Submitter:	Samantha Cope
On Behalf Of:	
Committee:	House Committee On Health Care
Measure, Appointment or Topic:	HB4040

Dear Members of the Oregon Legislature,

I am writing as a parent of a child with developmental disabilities and as someone who is already serving as a full-time caregiver, without pay, because the system currently leaves families with few viable alternatives.

I understand and respect the Coalition’s concerns regarding training, accountability, self-determination, and long-term transitions for children in the CEN waiver program. However, I believe these concerns overlook the realities families are living every day and miss a critical opportunity to stabilize and strengthen Oregon’s developmental disability support system.

Parents are already the primary caregivers, without compensation. Due to a nationwide shortage of personal support workers and extremely high turnover rates, many families are unable to consistently access agency-based providers. In practice, parents are filling these gaps out of necessity, not preference. Paying parent caregivers does not replace existing care, it acknowledges and stabilizes care that is already happening.

Parents know their children best. Children with developmental disabilities often have complex medical, behavioral, and communication needs. Parents have unmatched, lived expertise in recognizing triggers, preventing escalation, managing health concerns, and advocating effectively. This is especially critical for children with compromised immune systems or high behavioral needs, where missed cues or delayed responses can result in medical crises or school disruptions.

Paying parents increases continuity, not reduces choice. Continuity of care is one of the most evidence-based best practices for individuals with developmental disabilities. Allowing parents to be paid does not eliminate access to outside providers, it ensures stability when providers are unavailable. Families should retain the option to transition to agency-based support when appropriate, just as they do now.

Concerns about training and accountability can be addressed, without excluding parents. Parents can meet the same training, certification, and oversight requirements as other personal support workers. Excluding parents entirely assumes a lack of professionalism that does not reflect the reality of families who already manage medications, therapies, behavioral plans, and care coordination daily.

Supporting parent caregivers reduces strain on schools and systems. When children are sent home early due to health or behavioral challenges and parents must leave work repeatedly, the result is financial instability for families and increased stress on schools and agencies alike. Paying parents as caregivers allows families to be available when needed without risking job loss or poverty.

Agency structures are not inherently superior. While agencies provide important services, many operate with limited understanding of the day-to-day realities of raising a child with disabilities. Families often experience systems that are rigid, legalistic, and disconnected from lived experience. Paying parents is not about dismantling agencies, it is about recognizing families as legitimate, skilled partners in care.

Finally, this proposal is not about replacing professional providers. It is about responding honestly to workforce shortages, respecting family expertise, and creating flexible, humane policies that reflect how care is actually delivered today.

Paying parent caregivers keeps families financially stable, children safely supported, and systems functioning. Oregon has the opportunity to lead with compassion, pragmatism, and trust in families.

Thank you for your time and consideration.

Sincerely,
Samantha Cope
Parent and Caregiver