Co-Chair Senator Campos, Co-Chair Representative Valderrama, and members of the Joint Committee On Ways and Means Subcommittee On Human Services.
My name is Jennifer Whitten. I am in support of HB 5026 to fully fund ODDS.

I am compelled to submit a statement after listening to the comments made about Senate Bills 91 and 646 at the March 2nd hearing.

I'm an Oregonian, and I have been an Oregonian my entire life. I'm raising a son with developmental disabilities here in the only home we have ever known. Our family has the great privilege of one parent being gainfully employed - my son's stepfather is able to work outside of the home while I have spent the last 14 years attending my son's needs. I have met so many families in this journey of being a parent of a disabled child that do not have the same fortune. But empathy allows us to hold space and validate the experiences of others. I am undeterred in my hope that - as public servants - our elected officials are capable of deep empathy.

In order to qualify for disability services in Oregon, a child needs more than a simple doctor's note. There is an independent evaluation and eligibility process that takes months. Once approved for services, there are additional assessments that must be done to calculate supported care hours. Contrary to Senator Gelser-Blouin's apparent belief, these assessments do not base care hours on 'tying shoes' or 'cutting meat.' Perhaps those are the supports her own child needed at six, but her statements are not comprehensive of the services ODDS exists to provide. The assessments consider children who may elope from home in the middle of the night, teenagers who need their faces shaved before school, and choking protocols for a child at risk of dying during breakfast. These are activities the state will pay any adult without a felony to perform.

It is worth noting that even IF a child qualifies for support hours with ODDS (and their families undertake the great labor of hiring, training, supervising, scheduling, retaining a caregiver) a parent is not permitted to leave their child unsupervised with that caregiver. This is key to the underlying culture of poverty for families impacted by disability. Parents may not hire a state funded caregiver so they can go to work. That is not the intent of the program. The parent is expected to be available to fill all 'parenting' activities that a typically developing child might also experience. If the child needs a hug, the parent must be there. If the child wants to play a game, the parent must be there. If the child wants to know what is for dinner, the parent must be there to answer. If you are wondering what the point of hiring a caregiver is, if the parent is required to be present while someone else is paid to perform these activities in front of them, you have discovered why so many families 'choose' not to utilize DSP hours. Caregiving hours are a directive to parents to NOT work in order to receive even mediocre support. The current policies are absurdist at best. Senator Gelser-Blouin was correct on one sentiment - many parents choose to just provide this care themselves than to hand-hold an underqualified, unreliable, caregiver-of-the-week.

If the conflict of interest that prevents parents from being paid caregivers is due to parents being both the decision maker on a child's service plan AND a paid caregiver, we know that this only typically applies to one parent. In a two parent household one parent could be a paid caregiver while the other is the decision maker on the case. But that option is also blocked by current policy. As is the concept of a step-parent being paid as a caregiver. An adult sibling, who lives in the home, is welcome to be paid as the child's DSP. A grandparent who lives in the home is also welcome to be paid as the child's DSP. The only person who lives in the home and cannot be the child's DSP is also the person expected to support the child financially. The parent.

But only until the child is 18. The arbitrary line where parents are permitted to be paid caregivers for their children and all moral questionability vanishes. Senator Gelser-Blouin expressed the concerns of adults with disabilities who would not have wanted their parents paid prior to the day they turn 18. Are we also listening to those who *would* have wanted that option for their parents? Or do their voices not matter, since they are in disagreement with this narrative? I wonder if the same adults were asked if they were opposed to their families drowning in credit card debt, defaulting on their mortgage, or going without food and healthcare to support their child. I would hazard a guess that most children would not want to feel like the cause of their family's financial instability. **No child** should ever be asked to carry those burdens of awareness. We do not tell school children that their education is a great expense and inconvenience to taxpayers. We do not point out all of the people in their lives who are being paid to interact with them. Why should we intentionally generate guilt in disabled children over their parent's employment? Typically developing children are not baited with questions about how they would feel if their parents were paid to care for them. Doing so to disabled individuals is borderline abusive.

My child did not get to choose his disability. He did not get to choose the way it limits him. It should not be a 'philosophical' dilemma for society to step in to support kids and their families. Senator Gelser-Blouin wielded the word 'entitlement' like an insult this week. But I fundamentally believe that my child IS entitled to equal access in life, regardless of his diagnosis. He should not be made to consider the expense his disability has on his family, or on society.
I promise, the cost has been the highest for him.

The economic feasibility of being a volunteer full time caregiver *in addition* to being a parent wears thin. We no longer live in a society where even two parent families can realistically rely on a single income. In 2017, two thirds of families with children under 18 identified as dual income households. Considering the current rate of inflation, housing costs, and living expenses, we must acknowledge that relying on unpaid parent caregivers is relegating disabled children to a life of financial instability. A disability diagnosis should not be synonymous with poverty. We are capable of more. We must do better for parents of newborns, pregnant women, newly adoptive parents, young families who are receiving news of developmental differences in their child. The status quo cannot remain. Per census data in 2019, The percentage of children with a disability in the United States increased between 2008 and 2019, from 3.9 percent to 4.3 percent. Disability rates in the United States are highest among American Indian and Alaska Native children (5.9 percent) We cannot continue to ignore the most underserved populations. There will be lasting, long term impacts to our inaction. Deferring an expense today will only lead to larger, broader issues in the future. Contrary to Senator Gelser-Blouin's fearmongering statements made on March 2nd, Oregon will not go backwards to an age of institutions simply because we treat families with disabled minor children as equal to families with disabled adult children. There is no evidence that Oregon favors regression on matters of social justice. We will also not accept indifference. It is inarguable that our children have rights. Momentum for this movement is building nationwide. This is no longer a state-by-state conversation. The position Oregon takes now will be remembered. When the opportunity to choose progress has presented itself across history, there is little grace extended to those in favor of apathy.

A public school education was not always a right, nor accessible for every child, and continues to be steeped in discrimination today. Yet the state assigns hundreds of millions of dollars yearly to the education of all children. Oregon taxpayers have voted again and again in favor of schools. We've passed measures to ensure other people's children get to go to preschool. We fund employment related daycare. We build public parks and playgrounds. I cannot be convinced that Oregonians do not care to support each other's children. Systems change.

Most of us have known disability close to home or in our communities. It is spoken about with hushed voices and a solemn demeanor. It is simple and surgical to deny the request of desperate families on the grounds of budget. But very few people would look in our eyes and tell us they would gladly take our spots for free. There is no 'village' of people waiting to step in. There are no specialized babysitters on-call. There is no pressure to relieve the shortage of caregivers for minors. As parents we are told we are heroes. Miracles workers. A spiritual gift to the world. But the moment we break the shroud of silence placed upon us, we have been met with condemnation. Suddenly we are viewed as opportunists, not missionaries. Greedy, not 'chosen for a greater purpose.' The highly specialized and exhaustive list of tasks we perform daily for our children have been reduced to 'cutting meat' and 'tying shoes.' The disdain with which our publicly elected voice has spoken about us this week is evident. We are listening. Our children are listening. If there is some residual bias in the hearts of an elected official, an inclination to reject the very concept of a parent being paid to provide care to their disabled minor, I sincerely hope that representative considers their position and power as a voice of the people. I hope they consider their own internalized discriminatory preferences that have contributed to - and will continue to support - a system where disabled Oregonians and their families are categorized as sub-citizens.

As I look toward the future, I can imagine parents receiving a diagnosis that was once crushing, heartbreaking, dependency driven, with a shortened life expectancy attached. And I imagine those parents breathing with relief as the safety net closes around them. I imagine parents who once spent sleepless nights scouring the internet for ways to pay their mortgage finally getting to rest. I imagine them able to meet the next day ready to support their child without sacrificing their own physical and mental health. And I have a secret, tiny, flicker of hope that someday a parent will receive a diagnosis and they will feel a tiny spark of elation. Because they have joined a club that is no longer marked by suffering, scarcity, stress, and survival. Just imagine, a world where a disability is welcome with joy.

Thank you for your time.
Jennifer Whitten