Oregon lacks behavioral and medical health providers to work with young adults who are medically complex.

Adult providers do not accept YAMC because they do not accept OHP. (Many practitioners often are providers who accept OHP, and families of YAMC are often anxious about working with a VIP versus an HIC.)

Adult providers do not accept YAMC because they are not reimbursed (or not reimbursed at a rate equal to a standard visit) for longer appointments.

Few service models perpetuate providers not wanting to work with patients who require a 40 versus 20 minute appointment.

Adult providers do not accept YAMC because they lack understanding or familiarity with their conditions or are uncomfortable working with them.

Some child psychiatrists will not see youth who are older than 18 years; some adult providers will not see adults who are younger than 24 years.

Pediatric providers may be more comfortable referring to internal medicine than family medicine because of the lack of behavioral or medical health providers.

Pediatricians do not have a resource that describes how to work with family members of a YAMC patient/appreciate for showing the family member that they have been heard.

PCPs and specialists do not have a consistent way to provide families with referrals to adult providers.

Some pediatric practices expect that adult primary care is helping to prepare pediatricians for the transition.

Pediatric providers may lack access to transitional care and at times lack a primary care provider to coordinate care.

Specialists may have varying degrees of understanding about transition, and parents of YAMC can consider one of their child's specialist's desire to be their "medical home."

Adult providers who work with YAMC lack understanding of the developmental needs of young adults, which inhibits their ability to communicate/work effectively with YAMC.

Some adult providers do not listen to young adults when they explain their expertise and history with their conditions.

Adult providers who work with YAMC lack knowledge/experience with YAMC processes.

Adult providers who do not accept YAMC lack understanding of how to work with YAMC patient.

Adult providers who do not accept YAMC lack knowledge/experience with YAMC providers.

Pediatric providers lack access to a warm handoff to an adult provider and sometimes do not know that they have the information because it is buried in the EHR.

Pediatric and adult behavioral/mental and physical health providers lack knowledge about healthcare transitions; this is a "new concept." Pediatric physical health providers do not understand what围on care transitions should entail and are figuring transition out as they go. Pediatric behavioral/mental health providers do not know or are not tracking that a child's care will cease once the CHM turns 18.

JCT is a consideration for their child's healthcare and/or the incremental steps to take to begin preparing themselves/their children for transition.

Parents are reluctant to give up their caregiver role.

Concurrent transitions (to adult healthcare, work, independent living) compose the barrier to adult healthcare. This relates to Quality of Life.

Parents often lack understanding that HCT is a consideration for their child's healthcare and/or the incremental steps to take to begin preparing themselves/their children for transition.

Developmental disability and foster care staff lack understanding about health care transition and how to contribute to the transition preparation of their clients.

Some pediatric practices expect that adult primary care is helping to prepare the YAMC locate adult specialists.

### Inadequate Preparation for Transition from Pediatric to Adult Healthcare for Oregon Young Adults With Medical Complexity: Root Cause Analysis

**Problem Statement**

Young adults with medical complexity (YAMC) and their families are not adequately prepared for, or supported in, the transition from pediatric to adult healthcare.

- A transfer package has not been uploaded to EHR or is not immediately visible in EHR, helping to prepare adult providers to receive YAMC.
- Healthcare settings lack secure methods to ensure the shared care plan is shared in a timely manner with the right providers.
- Settings are not created through which YAMC care is improved.
- There is a period of time between 8 and 12 years old when we should be intentional about transition and the patient, the families and primary care are not informed, and the bulk of supports are available only through the education sector.

**Policies**

- Healthcare settings inconsistently use technology to support transition and improvement of self-management skills.
- Developmental disability and foster care staff lack understanding about health care transition and how to contribute to the transition preparation of their clients.
- Some pediatric practices expect that adult primary care is helping to prepare the YAMC locate adult specialists.

**Place/Technology**

- There is a period of time between 8 and 12 years old when we should be intentional about transition and the patient, the family and primary care are not informed, and the bulk of supports are available only through the education sector.

**Procedures/Materials**

- Providers lack access to a warm handoff to an adult provider and sometimes do not know that they have the information because it is buried in the EHR.
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 care needs (CYSHCN). OCCYSHN does not provide direct clinical care. We support systems of care so they are better equipped to meet the needs of this vulnerable population. See OCCYSHN’s website for more about our work.

Oregon is one of ten states participating in a four-year (2017-2021) initiative to improve the quality of life for children with medical complexity (CMC) using a Collaborative Improvement and Innovation Network (CoIIN) approach. The initiative is funded by the U.S. Maternal and Child Health Bureau, and led by Boston University. OCCYSHN is leading Oregon’s participation in the CoIIN.

Oregon’s project Advisory Team consists of Family Representatives, who are parents of young adults with medical complexity, and representatives of Children’s Health Alliance/Foundation, OHSU General Pediatrics, Shriners Hospital for Children Portland, and OCCYSHN.

The Oregon team identified transition from pediatric to adult healthcare providers as the focus for its quality improvement (QI) work. We selected this area of focus because CYSHCN less often receive services necessary to transition to adult healthcare providers than children and youth without special health care needs. Additionally, the issue is an OCCYSHN priority for its Title V Maternal and Child Health Services Block Grant work.

The Oregon team created the following problem statement to focus its QI work: “Young adults with medical complexity (YAMC) and their families are not adequately prepared for, or supported in, the transition from pediatric to adult healthcare.” We used a fishbone diagram tool to guide a root cause analysis of our problem statement. A root cause analysis seeks to identify the primary reasons underlying a problem. The results of our analysis appear on page 1. We created the problem statement and populated the fishbone diagram using data and information from

- Interviews our Family Representatives conducted with parents of young adults between the ages of 18 and 23 years who are medically complex,
- Group discussions with pediatric medical providers,
- Advisory Team input,
- Notes from Oregon Family to Family Health Information Center listening sessions and a panel focused on health care transition for youth with special health care needs, and
- OCCYSHN’s 2015 Needs Assessment results and 2014 listening sessions and group interviews conducted across the state.

After populating the diagram, the Advisory Team reviewed and added additional causes, then prioritized causes by multi-voting. During the multi-voting exercise, each Advisory Team member had five votes to identify where they would like the project to focus. The top three causes prioritized were:

- Adult providers do not accept YAMC because they are not adequately reimbursed for the longer appointments required.
- Pediatricians do not assist in the transition to adult health care, nor do they provide families with referrals to adult providers.
- Adult providers do not accept YAMC because they lack understanding of, or familiarity with, their conditions, or because they are uncomfortable working with them.

Subsequent briefs will describes QI projects designed to address these root causes.