

Submitter: Sarah Reed
On Behalf Of:
Committee: Senate Committee On Health Care
Measure: SB1565

To Whom It May Concern,

I am in support of SB1565. My son has down syndrome and autism and he is non-verbal. As his Mother, I am his most qualified caregiver. He was thriving and his behaviors had decreased during covid when I was his paid caregiver. He has had increased behaviors again now that he is with an outside caregiver; this it turn increases the cost of care (higher behavior = higher support needs = higher cost). Please approve SB 1565.

Thank you kindly,
Sarah Reed

"Disabled children deserve better!

During the COVID-19 Public Health Emergency, Oregon temporarily established a paid parent caregiver program for minor children. 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 has applied for a new 1915(c) waiver, called the Children's Extraordinary Needs waiver, but is choosing to interpret the funding options narrowly and throttle eligibility.

Since the end of the Public Health Emergency's temporary program, families of children with disabilities have faced impossible choices and consequences. Some have even had to give them up to an overwhelmed foster care system to be able to earn an income.

SB 1565 uses the framework established by SB 91 and would make three simple tweaks:

Require the state to look for any funding mechanism available, including the 1115 waiver. (The Centers for Medicare and Medicaid have advised using 1115 waivers for paid LRI (legally responsible individual) programs due ease of implementation.)

Require the state to follow through on its promise to taxpayers and disabled children by prohibiting transfers of these funds out of Home and Community Based Services.

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. The current average utilization rate is 65 percent. (ODHS says they budget these programs based on the average utilization rate — the amount of hours children have been historically able to use, not the amount the state's own assessment determines they need.)

For example: if a child needs 500 hours of paid attendant care per month and can

use zero hours because of a lack of available qualified caregivers, the parent could use up to 65 percent of them.

If the child is able to use 40 percent of their hours, the parent could use 25 percent of them.

If the child is able to use 85 percent of their hours, the parent would not qualify for hours.

Other states have determined paid LRI programs to be budget-neutral because they offer a path to a service the state has already promised. However, we are hoping this is a reasonable fiscal compromise that can pass political muster in Oregon.

Support SB 1565!

From Surviving to Thriving.

Advocates for Disability Supports"