



# Oregon

Kate Brown, Governor

## Department of Human Services

*Oregon Disabilities Commission*

500 Summer St NE, E-02

Salem, OR 97301

[OregonDisabilities.Commission@odhsoha.oregon.gov](mailto:OregonDisabilities.Commission@odhsoha.oregon.gov)

August 10, 2022



To:

Governor Kate Brown and Rosa Klein, Governor's Office

Lilia Teninty, Director Office of Developmental Disabilities Services (ODDS)

Dana Hittle, Interim State Medicaid Director Oregon Health Authority (OHA)

From:

Oregon Disabilities Commission (ODC)

Re:

Paid Parent Caregivers Permanent Policy

During the July 14, 2022, Oregon Disabilities Commission (ODC) meeting, ODC Commissioners listened to testimony from 11 families regarding the temporary Public Health Emergency (PHE) policy allowing payment to parents who serve as Direct Support Professionals (DSPs) and Personal Support Workers (PSWs) for their children who require Children's Intensive In-Home Services (CIIS). These families consistently shared the positive impact of the paid parent caregiver policy, including better care for their children's specific needs, more reliable coverage, decreased time and anxiety related to the ongoing cycle of finding and training qualified caregivers, better health resulting in decreased emergency department use and hospitalization, increased financial stability, and increased family cohesion. These benefits are consistent with Oregon's health system transformation goal of family-centered, whole person care that supports health-related social needs, in addition to treating medical conditions.

Prior to the PHE, families describe an unworkable situation with an inadequate supply of caregivers that were able to consistently meet the specialized needs required of DSPs and PSWs. Too often, families were left with an allocation of hours that were not used and therefore had no value in supporting children with intellectual/developmental disabilities (I/DD) and their families. We must also recognize that insisting upon a caregiver from outside of the child's home being considered the "qualified" individual, despite the fact that it is the parents that will likely train the DSPs or PSWs, brings the training schools that individuals with I/DD were historically sent to, into the home. It would be nothing less than taking a step back in history via the child's front door.

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On behalf of the ODC, we respectfully submit this letter in support of a permanent policy allowing parents to serve as paid DSPs and PSWs, and request that as an initial step, OHA and ODHS facilitate a meeting in which families can have a direct dialog with a CMS representative who can share options available to Oregon and details about the policies in place in other states.

Sincerely,

Mark King, ODC Chair

Marsha Wentzell, ODC Vice Chair

ODC Commissioners

Brooke Eldrige  
Jenny Schoonbee  
Joanna Wilson  
Nancy Peterson  
Patrick Wilkus  
Roxie Mayfield  
Tata Blakely  
Tim Roessel