

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 HB3168. People like Yui need enhanced direct support for their safety and that of the staff she depends upon, especially when their disabilities cause highly unsafe behaviors.

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, and manage the direct care providers helping keep Yui safe and supported. Her continued lifelong safety will depend upon Oregon's 24-Hour residential home providers, their facility managers, and most importantly, the direct support staff they hire, train, oversee, and assign to Yui.

Currently, this future 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.

Through personal experience managing Yui's in-home caregiving program, I can say with absolute certainty that avoiding both serious incidents for Yui and ensuring the safety of her caregivers requires a significant amount of work. At the bare minimum, we need to:

- Carefully screen all prospective caregivers offered by agencies or directly registered by the state for both relevant experience and training in managing the specific unsafe behaviors, communication, and cognitive challenges of our daughter.
- Test for caregiver fit through a probationary / initial placement with our daughter. Trust and comfort between caregiver and Yui are crucial, and cannot be determined through resumes or interviews.
- Ensure caregiving activity schedules are tailored to both the strengths and weaknesses of the caregivers and to Yui's emotional state at the time (which can be very dynamic).

- Provide detailed coaching on communication and behavior support; have an experienced caregiver available for spot interventions for all new caregivers, and usually over extended periods of time.
- Plan, secure, and install all manner of safety equipment and residential accommodations to keep everyone as physically safe as possible.

High support needs I/DD individuals like Yui need a highly selective, carefully planned, and well-supported caregiving staff wherever they reside. It is my hope that measures like HB3168 will help create such an environment, and in doing so improve safety for both daughter and for those who will care for her in the future.

Thank you.