



June 2, 2022

Senate Interim Committee on Human Services, Mental Health and Recovery

RE: Opposition to Paying Parents to Provide Activities of Daily Living Supports to their Minor Children with Disabilities

Chair Gelser-Blouin, Vice Chair Robinson 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, family members with adult and minor children experiencing IDD, support services brokerages, advocacy organizations, and IDD service providers.

During the Public Health Emergency, the Centers for Medicare and Medicaid Services granted Oregon an exception to the federal prohibition on paying parents of minor children to provide attendant care for their minor children with IDD. Attendant care is helping a child with activities of daily living like eating, bathing, dressing, preparing meals, etc.¹ At the time the exception was granted, the pandemic made it difficult for families to have other people in their home providing this support because of potential COVID exposure.

As the Public Health Emergency winds down, so does this exception which prompts the conversation about if this practice of paying parents to provide activities of daily living support of their children should continue. We oppose the idea of continuing this practice.

Everyone, including children with disabilities, deserves to have choice and control over their lives. This is called self-determination. Self-determination gives all people a sense of pride and self-worth. When our members with IDD speak about what matters most to them, self-determination is at the top of the list because they know people with disabilities do better

¹ OAR 411-317-0000(18) "Attendant Care" means an hourly service that provides assistance with ADL, IADL, and health-related tasks through cueing, monitoring, reassurance, redirection, set-up, hands-on, standby assistance, and reminding. Attendant care is available through the Community First Choice state plan." OAR 411-317-0000(7): "Activities of Daily Living (ADL)" are the basic personal everyday activities, such as eating, using the restroom, grooming, dressing, bathing, and transferring."



when they get to choose their own services, the people who support them, goals, and activities. Self-determination is so important in the DD system that it is in Oregon Law.² Self-determination applies to children and adults with developmental disabilities. Furthermore, DD services must support self-determination, including supporting families with services based on self-determination of the child.³

As to the question of paying parents to provide activities of daily living support to their minor children, the Oregon DD system's collective decades of experience with paying parents of adult children must inform the path we choose. Our values of self-determination, personal choice of the person with a disability, and supporting Oregon families anchor the following reflections:

Paying a parent to care for their child can irrevocably change the relationship dynamic and can impact self-determination of the child. Relationships matter to all people. Paying a person to provide care to you changes the relationship. Boundaries get blurry: no longer are they your parent, they are a staff person who is tasked with following your direction as they care for you.

Adults with IDD have informed this conversation. They have experienced support from people who are their family members. They tell us that this has changed the relationships in their families dramatically. They also tell us that the choice of whether a parent should be a paid support person in their child's life can only be made when the child is an adult. Until a child is an adult, parents should stay parents.

Adults with IDD have told us they have concerns about the self-determination of the child if the parent is paid to support them when they are still children. One member told us that when he had his stepmother support him between the ages of 19-22. It became a traumatic experience

² 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;
- (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.

³ ORS 427.007(1)(a) and (c).



because they fought over who could determine what he was going to do each day. She had a hard time not parenting him and struggled to support his goals when she was “on the clock.” Other members explained how difficult it could be for a child to ask their parent to stop being paid to support them when if they wanted to be supported by someone else in the future.

Family members of adults and children with IDD have also informed us that they have seen relationships change in their families when one family member started being paid. We have Coalition members who have chosen not to be paid even though they are eligible to be paid under this exception. They did not want to see their relationship with their children irrevocably changed by being paid to personal care for their own children. Coalition members have expressed lived experience from the strain of not having the opportunity to take a break or have access to needed respite support. Without the opportunity for breaks, relationships can erode, and the strain can be felt on all members of the family.

Leaning on parents to provide additional work hours might not be a safe or equitable way to address our DD system provider shortage crisis. Oregon has invested millions in new rate models, increased wages, collective bargaining and more to build the personal support worker and direct support professional workforce meet the demands. Much of this has happened in the last few years. As wages increase and career ladders strengthen, so will this workforce.

Oregon’s legislative leaders must commit to invest in on-going funding for Oregon’s DD support agencies to allow them to stabilize and build with quality staff in the numbers so urgently demanded by our people and families relying upon these essential services. This work has started, but it must continue. The need for a quality, well-trained workforce is needed in every area of our system. This investment is critical so that we are able to balance what is needed now and look to what will be needed in the future.

Now is the time to discuss Basic Income for all families and people with disabilities who struggle to make ends meet. DD Services are specifically created to support the person with IDD to develop or maintain skills, and provide them with case management, employment and specialized supports.⁴ These services are not a family income program. As families struggle during the pandemic and beyond, there should be a conversation about a Basic Income program for all families who need additional income. DD services are not and cannot be an income program for families. The path to Basic Income must be created through an income program for all families and people with disabilities using equity principles.

⁴ ORS 427.101(2).



It should also be noted that Medicaid is the primary vehicle to fund DD Services. Medicaid income and resource limits force people with disabilities to live with extremely low so they can keep the DD and medical services they desperately need to live and work in our communities. It would be unfair to use DD services to provide income to families while leaving people with disabilities behind.

Many systems have failed children with disabilities and should be held accountable for this failure. We recognize that other systems have failed families of children with disabilities. Childcare is impossible to find. Schools are still excluding children with disabilities or only allowing them to attend for a few hours a week. The focus should be on getting all the systems that touch children with disabilities to a place where they are truly supporting these children. It is not the responsibility of DD Services, by paying parents, to pick up where other systems have failed. Our job is two-fold: to ensure the other systems are fulfilling their charge to support children with disabilities and ensure DD Services is fulfilling its charge by supporting families in line with self-determination across the lifespan of people with disabilities.

We recognize that children with nursing needs require specialized and extraordinary support. The Oregon DD Coalition supports the exploration of creating a model of nursing supports, where parents with the medical training and expertise, or who can obtain the training and expertise, are able to be paid for their child's needed nursing supports. This service allows parents to provide a specialized medical support that they are specifically trained to perform rather than providing activities of daily living to their children. We understand that these children have specialized and extraordinary support needs that go beyond parenting or activities of daily living supports. This type of support is difficult to find. If the parent is already trained to support these needs, they can fulfill this role using their professional training.

Thank you for your strong leadership as we consider new solutions.