

February 6, 2023

To: Sen. Gelser Blouin, Chair, Senate Committee on Human Services
From: Katie Rose, Executive Director, Oregon Community Brokerages
RE: SB 91, requiring ODHS to request CMS approval to pay parents of minor children for their attendant care in specific circumstances and conditions

Oregon Community Brokerages is an association of the 14 Support Services Brokerages currently operating across the state of Oregon. We serve more than 7,500 adults with intellectual and developmental disabilities (IDD) living in their own or family homes, providing them with the case management and supports needed to connect them to community resources and direct service providers where they live.

We all want children with IDD to have ample, well-paid, well-trained support options to nurture their abilities to grow while safely supported. We want their family members to have their own needs met, remaining whole in the roles they play in family life. We have not yet built the provider landscape we need for this shared goal. In that absence, SB 91 seeks to strike a balance in the complex care dynamics of families of children with IDD.

The Brokerage service community has over 20 years of experience supporting and assisting adults with IDD to navigate paid service relationships with their parents. Parents are sometimes the safest and best solution to a person's in-home care needs. There are also potential risks, including isolation and a loss of self-determination. Guiding Oregon families to those positive outcomes for children will require mindful safeguards to honor the child's wishes and best interests.

Paying parents to care for their children will have outcomes that change both the families who use this policy and for the IDD service system itself. We appreciate that SB 91 creates the necessary structure and accountability measures to support positive results. These include:

#### **Training Requirements**

SB 91 requires that the state develop training for paid parent caregivers, client children, and case managers. This aims to give people the preparation and

information they need up-front to achieve better outcomes. When Oregon built inhome services through the Staley Settlement in the early 2000s, it was understood as a culture-setting event. We need to recognize this policy choice as another culture-setting event in Oregon's IDD community. With that understanding, we need to be clear about the work set in motion by this policy and set people up for success in every way possible.

### Commonsense Limits

This bill contains bumpers and intervention opportunities for regulatory entities. Relying too heavily upon any single caregiver is a recipe for burn-out, injury, and unintended errors. SB 91:

- Stipulates that no more than 30% of support hours can go to a paid parent.
- Directs employing agencies and parent caregivers to refrain from supplanting the supports already in place in favor of paying the parent caregiver.
- Limits the total parent provided paid support to 60 hours per week.
- Directs ODHS to create a process for a client child to object to the hiring of their parent as a paid caregiver.

Removing Employer-Employee Relationships from Immediate Family Members SB 91 requires that a paid parent caregiver must be employed by a direct support agency rather than an immediate family member and requires that there be no ownership or advisory control over that agency by the paid parent caregiver.

#### Anticipation of Federal Regulations

This bill was crafted with an understanding of the issues that may arise from parents being held to Medicaid rules and prohibitions in the following ways:

- Restricts parents from performing caregiving and other work that might be done congruent to the 1:1 care authorized and provided to their child.
- Restricts parent caregivers from performing work for the benefit of the entire family while Medicaid payment is rendered for 1:1 direct care to their child.
- Allows that alternative legal representation may be required to safeguard the decision-making authority from the paid relationship.
- Acknowledges that Oregon needs federal Medicaid match for these services to make them financially feasible.

Protection for IDD Eligibility and Service Standards

SB 91 looks beyond the parents and children directly impacted by this policy and makes clear that we cannot resource this solution by disqualifying other people with IDD from services, or by reducing their service allocations.

Paying parents to support their children's daily living needs will not solve the direct care workforce crisis. To support healthy dynamics and positive outcomes, we must:

## Continue to Address the Root Issue—a Lack of Provider Capacity.

Children and families entered the in-home service sphere with the K Plan, which expanded Oregon's use of in-home services. The available workforce has never been able to grow to fully meet this demand. In addition to tasking the system with the intentional work of developing provider capacity, we need to adequately fund provider agencies to hire and retain high-quality DSPs and continue to raise PSW compensation in pace with the economy.

# <u>Create Policy to Expand the Use of Technology as an Alternative to Paid 1:1</u> Support.

The data around the direct support workforce crisis tells us that there simply are not enough humans to fill the growing need for direct support, no matter the fiscal investment. Looking to technological advancements in assistance with daily living is the creative way forward in the face of this challenge.

Oregon Community Brokerages respectfully submits these ideas and observations in the consideration of SB 91. We must apply our shared values not only to the needs of the present, but to the future. The trajectory we chart with this decision will affect the lives of generations of people with IDD for years to come.