Wisconsin Youth Health Transition Initiative

**Slide 1**

**Wisconsin Youth Health Transition Initiative**

The Wisconsin Youth Health Transition Initiative is focused on providing up-to-date health care transition resources, materials, events and news related to health care transition for adolescent aged youth. This includes information and resources to drive individual, family, clinic practices, an organization’s transition initiatives forward, offering statewide activities such as webinars and conferences taking place in Wisconsin and nationally.

www.healthtransitionwi.org

**Wisconsin Medical Home Initiative (website)**

Physicians can learn strategies for promoting family involvement in clinic practice, and trainings are available for families on how to partner with their child’s physician. Conversations are focused on how families and physicians can share decision-making to promote optimal outcomes for children.

www.wismhi.org/wismhi/Clinicians/Family-Partnership

**Family Voices of Wisconsin (website)**

Helps families who have children with disabilities or special health care needs navigate health care and community supports. Their work focuses on education and information, family leadership and policy and systems change. They are the home of the Family Voices state affiliate organization and Wisconsin’s Family to Family Health Information Center. In addition, they are recognized as the family leadership hub for Wisconsin’s Children and Youth with Special Health Care Needs partnership.

www.familyvoicesofwisconsin.com

**Center for Patient Partnerships (website)**

The Center for Patient Partnerships works to empower patients in the healthcare system, advocating for patients and their families, educating future professionals, and performing research to help make medicine more inclusive.

www.patientpartnerships.org

**Patient Engagement in Redesigning Care (toolkit resources)**

Intended for use by hospital and clinic directors, managers, clinicians and researchers, this resource contains tools to strengthen the role of patients in teams designing health care delivery and quality improvements

https://www.hipxchange.org/PatientEngagement

**Family Engagement Categories (pdf)**

Intended for use in family engagement. Link to figure referenced in presentation.


**Providers and Teens Communicating for Health (PATCH) (website)**

They work in our communities to educate, engage, and empower young people in the State of Wisconsin to take control of their own health.

www.wipatch.org

**Learning Community May 2018 (direct link to presentation)**

Successfully Partnering with Youth: Strategies for Including Young Adult Perspectives to Improve Adolescent Health Outcomes - Wisconsin Transition Learning Community & PATCH

Presenters: Erica R. Koepsel, MA PATCH Program Manager and Eliette Soler, PATCH Teen Educator

View presentation at the following link: https://www.youtube.com/watch?v=p6wuJDhpl-E
The Wisconsin Youth Health Transition Initiative helps youth (ages 12 through 17), their families, and their health care team prepare for the change from child to adult health care. We offer information, tools, and resources about what to expect and how to prepare.

Our goal is to increase the number of youth who receive the support necessary to feel confident making individual choices about their health and health care.

We encourage idea sharing and best practices around health transition based on Got Transition’s Six Core Elements of health care transition.

**Health Transition Wisconsin**

**Moving from Child to Adult Health Care**

Very few youth receive the services necessary to successfully transition to adult life. These include areas like adult health care, decision-making, work, and independence.

**Nationwide**

1 out of 6 with special health care needs receive services

1 out of 7 without special health care needs receive services

**Wisconsin**

1 out of 5 with special health care needs receive services

1 out of 6 without special health care needs receive services

Data from the 2016 National Survey of Children with Special Health Care Needs including physical and mental health, access to quality health care, and the child’s family, neighborhood and social context. Access at childhealthdata.org.

**Tools & Resources Available**

- Checklists & Skill Building
- Pocket Guide
- Learning Community
- Wisconsin Regional Centers
- Education & Awareness Events
- Website

**National & State Performance**

**Youth & Families**

- Encourage Wisconsin’s youth and their families to make individual choices to enhance their health and well-being.
- Provide Wisconsin and national health transition tools and resources.
- Build Your Bridge trainings

**Health Care Systems**

- Partner with health care systems, providers, and the community to share health transition tools and resources statewide.
- Support practices and health care systems to initiate processes to increase awareness and skills that encourage successful health care transition.

**Community Supports**

- Provide youth with special health care needs and their families with connections to our network of Wisconsin collaborators.

**Website**

www.gottransition.org

**Contact**

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healthtransitionwi.org
Annotated Transition Resources

Wisconsin Youth Health Transition Initiative

Insights into the Patient and Family Experience


Thirty-five studies met the criteria for this systematic review of literature concerning the health care transition needs of adolescents and emerging adults with special health care needs. Findings indicated that these individuals want to be part of the transition process and seek providers who will listen and appropriately support their unique care needs. Some of the challenges for patients include a lack of a) organized transfer processes from pediatric to adult care, b) anticipatory guidance about health care transitions and, c) understanding of the differences between pediatric and adult care delivery systems. More research is needed to guide evidence-based practice.


Two parallel surveys, one of parents of adolescents with special health care needs and the other of health care providers (mostly pediatricians), demonstrated significant differences in the respective perceptions about the involvement and extent of providers’ responsibility across 13 transition activities. Broadly, parents were more focused on access, quality, and coordination of care while providers focused on health promotion (e.g., discussion on drugs, alcohol, sexual issues, and general health management). Despite several study limitations, the findings suggest a need for providers, adolescents, and their parents to openly discuss care needs and priorities relevant to transition activities.


This article includes personal perspectives from three young adults with complex health needs. Challenges and strategies relevant to meeting their needs are discussed and provide insights for improving the health transition experience for patients and providers alike.


Across four provider focus groups, 28 providers (primary and specialty care; physicians, physician assistants, nurse practitioners, registered nurses, and social workers) participated in semi-structured interviews concerning their perceptions about transition care and their patients’ self-care management. Six themes emerged: 1) identifying the appropriate time or age for transition, 2) providers’ challenge to support and encourage transition (i.e., reluctance to let go), 3) parental and patient fears related to transitioning to a new provider (i.e., fear of the unknown; lessening of parental involvement), 4) lack of provider experience and comfort with meeting transition needs, 5) need for consistent transition policies and tools, and 6) need for a collaborative pediatric/adult team approach to transition.
Insights into the Patient and Family Experience (continued)

5. WITH Foundation (formerly The Special Hope Foundation). (2016). Bridging the gap: Improving healthcare access for people with disability. Available at https://withfoundation.org/

Though specifically directed to health care professionals, this video is a powerful teaching tool for anyone seeking to understand how to best support people with disabilities. A woman with a disability and her husband share their experiences -- both good and bad -- with health care professionals. Their perspectives offer valuable teaching points for health care providers.

Total time: 10.43”. Alternate shorter version (6.09”): https://drive.google.com/file/d/0B5PGH8Hjq-zsZTh8kJKRE1kSzA/view?pref=2&pli=1


This video, useful for anyone supporting individuals with disabilities, focuses on the topic of supported decision-making from the perspective of a young woman with spina bifida. She shares her very personal feelings -- being scared of making a decision to have eye surgery and shutting down; feeling great to have support in making decisions, and having others see her as she would like to be seen.

There is an assumption that a person with a disability is a perpetual child. Guardianship in appointing someone else to make decisions can take away the legal status of an individual and make it a legal reality. Most people with disabilities are able to make their own choices yet some like others to help them make decisions. Individuals in this video also advocate for a legally recognized model of supported decision-making.

Total time: 10.56”. Alternate shorter version (9.29”): http://specialhope.org/healthcare-access-for-people-with-disabilities-special-hopes-video-shorts-tell-the-story/

Wisconsin-Specific Health Care Provider and Patient Resources


Each of Wisconsin’s 72 counties has an Aging and Disability Resource Center. These are intended as “one-stop” sites for information and assistance regarding services available for all individuals 18 years of age and older living in Wisconsin. Adult health care providers may refer a patient to the patient’s respective ADRC (based on county of residence) for general information on community resources available or for options counseling if the patient is in need of services to support management of chronic conditions or other special health care needs.


Five Regional Centers dedicated to supporting families with children and youth with special health care needs and the providers who serve them; special focus on youth transition. Locations: Chippewa Falls (Western), Madison (Southern), Neenah (Northeast), Wausau (Northern), and Wauwatosa (Southeast).