

Submitter: Noel Zeedyk
On Behalf Of: minor child
Committee: Senate Committee On Human Services
Measure: SB91

Hello, my name is Noel. I've worked in many roles across my adult life; becoming a PSW at age 18, providing respite, an adult foster care provider, stay at home mom, or Central Lane 911 call taker. I have a 14 year old daughter with Angelman Syndrome and I sit on the Angelman Northwest Board as Educational chair. In her case this syndrome comes with other diagnosis' such as Lennox-Gastaut (a complex multi type seizure disorder), cerebral ataxia, complex communication delays, low muscle tone, PICA (ingesting non edible objects) and other. Her syndrome also comes with global tendencies such as a fascination with water, needing "her people" gathered together, knowing no stranger (wandering) and a generally smiley demeanor. Smiling does not mean well behaved. She can smile will hitting, pulling hair and sometimes biting when she can feel a seizure coming on. Behaviors that often cause PSW to quit.

Our family made things work in her early years as my husband was the primary income earner while I focused on the care our daughter needed.

Covid brought that family relationship to light and left me a single mother with two children in the home 365 days a year. We have had the fortune to have some fun and kindly PSW's or DSP's over the years. I lean on them hard as I am only able to take clients when they can come watch my daughter. She often stays home around her monthly cycle due to seizures, when she's ill or when she's anxious - another seizure trigger. She is on multiple medications but still ends up in multiple night stays at the hospital each year due to cyclical vomiting (another disorder known to Angelman Syndrome). I know my daughters cues best. I can head off many illnesses / injury by steadfastly watching her. That is difficult to do when I am swapping a paid PSW for the ability to work 4-5 hours a day. We have also had the regular misfortune of PSW's quitting the day of, no showing, or being a poor fit for my daughter. We have had two abuse her. One deliberately administered a psychotropic med not prescribed to her that caused unconsciousness. The other left marks that do not align with accidents. The more outside PSW's we have the harder it is for Brielle to form authentic attachment - because who knows, she may never see that person again. She also experiences fear of being alone with new people. Please consider the two options and what is best for Oregon. An Oregon where unreliable homecare workers contribute to parents using all of their sick and vacation time on the sick or no show leave that PSW creates. Leaving the parent without vacation time, strained work relationships, already fatigued from working, running a home and 24/7 care taking when not in other roles. Leaving their child to grow up unable to form attachments, fearful to be left alone with people they do not know well . Worse, that as a non verbal child they won't have the ability to report something if . Or an Oregon where parents can find work part time work and be supported in caring for,

advocating for and knowing their child best. Taking them to the grocery store for a cookie recipe, swim lessons or a friends birthday party. The best integration is natural integration. Able to do all of this without the stress of training and re training new PSW's in desperation after a sudden quit. Free to take the time necessary to select a quality match. Supported in what they do best.

I originally came to the capital to help support our local homecare workers with fairer wages across the board. Gas reimbursement and equal wages are vital concepts Oregon must adopt in order to continue its commitment and reputation for fair inclusion of all persons. With inflation our current PSW's cannot afford to transport my daughter to appts (sometimes a couple hours away if at OHSU) or community inclusive events unless I pay their gas money in cash. This leaves the parent further taxed and ultimately a broken quality of life for our children.

Thank you.