



June 2, 2022

To: Rep Williams, Chair, House Committee on Human Services
From: Katie Rose, Chair, Oregon Developmental Disabilities Coalition
RE: Paying parents of minor children for their attendant care

Chair Williams and Members of the Committee:

The Oregon Developmental Disabilities Coalition (DD Coalition) is a group of approximately 40 organizations and individuals across Oregon that come together to advocate for the 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 represent advocacy groups including self-advocacy organizations, family peer support networks, DD residential providers, DD supported employment providers, and Support Services Brokerages.

Chair Williams, members of the committee, my name is Katie Rose, and I'm the Executive Director of the Oregon Support Services Association, the 14 Support Service Brokerages providing adults with intellectual and developmental disabilities case management in their communities across Oregon.

There is a diversity of opinions and experiences on today's topic, and I am delivering this as a representative of the Oregon DD Coalition to share the Coalition's perspective. This testimony is meant to be paired with that delivered by Gabrielle Guedon, who speaks to the experiences of adults with IDD. My testimony comes from the Oregon DD system's collective decades of experience with the practice of paying parents of *adult* children for their care. That experience and our values of self-determination, personal choice for people with IDD, and support for Oregon families anchor the following reflections:

When a child chooses to pay their parent to provide personal care, the parent-child relationship is fundamentally altered. That change can look very different from family to family, but it is a change, and parents and children are rarely able to anticipate the course of that change up-front. On a basic level, when a parent is paid to provide in-home services, they end up wearing multiple hats. Their time is split between being the decision-maker in the home, directing the finances of the home, acting as an unpaid natural support (parent), and serving as a paid support provider, employed by their child or another representative to perform the tasks required by their child. The line between

those roles is rarely clear in its division. Parents and children do not always know if they are “on the clock,” and that can lead to confusion and conflict.

I will walk through a few key tension points in this relationship to help illustrate the complexity of this relationship:

How does this paid relationship respond when a child wants something that their parent does not agree with? In the adult service world, where adult children have long been able to pay their parents for support, we see that when a person needs support to execute a choice, and a parent is paid for that support, children can be afraid to ask for what they want, for fear of judgment or denial.

How does this paid relationship respond when a child wants to learn and build skills from someone other than their parent? That is a very typical shift for kids and adults as they age, to want to develop relationships outside of their family. When families begin to count on the income earned through this work through new mortgages, car payments, and other financial commitments it can create a crisis of conflict for the child, forcing them to choose between following their own life goals and keeping the family financially stable. Families can become dependent upon the income from performing these services, despite the best of intentions. This skews the intent of IDD services from supporting the person to financially stabilizing the family.

Our members also have legal concerns about this paid relationship, which have been submitted for the record.

Medicaid-funded IDD Services have a specific purpose: to provide for a person’s disability-related needs as they work to acquire skills and reach life goals. These services are not intended to help stabilize a family’s finances or fill in for gaps in support from other institutions. We know the need expressed today is genuine, and we want to continue to find ways to support families that do not compromise the intent of these services or the self-determination and development of the people served.

So much of our world is designed to take power away from people with disabilities—say they are not safe to make their own choices, or they cannot be trusted to do so. We have worked for decades to advance self-determination for all people with IDD. The way we start out in life sets us on a trajectory. The DD Coalition believes that redesigning the service system so that these services start out focused on the family and their needs rather than the person sets us on the wrong trajectory for empowerment.

Thank you for your consideration today.