Oregon's Youth with Special Health Care Needs: Transitioning to Adult Health Care

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Moving from pediatric to adult health care can be a challenge for any young person. That transition may be especially complicated for youth with special health care needs (YSHCN). YSHCN usually need to find new health care providers who can treat their conditions. They might also need to navigate financial or legal changes. Most youth (age 18-23) in one study were unprepared to manage their own health care.[1]

YSHCN usually grow up to become adults with special health care needs. Over 90% of YSHCN live to adulthood, but they are less likely than others their age to complete high school, attend college, or be employed.[2] Health and health care are two key challenges to a successful transition to adulthood.[3] Because YSHCN are likely to become adults with chronic conditions, preparing for their adult health care can help contain costs and improve quality of life. [4]

The transition to adult healthcare is more successful when it is planned in advance,[5] but that planning does not always happen. National data show that most Oregon YSHCN (age 12-17) do not get the help they need transitioning to adult healthcare.

Value	Description
35.6%	Percent of Oregon YSHCN who got necessary transition services.
64.4%	Percent of Oregon YSHCN who did not get necessary transition services.

Data Source: National Survey of Children with Special Health Needs 2009/2010

Fewer than half of the health care providers who responded to OCCYSHN's 2015 Needs Assessment survey reported that they help teen patients prepare for adult health care. YSHCN confirmed those numbers in their responses. Only 12% of YSHCN said their doctor

To manage their own health care, young adults need the skills to:

- Find adult health care providers who can meet their needs
- Make and keep medical appointments
- Manage medications
- Make best use of their health insurance and other financial resources (e.g. Supplemental Security Income)

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talked with them about finding a new healthcare provider when they turn 18.

As part of the 2015 Needs Assessment, OCCYSHN held a panel discussion with families and professionals who serve YSHCN. Transitioning to adult health care was one of the discussion topics. The panelists said that while there are educational and vocational resources for Oregon YSHCN, there is less focus on their health care. Health problems can interfere with work or school, making it especially important for YSHCN to plan for their future care.

The panel concluded that Oregon health care providers need more guidance. Helping teen and young adult patients prepare for adult health care is not a regular part of medical training. Pediatric health care providers might not know how best to help. The panel recommended increased training for professionals on how to support patients as they transition to adult health care.

Panelists also noted that more support is needed for those families of YSHCN who might never be able to manage their own care, because their health conditions make it impossible. In addition to finding adult health care providers for their YSHCN, these families need to have legal and financial matters organized so that they can continue to manage their child's care into adulthood.

Health care providers can help youth with special health care needs transition to adult health care in the following ways:[6]

- Create and follow standard procedures in their practices to help YSHCN prepare for adult health care.
- Keep track of the YSHCN patients who are ready to transition to an adult care provider, and which patients have already done so.
- Discuss with YSHCN and their families what help they need to transition to adult health care.
- Work with each youth and family to make a plan that fits with the family's culture.
- Communicate the transition plan to the youth's adult health care provider.
- Be available to consult with new adult health care providers about the patient.
- Follow up with YSHCN 3-6 months after transferring care to see how things are going.

The full report of the 2015 Needs Assessment findings from the Oregon Center for Children and Youth with Special Health Needs is available online at www.occyshn.org\publications. This publication is available in alternate formats.

[1]McManus, M., White, P., Pirtle, R., Hancock, C., Ablan, M., & Corona-Parra, R. (2015). Incorporating the six core elements of health care transition into a Medicaid managed care plan: Lessons learned from a pilot project. Journal of Pediatric Nursing, 30, 700-713.
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[3]Park, M. J., Adams, S. H., & Irwin, C. E., Jr. (2011). Health care services and the transition to young adulthood: challenges and opportunities. Academic Pediatrics,11(2), 115-122.
[4] Perrin, JM, Bloom, SR, & Gortmaker, SL. (2007). The increase of childhood chronic conditions in the United States. JAMA, 297(4), 2755-2759.
[5]Got Transition. (2014a). News & announcements: transition planning impacts. Retrieved on December 20, 2014, from http://www.gottransition.org/news/index.cfm.
[6]VanLandeghem, K., Sloyer, P., Gabor, V., & Helms, V. (2014). Standards for systems of care for children and youth with special health care needs. A product of the National Consensus Framework for Systems of Care for Children and Youth with Special Health Care Needs project. Washington, DC: Association of Maternal & Child Health Programs.