

Youth with Special Health Needs Transition to Adulthood

Size of the Problem

There are an estimated 80,760 youth ages 12 to 18 who have special health care needs living in Minnesota - that is nearly 19% of the adolescent population.ⁱ

There are three major areas of transition:

1). Moving from school to work; 2). Changing from pediatric health care system to the adult system; and 3). Moving from dependence on family to independence. Independence might include living arrangement, managing one's health, or developing adult relationships.

Youth with special health care needs may require services to make a successful transition to adult life, including adult health care, work, and independence.

Transition		
Critical Element / Criteria	% Success (MN)	% Success (US)
Doctors have talked about changing needs.	58	46.2
Discussed how to obtain or keep health insurance as an adult.	21.4	21.3
Doctors discussed shift to adult provider if needed	22.3	19.4
Transition Outcome	52.9	41.2

Although there are limitations in the data, it is estimated that fewer than 52.9% of the youth with special health care needs in Minnesota receive needed guidance and support in their transition to adulthood.

Having a medical home – that is having a primary care provider who listens carefully and coordinates care and services – as well as having health insurance increase the likelihood that transition issues will be addressed.ⁱⁱ

Seriousness

Employment Persons with disabilities are about as likely as non-disabled peers to be employed in the ages 16 to 20 years according to the 2000

GENDER/DISABILITY STATUS	% EMPLOYED 16 TO 20	% EMPLOYED 21 TO 64
FEMALE / DISABLED	62.1	62.0
FEMALE / NON-DISABLED	60.6	79.9
MALE / DISABLED	57.5	67.6
MALE / NON-DISABLED	57.0	88.8

Census. For persons over 21, however, individuals with disabilities are significantly less likely to be employed than those without disabilities.

Disabled males experience a higher rate of employment as adults than they did as teenagers, but not to as large an extent as non-disabled peers regardless of gender. Women with disabilities are no more likely to be employed as adults than they were as teenagers.

Health Most adolescents with chronic conditions require coordinated care that frequently involves multiple health care providers. Locating adult primary care providers who are familiar with the adult sequelae of conditions originating in childhood can be difficult.



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If young people are not healthy they cannot reach their full potential in the classroom or on the job. Knowing how to manage health issues increases their chance of a successful transition from school to work and a productive adulthood.ⁱⁱⁱ

Interventions

Transition planning must begin at diagnosis. Adolescents need to know about their medical condition, and its treatment, records, health insurance, Supplemental Security Income (SSI), and the supports and services they need to have a successful transition. They should also be involved in the planning process at an individual level and also in committees that discuss and plan for children with special health care needs. Literature, informational sessions and advocacy for youth and their families are available through various organizations such as ARC Minnesota and PACER.

Individuals with Disability Education Act (IDEA) Amendments of 1997 states that when the child reaches 14 the IEP team must begin planning for the student's future. The IEP must include a statement of the student's likely transition needs and how these needs may determine what classes the student takes.^{iv} The Minnesota Disability Law Center provides a fact sheet stating the rights of disabled individuals under IDEA.^v

“Health Care Planning for Students” is transition information for youth, families and providers is available through Minnesota Children with Special Health Needs.

Status

Healthy People 2010 goal # 6 states “All youth with special health care needs will receive the services necessary to make transitions to all aspects of adult life, including adult health care, work and independence.”^{vi}

In 1993, the Maternal and Child Health Bureau established a Healthy and Ready to Work Initiative. Today projects around the country are working to ensure that health is part of the transition process and provide models of system change. One such program is at PACER Center in Minneapolis.^{vii}

Minnesota's Self Improvement Planning Process Division of Special education 2002 goal #3 states that “Transition planning will continue for secondary aged youth with disabilities and follow-up will occur for postsecondary-aged youth with disabilities.”^{viii}

Health professionals are active members on the Statewide Transition Interagency Workgroup. The mission of this group is to provide a state level policy forum to discuss issues and barriers in designing and delivering collaborative transition services to secondary-aged youth with disabilities in Minnesota. These professionals are working toward successful outcomes for students with disabilities in all adult roles.

ⁱ SOURCE: National Health Interview Survey of Children with Special Health Care Needs 2005/2006.

ⁱⁱ Kane, D., Kasehagen, L., Punyko J., et al “What Factors are Associated with State Performance on Provision of Transition Services to CSHCN?” *Pediatrics*, 2009; 124; S375-383. 2009.

ⁱⁱⁱ Healthy and Ready to Work. www.hrtw.org. “What's Health Got to Do With Transition? Everything!” 2004.

^{iv} Transition and Beyond...Now What? A guide for parents of youth with disabilities. PACER Center, Inc. pg.7. 2002.

^v Special Education Transition Planning. A fact sheet from the Minnesota Disability Law Center. May 10, 2002.

^{vi} All Aboard the 2010 Express. U.S. Department of Health and Human Services. 2001.

^{vii} Ibid Healthy and Ready to Work.

^{viii} Minnesota's Self Improvement Planning Process Division of Special Education. January, 2002.