

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 SB422, and encourage the committee to ensure that the bill includes adults with I/DD either through direct participation in a pilot program, or by becoming a part of the target population when learnings from the pilot program are considered for broad application. Many adults with I/DD like Yui are at risk of unsafe disruptions to service and placement, especially once their aging parents are no longer able to advocate and manage service transitions on their behalf.



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.).

Yui and many other adults with autism receiving services are equally vulnerable to the many safety risks that SB422 intends to address for children with I/DD exiting the state hospital or juvenile justice system.

Using ODDS data for 2023-24 on Medicaid waiver service enrollment . . .

- 58% of autistic adults had at least 1 of 4 unsafe behaviors in the past year including
 - Self-injury
 - Physical aggression
 - Sexual aggression
 - Property damage
- 30% of autistic adults need 24/7 direct supervision for all their activities of daily living (ADL)
- 20% of autistic adults need direct physical support for their activities of daily living.

Using ODHS data for 2023-24 on serious incident reporting + ODDS enrollment data . . .

- 63% of serious incidents involving autistic Oregonians under care involved adults
- 68% of serious incidents involving autistic adults were for emergency medical care
- 20% of serious incidents involving autistic adults involved hospitalization, suicide attempt, or some form of physical safeguarding intervention.

As concerning, the same ODDS / ODHS data I have received shows that serious incidents and abuse (both allegations and substantiated cases) involving IDD service providers to both children and adults 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 and the thousands of adults with I/DD like her will eventually and permanently enter what appears to be a deteriorating system of care unless something is done.

Given this situation, I ask that you not only give SB422 your support, but also ensure it expands its scope to include the equally at-risk population of I/DD adults with high support needs. I/DD adults of aging or deceased parents, are very much like the I/DD children the bill intends to serve; often without natural supports, and completely dependent of the state for their very safety and wellbeing.

Thank you.