

Submitter: Romi Ross
On Behalf Of: My son
Committee: Senate Committee On Human Services
Measure: SB91

My name is Romi Ross, and I live in Portland. My son is 9 years old, and is autistic, has Tourette syndrome, OCD, ADHD, and severe anxiety. I am also a behavior support professional, and have been working with children and adults with developmental disabilities with high behavior support needs for the past 25 years. And I am myself, neurodivergent – an adult with DD.

I am in here in support of SB 646, and SB 91 with modifications.

My son qualifies for the current program, due to his high behavior support needs. Because of his disability, he engages in physical aggression, self-injurious behavior, and property destruction. He has meltdowns that can last hours, and when the episodes end, he becomes deeply depressed and suicidal. He has intrusive thoughts, compulsions, painful tics all day and night, sensory challenges, and situational mutism. He is largely unable to leave the house because of anxiety, and requires a parent to care for him at all times.

Because of the severity of my son's behavior challenges and his anxiety, we are not able to bring an outside caregiver into the home. His parents are who he feels safe with. What's more, because physical interventions are often required for his safety and ours, it's even more crucial that the people supporting him are people who know and love him, who he feels safe with, and who can put his wellbeing above all else, even when that's not easy to do. Paid or not, we are providing his caregiving support. We are supporting him with his ADLs, his behavior management, and his crisis management, around the clock.

With respect to outside caregivers, my son is not able to endure changing schedules, substitute caregivers, and staff turnover, which, despite the best efforts of all systems, is universally a part of direct care staffing.

What troubles me most, and what concerns me about SB 91, is that my son didn't initially qualify for the current program, despite having the same needs then as he does now. It took a truly unreasonable, unfeasible amount of parent and physician advocacy to have the full extent of his support needs recognized on his CNA and ONA assessments. This isn't something most families can do. I am concerned that the significant limitations on eligibility in SB 91 will leave behind children with high support needs, who have families that aren't able to perform this high level of advocacy for them. Over the course of three months, and many, many meetings, doctor's appointments, emails, and phone calls, my son's CNA determination

increased from 156 to 268 hours. The only difference was that we fought a literal battle for his needs to even be acknowledged. Same child, same needs.

If this is what it takes for Oregon to adequately assess a child with a parent who speaks English, and who is a seasoned behavior analyst with experience navigating these systems--- How are we doing with single parents working two jobs? Immigrants, or ESL families? Families who are entirely new to their child's diagnosis, much less to describing the most painful and frightening details to a complete stranger? Or additionally marginalized families who may be afraid to share the most intimate details. I can tell you, we're not doing well. We need inclusive policies to protect the most vulnerable families among us.

I support SB 646 because it will include all of Oregon's disabled children who have attendant care hours, even when their assessments don't fully capture their needs, even when they've fallen through the cracks, as is often the case. I am concerned that children with high medical and behavior support needs will be left behind with SB 91, as it currently stands. I urge you to pass a bill that is inclusive, intersectional, and that best supports the largest number of disabled children possible.

Thank you,
Romi Ross