

Members of the Task Force on Universal Health Care,

Thank you for the opportunity to speak today. I come to you with good news and bad news.

The good news is that we found something that works for our state's most vulnerable and disabled children. During the pandemic, Oregon inadvertently launched a pilot program that transformed their lives and trajectory — 13 families were saved from the brink of homelessness, half of families reduced their need for other public assistance programs, hospitalizations of medically fragile children dropped dramatically and the vast majority of families reported their disabled children were happier, healthier and more included in their communities.

What was the program, you ask? Allowing the parents of minor children who receive in-home caregiver services to apply to work the same hours the state would be willing to pay practically anyone else to do.

Oregon is not unique in seeing the positive effects of paying parents for their life-saving labor. Colorado's permanent paid parent caregiver plan [has shown a six-fold reduction in hospitalizations](#).

Arizona recently passed a program that is identical to the one we are asking for and they are also seeing major benefits.

The bad news is that we are meeting roadblock after roadblock on the path to expanding this program and making it permanent. In February, the Medicaid Advisory Committee issued a unanimous letter asking the Brown Administration to come up with options for this and facilitate a meeting with Centers for Medicare and Medicaid.

Those things have not happened and time is running out. Hundreds of Oregon's most medically complex families are facing a fiscal cliff with the public health emergency set to end July 15.

Parents in the limited and temporary program have overwhelmingly reported positive changes in the last 14 months — including improved ability to achieve respite, afford mental health care and afford the expensive toys, therapeutic equipment and personal items their children require.

This type of program must be included in any health care plans moving forward.

In a survey conducted by the Oregon Advocates for Equitable Disability Services:

- 90.3 percent of respondents said their child's physical health improved
- 89.2 percent of respondents said their child's mental health improved

- Before the program, many of these children spent days and days in the hospital.

Seventy-two families said their children were hospitalized one or more days every year on average before the program, 15 of those for 10 days or longer. After the program?

The number of children who did not need to visit the hospital at all nearly doubled. Only 32 needed hospitalization, and only four of those were for 10 days or more.

- 69.9 percent said their child was more included in the community after the program and 28 percent said it was about the same as before.
- Families were on a wide range of public assistance programs prior to this income — more than half said they were able to reduce their reliance on those.
- What about the narrative of greedy parents taking up all the hours? *Even during a pandemic*, most (58.5 percent) continued to hire outside providers and those who didn't mostly said it was because they couldn't find anyone else or they were too worried about infections.

Two families reported their previously nonverbal children learned to talk when they were able to have daily stable parent support. Another child, an 11-year-old, achieved continence with his parent-caregiver. Many more have purchased wheelchair vans, therapeutic equipment and other items their children needed to adapt their environment to their unique needs.

These are just some of the many cool things that happen when we get taxpayer dollars out of a bureaucracy and into the hands of the people directly affected.

This program saves health care costs, it saves children's lives, it saves public assistance dollars and it reduces human misery. In all ways it is fulfilling OHA's mission to help "*people and communities achieve optimum physical, mental and social well-being through partnerships, prevention and access to quality affordable health care.*"

It also is what people with lived experience say is the best way to fulfill Oregon [law](#), which states that: "*Support for families with children who have developmental disabilities must be based upon principles of choice and self-determination, with families receiving the support they need to support their children at home.*"

Without this program we on the ground predict a wave of medically and psychologically complex children entering the overwhelmed foster care system or languishing in hospitals with nowhere to go.

This program is a win-win. Oregon gets a solution to its caregiver crisis, disabled children get access to their best-qualified caregivers and parents are finally valued for their incredible contributions in supporting their disabled children to live full, healthy and expansive lives in their own homes.

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