

Submitter: Michael Stevens
On Behalf Of:
Committee: Senate Committee On Human Services
Measure: SB646

My name is Mick Stevens. I am a proud parent of a 13 year old, 5 foot tall, 90 pound and growing girl, named Jillian. I call her Jilly. Jilly was born with Cerebral Palsy and also has Autism. Jilly is a quadriplegic with spastic movements and global developmental delays. Jilly has no ability to provide self care. I am responsible for meeting every single one of her needs to keep her safe and healthy. Because of Jilly's ongoing need for basic care and her need for high-level specialized care, I quit my full-time job to be her caregiver shortly after she was born. We were living in California at that time and receiving benefits from a program called In-Home Supportive Services ("IHSS") that allowed me to stay with her and reduce the impact of losing half of my family's income. With this program, I was able to care for Jilly in a way that greatly reduced unnecessary illnesses and injuries while allowing her to meet her maximum potential.

After moving to Oregon, I was shocked that Oregon doesn't have a similar program to pay parents. I searched exhaustively through several agencies provided by Developmental Disability Services to acquire a Personal Support Worker for Jilly. After five years of searching, Jilly and I finally received help. It took several months, with many hiccups and one trip to the ER, for Jilly's PSW to learn all about Jilly's needs and how to properly care for her.

Jilly's PSW is available to work a regular schedule of four days every week, which amounts to approximately a quarter of the monthly hours Oregon has deemed necessary to provide for Jilly's care. I provide Jilly's 1:1 care the other three-quarters of the time. In fact, her care goes beyond the allotted hours provided by the state of Oregon. Additionally, even though Jilly's PSW is amazing with Jillian, Oregon's PSW program requires that I be immediately available to provide support to Jilly's PSW, and Jilly's needs require that I be immediately available to provide support to Jilly, including 2:1 care.

After working with an amazing PSW, I am certain that no paid caregiver could ever give the support that a parent can. My daughter comes first, which means that I will go without sleep or meals if her needs require it. The temporary rule to authorize parents to be paid caregivers is making a huge difference. I appreciate and I am in full support of SB 646. Thank you very much for your time.