

Hello,

My name is Jennifer Murphy. I am the mother of the Preston age 9 and Parker age 6. These boys are the absolute joy of our life. Everything we do is for our boys. My husband works at a lumber mill to provide for our family. We have been married for 10 years. I have been home since Preston was born 9 years ago and he was in heart failure, waiting on open heart surgery. During that time, I was running a feeding tube, oxygen and lasics. Preston experiences Down syndrome, hypothyroidism, gluten intolerance celiac, colitis, food protein intolerance, has had open heart surgery repair, air way surgery, he has a very weak immune system, he relies on a wheelchair and full care. Preston is an angel! Parker is our 6-year-old son, he experiences severe autism, and most recent diagnosed February 2021 with type 1 diabetes. Parker is eager to learn everything he can he has so much determination. Parker lives in a very beautiful world of music and color. We would never change a thing about our kids. They are loved, chosen, and thriving. We love being their parents. It's very rewarding having children like mine. Our little guys battle big battles daily. Both of our children together have near 600 hours of paid k- plan help offered. While this sounds like it would meet our needs, it is not. The k plan is not meeting our needs. I'd like to talk to you today about why we are seeking a change in policy to allow Parents the option to permanently provide the paid services to their own minor child.

The struggle with the k plan:

There is and has been for a long time a major staff shortage .We are in a work force shortage crisis. There is no one to hire, yet alone qualified with my children. We have provider agencies looking for dsp's and there has been no dsp's to interview in over 1 year. This option would stabilize families financially. My husband and I can't find any one trust worthy, drug free, educated, or qualified to provide the care to our children. Our kids can't tell us how someone treats them or if someone has hurt them. I can't trust anyone under a nurse to run my child's insulin injections, to do the math, to check for ketones, to act with a glucagon injection if he goes into a low, in a seizure, or coma. Diabetes made our life a lot more intense . Diabetes requires 24-hour care. The dsp and psw are not drug screened to care for Oregon's most vulnerable children, and we can't put our kid's lives in the hands of strangers. The k plan needs re balanced. We don't have family and friends to hire. We can't allow the exposure with the covid and illnesses , when our kids are sick, they are often hospitalized, their immune systems are compromised. Workers can't come here sick! I have had one successful dsp that ended up moving, she was wonderful. I run adds , I have posted on job websites and can't find workers. An agency sent two 18-year-old girls here to interview, we had no other options, we had given them a try. They happened to be roommates, and they quit on day 2 of training! We struggle financially with one income; my husband has to have two open fmla open at all times one for each son for when an emergency happens. In our life, it's not if it happens it's when it happens. As you know, Fmla is not paid. In February 2021 my husband took 7 weeks fmla with parkers diabetes diagnosis we had to learn everything to care for our son. During those 7 weeks, we luckily got stimulus money to live off of. Then delta struck and we had to sheltered in place and I at that time began to get paid as one of my sons dsp. My husband had to return to work, after fmla was exhausted. So now our exposure is greater to covid and other illness again. This past 2 years has been the healthiest with contagious illnesses our family has experienced. It's extremely hard for my husband to carry a career with our childrens medical needs. Luckily, he has had very understanding bosses. I can't work outside of all the work I do 24-7 for my boys. We have had my husband home this past year 2 times and we experienced us as a family unit doing everything together. We would do activities and had lower stress. I had help full time with him home alongside me. The kids love their dad home helping them too. Working

together with our sons well, it was amazing! This option would give children and families a better quality of life. Life was less stressful, we had money to pay everything, not just live pay check to pay check. We have 2 kids, and both have a lot of needs. I have been forced out of the work force, and I am actually working at least 2 full time jobs. I'm not building a retirement or ssi benefits. I am unseen, unheard, and I am doing all the work. The work that Oregon will pay multiple people to do. We are the most qualified, loving caregiver our sons could have. We are the safest caregivers for our children. Being a caregiver is different than just a parent. I want recognized for my work. There is no day care option for kids like mine. I don't want day care. We want the option to be our child's care giver. My kids have 12 Dr's together, standing routine labs, and appointments. I run their iep, ifsp, order supplies. Our kids receive the most love, attention, and care by us, their parents. Parents in this population love their children. We have major life goals and we love our kids. When you support the parent, you support the child. We will always be our kid's best support. I can't express to you how one decision to allow paid parents, would positively impact many children and, many families. This option would allow parents to enjoy the time they get with their kids. Our kids aren't always the healthy kids. All the red tape and obstacles families like mine have to fight is so exhausting and needs improved. Please understand that all our needs are all different, we are voicing to you, to please change this option. Being paid parent would help our families in many ways. Allowing me to be my son's care giver has already positively changed our life. I have been able to purchase the boy's special needs toys, communication programs, and special needs programs that I would not have been able to provide. There are many families that this option would be life changing in a positive way. There is so much support for this option. I am thankful to find a very large growing group of parents that feel the same as we do. The one size fits all approach that the k plan has is leaving children without services that they are eligible for. Oregon doesn't have the workers to perform the hours they have approved through the very thorough assessments. I am doing the work, please recognize this. I want to be the one to do it. Give families options. Keep families together. Keep children healthier. Save Oregon money. We have two kids with the needs. I wouldn't mind respite alongside us for breaks but we want to be our child's main supporter. We are willing to do any training and home visits and whatever safe guards needed. We love our children and it's our mission to give them the best quality of life. With this paid parent option allowed by the PHE families such as mine have experienced all positive outcomes including more community outings and inclusion, healthier children with little to no hospitalizations, happier children, and thriving children, prevent homelessness, and foster placement. Colorado, California, and most newly Arizona allows paid parent care giver. It works. There is data to show how this program works. Some families would need or choose foster. Some would choose an outside dsp/psw. Some families would choose to be their own child's dsp/psw. Families need option to fit their child's needs. Some kids would tell you themselves they want their parent to be their caregiver if they were given a voice and choice. Paid parent option will help keep the child and family in countless ways. Parents are the experts on their child's needs. It will also save Oregon money. This is one testimony, there are so many more.

Sincerely, Jennifer Murphy

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