

## Medicaid DD services are critical for my daughter

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 requesting the Joint Ways and Means Committee ensure our state budget prioritizes the care and protection of people like Yui, who are some of the most vulnerable within the developmental disability community. Thousands of Oregonians like Yui are fully dependent on 24/7 caregiving in their family homes, or in licensed residential facilities. Without these services, she would live a painfully isolated life, and at constant risk of severe harm. Under the threat of significant cuts to Medicaid at the federal and state levels, please do your utmost to keep service funding for Yui intact.

## Your budget decisions will affect her safety



Yui is one of over 3,400 Oregonians who suffer from profound autism. Comprising roughly 27% of the entire autistic population, 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 for their physical safety, and continuous access to 1:1 skilled direct care for all their basic daily living needs (toileting, dressing, bathing, nutrition, medication, etc.).

Oregon's Medicaid waiver programs place Yui in the highest needs Service Group for her age through the Oregon Needs Assessment. Her Individual Service Plan then secures several essential services for her.

Medicaid Services for Yui	➡	Impact on her Life
(now) 500+ hours per month of in-home 1:1 caregiving		Protects Yui from injury, infection, malnutrition, dehydration, cognitive and emotional decline.
(in the future) 24-hr residential facility placement and 1:1 direct care staffing		
Home safety modifications		Protects Yui and her direct care staff from physical harm and emergency hospitalization due to her unsafe behaviors.
In-community safety equipment		
Behavioral consulting with caregiver training support		Fixes unavoidable* gaps in available service provider quality and standardized service plan coverage.
Case management with exceptions identification and processing support		
Care provider licensing, auditing & oversight		Provides preventative and reactive safety against incompetence, abuse, and inappropriate care plans.
Complaint investigations of / by service providers		

\*Profound autism often presents challenges not anticipated by standard policies and rules governing provider qualifications and program expenditures.

**Please prioritize DD budgets based on need and severity of outcome**

Oregon has challenging responsibilities when it comes to providing humane care to those in need. To meet these commitments, we must clearly identify those like Yui with the highest & most complex needs, and first protect them from harm. No doubt this will require difficult trade-offs in terms of service eligibility, licensing, pay rates, and service hour budgets for the entire developmental disability community. But to do otherwise will be to put the most vulnerable among them at the highest risk.

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 budgets should be protected. But with all these voices clamoring for your attention, I ask that you pause and realize that those with the greatest needs are those who cannot speak for themselves. Like my daughter. Oregonians with profound developmental disabilities are being made increasingly invisible, and are the easiest to leave behind and forget in times like these. Please do not.

Thank you.