

Submitter: Crystal Watson  
On Behalf Of: SB646  
Committee: Senate Committee On Human Services  
Measure: SB646

To Whom it May Concern,

Hello and thank you for taking the time to read this letter. I am writing in support of SB 646.

I am the mother to a sweet, funny, mischievous little boy. His name is Alex and he has Hunter's Syndrome. It's a rare, terminal genetic disease that affects his entire body. He has complex and progressive medical complications as well as progressive cognitive impairment. I have devoted the last 5 years to learning as much as I can about this diagnosis. I have invested heavily in the potential therapies and methods of communication and instruction that work best with this type of disease. The amount of research, training and investigation required to offer him the best quality of life is staggering. To my knowledge, he is the only child in the state of Oregon with this diagnosis. The education required to care for him is not common place.

We have, in the past, employed a small number of personal support workers. The hiring process can be lengthy and has meant potential applicants were hired for other positions while waiting for paperwork to process. Furthermore, that led to large gaps of service during times of turnover. We have had support staff unable to assist with his toileting needs or administer medication. For medically complex children, like Alex, that means the caregiver isn't able to be left alone with the child. We have also had great periods of compromised immune system health. That severely limited the number of people that could be around my son. We have also had workers heavily over medicate Alex and leave him in unsafe physical surrounds without supervision.

With the temporary allowance for parents to apply for this position, Alex was able to choose his most qualified and preferred caregiver. I feel honored that he chose me to fill this role.

He has since seen significant improvements in both his physical and cognitive health! His attendance at school is drastically improved. His need for acute medical treatment is admirably diminished. He has made gains towards many goals and maintained the skills that he did have. These things are huge for Alex. But, perhaps, most important to him is that he is happy. He feels safe and supported with consistent care. He is able to practice all of his therapeutic exercises with a consistent, dedicated provider that attends therapy with him and understands how best to support and encourage him. He expresses joy and love on a daily basis.

Please allow Alex, and other disabled children, to continue to choose the caregiver that is best for them.

Thank you again for your time and consideration on this incredibly important

topic. It means the world to an 8 year old boy named Alex.

Sincerely,

Crystal Watson