

Christina Riley
Jay
LD 206

Hon. Christina Riley
Jay ME rileyofjay@gmail.com
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Testimony to the Joint Standing Committee on Appropriations and Financial Affairs
LD 206; DHHS

On page 50 of the state budget as adopted on July 19, 2021, there is a \$465,000 Part DD allocation for a pilot program to employ parents of children with disabilities as caregivers for their children. The directive is clear: The department may adopt any rules necessary to implement the pilot program as long as the rules are adopted no later than January 1, 2022. At that time, Medicaid's standalone Appendix K would likely have opened a clear path for implementation of this program due to the covid public health emergency. The State of Oregon (and possibly others) implemented a program very similar to the one described in this budget.

On Tuesday, January 24, 2023, Kristen Figueroa, DAFS Commissioner, testified before this committee that the program was never implemented because of "concerns that the program is not permissible as well as possible unintended consequences of Medicaid eligibility." I am struggling to understand the disconnect there. I strongly suspect, based on the programs available in states like Colorado, that there is a path forward for employing parents as caregivers for their minor children with severe disabilities, even as the covid emergency ends.

It is difficult for a person with a normal life to understand the impact of having a child with a severe disability on daily routines. Whether the child will be able to get to school every day is not a given; health issues and medical appointments are outsized. Finding daycare can be straight-up impossible. Getting a good night's sleep is fodder for jokes in households like ours. Holding down a job can be impossible.

When my child was 13, his muscular dystrophy progressed to the point that I had to walk away from my dream job. The one person we most needed, who had shown up every day at 4:45 am so I could go to work, was retiring. Finding a replacement was a tall order. And I was exhausted from waking up every two hours to reposition my son - a job I have done every night for over ten years now. I was fortunate - my husband also had a good-paying job and we were able to survive.

Think about what that is like for a single parent, or when the remaining wage earner is not able to bring in enough to cover expenses. The desperation I hear from parents in those situations is heartbreaking. The child's need for extraordinary support is well-documented and the supply of capable, reliable workers is at an all-time low.

This pilot program would have begun to address this urgent need, and I do not understand why it was not implemented. I urge the committee to seek a better explanation as to why the will and intent of the legislature was ignored, and to insist that the program be implemented as required.