



Presentation to the Senate Health Care Committee Feb. 4, 2025

Chair Patterson, Vice-Chair Hayden and members of the committee,

My name is Shasta Kearns Moore with Advocates for Disability Supports. We are back for the third session in a row to ask you — as representatives of the Oregon legislature — to fulfill the promises of support you have made to us and broken again and again. We are here to ask you to affirm that we are the experts in what home support should look like to actually be helpful. We are here to tell you your system of care for disabled youth is broken and enormously complicated and to free us from that dysfunction with the stroke of a pen.

I want to first respond to the state's presentation submitted in testimony on the projected costs of removing the ban on parent-caregivers to these very high needs children. Let's be clear: These hours of support need exist. They are real. The process of obtaining them is not easy and the offer from the state in lieu of institutional placements is not optional.

Imagine it like this: there are three different types of hours.

1. Hours that are filled with good non-parent caregivers, whom you can pry from our cold dead hands. These are already in your budget and will stay in your budget.
2. Hours that are filled with second-rate workers whom parents will replace. These are already in your budget.
3. The third category represents the number of UNUSABLE hours. These are hours that because of workforce issues or the child's needs CANNOT be used. But those needs don't just disappear. We can't just put our children on a shelf. Those needs show up in our overwhelmed hospitals, our overwhelmed schools, our overwhelmed food banks. Those hours ARE ALSO already in your budget but in a very inefficient way.

THIS is why many states — like [Arizona](#), [Ohio](#), and [Delaware](#) — consider allowing this provider type to be budget neutral. The state is already obligated to provide this support and indeed is already doing so.

It's time to stop the sexist notion that this extraordinary care work can simply be absorbed without consequences. It's time to stop the unconscious bias that parents who have neurodiverse children somehow did something “wrong” and can't be trusted.

I am proud to be a member of this community. We are the strongest people you will ever meet. We are educators and nurses and caterers and professors and firefighters and mathematicians and millworkers and IT professionals and microbiologists and — yes — even care workers for *other* humans who don't happen to be our children. We represent an extraordinarily diverse cross-section of humanity. What we have in common is that we have put all of those other aspects of our identities on hold to love and care for our extraordinary children. Because they deserve it. And because no one else can do it better.

Oregon has gone farther than many other states in its care systems but it is still fundamentally patronizing and inefficient. As we learned from the temporary program during the COVID-19 Public Health Emergency, it turns out that when you simply pay people for the labor that you would pay anyone else to do, they can buy their own groceries, heat their own houses and pay their own rent. It is not rocket science. And, by the way, when you do that, it has predictable benefits to the children in the form of consistent, knowledgeable care, a stable environment and an advocate with resources to fight for all the other things they need.

We are all living in times of uncertainty, with AI rapidly changing traditional jobs and climate change threatening a natural resources-based economy. Investing in the care economy is the right thing to do for our community — and our species.

Submitted in written testimony are surveys, reports and data to back up what I'm saying here— as well as hundreds of constituents calling on you to fulfill your promise of support.

But what I'm really hoping you will hear and acknowledge today is the lived experience of so many in this room, online and who have submitted written testimony in stolen minutes of free time. *We* know what we need for our children to survive and thrive. Hear us. Reform Oregon's backward system so we can get back to what really matters: providing loving care for our extraordinary children.

Shasta Kearns Moore