

Outcome #5

Community-based service systems are organized for ease of use

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:

- 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 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 #5 assesses provision of community-based services for CSHCN and their families, which facilitates integration of services for CSHCN. Nationally, only 65.1% of CSHCN have access to community-based services that are easy to use, with states ranging from 54.3% - 73.5% as measured in the 2009/10 NS-CSHCN.

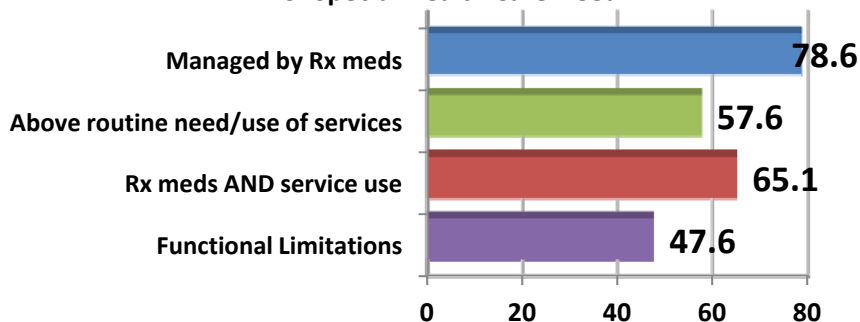
Measurement

For CSHCN to meet Outcome 5, families must have no difficulties or delays in getting services, and be only sometimes or never frustrated in efforts to get services for CSHCN. It is based upon the following 7 questions:

During the past 12 months did you have any difficulties or delays getting services for [child] because...

1. ...[he/she] was not eligible for the services? (C4Q03_A)
2. ...the services [SC] needed were not available in your area? (C4Q03_B)
3. ...there were waiting lists, backlogs, or other problems getting appointments? (C4Q03_C)
4. ...of issues related to cost? (C4Q03_D)
5. ...you had trouble getting the information you needed? (C4Q03_E) *Yes or no*
6. During the past 12 months did you have difficulties or delays for any other reason? (C4Q03_F) *Yes or no*
7. During the past 12 months, how often have you been frustrated in your efforts to get services for [S.C.]? (C4Q04) *Never, sometimes, usually or always*

Prevalence of Ease of Community-Based Service Access by Type of Special Health Care Need



- Access to community-based services differs by CSHCN's type of special health care need. Less than half of CSHCN who have functional limitations meet Outcome #5, compared to over ¾ of CSHCN whose condition is managed by prescription medication.

*Emotional, behavioral or developmental

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

30.5%
Uninsured
CSHCN

49.7%
CSHCN with one or
more EBD* issues

56.4%
CSHCN with more
complex needs

65.1%
All CSHCN

71.8%
Privately insured
CSHCN

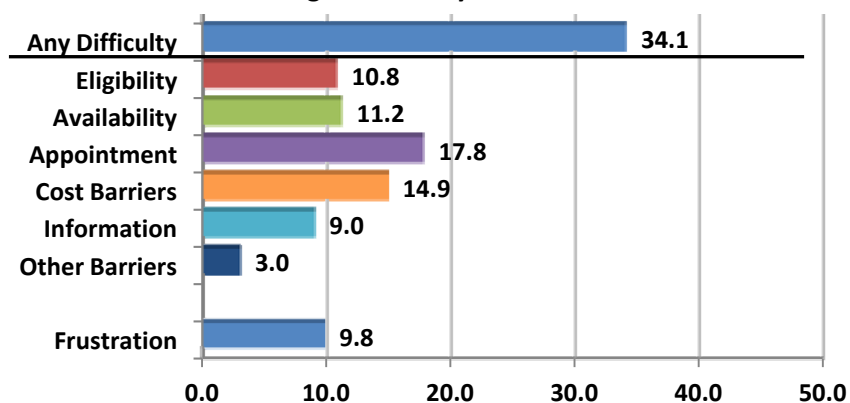
OUTCOME 5: EASY TO USE COMMUNITY-BASED SERVICES

beyond the medical home
 education
 access to services
 infrastructure supports
 integrated
 addresses whole person
 coordinated care
 health is not isolated
 reduce familial stress
 healthy communities
 horizontal integration
 good health systems
 communication

Structural support for optimal outcomes.
 CSHCN have complicated needs that are usually not isolated to a single doctor's office. CSHCN and their families often require services from multiple providers as well as schools and other community based organizations. Services must be organized in a way that reduces frustration; otherwise the barriers to access will leave children without needed services. Integrated and accessible services allow CSHCN and families to connect with the resources they need to grow and develop optimally.

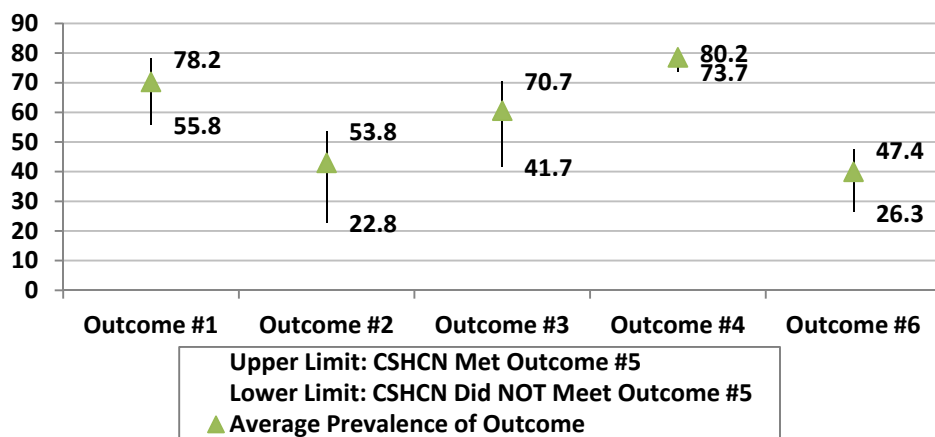
Trending Across Survey Years:
 Measurement changed significantly for 2009/10 NS-CSHCN, and therefore cannot be compared to 2001 and 2005/06 NS-CSHCN prevalence rates.

Prevalence of Specific Difficulties and Parental Frustration in Accessing Community-Based Services



- CSHCN were most likely to experience difficulty with waiting lists, backlogs, or other problems getting appointments (17.8%), with slightly lower rates for issues related to costs of care (14.9%).
- Almost 1 in 10 (9.8%) parents of CSHCN experienced frustration in efforts to get services for their CSHCN.

CSHCN who do not experience difficulties in accessing community-based services are more likely to meet all other MCHB Core Outcomes



- CSHCN who meet this outcome are over twice as likely to meet criteria for a medical home (53.8% vs 22.8%) and significantly more likely to report having adequate insurance (70.7% vs 41.7%), revealing the interconnected nature of the MCHB Core Outcomes

Taking it a Step Further:

The following are questions relating to Outcome #5 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:

- Do families know about all community-based services available?
 - How is information about these available services disseminated?
- Are communities properly structured to offer these types of services?
 - What infrastructure supports are needed to facilitate integrated systems?