



9320 SW Barbur Blvd, Suite 240, Portland OR 97219
Telephone: 503 636 1676

Website: www.AutismSocietyOregon.org
Direct Email: Tobi@AutismSocietyOregon.org

Federal Tax ID #: 93-0771249

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RE: In Support of SB 1565

To Chair Patterson and members of the Senate Health Care Committee:

As Executive Director of the Autism Society of Oregon and as a parent of Autistic young adults, I'm writing to ask you to support **SB 1565**, which uses the framework of legislation passed in 2023 (SB91) to equitably fund attendant care services for children with developmental disabilities determined to have "very high" behavioral health or medical needs.

The Autism Society of Oregon is the largest Autism nonprofit organization in Oregon and the only one that operates state-wide. We represent everyone in the Autism community, of all developmental levels and of all ages, from children through adults. Our mission is to create connections, empowering everyone in the Autism community with the resources needed to live fully. Through our educational, informational, and community support programs, we reach over 25,000 people each year throughout Oregon. We do not charge for our services and there are no membership fees.

During the COVID-19 Public Health Emergency, Oregon temporarily established a paid parent caregiver program for minor children with disabilities. The legislature saw the benefits of that program and passed SB 91 (2023) to make it permanent for the state's "very high needs" children. The Office of Developmental Disabilities Services (ODDS) has applied for a new 1915(c) waiver, called the Children's Extraordinary Needs waiver, but is choosing to interpret the funding options narrowly which is severely limiting eligibility for these families who are in difficult to desperate situations.

Since the end of the Public Health Emergency's temporary program, families of children with disabilities with very high behavioral or medical needs have faced heartbreaking choices. While ODDS determines how many community support hours each child is entitled to per month, there are simply not and have never been enough support providers. In my family, our late son was assessed at 365 hours per month. Until the temporary program, we were never able to find support workers for more than 160 hours per month and that was not often – even though we are in the Portland metro area and pretty well connected! The situation is much more difficult in rural areas.

Due to the lack of attendant care providers for children, parents are doing this work, unpaid, to the detriment of their family's financial stability and wellbeing. We are hearing of too many families who have had to make the heartbreaking decision to entrust their children with high behavioral or medical needs to an already overburdened foster care system. This is often the only alternative available or even suggested by ODDS to these families.

[SB 1565](#) uses the framework established by SB 91 and would make three simple tweaks:

1. Require the state to look for any funding mechanism available, including the 1115 waiver. This is the waiver suggested by the Centers for Medicare and Medicaid for these paid parent provider programs.
2. Require the state to follow through on its promises by prohibiting transfers of these funds out of Home and Community Based Services.
3. Allow all of the "very high" needs children eligible under SB 91 the opportunity to participate, while keeping funding capped to what has already been budgeted. This is accomplished through a system that allows parents to use the "deficit" of hours below the cohort's average utilization rate as determined by ODHS.

In determining the fiscal impact of SB 1565, it's important to note that other states have determined paid parent (or LRI – Legally Responsible Individual) programs are budget-neutral because these are services that the state has already promised to pay for. Many of us in the Autism community were very surprised to learn that funding for these services is not based on the hours determined by DD Services but by the average utilization rate of these hours. We hope that SB 1565 offers a reasonable fiscal compromise while giving children with disabilities the support they desperately need and have been promised by the state.

We are respectfully requesting your support for SB 1565. Thank you very much for your consideration.

Respectfully submitted,



Tobi Rates
Executive Director
Autism Society of Oregon