

February 6, 2026

Chair Nosse, Vice Chairs Diehl & Nelson, and Members of the Committee:

The Regional Family Networks are peer-to-peer organizations that empower families to build confidence and opportunity for their children with intellectual & developmental disabilities (I/DD), supporting full and enriching lives while strengthening families and communities. The Networks help create sustainable, community-based support systems and often serve as a trusted first point of contact when families encounter barriers within complex service and health care systems.

The Regional Family Networks support the current flexibility within the Children's Extraordinary Needs (CEN) program that allows parents to be compensated as Direct Support Professionals (DSPs) through provider agencies. This model has allowed families to meet extraordinary caregiving demands while preserving essential safeguards, including supervision, accountability, and independent oversight, that are critical in a service system designed to support children with significant medical and behavioral needs.

Section 14 would alter that framework by permitting parents to serve as Personal Support Workers (PSWs), eliminating the requirement for agency employment and the protections that accompany it. While presented as an additional choice for families, RFNs are concerned that this change reduces safeguards that are particularly important for children who are medically fragile, nonverbal, or behaviorally complex.

Agency-based employment offers far more than administrative functions. Provider agencies are responsible for supervision, incident response, service documentation, and corrective action when issues arise. For children who cannot reliably self-advocate, agencies often function as the primary independent check to ensure services are delivered safely and appropriately. Case management alone, which may involve limited in-person contact, cannot replace the day-to-day oversight provided through an employer-based model.

We are also concerned that a paid-parent PSW structure concentrates multiple roles in a single individual. In this model, a parent may serve simultaneously as employer, paid caregiver, and decision-maker for services. Even with strong intentions, this overlap creates inherent conflicts that are difficult to detect and address. For children enrolled in the CEN program, where care needs are intensive and risks are high, the consequences of these conflicts can be significant.

In addition, Section 14 moves forward without a clear assessment of fiscal or administrative impacts. Allowing parent providers to enroll as PSWs would necessitate expanded oversight, additional appeals processes, and increased compliance monitoring. Without a thorough fiscal analysis, it is challenging to substantiate claims of efficiency or cost savings.

For these reasons, the Regional Family Networks respectfully urge the Committee to remove Section 14 from HB 4040 and preserve the existing CEN structure that allows parents to be paid through provider agencies as DSPs. Maintaining this approach ensures families retain needed flexibility while upholding the safeguards necessary to protect children, support parents, and maintain the integrity of Oregon's developmental disabilities service system.

Sincerely,

Isis Thornton-Saunders
On Behalf of Regional Family Networks