



Fulfilling Our Promises: Allow Oregon's Children with Disabilities to Access Parent-Caregivers

Introduction

Oregon has long struggled to provide adequate in-home care for minor children with complex medical and behavioral needs. While parents of disabled adults can be paid caregivers, this option isn't available to children, leaving many young families with impossible choices.

In their latest technical guidance¹, the Centers for Medicare and Medicaid Services (CMS) affirmed: "States are **required** to ensure individuals have access to needed services and **states should strongly consider the authorization of legally responsible individuals [e.g. parents] to meet the requirement of ensuring the delivery of needed services.**"

"Tensy's Law"² would increase access to Oregon's Children's Extraordinary Needs (CEN) waiver; allow parents of minors to be personal support workers; and ensure this compensation comes from

¹ <https://tinyurl.com/dxcz56ja> HCBS Waiver Requests and Supporting Regulations; 42 CFR 440.180, 441.300-.310

² [SB 538](#): Chief Sponsors Sen. Patterson and Rep Neron; Co-sponsors: Sens. Frederick, Hayden, Woods; Reps. Nosse, McLain, Chaichi, Nelson, Grayber.

already-obligated funding. **The proposal ensures budget neutrality, saves the state money, avoids costly legal risks and fulfills our promises to our state's most vulnerable residents.**

State Savings and Economic Benefits

- [Research](#)³ from states like Colorado shows that paid family caregiving **improves health outcomes** for disabled children, resulting in fewer hospitalizations. This could **reduce emergency room visits** and other health care charges to the Oregon Health Plan.
- The Federal Medical Assistance Percentage provides 60 cents on every dollar, **more than doubling Oregon's investment** in this workforce and creating a multiplier effect in local and rural economies.
- **The Congressional Budget Office (CBO)** [estimates](#)⁴ that compensating family caregivers would raise caregiver wages and expand the workforce, allowing parents to either continue providing quality care at home or **return to their primary occupations**.
- Home-based care is generally **much cheaper than institutional care**. By compensating parents, Oregon can **prevent spending** on out-of-home settings, which cost up to three times more. The average *monthly* cost of a SACU placement is about \$103,000.

Survey Data From Impacted Families

[A survey of 124 families](#) eligible for Oregon's CEN waiver highlights the critical challenges these families face. The key findings include:

- **Unmet Care Needs:** Over **90% of families** are not able to use all of their assessed care hours. Workforce shortages and safety concerns about available caregivers were cited as the primary reasons.
- **Dependence on Public Assistance:** **75% of families** are using at least one public assistance program. However, **66%** state they could leave at least one assistance program if they were paid for their labor.
- **Improved Outcomes:** **88% of families** say their child's physical health would improve if parents were paid caregivers, and **90%** say their child's mental health and community inclusion would also improve.
- **Universal Support:** Every family surveyed (100%) expressed the need to expand the CEN waiver to all eligible children.

Legislative Background and Court Cases

- **These hours are hard to get and not optional for the state to provide.** Oregon's disabled children are exhaustively vetted and assessed annually for the number of hours required above and beyond typical parenting duties for children their age.

³ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9247720/>

⁴ <https://www.cbo.gov/publication/57632>

- Passed overwhelmingly in 2023, **S.B 91** set up a comprehensive waiver for parent caregivers. Although the initiative’s \$3 million GF budget was intended to **augment the existing budget**, it has been treated as the full program budget. Oregon spends \$305.7 million annually on HCBS — **a total of \$814.3 million including federal funds.**⁵
- An [injunction](#)⁶ in a Florida case requires the state come up with at least 90 percent of children’s assessed service hours.
- After slashing their paid parent allowance, Indiana is currently being [sued](#) by a coalition of disability rights organizations for violating these children’s Olmstead rights to live at home.

Additional Resources

- KATU series : “**I do not think that in my son's lifetime, he will see paid-parent caregivers,**” Calli said. “**That is part of why having this bill named after him, hopefully it will be his legacy.**”
https://katu.com/news/katu-investigates/parents-of-disabled-children-push-back-on-oreg-ons-reason-not-to-expand-paid-parent-care?fbclid=IwZXh0bgNhZW0CMTEAAR2aYRz8DdTR0IZiQf3lQ8rwQrddlx6jZx9lNjjDsGUa8RD8HESvC-Lr5LU_aem_pcgXxdc7nW0FPGsuf4nqtA
- **Read this excellent piece from InvestigateWest's Kaylee Tornay:**
<https://www.investigatwest.org/investigatwest-reports/new-oregon-program-pays-parents-to-care-for-kids-with-intensive-medical-behavioral-needs-but-few-can-access-it-17706750>
- **Dr. Carolyn Foster’s research** on poor quality and access to home care for children with Complex Medical Conditions
<https://journals.sagepub.com/doi/epub/10.1177/10848223231167878>
- On Dec. 3, 2022 the Autism Society of Oregon Listening Session heard story after story after story of how **profoundly impactful the temporary program was.** Documentarian Lenore Eklund turned that two-hour session (https://youtu.be/BvfpHXdb_wo) into a **20-min featurette:** <https://m.youtube.com/watch?v=5O6yeX-XAc&feature=youtu.be>

⁵ <https://tinyurl.com/4hj2euv8> Feb. 19, 2024 presentation to the JWM Subcommittee on Human Services.

⁶ <https://healthlaw.org/resource/u-s-v-florida-amicus-case-explainer/>