

Submitter: AnneMarie O'Neill  
On Behalf Of:  
Committee: Senate Committee On Human Services  
Measure: SB646

As a mother of a child with disabilities, I can attest to the difficulties placed on parents of disabled children. No one understands my son the way I do or has as much vested interest in his well-being. While I do not live in OR, a good friend of mine does, and I write on her behalf. Her daughter has Type 1 diabetes, ASD, and she is gifted. Her diabetes adds to her high anxiety caused by her autism and her mother has done an amazing job of calming her, socializing her, learning how to manage her diabetes, and getting her aid in school.

However, the toll it takes on her mother to check her blood sugar levels every 5 mins while at work is intense, as is the constant co-regulation and calming care needed for autism. Her mother often can not sleep, and she can not stop being vigilant. Several times she has had to leave her job as she could not get a hold of caregivers at the school when she has seen (via her phone) her daughter's blood-glucose levels get dangerously low. The mother and father's health has been significantly weakened due to their need to constantly care for their daughter and try to work to support her. My friend (the mother) works for a public school as a counselor and has had to take a leave of absence in the past in order to care for her daughter. This is not just disadvantageous for her and her family, it also puts the students that she counsels at a disadvantage and costs the school money. If she were able to be the primary caregiver for her daughter it would allow the family to stay out of debt, insure her daughter's safety and well-being, aid in all of their health, and allow the mother's current place of employment to seek a counselor that had less stress in their life and more energy to invest. More importantly, her daughter has so much to offer the world. She is incredibly bright, but due to her complex disabilities, she needs a level of support that is difficult to give from inconsistent aid. Her diabetes is deadly and her autism can cause her to have extreme behaviors that are not easily understood by those who are not educated in autistic care. However, with the right care, best given by those who love and know her best, she could greatly add to the world. Without it, she could die, or become considerably more delayed by the effects of stress due to inadequate care—which could then require government assistance anyway as the family would be put at a further disadvantage. Care now means less care in the future. She is an amazing child intellectually and emotionally who has so much to offer to society. Please save your government from having to care for her and her family in the future and give them the chance they desperately need now.

Thank you.