

SB-91

Dear Representatives,

I am writing this email to you with a very heavy heart pleading thank t you help Oregon's most vulnerable children keep access to their most qualified caregivers. I have been advocating for over a year to resolve my children's greatest barrier.... for a change to simply lift the prohibition of paid parent caregivers for minor children. The OAR 411-375-0020 is prohibiting my children from utilizing a parent paid caregiver for their home and community-based services. 411-375-0020 (2)(c) needs to be removed. Here is a recent quote from Melissa Harris, Deputy Dir. of Disabled and Elderly Health Programs Group at CMS, in case it's helpful for you: " There's nothing in the [Federal] waiver statute or regulation that prohibits family members from being paid caregivers". She went on to say it is totally "states' discretion." If a state isn't allowing it, it's because someone at the state wants it that way! Representatives, this is not ok. I want to tell you about our two boys. They are the light of our lives.

I am the mother of two beautiful boys aged 10 and 7. 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 in rural Winston, Oregon. We have been married for 11 years. I have been home since our 10-year-old was born and he was in heart failure, waiting on open heart surgery. During that time, I was running a feeding tube, oxygen and lasics. He experiences Down syndrome, Graves' disease, 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, feeding tube and full care. He is an angel!

Our 7-year-old son, he experiences autism, and was most recently diagnosed February 2021 with type 1 diabetes. He is eager to learn everything he can and shows us daily so much determination. He lives in a very beautiful world of music and color. We would never change a thing about our kids. They are loved, chosen, and happy children. 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 over 800 hours of paid k- plan help offered. While this sounds like it would meet our needs, it is not. The current 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 workforce shortage crisis. There is no one to hire, yet alone qualified with my children. We have provider agencies looking for dsp's and there had been no dsp's to even interview. This option would stabilize families. My husband and I can't find anyone trustworthy, 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. My children require a predictable environment and routine that only we can provide. 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 makes 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 children's services need to be re-balanced to fit every child's needs. I recognize the families it is serving, however there are hundreds of families all over Oregon that are not served mine included. We don't have family and friends to hire. We can't allow exposure to 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 2 successful dsps in 7 years. 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! The 2 were far from qualified. 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 a new diabetes diagnosis of our son we had to learn everything to care for our son. This temporary program has been allowed through the PHE. When the PHE ends May 11 so will this life line, and it will throw families into crisis. My husband had to return to work, after FMLA has 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 children's 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, healthier children. We have 2 kids, and both have a lot of needs. I have been forced out of the workforce to fill these hours and to provide the extraordinary care, and I am actually working at least 2 full time jobs. I am unseen, unheard, and I am doing all the work. The work that Oregon will happily pay multiple people to do. This budget exists under the K plan. I do not comprehend why SB 91 is making this look like a new budget. Any one besides a parent can work these hours today if the workers existed. Paid parents would help out the workforce shortage to send the DSPs and PWS to individuals who do not have a parent to fill the position. We (parents) are the most qualified, loving caregiver our sons could have. We are the safest caregivers for our children. 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 caregiver. My kids have 12 Dr's together, standing routine labs, and appointments. I run their IEP, IFSP, and order supplies. Our kids receive the most love, attention, and care from us, their parents. Parents in this population love their children. We have major life goals with their self-determination at all fronts and we love our kids. When you support the parent, we all know you support the child. We will always be our kid's best support and the most unfailing 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 healthy kids. All the red tape and obstacles families like mine have to fight is so

exhausting and needs improvement. This is a major barrier for my family. Please understand that all our needs in the disabled community are all different, we are voicing to you, to please change this option. Being a paid parent would help our families in many ways. It would help our state. Allowing me to be my son's caregiver has already positively changed our life. I have been able to purchase the boy's special needs toys, communication programs, have had more community inclusion and bought special needs programs that I would not have been able to provide. My 7-year-old is now verbal and has gained skills with his father as his dsp. There are many families that this option would be life changing in a positive way. There is so much support seen here in our community for this option. I am thankful to find a very large growing group of over 900 parents that feel the same as we do and are experiencing this barrier. This is a nationwide movement at this time. 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 extraordinary needs. We are willing to do any training and home visits and whatever safe guards needed. We do not want the k plan to go away for Oregonians, we do want change to allow the parent the option to be the paid provider in circumstances that it's needed. Families have to be trusted and are fully capable of selecting the services their child needs. 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 (there are 0 beds in Oregon available for IDD children. Foster placement is far more expensive for the state than paying a parent as a dsp. Many states offer these supports. It works. There is data to show how this program works. Some families would still need or choose to foster. Some would choose an outside dsp/psw. Some families would choose to be their own child's dsp. Families need options to fit their child's needs. No child should be forced to foster placement because this is not an option available. Some kids would tell you themselves they want their parents to be their caregiver if they were given a voice and choice. Why do adults have this option at age 18 but children do not? Paid parent options 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 as well. It's the right thing to do for children. The question is not IF these children need the care, it's who the state is willing to pay. Children are not getting the services. CMS has firm expectations that the children receive all Medicaid funded services. This barrier needs to be removed to ensure access to the children's entitlement attendant care. We do the assessments to prove the need regularly. By reading the 1915 c and the 1915 k this looks very doable if the powers that be will help the children. In fact CMS has stated so! Parents are the constant for these children and they love their children. I beg you to please sign sb -91 into law, I beg you to encourage a larger budget to cover more children, and I beg to help navigate a gap funding. I beg for hour caps or any way possible to stretch the funds to cover as many children as possible. I beg for any legislators to make this process and program to be as equitable as possible. Families should not be contemplating flooding other states that offer paid parent caregivers.

Thank you so much for your time legislators! I respect the process.

Sincerely Parent Advocate,

Jennifer Murphy