



**Testimony by Advocates for Disability Supports  
Before the Joint Ways and Means Committee  
RE: Support for Tensy's Law – Ensuring Access to Promised Medicaid Services for  
Oregon's Disabled Children**

**Co-Chairs Lieber and Sanchez, and Members of the Committee:**

We request SB 538 be scheduled for a hearing by the Joint Ways and Means Committee. This bill will expand the reach of the Children with Extraordinary Needs (CEN) Program, allowing parents and legal guardians of all children designated as extremely high needs (Level 5 medical or behavioral) to be hired as their child's caregiver for up to 40 hours/week. There is bipartisan agreement that SB 538 is good for Oregon's highest-needs children.

We recognize that the fiscal attached to SB 538 is a challenge. In light of a March 20, 2025 analysis by the Health Policy and Analytics Medicaid Division of the Oregon Health Authority that demonstrated **reduced medical service utilization by children who are part of the CEN program compared to their waitlisted peers**, we request that the fiscal be considered with the following additional context. We additionally ask that legislators **request an analysis of the amount the state spends on social services for families who are part of the 5m/5b service group and the potential expected savings** that could be realized if those families could be hired as paid caregivers for their children.

**KEY POINTS:**

- SB538 does not increase authorized hours- it simply narrows the difference between actual need and available care. It is a solution to the caregiver crisis.
- Savings from documented reduction of emergency department visits and primary care appointments as well as reduced family reliance on wrap-around social services are not reflected in the fiscal impact of the bill.

**Lessons from the temporary pandemic program**

**Facts**

- During the COVID-19 Public Health Emergency, Oregon used an 1135 waiver authority to temporarily allow parents to provide paid care to their minor children with I/DD.
- This program ran from Jan 21, 2021 until May 11, 2023. The temporary waiver expired with the ending of the Public Health Emergency.
- Children with very high support needs (eligible for at least 240 hours of care per month) were eligible. This totaled approximately 1080 children.
- Trends and data from this temporary pandemic program were used to calculate the fiscal for SB 538.

*Argument Against Expanding Paid Parent Caregiving:* This waiver saw an increase in hours utilization. The cost-per-case (CPC) for children who had a parent caregiver (\$10,312) was about 74% higher compared to children who were eligible but whose parents chose not to participate (\$5,927).

#### **Additional Context:**

- Utilization increased, not the number of hours children were qualified to receive. The hours parents worked as paid caregivers helped **narrow the difference between actual need and available care.**
- In a 2024 survey of parents of children assessed in the highest need group (5m/5b), 91% reported not using all of their allotted hours. The reasons given were not because of a lack of need, but because they could not find care workers, or the workers available were not skilled enough to handle their children's complex behavioral and medical needs. **There is a care worker crisis. SB 538 is a solution.**
- Providing an avenue for children to access skilled care increases costs because **it increases the utilization of already allotted hours.** If we are prioritizing the health and safety of children in Oregon, **this should be seen as a win.**
- Balancing the budget by facilitating conditions that prevent highest needs children from being able to fully access their allotted hours is dishonest, unjust, and violates these children's Olmstead rights to receive support in their own homes.

#### **A Wider View of Costs and Savings**

##### **Facts**

- The fiscal impact of the measure on DHS was returned as \$40.9 million in total funds in 2025-27. Costs increase in 2027-29 to \$70.9 million total funds.
- These numbers are based on experience with a similar program administered during the public health emergency, the estimate assumes 70% of provider parents will work as direct support professionals and 30% of parents will work as personal support workers. The assumed provider rates are \$42.24 per hour for agency direct support professional services and \$22.13 per hour for personal support workers.
- The Legislative Review Office returned a finding of no impact on state or local revenues.
- The fiscal and revenue impact statement reflects only provider rates and three new positions for up to a total of 2.25 FTE to administer this program.

*Argument Against Paid Parent Caregiving:* This program is an added cost to the state at a time when budget cuts need to be made.

### Missing Context

- With a 57.75 percent FMAP, the responsibility to the state is reduced to \$19,546,408 for the 25-27 biennium, and \$33,502,652 for the 27-29 biennium. Trends from the COVID-19 Public Health Emergency program were used to determine fiscal impact, but equivalent analyses were not done to determine savings.
- A March 2025 report from the Health Policy and Analytics Medicaid Division of the Oregon Health Authority examined service utilization of 5m/5b children who were part of and not part of the Children’s Extraordinary Needs Program (CEN). This program, created by SB91, allows paid parent caregiving for up to 155 families, capped at 20 hours/week.
  - This report compared 1) Children in the CEN to 2) Children on the waitlist for CEN and 3) Children who qualify for the CEN but are not on the waitlist for various reasons (referred to as “only in the 5m/5b service group”). Children were offered a spot in CEN by random lottery. Because of this randomization, children in CEN and children on the waitlist should not be systematically different from one another.
  - Because of the high level of needs, **all children were enrolled in the Oregon Health Plan.**
  - Parents who worked as their children’s caregiver during the temporary pandemic program reported that their **children were healthier with a parent caregiver compared to when they were cared for by agency-provided care workers.** The analysis corroborates this assertion.
  - **Children in CEN had significantly fewer primary care and behavioral health appointments** than both children on the waitlist and children only in the 5m/5b service group.
  - **Children in CEN had fewer emergency department visits** than both children on the waitlist and children only in the 5m/5b service group.
  - Hospitalizations and use of crisis services were about the same across all groups.
  - Because all children who qualify for CEN also qualify for Oregon Health Plan, **fewer medical appointments and emergency department visits equate to Medicaid savings for the state. However, these savings are not captured in the fiscal impact of this bill.**
  - Because of the July 1 2024 start date of CEN, the data reflects approximately 6 months of time. Although it is too early to draw a causal relationship between allowing parents to work as their child’s paid caregiver and the reduction in medical service utilization, parents have been saying this for years. That there is already a significant difference when examined experimentally is noteworthy. The report’s analysts encourage repeated

analysis over a longer study period to bring more clarity to the mechanisms driving these differences.

- Legislators are encouraged to **request an analysis of the Medicaid savings appreciated by reduced medical services utilization.**
- Parents who were part of the Temporary Pandemic Program reported that the consistent and stabilizing income earned from working as a paid caregiver allowed them to **leave other public assistance programs such as OHP for the family, SNAP, and SSI. However, these savings are not captured in the fiscal impact of this bill.**
  - A 2024 survey of parents of children assessed in the highest need group (5m/5b) found that **75% of families used at least one public assistance program in addition** to OHP for their 5m/5b child.
  - Based on their experience with the temporary pandemic program, **66% of families thought they would or may be able to leave at least one public assistance program** as a result of being able to be paid for 20 hours of caregiving per week. That number would rise with SB 538, which allows for 40 hours per week.
  - A case study of a parent who worked as a paid caregiver during the temporary pandemic program showed that when earning wages, they were able to leave SSI, SNAP, LIHEAP, and collect unemployment. In wages and benefits, paying this parent cost \$2,067 per month, only \$684 of which was Oregon's responsibility with FMAP. Once the pandemic program ended, this same parent returned to the social service programs they had previously left, raising state and federal obligations to \$4,641 per month. Presumably, state analysts could provide the specific proportion of those costs that were Oregon's responsibility.
  - Stabilizing families by providing a path to steady work in a population that often can not hold a steady job due to extraordinary caregiving responsibilities will not cost as much as is projected because **it will save the state money in Medicaid payouts and social service utilization.**

*Argument Against Paid Parent Caregiving* The added uncertainty from the Federal government makes it difficult to approve a bill with a large fiscal.

### **Missing Context**

- The added uncertainty makes SB 538 make *more* sense as it provides a path to guarantee skilled care to the most vulnerable children.
- With the current model disallowing hiring parents as caregivers, the state makes at least three payments — to a third-party care worker, to Medicaid for health care costs, and to social services to support families who have lost an income due to a parent needing to exit the workforce to provide care.
- By passing SB 538, the state will fund children and families, not agencies and systems.

**A single expenditure to parent caregivers will reduce the need to pay a third-party caregiver, save on Medicaid expenses, and reduce the need for social services. At a time when Medicaid and social services are being reimagined and federal dollars need to be stretched more than ever, this just makes fiscal sense.**

Thank you,

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