

Submitter: John Saito
On Behalf Of: Jamie Saito
Committee: Senate Committee On Human Services
Measure, Appointment or Topic: SB725

My name is John Saito, and I am the parent and guardian for my daughter Yui, a young adult with profound autism. I am writing in strong support of SB725 in order to drastically reduce the caseload on services coordinators serving individuals with intellectual or developmental disabilities.

For those unfamiliar with profound autism, here is what that means for Yui and our family:

- Yui cannot be safely left unmonitored for any length of time anywhere, even in our home.
- She needs direct, maximal assistance in dressing, toileting, personal hygiene, nutrition, and all other activities essential to daily life.
- Because of these challenges, Yui depends upon an array of critical services provided by ODDS and managed by her services coordinator. They include:
 - 24/7 1:1 professional caregiving
 - Home safety modifications and equipment
 - Personal safety and hygiene equipment (the portion not fundable by Medicaid)
 - Community programs for social enrichment

Yui's services coordinator must spend a significant amount of time working with us on utilizing these services, and due to her heavy caseload, her ability to address numerous important issues with the poor state of these services is constantly limited.

- Due to the caregiver workforce crisis in Oregon, we struggle to find enough qualified direct support staff. Over the past year, this meant engaging 11 different caregiver agencies, communicating caregiving requirements to all candidate, onboarding new hires, and appealing for additional billable hours for the one caregiver we can regularly rely upon.
- Due to highly constrained funding and expense guidelines, we regularly appeal for additional home safety and personal hygiene equipment for Yui. Most recently, those appeals included additional padded panels to protect Yui's head from injury when she bashes it against walls and doorframes; and new lockout suits to protect Yui and others from infection due to fecal smearing.
- Due to the limited number community program providers for truly high needs

individuals like Yui, we continue to endlessly hunt our area for adult day programs that will even consider someone like Yui due to her 1:1 support needs, limited communication, and behavioral risks.

Yui's situation, and that of her overtaxed services coordinator is far from unique. According to data I received from ODDS, 10,000+ out of 13,500+ autistic Oregonians enrolled in ODDS services need direct caregiving, and 7,000+ struggle with 2 or more unsafe behaviors.

Services coordinators are the lynchpin in the ODDS systems of care for people like Yui, and they are woefully understaffed and overextended. As a result, families like ours struggle to find and secure actual services, supports, and accommodations. I urge you to address this unacceptable weakness in our Medicaid waiver programs and pass SB725 as an important step in the right direction. Thank you.