OCDD
Oregon Council on
Developmental Disabilities
BETTER TOGETHER

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RE: Testimony to Senate Committee on Health Care for Senate Bill 538 (Neutral)

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

The Oregon Council on Developmental Disabilities (OCDD) works to create change so that people with intellectual and developmental disabilities (I/DD) can live full lives as valued members of their communities. Every child deserves to receive care that encourages independence, safety, and well-being. For children with intellectual and developmental disabilities (I/DD) who experience serious behavioral and medical needs, the shortage of in-home care workers limits opportunities to engage in the community and maintain their quality of life. Improving the system that supports family members who provide paid attendant care services for children with extraordinary needs would foster greater community inclusion and enhance well-being.

When the Oregon State Legislature established the Children with Extraordinary Needs (CEN) Waiver program under Senate Bill 91 (2023), they created a new system through which parents could be paid to provide caregiving services to children with heightened behavioral or medical needs. The CEN program sought to ameliorate the significant shortage in qualified home care workers that assist children with I/DD with the most significant needs. Since its inception the demand for the program quickly outstripped its resources. Because the program could only pay up to 155 parent providers and the number of children who otherwise are eligible for the program is closer to 1,500, a great number of children have been waitlisted for the program as families continue to struggle fulfilling their daily needs.

SB 538 seeks to address that problem in three ways:

- Eliminating the waitlist so that all children eligible for the CEN program may have a parent who is paid to provide services.
- Removing the restriction on the number of hours for which a parent may be paid to provide services, which is currently capped at 20 hours.
- No longer requiring that the parent provider needs to be connected as an employee to a provider agency.

The strategy of no longer requiring parents to be associated with a provider agency has raised some concerns among self-advocates given that a lack of oversight may complicate parent-child dynamics, limit a child's ability to assert their independence, and possibly lead to greater isolation. Strengthening other parts of the system may foster self-determination and help mitigate some of those risks such as counseling for transition-aged youth and their parents on subjects such as self-advocacy, supported decision-making, social emotional learning, and functional life skills, as well as more in-person contacts with case management throughout the year.

Given the extreme shortage of qualified caregivers, particularly in rural communities, Senate Bill 538 further establishes the CEN program as a viable alternative for children who need the greatest support. Limiting the number of children who are eligible for the program to 155 families greatly limits its efficacy. Whereas individuals with I/DD who obtain services through the K-Plan are entitled to services that the state is obligated to provide, those children who access the CEN program through a separate waiver process are not guaranteed the option of having their parent provide paid support. While the state is obligated to provide the supports that the CEN program does not cover, parents still face a barrier in obtaining those supports due to the lack of qualified trained caregivers in the community. As a result, many children cannot utilize fully the services hours allotted them. Allowing all children eligible for the CEN program to benefit from a paid-parent provider would help relieve the bottleneck.

Another factor that plagues the availability of caregiving services is a high rate of turnover. For children with high behavioral or medical needs, consistency and familiarity with the child receiving services is of utmost importance. Expanding the CEN program and hours available to parent providers promotes greater stability in care and that in turn also may reduce instances of abuse or neglect.

For parents providing such services, the CEN program's limit of 20 paid hours per week creates its own problems. Since a parent providing such services only gets paid part-time, they are more likely to have to supplement that work with a second job. The CEN program serves children who are in the highest needs categories and who are likely to need a higher number of hours in services and supports per week. To the extent that the children's care needs exceed 20 hours, even where professional caregivers are available, parents struggle to find a caregiver with the requisite training willing to work a small number of hours with a child with serious behavioral and medical needs. Removing the limitation on hours allows a parent to perform more paid attendant care services and that might increase the potential for burnout. However, it also relieves the parent of the need to work two jobs or to find a worker willing to pick up a limited number of hours or odd shifts per week.

Facilitating more paid-parent providers and permitting more hours per week under the CEN program will address the caregiving gap for children with extraordinary needs. By filling that gap, those children may have greater opportunity to engage in community life, as their family members will be less burdened by the need to take on other jobs or search for outside resources to help their children actively engage in the world around them. As a result, children could be more likely to explore their interests and take part in activities that promote their growth and independence.

Thank you for the opportunity to testify on Senate Bill 538.