

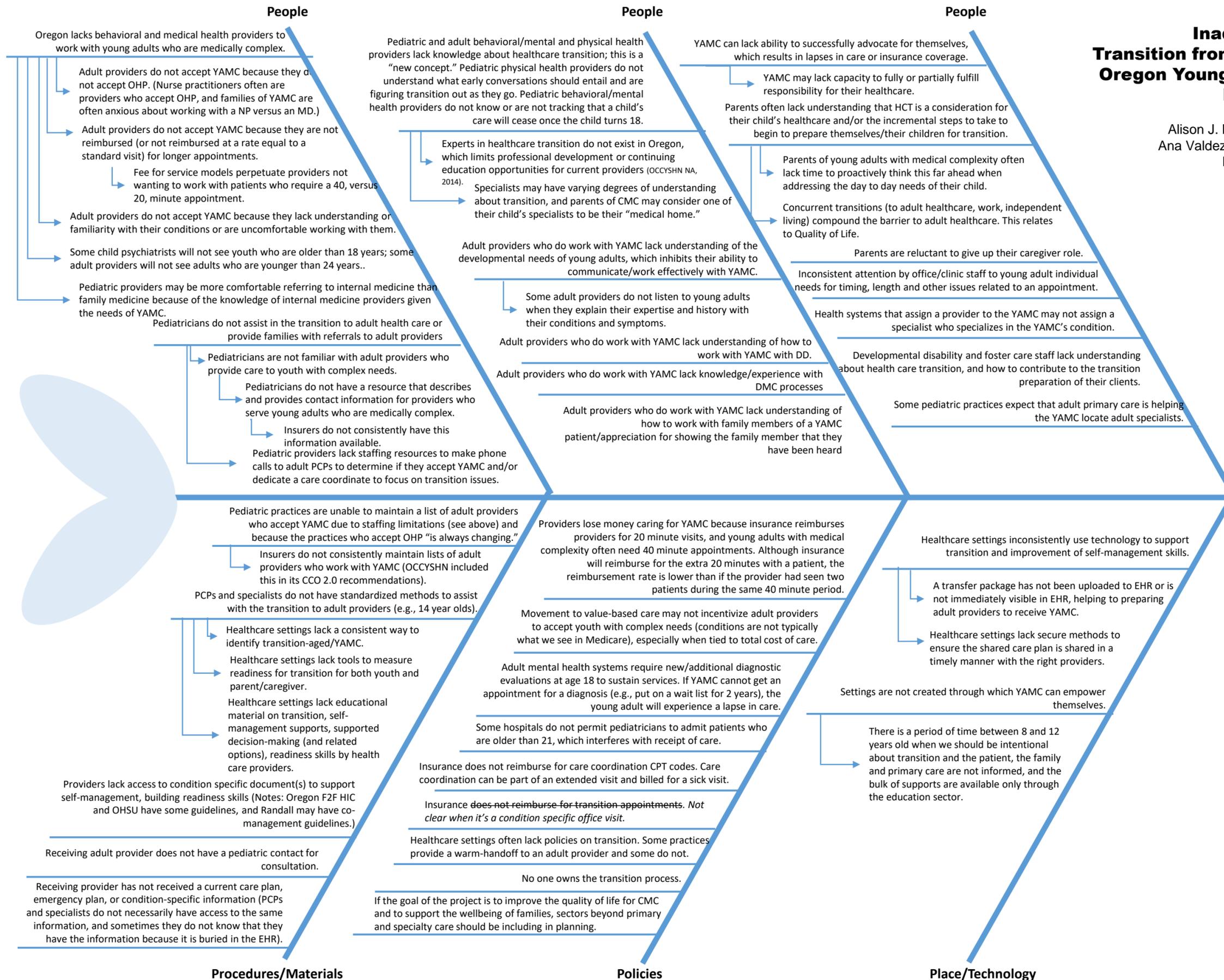
Inadequate Preparation for Transition from Pediatric to Adult Healthcare for Oregon Young Adults With Medical Complexity: Root Cause Analysis

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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



Collaborative Improvement and Innovation Network (CoIIN) for Children with Medical Complexity (CMC)

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 describe QI projects designed to address these root causes.