

Maryland Children and Youth with Special Health Care Needs Outcome #5

Community-based service systems are organized for ease of use

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

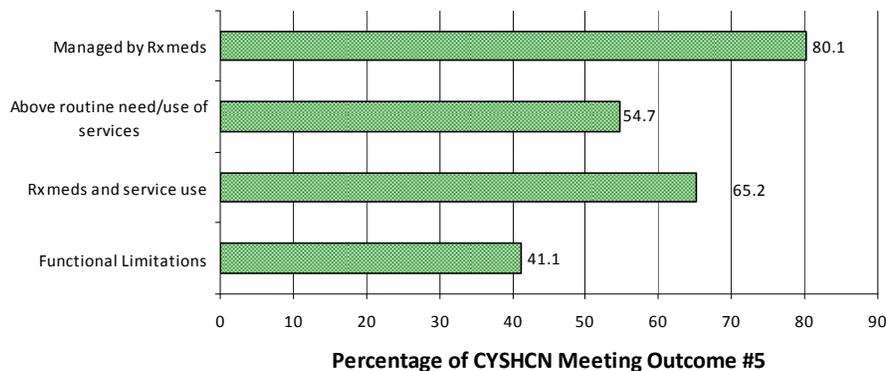
The National Survey of Children with Special Health Care Needs (NS-CSHCN) is designed to provide information on the CYSHCN population and to assist in the measurement of these core outcomes. Since 2001, the NS-CSHCN has been conducted every four years. The NS-CSHCN measures each core outcome with low-threshold criteria. Outcome #5 assesses provision of community-based services for CYSHCN and their families, which facilitates integration of services for CYSHCN. Nationally, only 65.1% of CYSHCN 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. Maryland matches the nationwide average with 65.1% of CYSHCN in the state meeting this outcome. Maryland ranks 29th 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.

FOR CYSHCN 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 CYSHCN. It 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?
2. ...the services [SC] needed were not available in your area?
3. ...there were waiting lists, backlogs, or other problems getting appointments?
4. ...of issues related to cost?
5. ...you had trouble getting the information you needed?
6. During the past 12 months did you have difficulties or delays for any other reason?
7. During the past 12 months, how often have you been frustrated in your efforts to get services for [S.C.]?

Figure 1: Prevalence of Ease of Community-Based Service Access in Maryland by Type of Special Health Care Need 2009-10



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

beyond the medical home
education
access to services
infrastructure supports

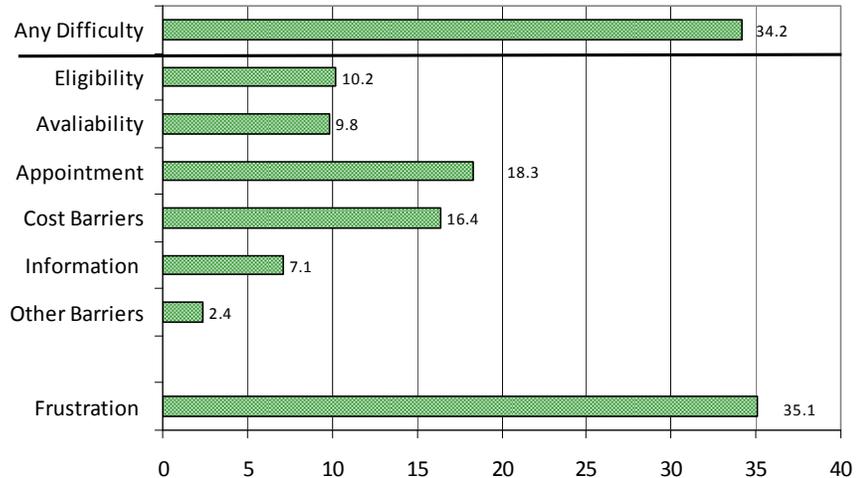
OUTCOME 5: EASY TO USE COMMUNITY-BASED SERVICES

integrated
addresses whole person
coordinated care
health is not isolated
reduce familial stress
healthy communities
horizontal integration

Structural support for optimal outcomes.

CYSHCN have complicated needs that are usually not isolated to a single doctor's office. CYSHCN 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 CYSHCN and families to connect with the resources they need to grow and develop optimally.

Figure 2: 2009-10 Prevalence of Specific Difficulties and Parental Frustration in Accessing Community-Based Services in Maryland



- Maryland CYSHCN were more likely to experience difficulty with waiting lists, backlogs, or other problems getting appointments (18.3%), with slightly lower rates for issues related to costs of care (16.4%)
- More than 1 in 3 (35.1%) parents of Maryland CYSHCN experienced frustration in efforts to get services for their CYSHCN.

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 CYSHCN:

- 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?

47.5
Hispanic CYSHCN

51.3
CYSHCN with one or more emotional, behavioral, or developmental issues

65.1
All Maryland CYSHCN

77.6
CYSHCN with adequate insurance

83.1
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