

Submitter: Cari Pagan
On Behalf Of:
Committee: Joint Committee On Ways and Means
Measure: SB5506

As an Oregon voter and parent of a beautiful, spirited 10-year-old daughter extremely impacted by disability, I ask you to support SB 91.

Please consider using general funds to continue funding the parent paid caregiver program as it has operated under the PHE temporary allowance, until SB 91 is passed and enacted.

This temporary allowance has helped so many families avoid upheaval. Helped so many disabled children avoid the hospital, emergency department and foster/institutionalized care. Countless families such as mine have experienced a degree of stability for the first time EVER with this program. Like many kids with extreme behavioral and medical needs, our daughter requires either my husband or I to ALWAYS be available. 24/7, night and day. Whether it's seizures, bowel issues, eloping or agitation resulting in injuries to herself or others, one of us must always be off work or able to leave work at a moments notice when behavioral or medical issues become more than what a non parent person is willing or able to manage. Nina's father and I are the people who know Nina best. There are few besides us who can commit to the tedious, complex and constantly changing demands necessary to manage her daily life. That said, she is an amazing, tenacious, resilient child who can learn and teaches us daily. We will give all we have and more everyday until our last, to help her have the most independent and quality life possible. Since being allowed to fill some of her allotted caregiving hours (that we've mostly been unable to fill for years prior) it has alleviated much of the disparity between the amount of hours we need to work to survive financially and the amount of hours we can feasibly work while keeping Nina safe and cared for. We've also been able to dedicate the necessary time to work with her on therapy goals such as toilet training. Life changing progress happening here over the last two years! ??

Passing SB 91 and allowing a bridge to fund the continued payment option for parent caregivers until this bill passes will be the difference between living in or out of crisis for many families. There are no natural supports to "transition to" when this temporary program ends. Competent, willing caretakers for children with this high level of needs simply DO NOT EXIST. Please don't allow May 11th to be a back slide for families like mine who work so hard for our vulnerable children and have seen so much progress with this program!

Thank you for your time,
Cari & Daniel Pagan