

My name is John Saito, and I am the parent and guardian to my daughter Jamie (Yui); a young adult with profound autism. I am writing about SB5526, and request that you target an appropriation amount for intellectual/developmental disabilities programs that exceeds the current Agency Recommended Budget of \$2.4 billion from the state (\$3.9B from federal funding). Oregonians like Yui are fully dependent on quality in-home caregiving, safe licensed residential programs, and inclusive enrichment programs. Without them, she would live a painfully isolated life, and at an unacceptably high risk of harm.

Yui is one of over 3,400 Oregonians who suffer from profound autism; comprising roughly 27% of the



entire autistic population under care by our Medicaid waiver programs. Those with profound autism also suffer from profound intellectual disability, minimal to no comprehensible language, mood, and anxiety disorders, and are prone to self-harm and aggression. People like Yui require 24-hour vigilant monitoring, and continuous access to 1:1 skilled direct care for all their basic needs (toileting, dressing, bathing, nutrition, personal safety, etc.).

Currently, Yui relies upon services coordination in Washington County, and a team of caregivers who tend to her basic needs in our family home. Once my wife and I are unable to host Yui in our home, her continued safety and quality of life will depend upon

Oregon's 24-Hour residential home providers, their facility managers, and the direct support staff they hire, train, oversee, and assign to Yui.

State funding for these services now and into the future is critical for Yui's wellbeing, and that of the tens of thousands like her with severe developmental disabilities. However, I fear that the current ARB for 2025-27 may be insufficient to meet their needs. There are many indications that our current funding levels are already creating an increasingly overburdened, unsafe, and underserved situation.

1. DD service enrollment actual growth is outpacing the forecasts used in budgeting

<https://www.oregon.gov/odhs/data/ofra/2025-03-idd-caseload-variance.pdf>

2. Serious incidents and abuse cases are growing faster than actual enrollment.

<https://www.oregon.gov/odhs/data/pages/otis-data.aspx>

<https://www.oregon.gov/odhs/data/Pages/odds-data.aspx>

3. Service coordinator workloads are already too high.

Collect the data from your counties to confirm, but in Washington County alone, average caseloads are in the 50s when they should be in the 30s or lower, depending on the average level need / complexity.

4. Direct caregiver pay rates are uncompetitive and unattractive.

<https://apps.oregon.gov/oregon-newsroom/OR/ODHS/Posts/Post/report-released-on-rate-and-wage-study-of-providers-serving-people-with-disabilities-older-adults>

5. Licensed residential care remains a concerning prospect for many living with aging family.

<https://www.oltco.org/ropgab-board-resources.html>

Oregon has significant quality and availability responsibilities when it comes to providing humane care to those with intellectual / developmental disabilities. I believe that to address these commitments, we must either increase funding to all critical I/DD programs, or significantly redesign our system of care with an even stronger bias towards prioritizing and safeguarding those with the highest & most complex needs. This would require difficult trade-offs in terms of eligibility, licensing, pay rates, etc., but anything less will be to condemn the most vulnerable like my daughter to a life not worth living.

I know you are facing daunting fiscal decisions, especially this biennium. I know many other worthy communities and causes are pleading their cases for why their program budgets should be protected and improved. With all these voices in your ears, I ask that you pause and consider the voiceless, like my daughter. Those with profound developmental disabilities are being made increasingly invisible, and are therefore the easiest to leave behind and forget. Please don't.

Thank you.