

February 5, 2023

To the Oregon Senate Human Services Committee,

My name is Jared Stram. I am a registered nurse and father of four and give this written testimony to support SB 646. Let me give you a little background; my youngest son Rowan is diagnosed with level 3 autism spectrum disorder (ASD) and an IgA deficiency leading him to be immune compromised. Rowan required hospitalization within a week of being born. At nine months old, Rowan contracted RSV and developed bilateral pneumonia and a bloodstream infection that resulted in a 10-day hospital stay in the ICU. He nearly required a mechanical ventilator due to the severity of his illness. In his short eight years, he has had 14 hospitalizations secondary to his immune deficiency and ASD.

Before implementing the temporary waiver allowing my wife to gain income from working as Rowan's PSW, we could not utilize a support person due to his immune compromise. Rowan's immunologist has given us explicit instructions to keep him at home, with the additional recommendation that Rowan does not attend public or private school due to his susceptibility to severe illness from viral and bacterial infections that are minor in the average child.

The temporary waiver allowing parents to earn income by providing care to their disabled child has been life-altering for my family. My wife has been unable to work due to the level of care Rowan requires. By allowing her to care for Rowan and earn an income doing so, we have been able to pay off his medical bills that had been stacking up for seven years; in fact, we have been able to become medical debt-free for the first time since he was born. I have needed to work many overtime shifts to maintain our family needs up to this point. Now, I can spend quality time with my children and participate in Rowan's care more. The results have been dramatic; decreased physical aggression, decreased illnesses, gains in his ability to care for his own needs, and he is happier to have both parents more often. , In addition, we have been able to afford many environmental modifications and items that have prevented Rowan from needing hospitalization despite the Covid-19 Pandemic.

Paid Parental caregiving for disabled children has several benefits, including.

- Economic stability: Providing a salary to parents of children with disabilities can help them financially and provide a stable source of income to cover their living expenses and the cost of caring for their child.
- Improved quality of care: When parents are financially compensated for their caregiving duties, they can provide higher quality care and support for their child, which can lead to better outcomes for the child.
- Recognition of caregiving as work: Paid caregiving for children with disabilities is seen as a form of work and a valuable contribution to society. This recognition and compensation can provide a sense of dignity and purpose to parents who may otherwise feel unsupported.
- Reduction in caregiver stress and burnout: When parents can receive financial compensation for their caregiving duties, they are less likely to experience stress and burnout, which can harm their health and the well-being of the child they are caring for.

- Support for families: Providing financial compensation to parents of children with disabilities can help to support families and reduce the burden on other government programs and services.

Studies have also shown that investing in programs to support families caring for children with disabilities can have positive impacts on children's health, development, and overall well-being, as well as reducing long-term health and social care costs.

A recent study in Norway examined the effects of a child with a disability on parental employment and income. It concluded that mothers of children with severe disabilities were able to work and earn less money if they did not stop working entirely. Fathers of children with severe disabilities were also affected negatively, as they tended to earn less income than fathers of a child without disabilities.

Wondemu, M. Y., Joranger, P., Hermansen, Å., & Brekke, I. (2022). Impact of child disability on parental employment and labour income: a quasi-experimental study of parents of children with disabilities in Norway. *BMC Public Health*, 22(1), 1813. <https://doi.org/10.1186/s12889-022-14195-5>

Another recent study investigated the quality of life of parents of disabled children. It concluded that mothers of disabled children expressed a significant decrease in their perceived quality of life. Quoting the article, "...it was shown that fathers spent less time with disabled children than mothers, and they could not help mothers with so much childcare." This statement is exactly what was occurring with my family due to the continued need for me to work overtime to supplement our family's income with my wife needing to stay home to care for Rowan. Paying her to remain home to care for him eased the financial burden, allowing me to insert myself in childcare more often; as a result, her, my own, our son, and our other children's quality of life has improved dramatically.

Ersin, I., Yumin, E. T., & Turkoglu, S. A. (2022). An investigation of factors affecting the quality of life in parents of chronically disabled children. *Annals of Medical Research*, 29(6), 574–579. <https://doi.org/10.5455/annalsmedres.2021.10.590>

As a medical professional and a father of a disabled child, I implore the committee of the imperative to pass SB 646 and allow parents to work as paid caregivers for their disabled children. This bill is budget neutral, as it utilizes an already funded program. It maintains equity within the service delivery, as parents are already allowed to be paid caregivers for their children if they are over 18. This program can also make use of the 2:1 Federal Match from CMS, lowering its economic impact on Oregon. Regarding SB 91, I find that as it is written, it is too restrictive, and not family friendly and would not support its passage without significant changes.

Sincerely,

Jared Stram, RN, BSN, MBA-HCM, CMSRN