



November 1, 2019

Health Systems Division Rules Advisory Committee

OCCYSHN

Oregon Center for Children and
Youth with Special Health Needs

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Dear Health Systems Division Rules Advisory Committee:

The Oregon Center for Children and Youth with Special Health Needs (OCCYSHN) is Oregon's public health agency for children and youth with special health needs. We are grateful for this opportunity to provide input to the CCO 2.0 rules. It is a federal Maternal and Child Health Bureau priority to ensure that youth with special health needs can transition successfully from the pediatric to adult health care systems. Our recommendations are aimed at that goal.

Nearly one in five Oregon children has an identified special health care need.¹ More than 90% of these children live to adult-hood, but they are less likely than their peers to complete high school, attend college, or be employed.² Optimizing health and ensuring access to high quality health care are two key components of a successful transition to adulthood.³

The American Academy of Pediatrics reports that a lack of support for transitioning youth with special health care needs from pediatric to adult health care is associated with loss to care, higher costs of care, including higher emergency department use and hospitalization.⁴ Nearly three-quarters of youth (age 12-17) with special health care needs reported that they did not receive services necessary for the successful transition to adult health care.⁵ The CCO 2.0 rules offer a valuable opportunity to address the particular needs of young adults transitioning from pediatric to adult health care.

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¹ Child and Adolescent Health Measurement Initiative. (2019). 2017-2018 National Survey of Children's Health (NSCH) data query. Retrieved 10-22-2019 from <https://www.childhealthdata.org/browse/survey/results?q=7282&r=39>.

² U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. (2013). The National Survey of Children with Special Health Care Needs Chartbook 2009-2010. Rockville, MD: Author.

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 White, P. H., Cooley, W. C., Group, T. C. R. A., Pediatrics, A. A. O., Physicians, A. A. of F., & Physicians, A. C. O. (2018). Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home. *Pediatrics*, 142(5), e20182587. <https://doi.org/10.1542/peds.2018-2587>

⁵ Child and Adolescent Health Measurement Initiative. (2019). 2017-2018 National Survey of Children's Health (NSCH) data query. Retrieved 10-22-2019 from <https://www.childhealthdata.org/browse/survey/results?q=7276&r=1&r2=39>



RECOMMENDATIONS

1. Overall Use of “Transition”

The word “transition” is used frequently in the proposed CCO 2.0 rules. It usually refers to the transition of care from one provider or institution to another; but sometimes it refers to other sorts of transition, like changing CCOs or providers. When OCCYSHN talks about “transition,” we are talking about youth with special health care needs *transitioning from pediatric to adult health care providers and systems*.

OCCYSHN RECOMMENDS that when the word “transition” is used in the rules, it’s meaning is clarified as to what sort of transition is meant. For example, “care transition,” or “transition to a new CCO,” or “transition from pediatric to adult health care.” This will help clarify the intent of each rule.

2. Proposed Rule 410-141-3705 Criteria for CCOs (1) (C)

Existing draft language: “Contract provisions, including an approved Transformation and Quality Strategy (TQS) and work plan for implementing health services transformation, shall describe how the CCO will comply with transformation requirements under these rules throughout the term of the CCO contract to maintain compliance.”

OCCYSHN RECOMMENDS that activities related to the transition from pediatric to adult health care for youth with special health needs be included in TQs, and that value-based payments be made for these activities.

3. Proposed Rule 410-141-3705 Criteria for CCOs (12)

Existing draft language: “CCOs shall assure that members have a choice of providers within the CCO’s network, including providers of culturally and linguistically appropriate services and their providers participating in the CCO and shall: (A) through (I)”

OCCYSHN RECOMMENDS that CCOs be required to identify adult health care providers who are prepared to care for young adults with special health care needs and provide a warm hand-off for youth and young adults transiting from pediatric to adult care. This must include primary care, specialty and subspecialty care.



Thank you for your efforts to improve Oregon's health care systems. CCO 2.0 has the potential to improve care and reduce costs for young adults with special health care needs, which would benefit us all.

Sincerely,

A handwritten signature in black ink, appearing to read "Benjamin Hoffman", is written over a light gray circular stamp.

Benjamin Hoffman, MD

OCCYSHN Director

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