Submitter: Melinda Cain

On Behalf Of:

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

Measure: HB5026

My name is Melinda Cain and I am the mother of a 6 year old child that has cerebral palsy, ADHD, Autism, epilepsy, a Chiari malformation, a chromosome deletion and is g-tube fed. Do you want to know how many DSP’s we have been through in 2 yrs? NINE. Nine DSP’s and I can’t tell you the amount of PTSD, depression and overwhelming sense of defeat it has caused my husband, and I. They quit because our son is “too much”; between having to tube feed him every 2 hours, administer seizure meds and mitigate his behaviors because he does not yet know how to regulate them and monitoring for seizures…”it’s too much.”

CPS was following us for a while for our son’s “failure to thrive.” The drs wouldn't believe us when we told them we were having a difficult time having the DPS' follow the feed orders. The DSP's that were hired to feed him, wouldn’t. After repeated training, reminders and explaining the importance of nutrition, they still would not take the time.

One time, another DSP picked our son up by his arm, carried into his room, set him on the floor roughly and slammed the door, locking him in there and telling us we were awful parents and that our child was spoiled. Although our child is on the spectrum and has behavior issues due to this…

The only way my husband and I can survive financially is if I work during the day and he works at night. Because of this, we have no time to provide the proper therapies for our son. He is supposed to be receiving physical therapy, behavioral therapy, eating therapy, and one other one I can’t think of right now. He needs new inserts for his shoes due to having a gait, which we haven’t been able to set up an appointment for. Because guess what? We must work. We were supposed to take him to the CDRC for an evaluation and to get therapies started for him. But we can’t. We can’t work and take him to three – four different therapies a week. And the DSP’s sure as hell can’t drive him to his therapies…so guess who is getting the raw end of this deal…the CHILD.

Because neither dad nor I have the option to stay home because we must provide for our other children, our disabled six year old son is missing out on crucial therapies imperative to his development. He is not being given equal opportunities because for some reason the state of Oregon thinks it’s better for a stranger to provide medical care for our children, rather than the parents who are trained firsthand by the doctors on how to properly provide support for our children. And our son needs around the clock care because of his epilepsy and tube feeds. So even when we’re not working. We’re working and providing care to our son beyond “normal” care.

No one is looking to get rich here. No one is trying to stay home and “live off the government.” What we are trying to do is limit the amount of neglect our children experience. The amount of ever-loving stress we experience trying to find a DSP. Hoping they stick around. To limit the number of barriers they experience due to no fault of their own. And limit our heartbreak and the feeling of unjust because our children deserve and have the right to every opportunity and therapy and need out there to access resources to improve their quality of life, but we as parents can’t give that to them because society says we have to work so we don’t end up living on the streets, but then our children don’t get the proper care they have the right to because the state of Oregon decides that strangers are better suited at addressing and taking care of our children’s medical needs. The need to pass this bill. is for the children and giving them what they need, to properly care for their medical needs…not live off the government or getting a free ride or however it was grossly stated. When you have a medically complex child, there is no such thing as sitting on your ass, at home. EVER. I’ve lived 12 yrs in the six he has been alive.

Thank you for your time,

Melinda