

Submitter: Alicia Bodine

On Behalf Of:

Committee: Senate Committee On Human Services

Measure: SB91

Chair Gelser Blouin, Vice Chair Robinson, and Members of the Committee, Oregon's Developmentally Disabled children deserve access to the best, most qualified caregivers, their parents. No one knows the needs of our states most vulnerable children better than their parents. Please pass SB 91 with amendments to make it more accessible out of committee.

My name is Alicia Bodine. I am a single mom to an amazing little girl named Zoë who is 8 years old. We live in Dallas, Oregon and I am writing in support of SB 646. Zoë has Down Syndrome, hemiplegia cerebral palsy, right side complete hearing loss, and was recently referred to the Autism clinic for an Evaluation. She is cognitively around 18 months old and is completely non verbal. She can walk very short distances around the house with assistance, but cannot walk unassisted.

She spent 10 days on life support and As a baby, her doctors did not want her in daycare due to her health, which meant I could not work. Later, She did 1 1/2 years of preschool but she spent more time at home sick than she did at school because she caught every illness that kids came in with. I chose to homeschool her during covid even when schools reopened because our school district will not allow 1:1 aids. Before parent pay, I was on food stamp assistance. We live with my mom because my only income was child support.

I tried hiring a PSW for Zoë, and even though it was a family friend, Zoë's anxiety skyrocketed. She started to panic any time I left the room even we were around family. When I needed to go to the store, i would get phone calls or texts asking about her care. And i could only find someone for 3-10 hours a week at most. Or they would cancel because of other obligations. But any illness with the psw and Zoe got sick. A head cold can turn into a 6 week illness with rounds of antibiotics, urgent care and doctor visits.sometimes even hospital. Once my mom retired she was able to cover more hours, but still not enough that I could work. When applying for assistance in the past I was actually told by a state worker that Zoë didn't qualify for assistance because I do not "contribute to society".

Then parent pay started. I was not told about it for almost a year. Zoe was 25 hours short from qualifying. When her Evaluation came up last June, she finally qualified. It was perfect timing because my uncle was diagnosed with cancer and my mom had to become his caregiver which meant less hours that she could help me with Zoë. I was able to get off of food stamps and I started being able to afford the more specific foods Zoë doesn't gag on and that she enjoys eating. I could pay for gas to take her on more outings or to attend more therapies. I have been able to buy her equipment that insurance denies. And because there are not a lot of people coming through the house, Zoë has not had to be admitted to the hospital and has hardly been sick at all. Her doctors and therapists are so happy with the progress she is making now that

her body not constantly sick. Even though her system is weak, it has never been this good. She is thriving and her anxiety and PTSD is Down so low because she has routine and knows she is safe. No one knows her gestures, sounds or eye contact like I do. And Although she is non verbal, she prefers to have me help her with things than someone else.

SB 646 would benefit so many families and more importantly our vulnerable children financially, physically and mentally. While, some people don't think parents should get paid, our children only qualify for hours based on their needs which are above and beyond what a typical parent would need to do. We know our children best. Our children know that they are safe with us. And while more parents would be getting paid, there are different forms of Assistance that they would no longer need to rely on such as food stamps. The money that they make and taxes we pay would then be going back into our economy so we can "contribute to society".