

Outcome #1

Families are partners in decision making at all levels

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, these systems are easy to navigate and foster positive experiences between families and health service providers. Advancing integrated systems of care for CSHCN and their families is a national mandate under Public Law 101-239 and is 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 help determine progress towards these goals, the Federal Maternal and Child Health Bureau established the following six core outcomes that facilitate integrated systems of care for CSHCN:

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

The National Survey of Children with Special Health Care Needs (NS-CSHCN), which has been conducted every four years since 2001, is designed to provide information on the CSHCN population and to assist in the measurement of these core outcomes. The survey 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 CSHCN nationwide meet Outcome #1, with states ranging from 61.8% - 77.6%. Assessment of the variation between states and within demographic or other subgroups of CSHCN is critical to developing appropriate interventions and policy responses.

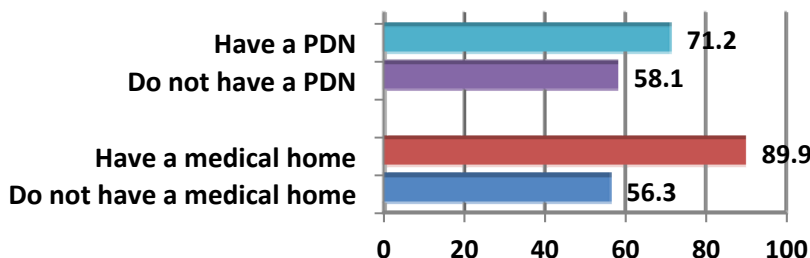
Measurement

CSHCN meet Outcome 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 other health care providers work with you to make decisions about [his/her] health care services and treatment. During the 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] health care or treatment? (C6Q21)
2. How often did they encourage you to ask questions or raise concerns? (C6Q22)
3. How often did they make it easy for you to ask questions or raise concerns? (C6Q23)
4. How often did they consider and respect what health care and treatment choices you thought would work best for [S.C.]? (C6Q24)

Proportion of CSHCN Meeting Outcome #1 by Presence of a Medical Home and Personal Doctor or Nurse



- CSHCN with a personal doctor or nurse (PDN) are more likely to receive care where their families are partners in decision making than CSHCN without a PDN.

- CSHCN with a medical home are more likely to meet Outcome #1 than CSHCN without a medical home.

*Emotional, behavioral or developmental

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

57.6%
Uninsured
CSHCN

61.5%
CSHCN with one or
more EBD* issues

65.9%
CSHCN with more
complex needs

70.3%
All CSHCN

76.0%
Privately insured
CSHCN



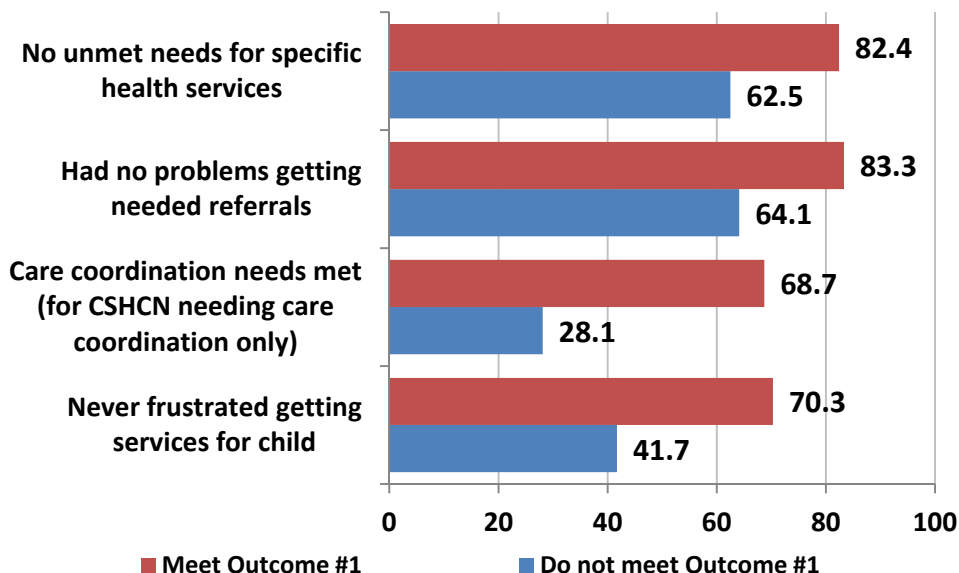
Setting the stage for optimal health trajectories.

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 CSHCN meet this core outcome. Vulnerable CSHCN, 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.

Trending Across Survey Years:

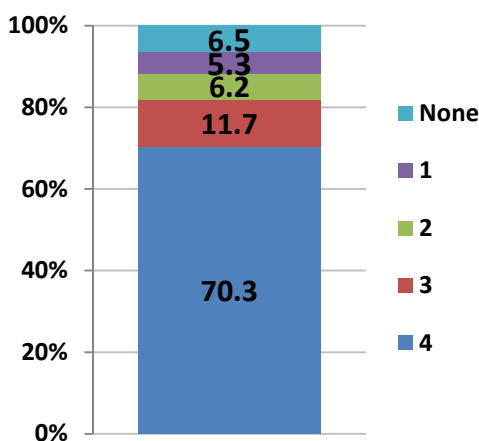
Measurement changed significantly for 2009/10 NS-CSHCN, and therefore cannot be compared to 2001 or 2005/06 NS-CSHCN survey findings.

Experience with care for CSHCN who do and do not meet Outcome #1



- CSHCN who meet Outcome # 1 have a lower probability of experiencing frustration seeking services or having unmet needs for specific health services than CSHCN who do not meet Outcome # 1
- CSHCN who meet Outcome #1 have a higher probability of having their care coordination needs met and having no problems getting needed referrals than CSHCN who do not meet Outcome # 1

Number of Shared Decision Making Elements Met



The chart to the left shows the percentage of parents reporting various number of elements of shared decision making elements met their child's care. Nationally, 6.6% of CSHCN have families who experience no elements of shared decision making.

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 CSHCN:

- 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?