

SB 91

2-5-2023

Chair Gelser Blouin, Vice Chair Art Robinson and Members of the Committee,

My name is Jennifer Murphy and I am in support of SB 91 with amendments. We must and should have a program for children to have the option of a paid parent caregiver. I am asking for an amendment for the hours to be written "per child", not "per household". 60 hours per household would be unjust and unfair to the child/ children in situations with multiple eligible siblings. My two eligible children that are level 5 exclusive focus right now, would **not** each be served independently with "per household". Each child MUST be served equitable and have access to 1-1 care that is required with exclusive focus to keep them safe. The way SB 91 is written currently, 1 child would qualify and 1 wouldn't or we would have to split the 60 hours between 2 eligible children. Both children currently are eligible for the temporary program. Please make this equitable. I am also asking to amend the agency cap. In rural Southern Oregon there are 4 agencies total in our county. A cap would create wait lists and potentially keep families from utilizing the program due to the cap that would be creating limited spots. I fear the possibility of families being turned away with limited spots available.

I am a proud mother to my two amazing sons who both experience disability and high medical diagnoses. We are incredibly thankful for our children. The boy's world is full of purpose and love. They're both level 5 exclusive focus according to Oregon Needs Assessment. They both require 1-1 support. Our youngest is 6 and our oldest is 9 years' old. Everything my husband and I do is for our boys, with their quality of life, health, and self-determination at our forefront. I have been home almost 10 years since our oldest son was born with a host of medical conditions. My husband provides for us working in the timber industry. He has to keep 2 open FMLA's at all times due to our kid's medical diagnoses. It was made very clear at 6 weeks old that our son needed me full time. I had to quit the workforce to help him thrive and to live with the amount of support needed. Today it remains impossible for me to work a paid job due to my children's medical care they both require daily. Many specialists have told us our oldest wouldn't have survived without the love and support we have delivered. He is a miracle! He was born with an AVS and AVSD heart defect that needed open heart surgery, down syndrome, a collapsing airway, fpies, and several autoimmune disorders. He also relies on full lift and support of a wheelchair. He is nonverbal. Our youngest experiences autism and type 1 diabetes. He requires insulin throughout his day every day to live. It's a huge responsibility, several agencies won't allow a DSP to manage these needs due to liability. He is a beautiful boy with his own drum beat, one we are so proud he marches to! The state says my children need attendant care support above their non disabled peers to remain safe and independent in their home and community. The state tells me what hours they are willing to pay for through Medicaid attendant care services. Thankfully today we are not here to ask for these hours to be granted. The hours are there to use as long as we can find outside DSP's/ PSW's. If the workforce was available today, these hours would be paid for with these supports already approved. It is a problem that Oregon budgets on used hours and not allocated hours. This shouldn't be such a cost increase if we budgeted for what has been made available for the child. I don't see this as a new program as this work exists and is recognized as long as you are not the parent and is paid no problem to anyone but a parent caregiver. It appears we don't need the services by not utilizing them and risks cuts to the hours. That is not the case. I'm filling these services and it goes unnoticed, and unrecognized. The change that I seek would be allowing a parent to fill this position. It is important to know anyone can be hired for this job except a felon and a

parent of the minor child. With adult children, their parents are able to be hired for this care when the child turns 18. There is no 60-hour restriction cap with adult children/ parent employment through many agencies in Oregon. During the PHE for the first-time parents of minors could fill these positions for Oregon's highest need children that had at least 240 hours per month or on the CIIS waiver. The change has been pivotal for my two children having access to a paid parent caregiver. More community inclusion, healthier, better quality of life, and more skills gained. Paid parent caregiver is what has always been missing. These attendant hours historically for my children haven't been utilized for several reasons...It is nearly impossible in rural southern Oregon to find support workers. Rural Oregonians have unique needs that must be met and thought about. This is a workforce shortage crisis. We have found 3 reliable staff in 9 years. I have found those staff on my own. I haven't had luck with agency recruitment. The stranger route through agencies hasn't worked for us, the staff quit, are not drug tested, and simply don't understand my children's needs. One support worker we hired, my son that experiences autism couldn't handle her being in his home, it stressed him to have her here. Two others sent with zero experience quit on day 2 of training. My kids don't want strangers in their home doing the support tasks. My children require a routine with consistent, predictable, days for success. I am able to provide that to them, I am the constant, the one they can always count on being there. I know what they need by a sound or a look on their face. Abuse rates are very high for vulnerable children. My kids can't tell me if someone has harmed them. I have to protect them and keep them safe. My husband and I have a strong determination for the boys to support their self-determination and dreams and all the possibilities. We believe the services and support we deliver now will lay the foundation for many possibilities for the future. I believe the boys will be more independent adults with this level of support. Another concern is the support workers bringing in illness to our medical complex children. Before the PHE our oldest son was hospitalized several times a year for illness. As parents we take every precaution to not bring sicknesses in. In 3 years now, our oldest son has not been hospitalized, not even once. That has got to be a cost savings to be recognized as they both have Medicaid. Our children have been the most stable through the PHE with getting these supports given by the most qualified parent caregiver. Paid parent caregivers are part of the solution to home and community based services. We can help the workforce shortage. I'm asking the committee to help with amendments to find common ground and a program that can work for these children and please elevate this need to the next steps in developing a program. Please pass a program through the committee. Please help with allowing my children to live their best lives to the fullest quality possible. Please let them thrive with services and not just survive. A parent caregiver program would help so many families. Families having choices in how to best utilize the attendant care for their child is vital to the child's success. Families must be trusted to make choices. Many states have this option. It is my prayer that Oregon legislators and stakeholders can see the positive outcomes for Oregon's most vulnerable children and find the way to pave the path to forming an equitable program into law for the children.

Thank you.

Sincerely,

Jennifer Murphy (Winston Oregon)