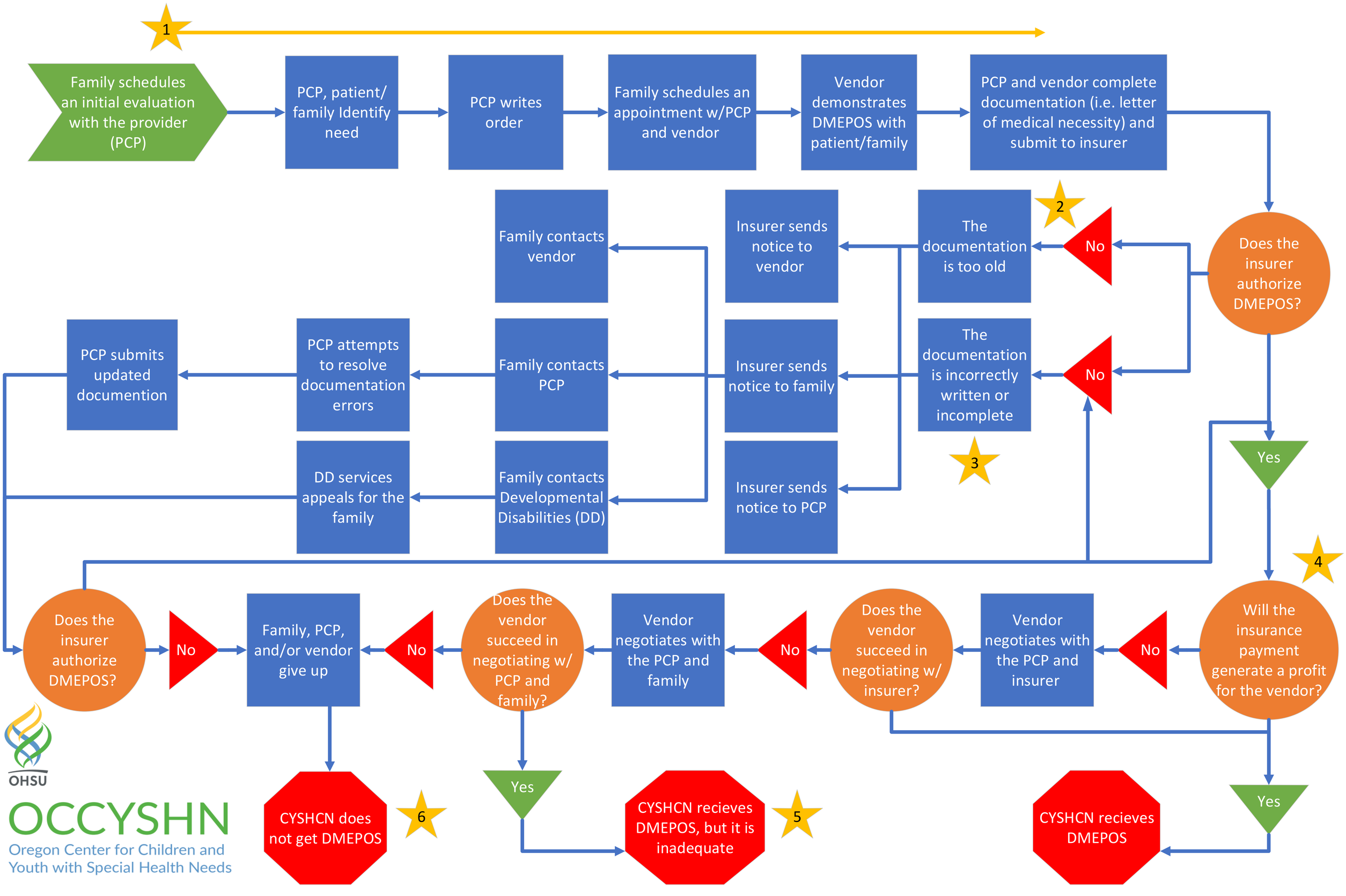
Improvement Opportunities for Oregon CYSHCN Access to Durable Medical Equipment, Prosthetic, Orthotic, and Medical Supplies (DMEPOS)

When families have a child or youth with a special health care need (CYSHCN), they may need access to durable medical equipment, prosthetic, orthotic, and/or medical supplies (DMEPOS). This graphic depicts the experience of Oregon families of CYSHCN attempting to access DMEPOS beginning at the initial evaluation. Three outcomes are possible: DMEPOS receipt, receipt of inadequate DMEPOS, or no receipt. The complexity of the roadmap increases when a greater DMEPOS need exists and more providers are involved.



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Summary of DMEPOS need among OR CYSHCN

Children and youth with special health care needs (CYSHCN) can require different types of durable medical equipment, prosthetic and orthotic devices, and medical supplies (DMEPOS) to maintain their health and quality of life (see Exhibit 1). Oregon families of CYSHCN reported that they experience difficulties accessing DMEPOS, such as long wait times for, and lack of full insurance coverage of, these items. To better understand the difficulties reported by families, OCCYSHN gathered information from Family Leaders and professionals who work with CYSHCN and their families (see Exhibit 2) to develop the roadmap on the previous page. We intend the graphic to provide a general representation of the experiences that families of Oregon CYSHCN encounter; experiences may vary slightly depending on the specific type of DMEPOS needed, provider experience ordering DME, and insurer. The following starred points present examples of unintended, challenging consequences for families and health care providers in this process.

Unintended Consequences of DMEPOS Process Barriers:

1 A family must request a face-to-face appointment with their primary care provider (PCP) to discuss why the child needs DMEPOS. Afterwards, the family schedules and meets with an allied therapist (often a physical therapist) and a DMEPOS vendor at the same time to determine the appropriate equipment fit. Coordinating an appointment where the allied therapist, vendor, and family are present can be challenging. This responsibility falls to the family with little or no support from the health care system.

2 Insurance requires PCPs, allied therapists, and vendors to meet with the patient and family, and submit documentation, within specific timeframes. These timeframes often challenge providers given the coordination involved in #1. If meetings occur, or documentation is submitted, after the insurer's required timeframe, the insurer will deny the request and the family, providers, and vendor must repeat the steps in #1.

Some timeframes are so difficult that a child's basic needs can go unmet if a mistake occurs. For example, one Family Advocate described a food security challenge with 30-day timeframes for submitting enteral feeding supply requests. CYSHCN with conditions requiring feeding supports need to be able to ingest their nourishment requirements daily. When families miss the timeframe to submit the request, they must find workarounds (e.g., blending, thinning out remaining feeding supplies) to keep their child from going completely hungry.

3 Incorrect documentation can result from providers having varying degrees of understanding the order process. Health care professionals, especially new professionals, may lack knowledge of existing documentation standards, or Oregon Administrative Rules (OARs), for DMEPOS prescriptions. Documentation corrections require clinic resources to revise and resubmit. Providers must use non-billable time between patients to make corrections and update documentation. In some instances, vendors may require additional documentation from the provider. If the family has multiple providers, the referring primary care provider who initiated the DMEPOS process must submit the documentation on behalf of the child's care team. Revising and resubmitting documentation contributes to longer wait times for the child.

4 The child's insurer determines the costs covered for DMEPOS, and Medicaid coverage can be too low to pay for the exact DMEPOS needed. For example, an Assistive Technology Professional (ATP) noted that Medicaid sets a $1500 allowable for gait trainers and walkers, which does not allow for all manufacture parts to be included. Additionally, the ATP reported that medically complex children need equipment beyond what Medicaid allows, and the family and provider have to compromise with alternative equipment.

5 Families also encounter challenges with commercial insurers, and in some cases the challenges seem illogical. For example, one Family Leader shared that their commercial insurance plan covered a $7,000 wheelchair that did not meet their child's health needs, but was unwilling to cover a $3,000 wheelchair that did.

Exhibit 1. Definitions.

Durable medical equipment: Devices that can withstand repeated use, and can be reusable and be removable. Some examples include wheelchairs, crutches, and hospital beds.

Prosthetic and orthotic devices: Medical devices that replace all or part of an internal body organ. Some examples include ostomy bags and supplies, or leg, arm, back, and neck braces and artificial replacements.

Medical supplies: Health care related items that are disposable and cannot withstand repeated use. Some examples include diapers, syringes, gauze bandages, and tubing.

Exhibit 2. Information sources.

- Experiences of allied therapists providing DMEPOS services to Oregon CYSHCN.
- Experiences of Family Leaders participating on OCCYSHN's Children with Medical Complexity Collaborative for Improvement and Innovation Network team.
- Experiences of OCCYSHN staff who support the CaCoon public health nurse home visiting and shared care planning programs
- Experiences of Oregon Family to Family Health Information Center staff working with Oregon families of CYSHCN.
- Gallarde-Kim, S., et al. (2020). Health care needs access to care, and experiences of racism for Black children and youth with special health care needs and their families. Oregon Title V needs assessment chapter 3: Children and youth with special health care needs. July 15, 2020. Retrieved from https://www.ohsu.edu/occyshn/assessment-and-evaluation
- Gallarde-Kim, S., et al. (2020). Escúchenos! Immigrant Latino parents of children and youth with special health care needs in Central Oregon share their experiences accessing health care. Oregon Title V needs assessment chapter 4: Children and youth with special health care needs. Retrieved from https://www.ohsu.edu/occyshn/assessment-and-evaluation
- Martin, A.J., et al. (2015). Oregon's children and youth with special health care needs: Title V Maternal and Child Health Block Grant five-year needs assessment findings
- Oregon Secretary of State (n.d). Durable medical equipment, prosthetic orthotics and supplies (DMEPOS): Definitions.
- Regional listening sessions conducted in 2014 with professionals who serve Oregon CYSHCN and their families.

6 A public health nurse reported they struggled to get their client incontinent supplies despite having access to public health insurance. The public health nurse explained:

"The child has issues with incontinence. They don't qualify for diapers, even if the child has [Oregon Health Plan]. She uses a walker and has [cerebral palsy] They don't qualify for [Developmental Disability] services and don't qualify for any services really, even respite care. And they can't get diapers. This child has qualifying conditions, so how can [Oregon Health Plan and Developmental Disabilities] say no with these issues?"