

Outcome #6

CSHCN youth receive services needed for transition to adulthood

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

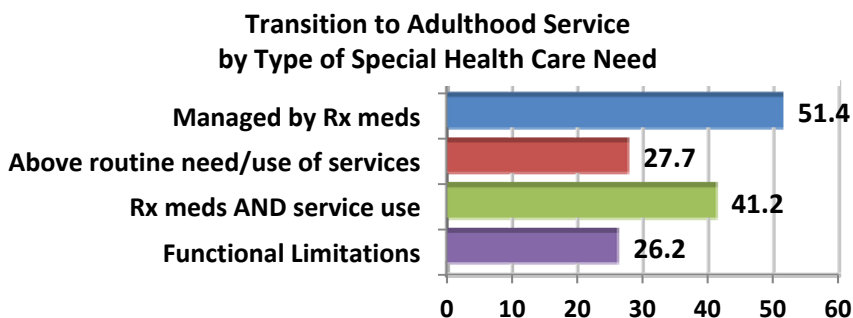
The National Survey of Children with Special Health Care Needs (NS-CSHCN) is designed to provide information on the CSHCN population and to assist in the measurement of these core outcomes. Since 2001, the NS-CSHCN has been conducted every four years. The NS-CSHCN measures each core outcome with low-threshold criteria. Outcome #6 assesses transition services for CSHCN 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 CSHCN receive transition services, with states ranging from 31.7% - 52.7%, as measured in the 2009/10 NS-CSHCN.

Measurement

For CSHCN to meet Outcome 6, the following criteria must be met (CSHCN 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 (C6Q0A_B)
 - Changing health needs as youth becomes an adult (C6Q0A)
 - How to maintain health insurance as an adult (C6Q0A_E)
2. Doctor usually or always encourages the youth to take age-appropriate responsibility for managing his or her own health needs (C6Q08)

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



- CSHCN whose condition is solely managed by prescription medication or in combination with above need/use of services are more likely to meet transition to adulthood criteria.
- CSHCN with functional limitations are least likely to meet transition to adulthood criteria.

*Emotional, behavioral or developmental (EBD) issues

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

19.6%

Uninsured
CSHCN

28.9%

CSHCN with one or
more EBD* issues

32.5%

CSHCN with more
complex needs

40.0%

All CSHCN

50.2%

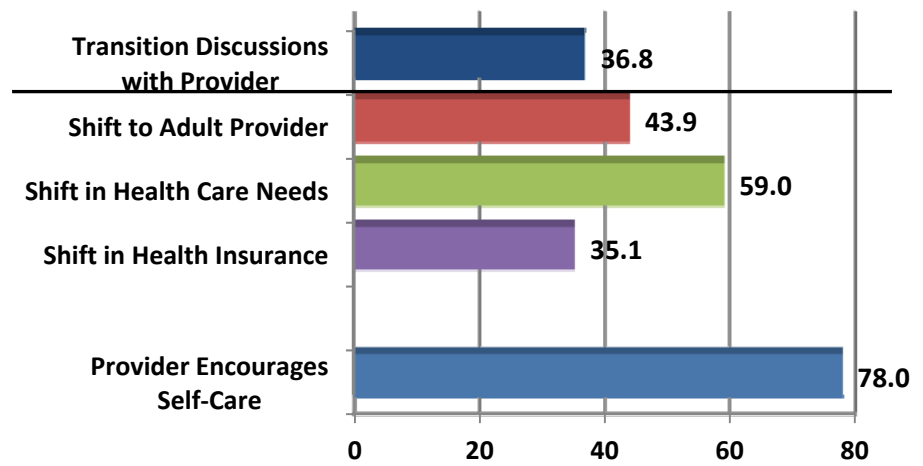
Privately insured
CSHCN

continuity through stages
support during critical periods
resilience
lasting effects
personalization
decision-making
discussion and planning
lifelong health
face challenges independence
OUTCOME 6: TRANSITION TO ADULT CARE
reduce stress
no gaps in care
involvement
self care skills

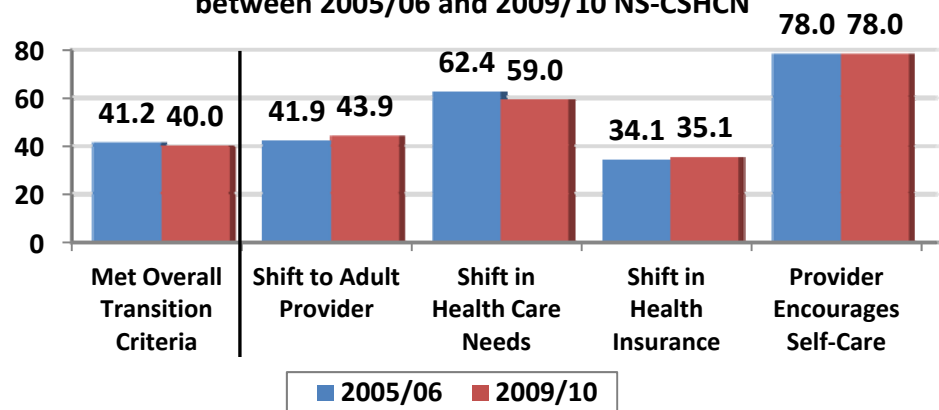
Providing the ingredients for resiliency through change.

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. CSHCN 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 the one that CSHCN are least likely to meet.

Prevalence of Specific Transition Discussions with Provider and Encouragement of Self-Care



Shifts in Prevalence of Transition to Adulthood Discussions between 2005/06 and 2009/10 NS-CSHCN



- CSHCN are most likely to receive encouragement to take age-appropriate responsibility for managing his or her own health needs (78.0%).
- However, less than half of CSHCN (age 12-17 years) have had discussions regarding transition issues with their provider, with lowest rates for discussions on shift in health insurance and shift to adult health care provider.

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 CSHCN 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?