



Presentation to Senate Human Services Committee

Senate Bill 538 and the Children's Extraordinary Needs Program

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Services (ODDS)

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Agenda

- I. **ODDS introduction**
- II. Background information
- III. Children's Extraordinary Needs (CEN) program
- IV. Senate Bill 538
- V. Preliminary fiscal impact
- VI. Questions

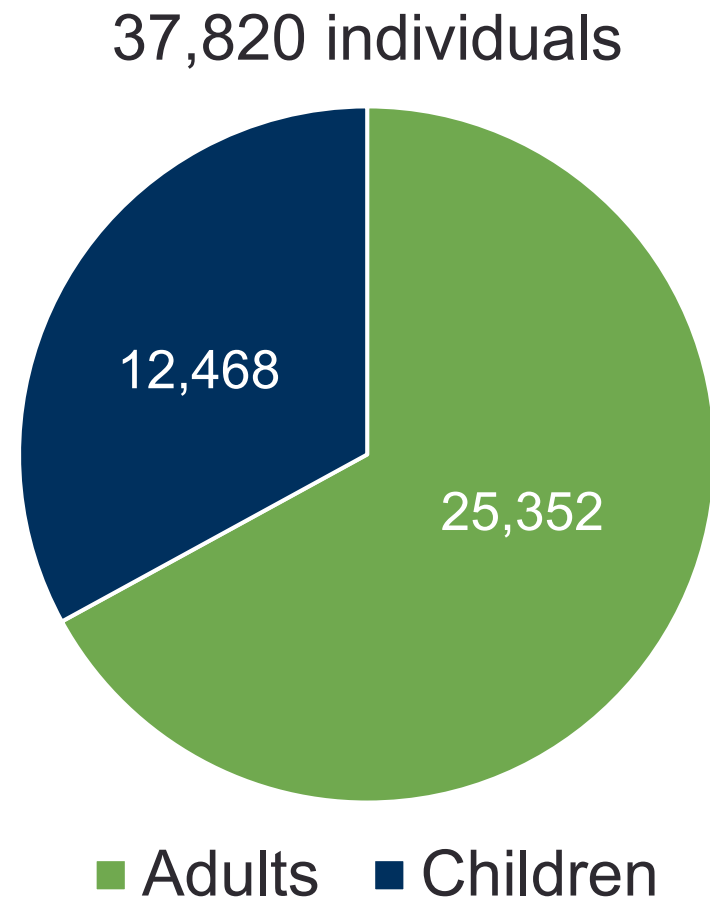
Office of Developmental
Disabilities Services



Office of Developmental Disabilities Services (ODDS)

ODDS leads and oversees the statewide system of services and supports for:

- Children and adults with intellectual or developmental disabilities (I/DD).
- Children who are medically involved or medically fragile.



Our mission and vision

Mission: ODDS, partners and the intellectual and developmental disabilities (I/DD) community work together to provide services, supports and advocacy that empower Oregonians with I/DD to live full lives in their communities.

Vision: People and families access quality supports that are simple to use and responsive to their strengths, needs and choices, while they live and thrive as valued members of their community.

- Children with I/DD grow up with the same expectations as any other child — to become contributing members of their communities.

Core values of person-centered practices



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- II. Temporary pandemic program**
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Temporary paid-parent care during the pandemic

Oregon was one of several states that allowed parents to provide paid care to their minor children with I/DD during the COVID-19 Public Health Emergency.

- Intent: Limit exposure of children with the highest risk for severe complication or death due to COVID-19 by replacing outside caregivers with parent care.

Oregon used an [1135 waiver authority](#) for the temporary program.

- Program could not be extended beyond the public health emergency.
- Program ended with the federal public health emergency on May 11, 2023.

Temporary pandemic program: Eligibility

Children eligible for 240 hours of care per month or more were eligible for the temporary paid-parent program.

- This level of care indicated that these children had very high support needs.
- About 1080 children were initially eligible for the program.

The **program was intended to replace outside caregivers** with parent caregivers for children with the highest risks related to COVID-19.

- Instead, the **system saw an increase in hour utilization rather than replacement.**

Cost of temporary pandemic program

Cost-per-case (CPC) for children who had a parent caregiver was about 74% higher than children who were eligible but whose parents did not participate.

- Monthly CPC for those eligible **and** participating (child had at least one paid parent) **\$10,312**
- Monthly CPC for those eligible and **not** participating (no paid parent working for child): **\$5,927**

Additional cost to the system due to paid parents was about **\$1.9 million TF per month** while the program was operating from Jan. 21, 2021, through May 11, 2023.

Senate Bill 91 (2023 Legislative Session)

- Directed ODDS to apply for federal approval to pay parents to provide attendant care to their own children with very high medical or behavior support need.
- Allocated \$6M GF for parent-delivered attendant care for the 2023–25 biennium.
- Required training for parent providers and children.
- Prohibited parent providers from simultaneously caring for other young children or vulnerable people during the delivery of paid care.
- Limited parents to providing paid care during non-school hours, with some exceptions.
- Limited parents from being paid for tasks not directly related to a qualifying child's disability-related needs.

Attendant care

Attendant care is an hourly service that supports individuals with disability-related:

- Activities of Daily Living (ADLs): tasks like bathing, eating, and positioning.
- Instrumental Activities of Daily Living (IADLs): such as shopping, money management, and cooking.
- Health-related tasks: such as G- or J-tube feeding or oral suctioning delegated by a nurse.

Attendant care helps individuals complete these tasks through cueing, monitoring, reassurance, redirection, set-up, hands-on, standby or reminders.

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Children's Extraordinary Needs program: Design

To enact SB 91, ODDS engaged parents, advocates and other partners to design the program. This included:

- Hosting workgroups on hour limits, capacity, eligibility specifics, provider qualifications, and other program details.
- Offering Tribal Consultation.
- Conducting an online survey.
- Convening a Rule Advisory Committee.
- Collecting and responding to public comments on the waiver application and administrative rules.

Children's Extraordinary Needs Program: Implementation

Children's Extraordinary Needs (CEN) 1915(c) Home and Community-Based Services Waiver was federally approved with an effective date of July 1, 2024.

- Program funding accommodates 155 children at a time.
- Established waitlist currently has about 1,600 additional potentially eligible children.
- Provides access to up to 20 hours per week of paid attendant care by a child's parent.
- Parent must be employed by a provider agency as a direct support professional (DSP) and must meet all DSP qualifications.
- Parent providers must receive training on requirements for delivering Medicaid services, including impact on parent-child relationship dynamics related to discipline, supervision, physical intervention and self-determination.

Children's Extraordinary Needs Program: Eligibility

To qualify, a child must:

- Be a resident of Oregon.
- Meet I/DD eligibility or meet eligibility criteria for the Medically Involved Children's Waiver or Medically Fragile Model Waivers.
- Meet ICF/IID, Hospital, or Nursing Facility Level of Care.
- Be receiving Medicaid Title XIX benefit package through OSIPM or HSD medical programs.
- Be assigned to the highest Oregon Needs Assessment service group due to their very high medical (5m) or very high behavioral (5b) support needs.
- Live in the family home.

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Senate Bill 538

Senate Bill (SB) 538 expands coverage of the Children's Extraordinary Needs (CEN) Program to serve all children with very high medical or behavior needs who are medically fragile, medically involved or have intellectual or developmental disabilities (I/DD). This includes:

- All qualifying children with I/DD who receive case management services from community developmental disabilities programs.
- All children who qualify for Children's Intensive In-home Services (CIIS) who have very high behavioral or medical needs.

At this time, the number of children who would qualify is roughly 1,700.

Senate Bill 538: Key provisions

- Maintains Senate Bill 91's eligibility criteria: Children in the highest service group due to very high medical or very high behavioral needs (in "Service Group 5bm and 5b").
- Allows option for parent providers to work as personal support workers (PSWs) in addition to current requirement of being direct support professionals (DSPs).
- Prohibits ODDS-imposed weekly hour caps.
- Prohibits enrollment capacity limits.
- Maintains ability for ODDS to manage the cost, size, and growth rate through other program changes.
- Requires ODDS to request federal approval to make these changes by Jan. 1, 2026.

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Fiscal impact of Senate Bill 538

- An authorized hour of services only costs the state money if a child is able to, and chooses to, utilize that hour (i.e., has a provider and receives an hour of service).
- On average, children don't typically access all their authorized hours of attendant care for a variety of reasons, such as turnover, parent choice and provider availability.
- The estimated fiscal impact of this bill is a result of the estimated number of additional **utilized** hours ODDS anticipates will result from its passage.
- Based on historical data from the temporary PHE paid parent program, ODDS anticipates SB 538 would significantly increase hour utilization among children.

Fiscal impact: Hour authorizations

To price SB 538, ODDS first looked at the hour limits by age group of eligible children:

In Service Group 5b or 5m			
Service group by age	Infants/Toddlers Age 0-3	Children Age 4-11	Adolescents Age 12-17
Number of children	83	715	893
Monthly hour limit*	61 every month	152 in school months 174 in summer months	239 in school months 282 in summer months

During the school year, children spend a lot of time at school and are entitled to a free and appropriate public education that includes meeting their ADL, IADL, and health-related needs during the school day. ODDS services cannot supplant what is available at school.

*not including any approved exceptions or higher historical authorizations

Fiscal impact: assumptions

Factor	Assumption	Explanation
Participation	70% of eligible children would participate totaling 1,198 children	This is consistent with enrollment data from the first six months of the CEN program.
PSW-DSP hour split overall	30% hours delivered by PSWs; 70% delivered by agency DSPs	During the temporary paid parent program, more parents chose to be DSPs rather than PSWs. PSW usage was about 35%. ODDS rounded down to 30% to price this bill since the long-term trend has been for more DSP billing.
Utilization by parent providers	64% of authorized hours filled by parent providers	Children with parent providers, historically, utilize more of their authorized hours than children with only non-parent providers. ODDS assumes children will still access some paid care through non-parent providers and not utilize all authorized hours.

Fiscal impact estimate

25-27 Biennium with January 1, 2026, implementation

	GF	OF	FF	TF
Estimated cost	\$ 32,770,271	\$ -	\$ 45,172,686	\$ 77,942,957

27-29 Biennium

	GF	OF	FF	TF
Estimated cost	\$ 55,912,938	\$ -	\$ 77,596,978	\$ 133,509,916

Questions?

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