



February 5, 2025

To: Senator Patterson, Chair, Senate Committee on Health Care

From: Oregon Developmental Disabilities Coalition

RE: Senate Bill 538 (Neutral)

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To Chair Patterson, Vice-Chair Hayden, and Members of the Committee:

The Oregon Developmental Disabilities Coalition (DD Coalition) is a group of approximately 30 organizations across Oregon that promote quality services, equity, and community integration for Oregonians with intellectual and developmental disabilities (I/DD) and their families. Our members include the Oregon Self-Advocacy Coalition (a statewide coalition of people with I/DD or “self-advocates”), peer-based family support organizations, support services brokerages, advocacy organizations, and developmental disability providers and the DD Act Network Partners.

All children deserve individualized care that fosters their growth, independence, and well-being. However, access to home care for children with intellectual and developmental disabilities with complex behavioral or medical conditions remains limited and difficult to obtain—particularly in rural settings. Senate Bill 91 (2023) attempted to address the issue by authorizing parents to provide attendant care services with compensation through the Children with Extraordinary Needs (CEN) Waiver program. However, the Department of Human Services (DHS) limited the cost and size of the program. As a result, there are more children eligible for the CEN program than the program accommodates. The number of hours per week for which parents may be compensated has been limited to 20, and it also required parent participants to be employed by a provider agency to provide care. At full capacity, the CEN program serves 155 children, and those the program cannot serve joined an initial waitlist of approximately 1,500 children.



Senate Bill 538 makes three notable changes to the CEN program. First, it eliminates the waitlist meaning that any child who is eligible for the program may benefit from a paid-parent caregiver. Second, the CEN program no longer applies a 20-hour cap on the number of hours for which a paid parent provider may be compensated. Third, it eliminates the requirement that the paid parent must be employed by a provider agency by permitting another parent to be the employer.

Removing the requirement that paid-parent caregivers must be employed by an outside support organization and permitting direct employment by a family member does raise questions with respect to the self-determination of the child. The connection to an outside support organization helps paid parents to navigate those issues. Paying parents for caregiving services alters the parent-child relationship, introducing new complexities in decision-making about the child's care. Provider agencies have a crucial role to play in helping families navigate these changes and ensuring informed, balanced decisions. As children approach the transition age of 18, provider agencies offer valuable support to families by helping navigate the shift towards greater independence while also addressing the complexities of whether to maintain paid-parent supports.

It is important to recognize that for many of these families, there is a crisis in obtaining the supports needed to keep children with the highest needs safe. Families are in a tough position given the shortage of properly trained Direct Support Professionals. With the CEN program, families can at least provide the care to those most significantly impacted youth.

Giving a parent the opportunity to provide these services themselves is a necessary stop gap, but addressing the root causes of what drives that need is also important. That is why the DD Coalition's legislative funding priorities include increased funding for expanding both existing and new family networks, case management services, direct service rates and wages, and self-advocacy networks. In addition to those things, direct monetary interventions that benefit the families of children with the highest I/DD-related needs may do just as much if not more than paying parents as providers.



Being a paid-parent provider with no limit on hours except those assigned by the Oregon Needs Analysis process may increase the physical, emotional, and mental exhaustion caregivers often experience due to the demands of providing care over time. With one parent serving as the “employer” and the other parent the “provider,” the evolving family dynamics can create significant caregiver stress. It’s essential to prioritize the well-being of the child, the parent caregiver, and the family as a whole. The need for caregiver support such as respite care and other resources that promote resilience is crucial to the efficacy of the CEN program.

Paid-parent providers should still receive the training required under the existing CEN program. With no provider agency involved, DHS could consider whether two in-person contacts per ISP year for children in the CEN program is sufficient. Finally, greater care will need to be taken to ensure that ISPs truly foster the child’s chosen pathway toward growth, independence, and well-being. With those considerations in mind, SB 538 is more likely to create a pathway for Oregon’s children with I/DD to receive the care they deserve.