

To the Oregon Senate Committee on Healthcare,

My name is Jared Stram. I am a registered nurse and father of four, and I submit this written testimony in support of SB 538. Let me provide some background; my youngest son, Rowan, is diagnosed with Level 3 Autism Spectrum Disorder (ASD) and an IgA deficiency, which makes him immunocompromised. Rowan required hospitalization within a week of birth. At nine months old, he contracted RSV and developed bilateral pneumonia and a bloodstream infection, leading to a 10-day hospital stay in the ICU. He nearly required mechanical ventilation due to the severity of his illness. In his short ten years, he has had 14 hospitalizations due to his immune deficiency and ASD.

Before the implementation of the temporary waiver during the COVID-19 pandemic allowing my wife to earn income as Rowan's DSP, we were unable to utilize a support person due to his immune compromise. Rowan's immunologist has explicitly instructed us to keep him at home, with the additional recommendation that he not attend public or private school due to his high susceptibility to severe infections.

The ability for all parents to be compensated as caregivers, as proposed in SB 538, would be life-changing for families like mine. During the temporary waiver period, my wife was able to provide the care Rowan requires while earning an income—something that had previously been impossible due to the intensity of his needs. This financial stability allowed us to pay off seven years' worth of accumulated medical debt, making us medical debt-free for the first time since Rowan was born. Before the waiver, I had to work frequent overtime to support our family, leaving little opportunity to be present for my children. With both parents actively involved in Rowan's care, we saw remarkable improvements: reduced physical aggression, fewer illnesses, increased independence in daily tasks, and an overall happier child. We became able to afford essential environmental modifications and medical necessities that helped keep Rowan out of the hospital, even throughout the COVID-19 pandemic. Restoring this support through SB 538 would ensure that families like mine are not forced back into financial and emotional hardship simply because they are doing what any parent would—caring for their child.

Paid parental caregiving for disabled children has several benefits, including:

- **Economic stability:** Providing a salary to parents of children with disabilities helps them financially and provides a stable source of income to cover living expenses and the costs of care.
- **Improved quality of care:** When parents are financially compensated for their caregiving duties, they can provide higher-quality care and support, leading to better outcomes for the child.

- **Recognition of caregiving as work:** Paid caregiving acknowledges the valuable contribution of parents and provides them with dignity and purpose.
- **Reduction in caregiver stress and burnout:** Financial compensation alleviates stress and burnout, improving the well-being of both the caregiver and the child.

Studies have shown that investing in programs to support families caring for children with disabilities positively impacts children's health, development, and overall well-being, while also reducing long-term healthcare and social service costs.

A recent study in Norway examined the effects of having 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 also earned less income than fathers of children 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 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. The study stated, "...it was shown that fathers spent less time with disabled children than mothers, and they could not help mothers with so much childcare."

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 urge the committee to pass SB 538 and allow all parents to work as paid caregivers for their disabled children. This bill maintains equity within the service delivery system, as parents are already permitted to be paid caregivers for their children once they turn 18.

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