



October 8, 2024

Speaker Fahey, President Wagner, and Co-Chairs of the Joint Committee on Ways and Means,

We write to you today to share a value and intention well in advance of the 2025 legislative session. In the interest of transparency and collaboration, we want you to know that we look forward to building on the work we have done to serve Oregon's children with the highest medical needs, who qualify for care and services, with what we are calling "Tensy's Law."

Tensy is one of hundreds of Oregon kids who need unique, specialized, and around-the-clock attention due to high medical and behavioral needs. His family works hard to ensure he receives life-sustaining care, but they also work hard to ensure that children with extraordinary needs are understood and addressed in policy. These children have been assessed to need care beyond typical parenting workloads, but due to a persistent workforce shortage, many families cannot find a qualified caregiver to fill their children's assessed care hours. Parents fill the gap by providing this needed and specialized care without compensation, and they sacrifice employment opportunities to do so. As a result, many parents find themselves in the position of having to choose between putting food on the table and providing necessary care for their children.

During the COVID-19 pandemic, Oregon's experience with a temporary paid parent caregiver program has shown this approach to be an effective way of meeting the state's obligation to provide care for these children. Other states like Colorado, Arizona, Idaho, Ohio, and Minnesota already allow parents to work as in-home care workers for their children<sup>1</sup>. Research from other states, such as Colorado, shows that paid family caregiving improves health outcomes for medically fragile children, resulting in fewer hospitalizations.<sup>2</sup> This could reduce emergency room visits and other health care charges to the Oregon Health Plan. The Congressional Budget Office estimates 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.<sup>3</sup>

In 2023, our Legislature took action to help Oregon families navigate life with disabilities and ensure access to needed care. With overwhelming bipartisan support, we passed SB 91 to create the Children's Extraordinary Needs (CEN) waiver, which allows children with very high needs to receive paid care from their parents or guardians. However, more than 1,500 children

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<sup>1</sup> Minnesota Department of Human Services. [Spouses and parents of minors can be paid to provide PCA services.](#)

<sup>2</sup> Carter, K. et al. (2022). [Employing Family Caregivers: An Innovative Health Care Model.](#) Pediatrics. 2022 Jun 1;149(6):e2021054273. doi: 10.1542/peds.2021-054273.

<sup>3</sup> Congressional Budget Office. (2021). [Economic Effects of Expanding Home- and Community-Based Services in Medicaid.](#)

are eligible for the CEN program, but the program launched on July 1, 2024 with only 155 available spots<sup>4</sup>. This means a staggering 90 percent of eligible children, including Tensy, are still unable to access this essential program.<sup>5</sup> Tensy's Law would address this by allowing all eligible children a spot in the CEN waiver.

With this letter, we hope to stress Oregon's obligation to respond. We signatories understand that the Centers for Medicare and Medicaid Services (CMS) has strongly encouraged states to consider family caregiving options.<sup>6</sup> CMS is also taking active steps to ensure states provide the hours of care their assessments indicate are necessary. It's important to recognize that these are not new services being requested; rather, they are hours of care that have already been deemed essential. Consequently, this should not be seen as a new budgetary burden but rather as a fulfillment of Oregon's existing obligations. **By enacting Tensy's Law, Oregon has the opportunity to deliver on a long-standing promise to support its disabled children and their families**, and to come alongside the growing number of states that have leaned in to solve this challenge.

Thank you for taking time to consider the work at hand and our intentions for 2025. We urge you to join us in prioritizing Tensy and the many Oregon children he represents.

Signed,



Senator Deb Patterson



Representative Courtney Neron



Senator Cedric Hayden



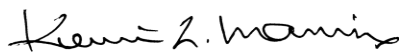
Representative Rob Nosse



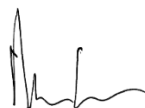
Representative Emily McIntire



Representative Dacia Grayber



Representative Kevin Mannix



Representative Mark Owens



Representative Farrah Chaichi

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<sup>4</sup> Oregon Department of Human Services. [Children's Extraordinary Needs Program](#).

<sup>5</sup> Wright Gazaway (August 13, 2024). [Parents of severely disabled children beg Oregon to expand paid parent care program](#). KATU.

<sup>6</sup> Center for Medicare and Medicaid Services. (July 2024). [1915\(c\) Waiver Instructions, Technical Guide and Review Criteria](#).