

Submitter: Susan Gallagher-Smith
On Behalf Of:
Committee: Joint Committee On Ways and Means
Measure: SB5506

Greetings.

I'm the proud mother of a nine-year-old disabled son. Ending PHE means the end of access to personal support and care services for my child.

My child has multiple disabilities; one of which is type 1 diabetes. He requires personal support and care service providers to be trained in how to administer sliding scale insulin as well as other diabetes management tasks. The medical complexity of his care requires nurse delegation.

We are one week shy of a year of waiting to be assigned a nurse. With the nurse turnover and the impending dramatic increase in need for delegations, I suspect my child is likely a year or more away from being added to a state nurse's caseload.

When PHE ends our family will have participated for roughly 6 weeks. This additional funding has and will improve both my child's safety and quality of life. We'll be able to go do things non-disabled families access without a second thought like outdoor music and theater events in Eugene and Springfield. I can explore providing private funding for a nurse to delegate until we can access state funding.

The end of access to PHE plus the limited access to nursing delegation means my child will not be able to access county and state services due to his disability. That's discrimination.

One would think SB 91 would help families like mine. While his needs are great and complex, it's doubtful he'll qualify for paid-parent care. SB 91 doesn't seem broad enough to support children like mine and thus we're stuck.

He has 358 hours in non-school months that we cannot fill because of his disability and accommodations. That's 358 hours I cannot be paid for. 358 hours I must provide while also being a fulltime business owner and fulltime parent caring for our home, yard, etc.

This is a frightening time for my family. Sadly, I know I'm not the only parent worried about what will happen after May 11th. Please help.

Warm regards,

Susan Gallagher-Smith