

6 Performance Measure:

Youth with special health care needs receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.

Transition refers to the life span process of preparing for and then moving from a child-oriented perspective to one that supports the individual as he or she matures toward adult life. This requires coordination and communication in preparing families and youth with special health care needs (YSHCN) in moving from child-oriented services and supports to those that target adults. This is particularly relevant in the transition from pediatric to adult health care providers.

Why Is This Important?

While rapid advances in medical science have enabled over 90% of children born with special needs to reach adulthood, many are less likely than their non-disabled peers to finish high school, pursue post-secondary education, get jobs, or live independently. Few coordinated services have been available to assist them in the developmental transition from school to work, home to independent living, and pediatric care to adult health care. As a result, many young adults are forced to remain dependent on family members and the pediatric service system.

YSHCN want a full range of opportunities like everyone else and deserve a coordinated service system. Although Federal mandates exist and more inclusive opportunities are available, outcomes for YSHCN remain poor. The challenge is to simultaneously improve the system that serves YSHCN

and to prepare youth and their families with the knowledge and skills necessary to promote self-determination, wellness, and successful navigation of the adult service system.

State Strategies for Transition

All states have achieved partial implementation of ensuring that youth make the transition to adult life, although different processes may be used to reach this goal. Examples of strategies are presented below:

1. States are establishing youth advisory boards comprised of young adults to obtain first-hand insights into state priorities as well as to build leadership and advocacy skills.
2. Training materials and workshops are being developed to prepare youth for self-determination, by enhancing their capacity to communicate with providers and to increase their knowledge about services and supports.
3. State Title V programs are providing regional training and technical assistance to providers who coordinate transition to adult services, including the medical home.
4. State Title V and education systems are collaborating in the development of statewide data systems that include anticipated health care needs to assist agencies with planning to meet these needs.