

Submitter: Ashley Wells
On Behalf Of:
Committee: Senate Committee On Human Services
Measure: SB646

To whom it may concern,

During the Covid public health emergency, parents of minor children with ID/DD were temporarily allowed to be paid caregivers for their own children. This was an absolute life changer that desperately needs to continue. It was essential to survival and quality of life for many families, including mine, and it continues to be essential. I have 2 children with multiple diagnoses, including significant language delays and behavioral issues. Many of us have kids that require extra. Extra services, extra attention, extra medical care, extra appointments, extra patience, extra time, and extra care. In southern Oregon, there is a severe lack of services. In Douglas county, we have to travel for needed services, which makes holding a regular job impossible. Our kids get sick more and need to miss more school, or be home schooled in some cases. No one knows and cares about these kids like we do. We are the experts on our children, and being paid parent caregivers has significantly increased quality of life for so many families. Plus, finding a good, qualified DSP who fits your family dynamic is pretty much impossible thanks to the shortage of workers.

Some examples of the challenges we face:

1) My 2 children benefit from ABA therapy (Applied Behavioral Analysis; it is a play based therapy that targets maladaptive behaviors.) Those services ended in Douglas county and I had to drive my kids to Eugene three times a week for several months, until their services ended there. Now, we are starting with a new provider coming into Douglas county, but we still need to be home for appointments. My kids will require 20-25 hours a week of therapy to start, and I will be involved. At the moment we have parent training on Mondays and Fridays.

2) This past winter, illnesses hit our home hard, between 4 kids, there was a solid 4 or 5 weeks where at least 1 kid was home from school sick. This happens frequently enough to cause issues with any other job.

3) My oldest son has severe self harm behaviors and has started staying home on Wednesdays from school to help regulate, and it has been extremely beneficial for him.

4) Whenever my kids require an appointment, (Which is fairly regular) it takes more time and planning than it does for a neurotypical child. Many appointments are out

town in Eugene or at Doernbecher's in Portland and require an entire day.

5) Before the PHE and the temporary allowance, my kid's attendant care hours were not being used, as we couldn't find a DSP that was a good fit for us.

SB 91 limits families to 60 hours a week, even with multiple children, which is not equitable for both children.

Passing SB 646 is essential.
Nothing about us without us.

Thank you,
-Ashley Wells