Oregon DD Coalition | Advancing Opportunities

February 3, 2023

To: Sen Gelser Blouin, Chair, Senate Committee on Human Services

From: Oregon Developmental Disabilities Coalition

RE: Senate Bill 91

To Senator Gelser Blouin and members of the committee,

The Oregon Developmental Disabilities Coalition (DD Coalition) is a group of approximately 40 organizations across Oregon that come together to advocate for services to further the values outlined in ORS 427.007: to support people with intellectual or developmental disabilities (IDD) to exercise self-determination, living and working in the most integrated community settings, and providing services for families to raise their children at home. Our members include a statewide coalition of people experiencing IDD, peer-based family support organizations, support services brokerages, advocacy organizations, and IDD service providers.

We believe that Oregon is strongest when everyone, including children with disabilities, has choice and control over their lives. This is called self-determination. When Coalition members with IDD speak about what matters most to them, self-determination is at the top of the list. They know people with disabilities do better when they get to choose the services they receive, the people who support them, their life goals, and daily activities. Self-determination is so vital to the IDD system that it is in Oregon Law.[1] Self-determination applies to both children and adults.

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[1] ORS 427.101(8): "Self-determination" means empowering individuals to:
(a) Make their own choices and decisions;
(b) Select and plan, together with freely chosen family members and friends, the developmental disability services that are necessary for an individual to live, work and recreate in the setting that the individual chooses and in the community;
(c) Control, or have input regarding, the manner in which resources are used to obtain needed services and supports, with the help of a social support network if needed;

Furthermore, IDD services are directed to support self-determination, including supporting families with services based on the self-determination of the child.[2]

Adults with IDD have shared concerns with the DD Coalition regarding the self-determination of the child if the parent is paid to support them when they are a minor. One member told us that he had his stepmother support him between the ages of 19-22. It became a traumatic experience because they fought over who could determine what he was going to do each day. She had a hard time not acting as the parent during her "on the clock" hours. Other members explained how difficult it could be for a child to ask a parent to give up payment to support them when they want to be supported by someone else in the future. **<u>While SB 91 does not address all these concerns, it would require that paid parent caregivers must be employed by an outside support organization instead of direct employment by a family member.</u>** This may help to mitigate the inherent risk in the direct employment of a family member.

<u>SB 91 seeks to find the appropriate role for paid parents in the IDD service system</u>. Paying parents to provide care for their children does not work for every family. This bill does not open the option to pay parents to every child with IDD, but instead looks for how this service could positively augment the services that already exist. We recognize that our society still does not meet the needs of all families of children with disabilities. Childcare is difficult and too often impossible to find. Schools are still not consistently including children with disabilities or offering them a full school schedule. As Oregonians, our policy solutions should focus on the collection

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(d) Live an autonomous life in the community, rich in community affiliations, through formal or informal arrangements of resources and personnel and contribute to their community in the ways they choose;
(e) Have a valued role in the community through competitive employment, organizational affiliations, personal development and general caring for others in the community, and to be accountable for spending public dollars in ways that are life-enhancing for the individual; and
(f) Speak or act on their own behalf or on behalf of others, including participating in policy-making and legislative processes.

[2] ORS 427.007(1)(a) and (c).

of systems that serve children with disabilities and encourage their coordinated efforts to improve lives.

<u>SB 91 acknowledges the issues that can arise from applying Medicaid regulations to routine family dynamics.</u> It prevents parent caregivers from carrying out household or family tasks while at the same time providing paid support to their child with a disability, in violation of Medicaid rule. This bill also takes into consideration that legal representation may be needed to safeguard the decision-making authority from the paid-parent relationship.

While SB 91 addresses the need for training for paid parent caregivers, children receiving support, and service coordinators, it does not have clear guidance on who would create and deliver that training, or the timeline for doing so. SB 91 allows for these important training details to be worked out in the rulemaking process. The Oregon DD Coalition would appreciate legislative clarity on the training aspects of this bill and looks forward to furthering the conversation about this.

We acknowledge the on-going direct care crisis in Oregon and nationwide, which has led so many children with IDD and their families to go without adequate care options. SB 91 does not directly address this crisis. After years of underfunding, Oregon has begun and must continue to invest much needed funding to increase wages for the personal support worker and direct support professional workforce. We are grateful to see substantial investments over the last few years. As wages increase and career ladders strengthen, so will this workforce.

It is important that on the road to improving workforce capacity, we look toward solutions that take into consideration our shared history, and the voices of adult self-advocates. This legislation could chart a new trajectory for Oregonians with IDD. We want that trajectory to follow our shared values.