

Submitter: Andrea Lewis

On Behalf Of:

Committee: Joint Committee On Ways and Means Subcommittee On Human Services

Measure, Appointment or Topic: SB5547

Good morning,

Today I am writing this testimony in support of Tensys law. I am the mother of a 13-year-old boy named Alex, who is greatly affected by nonverbal autism, as well as a disorder of the immune system known by the acronym P.A.N.D.A.S. Both the autism, and the immune system disorder have a large impact on our families lives, in the realm of behaviors. Because of this, and it's severity, Alex is eligible and entitled to hundreds of support hours a month that are unable to be filled, due to the lack of support people experienced enough to care for him in our area. I have been unable to work to my full capacity, because of his high behaviors and the emergent need for me to be around in an instant. Alex's high level of care cannot be fully met without the presence of his mother full-time. The level of care that Alex requires is above and beyond the natural parenting of a boy of his age. Also due to the immune system component of his secondary disorder, having a DSP come into the home to fulfill any amount of care hours is a risk to his immune system, and therefore actually increases the severity of his disorder by exacerbating symptoms if exposed to certain viral and bacterial triggers. The health and safety of Alex, is a great priority, and he benefits greatly from having his parents as his primary support people. Hundreds of hours that he is eligible for every month, that he has the right to be filled and to have qualified safe care, are left unused because of the lack of support care at this level available from people outside of our home. There are thousands of families in Oregon, who Are going above and beyond the standards of everyday parenting for children of all ages and high medical and behavioral needs. We are suffering, because of the lack of support in this area. This bill would take tons of families out of poverty, and save the state money on things like snap benefits And other government assisted programs. All while keeping our children healthy, safe, and cared for by those who know the ins and outs of their high level of disability, mom and dad.

Legally these children are owed to have this right fulfilled. Any other person, can sign up as a support person for an agency and be paid the same money to take care of our kids. People with no experience, without the level of knowledge and lived in experience that it takes to be able to care for these extraordinary children.

Please take time today to greatly consider the positive impact that this has on the health, and lives of our children with high behavioral and medical needs in the state of Oregon.

Thank you,
Andrea Lewis