FACT SHEET

Improving the Transition from Pediatric to Adult Health Care for Oregon's Youth with Special Health Care Needs

Rev. 4/26/2021

Youth with special health care needs (YSHCN) face adverse outcomes when they don't have a structured pediatric-to-adult health care transition process. These outcomes include problems with treatment adherence, gaps in care, dissatisfaction with care, avoidable morbidity, and preventable hospital visits.[1,2] Successful transitions to college, employment, and independent living often depend on the ability of youth and young adults to manage their own health care and navigate adult systems of care.

The aim of health care transition (HCT) is to (1) ensure an organized clinical process in pediatric and adult practices to facilitate HCT preparation, transfer of care and integration into adult-centered care, and for youth who are able, (2) improve the ability of youth and young adults to manage their own health care and effectively use health services.[3]

According the 2018-19 National Survey of Children's Health, 45% of Oregon youth aged 12-17 had a special health care need.[4] Family members of those youth with special health care needs reported that:

- 69% did not get health care transition preparation services
- 38% did not have time alone with their provider during their last check-up
- 21% did not learn skills for managing their own care from their health care providers
- 44% did not get help from their health care provider to understand the changes in care that happen at age 18. [5]

For young adults with special heath care needs, effective transition from pediatric to adult health care results in

increased:

- ↑ Adherence to care
- ↑ Adult clinic attendance
- ↑ Patient satisfaction
- ↑ Quality of life
- ↑ Self-care skills

and ***decreased:***

- ↓ Lapses in care
- ↓ Perceived barriers to care
- ↓ Hospital admission rates
- ↓ Hospital lengths of stay
- ↓ Morbidity and mortality

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OCCYSHN Strategies and Activities to Improve Health Care Transition (HCT) for Youth with Special Health Care Needs (YSHCN)

Educate and train health care providers and families of YSHCN about best practices to support successful HCT.

- ✓ OCCYSHN hosts regular statewide conferences to build capacity for cross-systems care coordination, including support for HCT.
- ✓ OCCYSHN and the Oregon Family-to-Family Health Information Center offer a regular 60-minute training called "Planning for a Healthy Transition," for YSHCN and their families.

Expand HCT quality-improvement and infra-structure efforts in both pediatric and adult clinic settings.

- ✓ As part of the Children with Medical Complexity Collaborative Improvement and Innovation Network (CMC CoIIN), OCCYSHN partners with Doernbecher General Pediatrics and Adolescent Health Clinic and others on quality improvement.

Build partnerships with key stakeholders to advance "what works" in Oregon.

- ✓ OCCYSHN tracks and supports HCT efforts statewide, and promotes successful strategies and lessons learned.

Expand the involvement of YSHCN needs and their families in efforts to improve HCT.

- ✓ OCCYSHN engages parents and youth to share their lived experience with health care professionals in training and technical assistance activities.

Advocate for HCT provisions in health policy and administration.

- ✓ OCCYSHN offers HCT input on Medicaid contracts, Patient-Centered Primary Care Home Standards, and Department of Consumer and Business Services Insurance Council policies, among others.
- ✓ OCCYSHN promotes the use of HCT-related billing codes and value-based payment options with public and private insurance payers.[6,7]

Oregon Center for Children and Youth with Special Health Needs (OCCYSHN) is Oregon's public health agency for children and youth with special health care needs. OCCYSHN is funded through the Oregon Health Authority, with a designated portion of the state's annual US Maternal and Child Health Bureau (MCHB) Title V Block Grant.

Oregon is one of 36 states and territories that has selected health care transition for YSHCN as an MCHB National Performance Measure.

OCCYSHN is interested in collaborating to improve HCT. Contact Marilyn Berardinelli, berardin@ohsu.edu or Alison J. Martin, martial@ohsu.edu.

For additional HCT resources, visit GotTransition.org. Got Transition® is operated by The National Alliance to Advance Adolescent Health with funding support by the Health Resources and Services Administration of the U.S. Department of Health and Human Services under grant number, U1TMC31756.

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[1] Gabriel P, et al. Outcome evidence for structured pediatric to adult health care transition interventions: A systematic review. *The Journal of Pediatrics*. 2017;188:263-9.
[2] Schmidt A, et al. Outcomes of pediatric to adult health care transition interventions: An updated systematic review. *Journal of 3. Pediatric Nursing*. 2020;51:92-107.
[3] White P, et al. Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics*. 2018;142(5):e20182587.
[4] Child and Adolescent Health Measurement Initiative [CAHMI]. (2020). 2018-2019 National survey of children's health (NSCH) data query. Retrieved from www.childhealthdata.org.
[5] The Child and Adolescent Health Measurement Initiative advises that consumers use caution when interpreting these estimates due to small sample size.
[6] McManus M, et al. *Recommendations for Value-Based Transition Payment for Pediatric and Adult Health Care Systems: A Leadership Roundtable Report*. Washington, DC: The National Alliance to Advance Adolescent Health, 2018.
[7] McManus M, et al. *2020 Coding and Reimbursement Tip Sheet for Transition from Pediatric to Adult Health Care*. Washington, DC: Got Transition®, 2020.

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