

## Background

Health care transition (HCT) is “the process of getting ready for health care as an adult.”<sup>1</sup> The lack of a structured, successful transfer from pediatric to adult healthcare has been associated with challenges with treatment adherence, gaps in care, dissatisfaction with care, and preventable hospital visits.<sup>2,3</sup>

The Oregon Center for Children and Youth with Special Health Care Needs leads Oregon’s participation in a 10 state learning collaborative focused on children with medical complexity. We partner with Family Leaders, and a physician and nurse from OHSU’s General Pediatrics and Adolescent Health Clinic in Portland, Oregon.

Our project focuses on improving HCT for young adults with medically complex conditions (YAMC).

At the start of our project, our family leaders interviewed 12 caregivers of YAMC whose youth were ages 18 through 22 years and recently transferred. Caregivers reported that they were not prepared for transition or supported in the actual transfer from pediatric to adult health providers.<sup>4</sup>

Our quality improvement (QI) project sought to prepare YAMC and their families to transfer to an adult primary care physician (PCP), help identify an adult PCP, and support establishing care with the adult PCP.

### Study authors:

Alison J. Martin, PhD, MA, [martial@ohsu.edu](mailto:martial@ohsu.edu)

Reyna Lindert,

Ana M.D. Valdez, Family leader

BranDee Trejo, Family leader

Tamara Bakewell, MA, Family leader

Shreya Roy, PhD

Marilyn Berardinelli, BS

Sheryl Gallarde-Kim, MSc

Reem Hasan, MD, PhD

**OCCYSHN**

Oregon Center for Children and  
Youth with Special Health Needs  
[www.occyshn.org](http://www.occyshn.org)

# Pediatric Primary Care Provider Concerns and Preparation for Adult Healthcare Transfer of Medically Complex Young Adults

QI test period: September – December 2019

## Quantitative Results

Eligible patients	41
Pediatrician denial	26 (63%)
Pediatrician approval	15 (37%)
Patient/family enrollment	8 of 15 (53%)

## Qualitative Results: Reasons for declining

### Provider reasons

- YAMC not ready
- YAMC experiencing active health problems
- Provider desire to keep patient in panel

## Quality Improvement Intervention

Three-stage intervention to prepare for transfer:  
(1) understanding the medical home;  
(2) creation of a medical summary; and  
(3) identification of adult PCPs.

## Participants & Recruitment

### Eligibility Criteria

- Age 17 years and older
- Pediatric Medical Complexity Algorithm Complex Chronic Disease category (Simon et al, 2014)
- Likely transfer within 12 months

Physician or nurse requested pediatrician permission to approach the YAMC, after which the youth and family were approached to participate.

## Learning

Discussion of primary care transition needs to start when the patient is younger to prepare patients, families, and providers.

A clinic policy for age of transfer, or age for determining when transfer would occur, is essential.

## References

<sup>1</sup>Got Transition. (2014-2021). *What is health care transition?* Retrieved from: <https://www.gottransition.org/youth-and-young-adults/>.

<sup>2</sup>Gabriel P, et al. (2017). Outcome evidence for structured pediatric to adult health care transition interventions: A systematic review. *The Journal of Pediatrics*, 188, 263-9.

<sup>3</sup>Schmidt A, et al. (2020). Outcomes of pediatric to adult health care transition interventions: An updated systematic review. *Journal of Pediatric Nursing*, 51, 92-107.

<sup>4</sup>Roy, S, et al. (under revision). “All circuits ended”: Family experiences of transitioning from pediatric to adult healthcare for young adults with medical complexity in Oregon. *Journal of Pediatric Nursing*.

This project is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under UJ6MC32737, CMC CoIIN project. This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS, or the U.S. Government

