

Selected Annotated Youth Health Transition Resources for Health Care Providers

This annotated list has been compiled by the Waisman Center for Health Care Professionals. It includes several of the resources that ground our transition work, as well as opportunities to participate in CME, or to facilitate further understanding of the lived experiences of individuals and families with disabilities.

Foundational Transition Research

1. White PH, COOLEY WC, TRANSITIONS CLINICAL REPORT AUTHORIZING GROUP, AMERICAN ACADEMY OF PEDIATRICS, AMERICAN ACADEMY OF FAMILY PHYSICIANS, AMERICAN COLLEGE OF PHYSICIANS. Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home. *Pediatrics*. 2018; 142(5):e20182587

This foundational article is a primary source that guides our work in youth to adult transition at the Waisman Center. The article has been updated recently and reflects current data on the progress of transition in the medical home in the United States.

Continuing Medical or Nursing Education

2. American Academy of Developmental Medicine and Dentistry [AADMD]. (2016). *NPEDD webinar series Nurse practitioner education in developmental disabilities*. Available at <http://aadmd.org/npedd-webinar-series>

A great CME for providers with limited knowledge of disabilities and the unique health issues that comes with them who are looking to learn about developmental disabilities and pearls for multiple facets of caring for individuals. No-cost 7.0 credit hour webinar series (approved for CEU by the American Association of Nurse Practitioners (Program ID 1503144. Sponsored by United States Department of Health and Human Services, Administration on Developmental Disabilities and the Florida Developmental Disabilities Council, Inc. and the Carolina Institute for Developmental Disabilities.

3. American Academy of Developmental Medicine and Dentistry [AADMD]. (2016). *PEDD webinar series Physician education in developmental disabilities*. Available at <http://aadmd.org/page/pedd-webinar-series>

For new learners with minimal background in transition and developmental disabilities who want a thorough grounding using online education resources. A series of 12 webinars recorded in 2012; offers downloadable slides and a quiz that can be taken at the end for CME or to get a certificate for those health professionals who don't use CME. The course is free, but a user needs to register, provide a "profile" and create a user ID and password. The Transition module (#9) contains good basic and accurate information about youth to adult health care transitions with links to lots of good resources though not a lot of practical steps for immediate implementation into practice.

4. American College of Physicians. (2016). *Guidelines and tools developed for pediatric-to-adult health care transitions initiative*. Available at <https://www.acponline.org/acp-newsroom/guidelines-and-tools-developed-for-pediatric-to-adult-health-care-transitions-initiative>

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With customization to individual clinical practice situations, primary and specialty care providers will find these comprehensive transition guidelines and tools particularly practical. Multiple versions in four categories (teen, adult, caregiver, and provider) are available by specialty and by condition. The well thought out, well-written questions are provided in a format patients can understand and quite succinctly inquire about different areas of knowledge that will benefit a patient and their care – do you know your meds and what they are for, when to take, etc.; do you know who to call in an emergency; can you identify your insurance provider and how to contact them, etc. Aligned with Got Transition™ resources.

5. The National Alliance to Advance Adolescent Health. (2016). *GotTransition*. Available at <http://www.gottransition.org>
6. Vanderbilt Kennedy Center for Excellence in Developmental Disabilities. (2016). Health care for adults with intellectual and developmental disabilities Toolkit for primary care providers. Available at <http://vkc.mc.vanderbilt.edu/etoolkit/>

Appropriate for any health care provider working with adults with intellectual and developmental disabilities (IDD), this toolkit deals with strategies for effective interaction with adults with IDD in a healthcare setting, including broad suggestions for strategies to use in interacting with patients with detailed content concerning specific conditions and, particularly, responding to behavioral and mental health challenges often encountered.

Insights into the Patient and Family Experience

7. Betz, C.L., Lobo, M.L., Nehring, W.M., & Bui, K. (2013). Voices not heard: A systematic review of adolescents' and emerging adults' perspectives of health care transition. *Nursing Outlook*, 61, 311-336. <http://dx.doi.org/10.1016/j.outlook.2013.01.008>

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.

8. Geenen, S.J., Powers, L.E., & Sells, W. (2003). Understanding the role of health care providers during the transition of adolescents with disabilities and special health care needs. *Journal of Adolescent Health*, 32(3), 225-233. [An older article yet offers relevant insights]

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.

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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.

9. Hopper, A., Dokken, D., & Ahman, E. (2014). Transitioning from pediatric to adult health care: The experience of patients and families. *Pediatric Nursing*, 40(5), 249-252.

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.

10. O'Sullivan-Oliveira, J., Fernandes, S.M., Borges, L.F., & Fishman, L. N. (2014). Transition of pediatric patients to adult care: An analysis of provider perceptions across discipline and role. *Pediatric Nursing*, 40(3), 113-120 and 142.

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.

11. 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://withfoundation.org/healthcare-access-for-people-with-disabilities-special-hopes-video-shorts-tell-the-story/>

12. WITH Foundation (formerly The Special Hope Foundation). (2016). *Supported decision making Gabby's story*. Available at <http://specialhope.org/>

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

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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

13. Wisconsin Department of Health Services. (2016). *Aging and Disability Resource Centers (ADRC) Consumer Page*. Available at <https://www.dhs.wisconsin.gov/adrc/index.htm>

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.

14. Wisconsin Department of Health Services. (2016). *Regional centers for children and youth with special health care needs (CYSHCN)*. Available at <https://www.dhs.wisconsin.gov/cyshcn/regionalcenters.htm>

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).