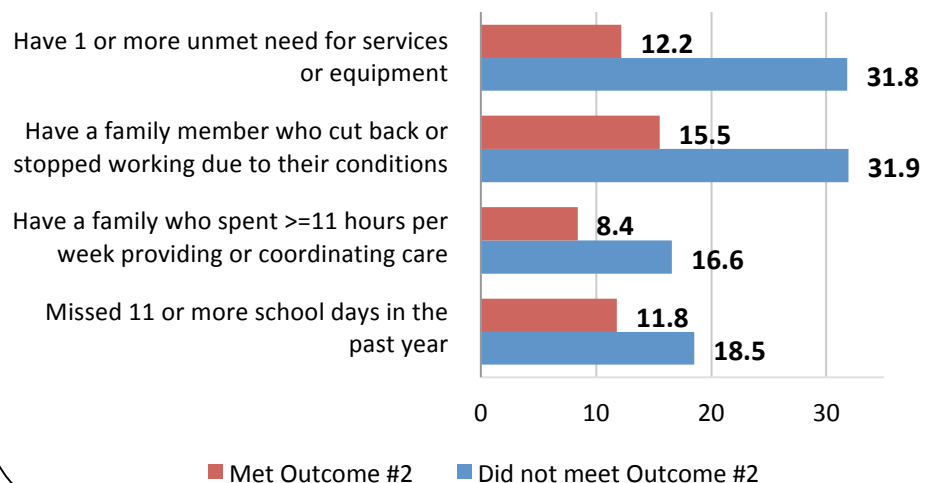
The medical home ensures that children have easy and timely access to appropriate, individualized and comprehensive health care. It means families are given the information and framework to be actively engaged in their child's care. It also gives children support and consistency throughout childhood's 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 CSHCN 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.

Percent of CSHCN Meeting Medical Home Sub-Components



- Effective care coordination and family centered care are the two medical home subcomponents least likely to be met.

Experience with care, impact on the family and missed school for CSHCN with and without a medical home. Percent of CSHCN who...



Trending Across Survey Years: Measurement changed just slightly for 2009/10 NS-CSHCN, and therefore can be compared to 2005/06 NS-CSHCN survey findings.

Taking it a Step Further:

The following are questions relating to Outcome #2 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 CSHCN:

1. Is the medical home consistent and continuous?
 - Does child have access to the same health care providers within their medical home through changes in income, jobs and insurance status?
2. Do families have a choice of providers so that they can find the best fit?
3. Are families educated about all of the resources and options available to them within their community?