

June 3rd 2022

Senate Committee on Human Services

My name is Jessa Reinhardt, I live in the small logging town of Vernonia. I am the mother of three beautiful children, one of them is autistic with multiple mental health diagnoses. I am here to represent the stories, struggles, and hopes of the hundreds of families, organizational leaders, and disabled children and adults who support a permanent and expanded parent caregiver program.

From the moment we heard that first heartbeat, we have been in love with our children. We prepared for their arrival in every possible way. However, our children who represent only 0.6% of the most disabled children in the state, require herculean parenting and above and beyond caregiving. We are incredibly fortunate to be living in a time where we have unprecedented access to information regarding our children's specific disabilities giving us the unique ability to care and support them unlike anyone else can.

We agree with Medicaid's Self Directed Services. As the child's legal representative, we are asking for the ability to direct our own children's care and choose the most appropriate caregiver for them until the child is reasonably able to do so themselves. This is incredibly important to my family as 6 years ago, my husband quit his job to be our 7 year old's full time caregiver after witnessing the severe anxiety and trauma she was experiencing in group care. She has told us she does not want an outside caregiver. In her own words, submitted as testimony:

"Strangers don't know what I need. Like stuff that I can't eat and my medicine, they might not know how to do it. We also have fun with Dad. Strangers probably don't have time to play with me and don't know which movies are too scary for me to watch. I get nervous sometimes probably when strangers are at my house. Strangers probably don't know how to keep me safe."

There are many reasons a family may choose to be their child's caregiver: fear of abuse and neglect, the child's preferences, or just wanting to be a normal family without the constant parade of workers, doctors, and educators in and out of our lives

We agree that respite is important and are grateful that respite care is provided through the K-plan. Let me be clear, respite care is NOT attendant care. Attendant care is the medical and behavioral supports a disabled child requires that is above and beyond the needs of a typical child. Over the last 15 months of this temporary program, there have been NO adverse events to children or parents, in fact the exact opposite has occurred, children are thriving like they never have before.

It is important that we do not limit which children have the option to choose parents as their support providers. ODDS has already determined through thorough evaluations the 4,333 children who require enough additional support to warrant attendant care services. There is no reason to remove a viable support option from any disabled child, they all deserve the opportunity to be supported by the best possible caregivers.

Furthermore, we should not limit the hours a parent is eligible to support their child, it should be left up to the family to decide how much they can and want to work, respite is available for breaks when needed.

We have been treading through a labor shortage for many years, employing parents as support providers allows for more caregivers to fill critical positions in group homes, nursing facilities, and in the homes of seniors. It is difficult for us to process hearing employing parents is a budgetary issue. That tells us that the state is accepting of our children not receiving the care they need and qualify for.

The bottom line is, our children have needs that are not being met and supports that were promised to them but left unfilled. All we ask of you all today is to allow the legislative process to move forward. We are happy to work collaboratively on potential safeguards. But are fed up with outsiders directing what is best for our children, how we should raise them, and how we should run our households. Those individuals are not our children, they do not represent our children, and they will never ever love nor know our children better than us.

Thank you,

Jessa Reinhardt