

Testimony in favor of Senate Bill 5515 to provide additional funding

As a mother to a child with a rare condition (only one in the state of Oregon) having individuals to help brainstorm, lead me to resources, encourage our family and provide direct hands on support in the areas of physical, occupational and speech therapy not to mention countless conversations with preschool teachers to improve the accessibility of the classroom has been impactful. The life of a caregiver to a one-of-a-kind kid with unique abilities is not one you can prepare or equip yourself prior to birth. As a transplant family living in a state without family even within driving distance the individuals within the NWRESA have been a huge source of guidance, support and encouragement throughout every stage of our life. We are a family with resources that allows us to provide additional healthcare options from private providers to our doorstep to serve our child. I acknowledge that this is not the norm. As someone with the cognition, mental fortitude and ability to advocate for my child without fear of repercussion or willingness to give up I recognize that is also not the norm. However, our lives and family unit are not the ones that will be severely impacted with less resources. We will make due. Yet, there are dozen and dozens and dozens of other families that rely solely on the support, knowledge and engagement of the individual's providing services to their children. Reducing the funding just produces a ripple effect downstream for parents, schools and society. Not serving kids even at bare minimum level of effectiveness is cruel. A non-verbal child should have access to weekly speech therapy, not every 3-4 weeks. That is ineffective and inhuman. This has been the recent result of less funding and will be the continued result of less funding if this measure is not approved. Kids with disabilities should be protected at all costs. I invite any of the people reading this who do not have experience caring for a rare child with a multitude of disabilities into our home for a week. I am imagine the experience would be quite eye opening and pivotal in your decision regarding this matter.