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On Behalf Of:  
Committee: House Committee On Health Care  
Measure, Appointment or Topic: HB4040

Parents of children with disabilities already have to fight for everything, but they shouldn't have to fight for Medicaid and options for parent caregivers. I am submitting testimony in support of HB 4040 based on lived experience navigating Medicaid failures and their real, long-term consequences for disabled children and their families.

I am proud to now live in Oregon after my husband's military retirement after nearly 22 years, and I am glad to pay taxes in a state that reinvests them into its people and infrastructure. I can see my tax dollars at work here in tangible ways. That was not my experience in Texas.

While my children are now adults, my family lived near Fort Hood in Texas while my husband was on active duty. We repeatedly attempted to access services and supports for our disabled children and were unable to do so. Providers were unavailable, waitlists were endless, and the system assumed care existed when it did not. Families like mine were left to fill the gaps alone.

As a direct result of these failures, my oldest son ultimately ended up in a state institution. That placement cost the state more per person than appropriate community-based supports ever would have. It was not caused by parental neglect or unwillingness. It was the predictable outcome of a system that refuses to provide flexible, realistic supports while children still live at home.

Oregon has rightly recognized that large institutions are inhumane and has moved away from them. I agree with that value. However, eliminating institutions without adequately supporting families does not create safety. It shifts risk into group homes or unstable in-home care arrangements with rotating strangers. That is not humane care. That is displacement.

There is a nationwide direct care workforce shortage. When providers do not exist, parents become the providers by default. The state accepts this labor when it is unpaid but resists it when families ask to be paid. It makes no sense to insist that only strangers should be paid to provide care while parents perform the same skilled work for free. High turnover, frequent call-ins, and constant staff changes increase the risk of neglect and abuse. Children are safest when care is consistent and delivered by someone who knows their medical needs, communication differences, and behavioral triggers.

Paid parent caregiving directly increases safety. Parents of medically fragile children or children with severe behavioral needs are often expected to maintain employment while managing caregivers who call in constantly, quit, or are fired because the work is too demanding. That instability creates crisis conditions. Allowing a parent to be paid stabilizes care, reduces emergencies, and ensures children receive consistent treatment instead of repeated hospitalizations or placement disruptions.

One parent may still want or need to work, and families should not be punished for that. For medically fragile children and severe behavioral cases, parental income should not block access to care. The goal should be treatment and stability, not forcing families into poverty to qualify for help.

HB 4040 allows parents in the Children's Extraordinary Needs waiver to serve as paid support workers when providers are unavailable. It should also remain an option even when providers exist, because the state gets more effective care for fewer dollars this way. Oregon currently limits paid parent caregiving to 155 children while more than 1,500 are eligible. Expanding flexibility would keep more children safely at home and reduce reliance on far more expensive placements.

Providing strong supports when children are young reduces long-term costs when they become adults. Oregon needs to plan forward, not react after harm has already occurred.

Oregon has chosen humanity. HB 4040 reflects that choice. Thank you for continuing to invest in people, not just systems.