



February 23, 2022

Lilia Teninty, Director  
Office of Developmental Disability Services  
Dana Hittle, Interim Medicaid Director  
Oregon Health Authority  
*Via email*

Dear Ms. Teninty and Ms. Hittle,

During the 1/26/22 Medicaid Advisory Committee (MAC) meeting, MAC members listened to testimony from two 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 240 hours or more of attendant care per month or qualify for children's intensive in-home services (CIIS). We are aware of similar written and oral testimony from 30 families that was delivered to the Oregon Health Policy Board in December 2021. These families have consistently shared the positive impact of the paid parent caregiver policy, including better care for their children, decreased time and anxiety related to the ongoing cycle of finding and training qualified caregivers, better health resulting in decreased emergency department use, and increased financial stability and housing stability for the entire family. These benefits are consistent with the State'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 appropriate caregivers willing to serve as PSWs and DSPs. Too often, families are left with an allocation of hours that are not used and therefore have no value in supporting children with developmental disabilities (DD) and their families.

We appreciate the 1/7/22 letter from ODHS and OHA and the 12/14/21 webinar on this topic, both of which describe the complexities and financial trade-offs of Oregon's approach to supporting children with DD. However, the public testimony provides valuable insight into the lived experience of families, and this experience needs to be reflected in Oregon's approach to supporting children with DD.

On behalf of the MAC and families, we respectfully submit this letter in support of a permanent policy allowing parents to serve as paid PSWs and DSPs, 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,

Lavinia Goto, RN, CDE, MPH, MBA, DHA  
Medicaid Advisory Committee Co-chair

Leslee Huggins, DDS, MS  
Medicaid Advisory Committee Co-chair

Medicaid Advisory Committee Members

Daniel Alrick, Chair, Oregon Council on Developmental Disabilities

Brandy Charlan, Caregiver and OHP Member

Adrienne Daniels, Deputy Director, Integrated Clinical Services, Multnomah County

Lavinia Goto, Project Manager of LTC Innovation & SDOH, NorthWest Senior & Disability Services, and Operations Manager, Oregon Wellness Network

Miguel Angel Herrada, Health Equity and Diversity Strategist for PacificSource, Central Oregon

Leslee Huggins, Pediatric Dentist and Orthodontist, Capitol Dental Care/InterDent

Jeremiah Rigsby, Chief of Staff, CareOregon

Divya Sharma, Chief Medical Officer, Central Oregon Independent Practice Association

Kärun Virtue, Chair, Lincoln County Community Advisory Council

Rachel Currans-Henry, Strategic Initiatives Administrator, Aging and People with Disabilities, DHS

David Inbody, CCO Operations Manager, Oregon Health Authority

John Santa, OHPB Member and MAC Liaison (non-voting)