MARYLAND OFFICE FOR GENETICS AND CHILDREN WITH SPECIAL HEALTH CARE NEEDS

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Maryland Children and Youth with Special Health Care Needs Outcome #6

CYSHCN youth receive services needed for transition to adulthood

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

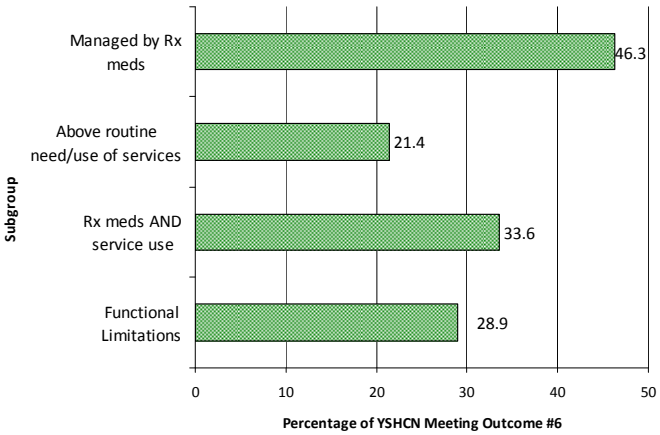
The National Survey of Children with Special Health Care Needs (NS-CSHCN) is designed to provide information on the CYSHCN population and to assist in the measurement of these core outcomes. Since 2001, the NS-CSHCN has been conducted every four years. The NS-CSHCN measures each core outcome with low-threshold criteria. Outcome #6 assesses transition services for youth with special health care needs (YSHCN) age 12-17 years old as they move to adult services, including health insurance coverage, changing providers and the increasing need for self-care that are critical for transition to adulthood. Nationally, only 40% of YSHCN receive transition services, with states ranging from 31.7% - 52.7%, as measured in the 2009/10 NS-CSHCN. In Maryland, 36.8% of YSHCN meet this outcome. Maryland ranks 40th in the nation. Assessment of the variation between states and within demographic or other subgroups of YSHCN is critical to developing appropriate interventions and policy responses.

For YSHCN to meet Outcome 6, the following criteria must be met* (YSHCN age 12-17 years only):

1. The youth's doctor has discussed each of the following 3 topics with him/her (or parent indicated that such discussions were not needed):
   - Transitioning to doctors who treat adults
   - Changing health needs as youth becomes an adult
   - How to maintain health insurance as an adult
2. Doctor usually or always encourages the youth to take age-appropriate responsibility for managing his or her own health needs

**This measure has been endorsed by the National Quality Forum (NQF)*

Figure 1: Transition to Adulthood Service by Type of Special Health Care Need in Maryland in 2009-10



- Maryland YSHCN whose condition is solely managed by prescription medication or whose condition is managed by prescription medication in combination with above routine need/use of services are more likely to meet transition to adulthood criteria.
- Maryland YSHCN who have above routine need/use of services are least likely to meet transition to criteria

* 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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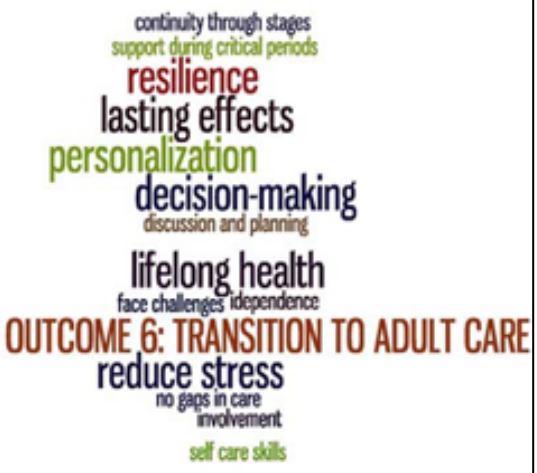
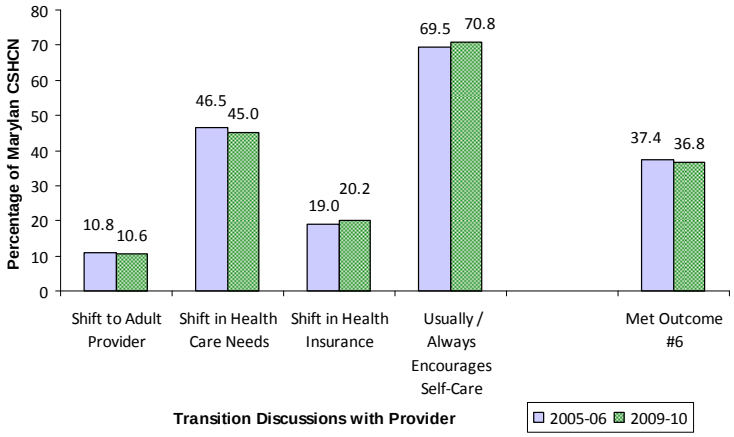


Providing the ingredients for resiliency through change.

The transition to adulthood is a critical developmental period during which youth undergo extra stress and are particularly vulnerable. The way critical periods are managed can lead to different stress response patterns and different functional trajectories. Proper support during transitions is crucial for preventing long term negative consequences. YSHCN benefit from continuity of care and support as they progressively assume more responsibility for their health needs. Children who do not receive transition services are more likely to have unmet health needs as adults. The importance of this outcome is clear, yet it is one that YSHCN are least likely to meet.

Figure 2: Percentage of Maryland CYSHCN Meeting Transition Sub-Indicators in 2005-06 and 2009-10



- Among Maryland YSHCN, the percent meeting Outcome #6 decreased slightly from 37.4% in 2005-06 to 36.8% in 2009 -10.
- Maryland YSHCN are most likely to receive encouragement from providers to take age appropriate responsibility for managing his or her own health needs (70.8% in 2009-10).
- Less than half of YSHCN (age 12-17 years) or their caregivers have had discussions regarding transition issues with their provider, with the lowest rates for discussions about a shift to adult health care providers and about a shift in health insurance.

Taking it a Step Further:
The following are questions relating to Outcome #6 that cannot be answered by this national survey data but are important to consider when evaluating how transition to adulthood can assist in improving the health and well-being of YSHCN into early adulthood:

- Was the transition to adulthood successful? How would we measure that success?
- What transition and self-care planning occurred earlier in life to prepare for transition?
- In what areas are youth taking appropriate responsibility for their own well-being with regard to nutrition, exercise, social role, self-support and reproductive future?

27.1 **Black, Non-Hispanic CYSHCN**	**30.0** **CYSHCN with inadequate insurance**	**36.8** **All Maryland CYSHCN**	43.9 CYSHCN with adequate insurance	52.2 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