“Today’s young people who are leaving their pediatric care and moving toward the adult health system are doing things they have never done before. This “transition” is a critical time for young adults as they are often accessing the health system independently for the very first time.”

Center for Healthcare Transition Improvement
www.gottransition.org

FOR EVERY CHILD WITH SPECIAL NEEDS AND THEIR FAMILIES

WISCONSIN DISPARITIES

- Youth with one or more emotional, behavioral or developmental (EBD) issues are less likely to receive transition services.
  - 51% No EBD issues
  - 32% EBD issues

- Girls are more likely to receive transition services.
  - 52% Girls
  - 38% Boys

- Youth with a medical home are more likely to receive transition services.
  - 55% With a medical home
  - 36% With no medical home

- Youth with inadequate insurance are less likely to receive transition services.
  - 50% Adequate insurance
  - 35% Inadequate insurance

National Performance Measure 6

Transition

Youth with Special Health Care Needs (YSHCN) receive the services necessary to make transitions to all aspects of adult life, including adult health care, work and independence

<table>
<thead>
<tr>
<th>Wisconsin Rate</th>
<th>44.4%</th>
</tr>
</thead>
<tbody>
<tr>
<td>National Rate</td>
<td>40.0%</td>
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</table>

Why is this important?

While rapid advances in medical science have enabled nearly all children born with special needs to reach adulthood, YSHCN are much 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 their transitions from school to work, home to independent living, and child and family-focused care to adult-oriented care. Transition planning must begin early in order to move children and families along in a developmental fashion.

One of the greatest challenges in planning is how to help adolescents and families make a successful transition from the pediatric to adult health care system. The goal is to improve the system that serves youth while simultaneously preparing them and their families with the knowledge and skills necessary to promote self-determination, wellness and successful navigation of the adult service system.

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1 The estimate for this outcome was arrived at using eight questions from the 2009-2010 National Survey of Children with Special Health Care Needs that asked if doctors of CYSHCN ages 12-17 usually/always encourage increasing responsibility for self-care AND (when needed) have discussed transitioning to adult health care, changing health care needs, and how to maintain insurance coverage.

CYSHCN Program Outcomes Report 2013
Wisconsin Youth Health Transition Initiative

The Wisconsin Youth Health Transition Initiative supports health care provider transition champions as they address transition issues in their own practices and health systems. The Transition Initiative coordinates and facilitates activities so that providers can network and share best practices around transition.

The "Health Transition Wisconsin" website was officially launched in 2013 as a resource for providers, collaborators, youth, and families. http://www.healthtransitionwi.org/. 608 individuals visited the site 1,245 times during the first year.

Activities in 2013

At the Regional Centers for CYSHCN

- The Southern Regional Center collaborated with the Board for People with Developmental Disabilities "Let's Get to Work" project on a transition-focused training for 250 participants.
- The Western Regional Center contracted with the Department of Human Services in Chippewa County through the Children with Differing Abilities program to provide transition planning and support to 15 young adults and their families.
- The Southeast Regional Center held two workshops: 13 adults and 6 youth attended a workshop focused on self-determination and independent living; 84 parents and providers attended another workshop focused on do-it-yourself (pro se) guardianship.
- The Northeast Regional Center held a guardianship workshop for 42 parents, youth and professionals from 11 of the 17 counties they serve. It included an overview of the guardianship process, overview of guardianship forms, and a parent panel.

Family Voices of Wisconsin

Conducted 7 "What's After High School" trainings for 166 participants in partnership with the Regional Center serving the area and with community partners including Aging and Disability Resource Centers, county public health departments, children's long term support, and local hospitals.

Wisconsin Youth Health Transition Initiative

- Co-sponsored a webcast of the Baylor University "Chronic Illness and Disability Conference" in Madison; 38 local providers participated.
- Formed the statewide Learning Community to bring together health care providers from throughout Wisconsin; three webinars were held.
- In 2014, four Transition Quality Improvement Grants were funded by the Wisconsin CYSHCN Program and administered by the Youth Health Transition Initiative. The grants support health transition quality improvement efforts at the practice level.

Wisconsin Transition by Subgroup

The percentage of families who receive transition services varies by the type of special health care need, family structure, household income and type of insurance.

By type of special health care need (percent meeting the outcome)
- Managed by prescription medications (53.1)
- Above routine need/use of services (30.8)
- Prescription medications and service use (47.0)
- Functional limitations (25.5)

By family structure (percent meeting the outcome)
- Two-parent biological or adoptive family (50.3)
- Two-parent family, at least one step-parent (50.1)
- Mother only–no father present (36.3)
- All other family structures (24.1)

By household income as measured by Federal Poverty Level [FPL] (percent meeting the outcome)
- 400% FPL or more (58.4)
- 300-399% FPL (43.3)
- 200-299% FPL (38.6)
- 0-199% FPL (36.0)

By type of insurance (percent meeting the outcome)
- Private insurance only (53.3)
- Public insurance only (26.9)
- Both public and private insurance (39.6)
- Uninsured (NA*)

* Sample sizes too small to meet standards for reliability or precision