

Letter to the Director of Oregon Developmental Disabilities, Oregon State Medicaid, and members of Interim Committee on Human Services:

June 1, 2022

**Re: Extending payments to parent caregivers of individuals with significant intellectual disabilities, autism, and behavioral challenges after the Public Health Emergency has expired.**

The Public Health Emergency is due to expire soon.

Throughout the pandemic, families, caregivers, and state and federal agencies have all been forced to adopt new rules and find new strategies to deal with the challenges of daily life. One upside of this sudden upheaval has been the ability to assess the strengths, weaknesses, and failures of the status quo ante. One very obvious failure has been the shortage of direct support professionals (DSPs), which had been growing in past decades but reached crisis level during the pandemic. Accessing high quality care has become a major challenge for I/DD individuals and their caregivers.

The 1135 Waiver that was created during the public health emergency provided funding for parents of individuals with significant intellectual disabilities, autism and behavioral disorders to serve as paid caregivers of their family members with these challenges. For years, these “extreme caregivers” have struggled to find the outside care that was supposed to have been provided under Medicaid Home and Community Based Services (HCBS). There has always been a disconnect between qualifying for services and actually receiving sufficient high-quality care. Paying parents to provide that care themselves has helped to bridge that gap. It has allowed parents to leave their jobs but still be able to provide for their families, while ensuring that the needs of their intellectually or behaviorally challenged family members are met.

We believe this is one of the successes in the way the State of Oregon handled the public health crisis, and should be continued, even developed further, and that new programs should be put in place before the public health emergency provisions expire. People with I/DD, autism, and behavioral disorders are best served by developing long-term relationships with their caregivers. During the ongoing shortage of DSPs, it has been difficult to find these vital caregivers and even more difficult to retain them. So, who better to give sustained long-term care than parents?

As a society, we should support these families, and give them the right to choose how to best care for a child with mental, physical, or behavioral challenges. Many families choose to provide for their loved one outside of the home, in group homes or other long-term care facilities. Choosing to raise a child with these challenges in the family home is only possible when parents have the support of the loved ones’ siblings and of their communities, and resources available from the state and federal government. Such care goes far beyond the demands of normal parenting. Parents who choose this road are sacrificing their own lives, hopes, and dreams to provide care for another. Siblings become caregivers, as well. By paying parents as caregivers, we are providing them with the means to succeed.

An added bonus to extending this program is that paying parent caregivers to serve in this capacity may also free up the existing DSP workforce to provide services elsewhere, in group homes and other HCBS settings, in nursing homes, assisted living centers, or skilled nursing facilities. This is not only a more efficient and more effective way of providing care, it has the potential to save the taxpayer money by re-allocating already scarce resources. The money is there. The workforce is not.

The State of Oregon appears to be poised to support family caregivers whose loved ones face significant medical challenges. We welcome this step, but ask the state to go further. It is just as challenging, if not more so, to attend to the needs of a child with severe/profound intellectual disabilities, autism, or extreme behaviors. **We ask the state to make a parent caregiver program like this permanent, and to provide better resources for the families, including training, telehealth consultations with professionals, opportunities to network with other families online, and regular access to respite care.**

Let us turn the crisis created from the Covid pandemic into an opportunity to rebuild our system with new strategies for providing better care for the most vulnerable individuals and their families.

With hope for better outcomes,

Hugo Dwyer - Executive Director of VOR

Joanne St. Amand - President of VOR

*VOR is a national non-profit organization advocating for high-quality care and human rights for all people with intellectual and developmental disabilities. We support a full range of residential options and employment opportunities to provide families the ability to choose what is best for their loved ones with I/DD, autism, and behavioral challenges.*