

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 in strong support of SB134. People like Yui are especially vulnerable to unacceptably poor-quality care and outright abuse due her inability to self-advocate. Our state must ensure people like Yui, her parents and guardians have the right to monitor her care and treatment independently, and without interference from residential service providers.

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, and continuous access to 1:1 skilled direct care for all their basic needs (toileting, dressing, bathing, nutrition, personal safety, etc.).

In the near future, my wife and I will be unable to host Yui in our family home. We will no longer be able to directly select, monitor, and manage the care providers supporting her. Her continued lifelong safety 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.

Frankly, this reality makes me anxious, if not outright fearful.

ODDS / ODHS data shows that **serious incidents and abuse** (both allegations and substantiated cases) involving IDD service providers are outpacing enrollment growth in services. Moreover, serious incidents disproportionately occur in residential facilities, and disproportionately affect high and very high needs individuals. In other words, Yui will eventually and permanently enter what appears to be the least safe part of our IDD systems of care, and the situation is deteriorating.

Information from the Residential Facilities Ombudsman Program also reveals that **residential care providers** have numerous other quality of care problems. Common complaints by residents and their advocates included **involuntary ejection and abandonment, mismanagement of personal assets and overall poor-quality facility maintenance**.

**Top complaints by IDD residents** listed in the 2022 annual RFO report included:

- Involuntary move out notices without due process for the resident or supporters
- Abandonment at hospitals as providers refusing to accept return of residents
- Barriers to access personal finances, and financial exploitation
- Barriers to access of personal property or loss of property
- Increase in personal restrictions: access to clothing, food, freedom of movement
- Decrease in quality, cleanliness, upkeep, and accessibility of the living environment
- Untrained or inadequate staff resulting in lack of required social, medical, and basic care needs
- Threats of retaliation for communicating with RFO or case management
- Inappropriate restrictions on daily life, diet, or activities by provider or legal decision maker
- Inappropriate medications sought by provider or legal decision maker

To learn more, I personally interviewed a former RFO director last year, and learned that in addition to these continuing problems, the RFO often confronted **highly uncooperative residential service providers** who often **resisted access** to residents, their facilities, and their records. Moreover, **acts of retaliation against both residents and whistle-blowers** were a common problem with little protection.

Clearly, we have fundamental quality of care issues to confront, and they most definitely require better oversight of service providers. I believe SB134 is an important step in that direction. Hopefully it can help address the safety concerns I and other aging parents of I/DD adults have about residential care.

Thank you.