



June 2, 2022

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

Chair Williams, Vice Chair Ruiz , Vice Chair Scharf 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.

My Name is Gabrielle Guedon I'm a self-advocate and a person who experiences IDD and am the Executive director of the Oregon Self Advocacy Coalition. I live in Newberg, Oregon.

We all want what's best for children with IDD to develop and have a full life. We need solutions that provide stability for families. There is a genuine hurt coming from Oregon families right now. They are under tremendous strain.

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 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. 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.

When I was young, I was a medically fragile child. I was in and out of the hospital and the ICU due to a metabolic disorder. They told my mother that I would not survive into adulthood. The state offered to support my mom by paying her to be my provider but she said no because she was afraid it would change our relationship and wanted to support

me as a parent. Till this day she stands by her choice and doesn't regret it. She knew that I needed other people in my life to provide professional supports so that she could remain "mom" and that I could get the disability supports that I needed from those that were in place to provide them. She was concerned that our parent/child relationship would change and our relationship is strong today because of it.

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 minors. One member told us that when 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 parenting him and struggled to support his goals when she was "on the clock."

We have to consider—when will these parent caregivers get a break? Burnout is very real in these relationships. We have heard many stories from our members about the incredible toll on mental health and physical health when there isn't support.

You all have invested millions in new rate models, increased wages, collective bargaining and more to build the Personal Support Worker and Direct Support Professional workforce to meet the demands. Much of this has happened just last session in 2021. As wages increase, so will this workforce. This is what we need to create stability for *all families*.

We ask you to continue to invest in on-going funding for Oregon's DD support agencies. This will allow them to stabilize and hire and train quality staff in the numbers so urgently demanded by families relying upon these essential services. This work has started, but it must continue.

I want what's best for these children. I know we all want to see them have the opportunity to grow and develop like other children and have a rich life full of experiences. Coming together to make that possible is at the center of this issue. OSAC wants what's best for the future and our future generations of potential leaders who can work alongside me to fight for **their** rights and the rights of others with IDD.