Testimony in Support of SB 538 – Tensy's Law

Co-Chairs and Members of the Committee,

My name is Shasta Kearns Moore. I am here on behalf of hundreds of Oregon's highest needs children, like my son, who are unable to access their Medicaid services.

Please fund and prioritize Senate Bill 538, Tensy's Law, and remove the ban on parent caregivers.

Oregon has made a promise to these children: That they will be able to receive care in their homes instead of more costly out-of-home placements. Yet, for more than a decade, families have struggled to utilize these promised services. Oregon Department of Human Services data shows that about 40 percent of children's hours go unused —with some children unable to use any at all. These are children who struggle with the ordinary tasks of a typical day, who have multiple diagnoses and specialists and who — sadly, like several of our friends in the movement already — may not live to age 18 when the state *will* pay parents for caregiving.

Oregon has already obligated itself under federal Medicaid law, including Early Periodic Screening, Diagnostic and Testing requirements, a constitutional right to health care and the state's own K-Plan assurances to the Centers for Medicare and Medicaid. Many states, including Ohio, Delaware, and Tennessee, recognize paid family caregiver programs as budget-neutral because they fulfill an existing obligation. If another provider — any willing adult without a felony! — were available, the state would have to pay for ALL of these hours today.

The fiscal note also does not account for the cost savings that will result. Data from the temporary pandemic program and Oregon's tiny CEN waiver show that allowing parents to be paid caregivers reduces reliance on services. Submitted to written testimony are:

- An OHA report confirming a significant drop in health care costs among children in the CEN program compared to those on the waitlist.
- A case study illustrating how the government is now spending MORE on wrap-around services for an Oregon family that used to be paid for their care labor during the pandemic program.
- And a survey report showing that this is what hundreds of eligible families say they would do, too — provide better care for their precious children — saving lives, time, money and heartache.

Thank you,

Shasta Kearns Moore

Advocates for Disability Supports

Table of Contents

Page 1 ……………………………………………………Testimony of Shasta Kearns Moore delivered verbally to the Joint Ways and Means Committee April 4, 2025

Page 2 …………………………………………………Table of Contents

Pages 3 - 11 ……………………………………………..Oregon Health Authority Report

Pages 12 – 17 ……………………………………………Case Study

Pages 18 – 25 …………………………………………….Survey Report

Health care utilization related to the Children’s Extraordinary Needs (CEN) Program in 2024

Corrected March 20, 2025.

Context

Tamara Bakewell (OHSU), Shasta Kearns Moore (Advocate) and Alicia Ibaraki (Western Oregon University) reached out to OHA government relations regarding the CEN program to request data. They were working on a new bill with three legislators to expand the CEN program (SB 538). The advocates originally posed the following questions:

1. How many hospitalizations or crisis services did "very high needs"[1] children have/use in the last 12 months?

2. How many medical appointments did "very high needs" children have/use have in a typical month?

Summary of data report

Who is included: Children enrolled in Medicaid under 18 years of age who are in service groups 5m or 5b on the Oregon Needs Assessment. There were 1,687 children in ONA’s 5m/5b service group. For this analysis, we focused on 1,630 children who had Medicaid coverage for all of 2024 and were not also enrolled in Medicare.[2]

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[1] Advocates defined “very high needs” as children enrolled in Medicaid under 18 years of age who are in service groups 5m or 5b according to their Oregon Needs Assessment.

[2] See additional methods on exclusions for members who were dual eligible for Medicare or who did not have coverage for all of 2024.

Children are further grouped by their Children’s Extraordinary Needs (CEN) program status into three groups:

Group	Definition	Number
Currently CEN	Children enrolled in the Children with Extraordinary Needs as of August 1, 2024.	98
Waitlist	Children who were on the CEN waitlist as of August 1, 2024 (placed on the initial waitlist developed in May 2024 after the CEN lottery)	1,281
5m/5b only	Children under 18 and assessed as 5m/5b as	

of August 1, 2024 but not enrolled in CEN or on
the waitlist.
251

What & How: OHA was able to pull and analyze data to provide the following:

- Average use of services in four service categories over the last six months of 2024 (CEN program period, Figure 1):
  - Primary Care and Behavioral Health Appointments
  - Hospitalizations
  - Emergency Department Visits
  - Crisis Services (behavioral health crisis intervention and de-escalation)
- How service use varies between members during this period (Figure 2)
- Utilizations of services before and after the CEN program started (Figure 3)
- See additional methods and appendix table.

Where & When: Utilization of health care services paid for by the Oregon Health Plan in 2024. CEN program began July 1st, 2024. Results focus on enrollment and utilization in 2024.

Summary of Results

Overview: The data shows that children's use of primary care and behavioral health ambulatory or outpatient care varied depending on their CEN status — whether they were currently in the CEN program, on the waitlist, or only in the 5m/5b service group.

Key Findings

Figure 1

- Children in the **CEN program had fewer primary care and behavioral health appointments** than both children on the waitlist and children only in the 5m/5b service group.
- Children in the **CEN program 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.

Figure 2

- To highlight similarities and differences between groups and show more granular data, we visualized the utilization data with strip plots to provide additional context for the averages.

Figure 3

- No significant differences were found comparing utilization before the CEN program began compared with after, for any of the three groups.

Limitations: A longer study period could help reveal additional differences that were not clear in this analysis.

Figure 1: Average health care visits across groups

Last 6 months of 2024

First, we examined the average number of health care visits – specifically primary care and behavioral health appointments, hospitalizations, emergency department visits, and crisis services – based on whether the children were enrolled in the CEN program, on the waitlist, or neither.

We saw that:

- Children in the **CEN program** had an average of 7.1 primary care and behavioral health appointments, 0.8 hospitalizations, 0.2 emergency department visits, and 0.1 crisis services in the last 6 months of 2024.
    - That means for every 10 children there were, on average, 8 hospitalizations, 2 emergency department visits, and 1 crisis services.
- Children in the **CEN program** had fewer primary care and behavioral health appointments (7.1 visits) than both children on the waitlist (10.2 visits) and children only in the 5m/5b service group (10.3 visits).
- Children in the **CEN program** had fewer emergency department visits (0.2 visits) than both children on the waitlist (0.4 visits) and children only in the 5m/5b service group (0.5 visits).
- Hospitalizations and crisis services did not differ between groups.

*p-values < 0.05 indicates a difference from current CEN group, highlighted in blue.

Figure 2: Variation of service use

Last 6 months of 2024

To show how service use varies between members, we used strip plots. These plots show the number of visits as a purple diamond, grouped by CEN status. These plots make it easier to see how much variation there is within each group. We also added the average number of visits (blue lines, same as Figure 1) to show group differences more clearly.

For example, for Primary Care (PC) and Behavioral Health (BH) appointments during the last six months of 2024, members had an average of:

- **Currently CEN:** 7.1 appointments on average, with the highest being 98.
- **Waitlist:** 10.2 appointments on average, with the highest being 150.
- **5m/5b group only:** 10.3 appointments on average, with the highest being 123.

Note diamonds and lines overlap in this visualization. For example, 203 children did not have any primary care or behavioral health appointments, but only show as 3 marks.

*p-values < 0.05 indicates a difference from current CEN group.

Figure 3: Difference in service use before and after CEN program

Compares first 6 months of 2024 with last 6 months of 2024

To understand how the CEN program may have affected children's use of health care services, we compared utilization before and after the program started on July 1, 2024.

We focused on primary care and behavioral health appointments because they happen more frequently and provide more statistical power to detect differences.

Across all groups, members had more appointments before the CEN program started than after, but these differences were not statistically significant. For example:

- Children who are currently enrolled in the CEN program had an average of 7.0 primary care and behavioral health appointments in the first half of 2024, compared to 7.1 appointments in the second half. This difference was not statistically significant.
- As shown in Figure 1, children in the CEN program had significantly fewer appointments than the other groups after July 1. However, in the first half of the year, there were no significant differences among the three groups (7.0, 11.2 and 12.2).

*p-values < 0.05 indicates a difference from current CEN group by time. This includes differences within the current CEN group by time.

Data source

CEN program data. Claims from Medicaid Management Information System (MMIS), Decision Support and Surveillance Utilization Review System (DSSURS). Learn more about MMIS.

Data are preliminary and subject to change. Data current as of March 20, 2025.

Methods

- The initial list from the CEN program included 1,687 children in the ONA 5m/5b service groups (as of August 1, 2024). The final analytic sample included 1,630 Medicaid members in the ONA 5m/5b service group. Exclusion criteria:
  - Dual eligible children (n = 1), child who was enrolled in both Medicaid and Medicare, was excluded.
  - Children without continuous Medicaid enrollment for all of 2024 (n = 57) were also excluded.
- Data on health care utilization were based on count data, which were not normally distributed and left-skewed. As a result, we used negative binomial regression models to compare mean utilization between CEN groups and to assess differences before and after the CEN program start date (July 1, 2024).
- We tested for zero-inflation in the data using SAS, but no evidence of zero inflation was found.
- Primary care and behavioral health appointments, hospitalizations, emergency department visits, and crisis services were identified using procedure codes

(see Appendix for full code list).

  - Hospitalizations, emergency department visits, and crisis services were captured using a small number of specific, standardized codes.
  - Primary care and behavioral health appointments initially included typical office visit codes (e.g., "Established patient office visit") but were later expanded to include additional high-frequency codes observed in this population, such as "Adaptive behavior treatment."
  - **We welcome feedback on the procedure codes used to ensure accurate classification of appointments.**

- Primary care or behavioral health appointments, hospitalizations, emergency department visits and crisis services may occur on the same day and are not mutually exclusive.

You can get this document in other languages, large print, braille or a format you prefer free of charge. Contact the SHNAP Program at HRSN.data@oha.oregon.gov.

Appendix showing which procedure codes were used to define each utilization type.

Utilization	**Procedure Code**	**Procedure Description**
PC & BH Appointments	90785	Psychiatric services complicated by communication factor
PC & BH Appointments	90791	Psychiatric diagnostic evaluation
PC & BH Appointments	90792	Psychiatric diagnostic evaluation with medical services
PC & BH Appointments	90832	Psychotherapy, 30 minutes
PC & BH Appointments	90834	Psychotherapy, 45 minutes
PC & BH Appointments	90837	Psychotherapy, 1 hour
PC & BH Appointments	90846	Family psychotherapy without patient, 50 minutes
PC & BH Appointments	90847	Family psychotherapy with patient, 50 minutes
PC & BH Appointments	90849	Multiple-family group psychotherapy
PC & BH Appointments	90853	Group psychotherapy
PC & BH Appointments	90885	Psychiatric evaluation of hospital records, reports, testing, or data for diagnosis
PC & BH Appointments	90899	Other psychiatric service or procedure

PC & BH Appointments 96130 Evaluation of psychological test, first hour

PC & BH Appointments 96131 Evaluation of psychological test, each additional hour

PC & BH Appointments 97151 Behavior identification assessment by professional, each 15 minutes

PC & BH Appointments 97152 Behavior identification assessment by technician, each 15 minutes

PC & BH Appointments 97153 Adaptive behavior treatment by technician using an established plan, each 15 minutes

PC & BH Appointments 97154 Adaptive behavior treatment by technician with multiple patients using an established plan, each 15 minutes

PC & BH Appointments 97155 Adaptive behavior treatment by professional using an established plan, each 15 minutes

PC & BH Appointments 97156 Adaptive behavior treatment by professional with family using an established plan, each 15 minutes

PC & BH Appointments 99202 New patient office or other outpatient visit with straightforward medical decision making, if using time, 15 minutes or more

PC & BH Appointments 99203 New patient office or other outpatient visit with low level of medical decision making, if using time, 30 minutes or more

PC & BH Appointments 99204 New patient office or other outpatient visit with moderate level of medical decision making, if using time, 45 minutes or more

PC & BH Appointments 99205 New patient office or other outpatient visit with a high level of medical decision making, if using time, 60 minutes or more

PC & BH Appointments 99211 Office or other outpatient visit for the evaluation and management of established patient that may not require presence of healthcare professional

PC & BH Appointments 99212 Established patient office or other outpatient visit with straightforward medical decision making, if using time, 10 minutes or more

PC & BH Appointments 99213 Established patient office or other outpatient visit with low level od decision making, if using time, 20 minutes or more

PC & BH Appointments 99214 Established patient office or other outpatient visit with moderate level of decision making, if using time, 30 minutes or more

PC & BH Appointments 99215 Established patient office or other outpatient visit with high level of medical decision making, if using time, 40 minutes or more

PC & BH Appointments 99219 Initial hospital observation care per day, typically 50 minutes

PC & BH Appointments 99234 Hospital inpatient or observation care with admission and discharge on the same date with straightforward or low level of medical decision making, if using time, 45 minutes or more

PC & BH Appointments 99236 Hospital inpatient or observation care with admission and discharge on the same date with high level of medical decision making, if using time, 85 minutes or more

PC & BH Appointments 99291 Critical care, first 30-74 minutes

PC & BH Appointments 99292 Critical care, each additional 30 minutes

PC & BH Appointments 99305 Initial nursing facility care with moderate level of medical decision making, per day, if using time, at least 35 minutes

PC & BH Appointments 99306 Initial nursing facility care with high level of medical decision making, per day, if using time, 50 minutes or more

PC & BH Appointments 99307 Subsequent nursing facility care with straightforward level of medical decision making, per day, if using time, at least 10 minutes

PC & BH Appointments 99308 Subsequent nursing facility care with straightforward level of medical decision making, per day, if using time, 20 minutes or more

PC & BH Appointments 99344 Residence visit for new patient with moderate level of medical decision making, per day, if using time, at least 60 minutes

PC & BH Appointments 99345 Residence visit for new patient with high level of medical decision making, per day, if using time, at least 75 minutes

PC & BH Appointments 99347 Residence visit for established patient with straightforward medical decision making, per day, if using time, at least 15 minutes

PC & BH Appointments 99348 Residence visit for established patient with low level of medical decision making, per day, if using time, at least 30 minutes

PC & BH Appointments 99349 Residence visit for established patient with moderate level of medical decision making, per day, if using time, at least 40 minutes

PC & BH Appointments 99350 Residence visit for established patient with high level of medical decision making, per day, if using time, at least 60 minutes

PC & BH Appointments 99381 Initial new patient preventive medicine evaluation (younger than 1 year)

PC & BH Appointments 99382 Initial new patient preventive medicine evaluation (1-4 years)

PC & BH Appointments 99383 Initial new patient preventive medicine evaluation (5-11 years)

PC & BH Appointments 99384 Initial new patient preventive medicine evaluation (12-17 years)

PC & BH Appointments 99385 Initial new patient preventive medicine evaluation (18-39 years)

PC & BH Appointments 99386 Initial new patient preventive medicine evaluation (40-64 years)

PC & BH Appointments 99391 Established patient periodic preventive medicine examination (younger than 1 year)

PC & BH Appointments 99392 Established patient periodic preventive medicine examination (1-4 years)

PC & BH Appointments 99393 Established patient periodic preventive medicine examination (5-11 years)

PC & BH Appointments 99394 Established patient periodic preventive medicine examination (12-17 years)

PC & BH Appointments 99395 Established patient periodic preventive medicine examination (18-39 years)

PC & BH Appointments 99396 Established patient periodic preventive medicine examination (40-64 years)

PC & BH Appointments 99397 Established patient periodic preventive medicine examination (65 year old or older)

PC & BH Appointments 99401 Preventive medicine counseling, typically 15 minutes

PC & BH Appointments 99402 Preventive medicine counseling, typically 30 minutes

PC & BH Appointments 99408 Alcohol and/or substance abuse screening and intervention, 15-30 minutes

PC & BH Appointments 99487 Complex chronic care management services for two or more chronic conditions, first 60 minutes of clinical staff time directed by a physician or other qualified health care professional, per calendar month

PC & BH Appointments 99489 Complex chronic care management services for two or more chronic conditions, each additional 30 minutes of clinical staff time directed by a physician or other qualified health care professional, per calendar month

PC & BH Appointments 99495 Transitional care management services for problem of at least moderate complexity

PC & BH Appointments 99496 Transitional care management services for problem of high complexity

PC & BH Appointments H0004 Behavioral health counseling and therapy, per 15 minutes

PC & BH Appointments H0031 Mental health assessment, by non-physician

PC & BH Appointments H0032 Mental health service plan development by non-physician

PC & BH Appointments H0039 Assertive community treatment, face-to-face, per 15 minutes
PC & BH Appointments H2000 Comprehensive multidisciplinary evaluation
PC & BH Appointments H2021 Community-based wrap-around services, per 15 minutes
PC & BH Appointments H2027 Psychoeducational service, per 15 minutes
PC & BH Appointments S9480 Intensive outpatient psychiatric services, per diem
Crisis Services 90839 Psychotherapy for crisis, first hour
Crisis Services 90840 Psychotherapy for crisis, each additional 30 minutes
Crisis Services H0011 Alcohol and/or drug services; acute detoxification (residential addiction program inpatient)
Crisis Services H2011 Crisis intervention service, per 15 minutes
Crisis Services T2034 Crisis intervention, waiver; per diem
Hospitalizations 99221 Initial hospital care with straightforward or low level of medical decision making, per day, if using time, at least 40 minutes

Hospitalizations 99222 Initial hospital inpatient or observation care with moderate level of medical decision making. If using time, 55 minutes or more
Hospitalizations 99223 Initial hospital inpatient or observation care with high level of medical decision making, if using time, 75 minutes or more
Hospitalizations 99231 Subsequent hospital care with straightforward or low level of medical decision making, per day, if using time, at least 25 minutes
Hospitalizations 99232 Subsequent hospital inpatient or observation care with high level of medical decision making, if using time, 35 minutes or more
Hospitalizations 99233 Subsequent hospital inpatient or observation care with high level of medical decision making, if using time, 50 minutes or more
Hospitalizations 99238 Hospital inpatient or observation discharge day management, 30 minutes or less
Hospitalizations 99239 Hospital inpatient or observation discharge day management, more than 30 minutes
ED Visits 99281 Emergency department visit for problem that may not require health care professional
ED Visits 99282 Emergency department visit with straightforward medical decision making
ED Visits 99283 Emergency department visit with low level of medical decision making
ED Visits 99284 Emergency department visit with moderate level of medical decision making
ED Visits 99285 Emergency department visit with high level of medical decision making

A Case Study for Paying Parent Caregivers

Prepared for Advocates for Disability Supports
By Alicia Ibaraki, PhD., Max Powell, and Shasta Kearns Moore
January 29, 2025

Background

Oregon is facing a healthcare worker crisis, the consequences of which are borne especially by Oregon's youngest, most vulnerable residents and their families. Despite being assessed to qualify for a certain number of hours of care per month based on their medical or behavioral needs, data obtained from the Oregon Department of Developmental Disabilities spanning 2018-2023 showed that only approximately 60% of determined service hours are being utilized. In a separate study of families who qualify for these services, 57% cited a lack of available workers and 41% cited concerns about worker's ability to safely care for their children's complex needs as the reasons why they could not fully utilize their allotted hours.

Contributing to this shortage of qualified home health care workers is a rule in Oregon that disqualifies parents from being hired as their child's home care worker while their child is under 18 years old. An exception to this rule is the Children's Extraordinary Needs (CEN) waiver, which began in July 2024 after the passing of Senate Bill 91. This program allows parents whose children are determined to have very high medical or behavioral needs to be hired as a paid caregiver for their child. Initially,1,557 children were eligible for this program based on their scores on a rigorous, standardized, annual state evaluation. Due to the distorted allocation which treats these hours as a separate program, only 155 families, chosen randomly by lottery, can enroll at a time, leaving about 90% of eligible families without this option.

Sponsored by Sen. Deb Patterson for the 2025 Oregon legislative session, "Tensy's Law" would expand the CEN Program to serve more of Oregon's children. The CEN waiver is set up under the 1915(c) Medicaid waiver structure and receives a 60 percent Federal Medical Assistance Percentage (FMAP). Oregon pays 40 percent from the general fund budget. Almost all other in-home hours in the state are paid for through the 1915(k) Community First Choice state plan, which has a 66 percent FMAP. Oregon spends $305.7 million biennially on Home and Community Based Services — a total of $814.3 million including federal funds. These funds aren't dispersed directly to caregivers, rather, the state pays a set, state-chosen rate ($42.24 per hour for a Standard Model Agency and $34.99 for a Community Support Living Agency) to agencies, who then pay a percentage of that amount to care workers, known as Direct Support Professionals (DSPs). At these rates, expanding the CEN program to cover 1000 more children for 40 hours per week at a 60% FMAP rate puts Oregon's obligation between $29 million and $35 million.

Although the fiscal impact of implementing this law may seem prohibitive, models from other states that have adopted forms of paid parent caregiving challenge this assumption. Colorado has paid parent caregiving and considers their program budget-neutral. States have a legal obligation to provide home care benefits to eligible children. Neither the obligation nor the cost of those services change based on whether it is a parent or another hired worker who is providing the service, so hiring parents should not affect the overall budget. Colorado has additionally found that replacing RNs or LPNs with family members reduced staffing costs by approximately 30%-50% per hour and hospitalization rates were significantly lower than the national average for children whose caregiver was a family member, thus saving the state additional money in insurance costs. Colorado is not alone. Other states, such as California, Connecticut, Delaware, Florida, Kentucky, Massachusettes, and Utah have a form of a paid parent caregiver program. Illinois and Maine are in the process of establishing a program in 2025. These states mitigate costs by capping the number of hours parents can be paid to work. The most common cap is 40 hours per week, although some states cap by day or year.

When considering the fiscal implications of a potential law, the legislature must consider both direct and indirect costs. However, outcomes from Colorado suggest that direct and indirect savings are also possible and should be considered when determining a law's fiscal impact. During the COVID-19 pandemic, a temporary exception allowed parents to be hired as paid caregivers and served as a naturalistic experiment to understand potential savings. The following case study describes Max, a parent whose child is on the waitlist for the CEN program, and the impact a paid caregiving program had on their financial stability, need to rely on other social services, and overall quality of life.

Life Caring for a Child with Extraordinary Needs - Max's story

Max lives in a rural part of Oregon and is a caregiver to their 18-year-old adult child with physical/mental health disabilities, and an 8-year-old, Jamie. Jamie receives intellectual and developmental disability services and qualifies for the CEN program due to extraordinary behavioral needs, but is waitlisted. Max describes Jamie as a "wild little adventurer who cares strongly about animals and family." Jamie has multiple diagnoses including Autism with Pathological Demand Avoidance; Attention-deficit/hyperactivity disorder; Pica, Epilepsy, Hypermobile Ehlers-Danlos syndrome (joint hypermobility), and a platelet dysfunction.
Jamie needs 24/7 one-on-one care, and often two-on-one. Leaving the home for anything requires two caregivers. Behavior supports are a large part of his need, even small tasks like brushing his teeth can take 30-45 minutes to prevent escalation. Jamie gets occupational therapy, physical therapy, speech therapy and feeding therapy. The pica and epilepsy require constant supervision, as his most common seizure type are focal seizures that are subtle and easy to miss.
Max shares:

> "On a good day, we set up a visual schedule together in the morning. I spend two and a half hours cleaning up after he "helped" me make breakfast, and I'm happy about this because he tasted the butter I put on the toast. He didn't eat anything else. He watches YouTube videos about how make claymation movies, on repeat, all day. I spend 30 minutes just touching a toothbrush to his teeth. I serve snacks and drinks, the staff [a personal support worker] talks about how good a food tastes, and he might try a bite of food, or drink a Pediasure instead of having a full meal.
> I read next to him while he's on the tablet. I know he's listening because he gets mad when I stop reading. There are diaper changes every 2 hours and sterilizing inhaler equipment. I do drills with our service dog who is in training. We go outside on the playground, and all the neighbor kids ignore him for 2 hours so I and a staff member play Nerf guns with him. It's so cold now his fingers and ears are turning purple because he can't wear a coat or hat without a sensory meltdown, so I carry him kicking and screaming inside. He bites me. We cuddle and recover under a heated blanket, he takes a long bath and floods the bathroom splashing in it. I serve dinner and he eats a little bit. The window and door alarms and locks [to prevent elopement] are checked. Pica hazards are removed. Even though there were no appointments today, I've ignored about 10 phone calls, all the paperwork, and I haven't answered any emails. Jamie takes his evening

> medication, goes to sleep in a specialized bed called a cubby safe sleep bed. He actually sleeps tonight. This is a good day.
>
> On a bad day, we go to the emergency room because Jamie ate a light bulb and swallowed it. Jamie elopes from the ER and I spend 20 minutes chasing him in the woods. We are sent home from the hospital because they don't know how to keep him safe. Jamie has a post-ER meltdown: my bathroom gets flooded, a couch gets broken, staff and parents get bit and hit several times, and eventually the staff goes home because they can't handle it. My other child is stuck in their room the entire day for their safety. Because of the light bulb, we are constantly treating excessive bleeding in his mouth from a low platelet count. Jamie he doesn't eat or drink for two days and the pediatrician is ready to sedate him to place an IV to provide hydration and do a platelet infusion. Nothing gets done except trying to keep him calm - no medication, no schoolwork, no dishes, no one else gets to eat. He's headbanged to the point his face is bruised. He doesn't sleep for 72 hours straight and doesn't stop crying for most of that. We missed three appointments without calling to cancel during this time. I hope we don't get blacklisted from that clinic. I get a noise complaint from my landlord and a citation from the city I now have to appeal."

The Financial Strain of Caring for an Extraordinary Child

Before becoming a parent, Max worked as a manager at a grocery store. They were also attending college and pursuing a degree in computer science. Given the intensive demands of caring for Jamie, Max can no longer hold a regular job. They have tried in the past, but get fired for missing too many shifts. Now, Max picks up on-call shifts when they are able, working on average 5-10 hours per week. Despite having personal support workers staffed in the home, per ODDS policy (OAR 411-450 (d)
) Max can not leave Jaime under a support worker's supervision to go to work. Instead, Max must hire a separate childcare provider to look after Jaime, at their own expense.

Finding a caregiver who is comfortable with Jamie's behaviors and needs is becoming increasingly difficult. Jamie does not like other people to care for him — his behavior escalates greatly, and staff get hurt, sometimes seriously. Max and Jamie have also had negative experiences with caregivers in the past. Some have not fed him or changed him, stolen meds, restrained him, ignored him, and taken away communication devices. No staff member has known American Sign Language, Jamie's primary communication type. Many don't take Jamie's seizures seriously because they don't look typical.

To survive, Max relies on multiple government-funded social services including the Supplemental Nutrition Assistance Program, Supplemental Security Income, unemployment, and assistance programs for rent and utilities. Before being able to work as a paid parent caregiver, Max estimates the monthly cost to the state was $4,641.33 (see Table 1). Once Max was employed as a paid parent caregiver, Max either did not need, or was no longer eligible for the majority of the government-funded social services. The cost to the state — at the 34 percent general fund match — while Max was working was estimated at $684.24 with the remainder paid through the federal match.

Table 1. Monthly Government Benefits Received.

Category	(2021)- not working as a paid parent caregiver	(2022) - working as a paid parent caregiver
Wages	0	$1,981.46*
Paid Time Off	0	$31.02*
Supplemental Nutrition Assistance Program (SNAP)	$782	0
Supplemental Security Income (SSI)	$841	0
Employment Related Day Care (ERDC)	$845	0
Emergency Rental Assistance	$645	$53.75*
Low Income Energy Assistance Program (LIHEAP)	$208*	0
Oregon Lifeline (phone/internet credit)	$60	0
Unemployment	$1260†	0
STATE & FED GOVERNMENT TOTAL	**$4,641.33**	**$2,067.13**
Oregon's Share	**LESS than 4,641****	**$684.24**

*This value was reported as an annual sum or is a one-time annual benefit. The value reported in this table is 1/12th the annual amount.

†This value was reported as a weekly benefit. The value reported in this table is 4x the weekly amount

**We have requested data from OHA/ODDS to determine the specific proportion of these costs that Oregon is responsible for. Data will be provided as soon as it is available.

In addition to the cost savings, Max and Jamie's quality of life improved when Max was able to work as Jaime's primary caregiver. Max recalls, "I was able to focus on actually meeting his needs, and not just keeping him in [the home, (versus institutionalization)]. He was able to do things other kids get to do again - go to the zoo, play soccer. He had less hospitalizations, we had consistent skill improvement, he was learning to read. He was eating consistently. I had time to take him to weekly therapy appointments."

Since the paid parent program ended, Max is back to relying on social services. They are currently facing eviction from federal housing. Most of their time is spent meeting basic bare minimum needs- crisis care, food, and shelter. Many medical and behavioral needs are going unmet because insurance won't cover them and Max can't afford to pay for them out of pocket.

Conclusions and Recommendations

1. **Paying parent caregivers is likely more cost-effective than any alternative**. Children's medical or behavioral needs can reach a point where they can no longer be supported at home by Direct Service Professionals or Personal Service Workers, particularly given the shortage of available workers, their reluctance to work with such high-needs clients, and the limits of their expertise. When this happens, parents must either quit their job to stay home and care for their child themself, or make the difficult decision to put them into out-of-home placements. Both options are costly to the state. Parents who stay home will rely on social services, which in Max's case, cost the government more than twice what paying them to be a caregiver would have. If a child is institutionalized, an option Max is fighting to avoid, the costs are even higher. 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 Stabilization and Crisis Unit (SACU) placement is more than $103,000, many orders of magnitude higher than what the state would spend paying a parent caregiver.

    Recommendation: The Joint Ways and Means Committee should request an analysis of families who qualify for CEN using All Payer All Claims (APAC) data to understand the extent to which these families rely on other social services. This analysis should calculate the reduced need for these services and associated cost savings to the state if families worked 40 hours per week as their child's caregiver.

2. Consider Additional Indirect Cost Benefits When Calculating the Fiscal Burden of Tensy's Law. In addition to reduced utilization of social services, there are other savings that could be realized. Research out of Colorado found that paying family caregivers improved children's health outcomes and reduced hospitalizations. When Max became Jamie's primary caregiver, they noted his hospitalizations decreased. In a study referenced earlier, 88% of families surveyed believed their child would be healthier as a result of them working as their child's caregiver. Data obtained from the Oregon Health Sciences University's Doernbecher Children's Hospital on 1/24/2025 estimated that the direct cost to the hospital for a day of pediatric inpatient care is $4,524. The average length of stay is 5.8 days, for an average cost of $26,239.20 per child per hospitalization. Children who qualify for the CEN program also qualify for the Oregon Health Plan (OHP), Oregon's form of Medicaid program, on the basis of their disability, so the price of these hospital stays is often borne by the state. If 1000 children were able to enroll in the CEN program and each of their hospitalization counts was reduced by one occurrence per year, the savings to Medicaid would be over $26 million.

> **Recommendation:** When considering the cost of this bill, a comprehensive cost analysis should also include anticipated reduced costs to OHP. State employment economists should be consulted to account for additional, unnamed sources of indirect savings, such as an increased tax base by making unpaid caregiving paid work.

3. Oregon has an obligation to ensure individuals have access to needed services. This has been affirmed in the latest technical guidance from the Centers for Medicare and Medicaid Services (CMS). If there are not enough PSWs, DSPs, or nurses to provide the needed services, Oregon must come up with alternate options to meet their obligation.

Recommendation: Oregon should examine and follow the lead of what other states have done to solve a worker shortage and simultaneously balance costs. Colorado considers paying parent caregivers a budget-neutral proposition because the cost to pay a parent or an attendant is the same. Georgia and South Dakota were able to fully offset the new costs of funding family caregiving by realizing savings in other services no longer needed. Other states have contained costs by capping the number of hours parents can work. Arizona also was granted a temporary exception, similar to Oregon, that allowed them to pay parent caregivers during the pandemic. In September 2023, the Arizona Health Care Cost Containment System (AHCCCS) requested to make the policy permanent. On February 16, 2024, the Centers for Medicare and Medicaid Services granted this request allowing parents of minor children who require extraordinary care to get paid to provide attendant care up to 40 hours per week. There are existing models of how this can be done and it is time for Oregon to fulfill its promise to its children.

Executive Summary: Survey Report

Prepared for Advocates for Disability Supports
By Alicia Ibaraki, Ph.D.
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Overview:

124 families eligible to receive Children with Extraordinary Needs (CEN) benefits, based on their child's assessed high medical or behavioral needs, completed an online survey asking about their CEN status, current public assistance usage, and perspective about their children's care needs. Of the families represented in this data, 86% did not receive one of the 155 spots. There is a high utilization rate of public assistance programs among all responding families. More than half of the families (66%) thought they would be or may be able to leave at least one public assistance program if they were to get a CEN spot. Over 90% of families are not using all of their allotted hours, with a lack of caregivers or safety concerns about available caregivers cited as the primary reasons. The majority of families believe that having a parent as a paid caregiver will improve their child's physical and mental health, as well as their inclusion in the community. Having parents as a paid caregiver is either favored by or a non-issue for the majority of children. The majority of families would spend the extra income from CEN on meeting universal basic needs such as food, shelter, and transportation. Slightly less than half would also spend the money on improving their child's quality of life and inclusion in the community. Nearly half have medical needs and expenses not covered by insurance. ALL responding families encourage Oregon to expand the CEN program!

Method:

The following data represents responses from 124 families who have at least one child that is eligible for the CEN Program. The survey was distributed online in various affinity groups relevant to this population and additionally relied on snowball sampling methodology. These responses were collected between June 26, 2024 and September 9, 2024. Data was analyzed using IBM SPSS Statistics (Version 18). It is estimated 1500 children qualify for CEN, meaning this survey captures roughly 8% of the overall sample. The proportion of families in the sample who received versus did not receive a spot is similar to the actual breakdown of overall families that did or did not receive a spot (10% v 90%, respectively), however, given the sample size, results should be interpreted with caution.

Represented in the sample:
17 families (14%) received a **lottery spot**
79 families (63%) are on the **waitlist**
28 families (23%) are **not currently on the waitlist** but report meeting eligibility criteria

Of the families who were offered a spot, 16/17 (94%) accepted the spot and plan to work the maximum allowable hours, 20 hours.

Public Assistance Usage

75% of families (*N* = 93) with children who have very high medical or behavioral needs are using at least one public assistance program *in addition* to Medicaid for their high-needs child.

The most frequently used programs are OHP/Medicaid for family members, (71%); Supplemental Nutrition Assistance Program (SNAP) benefits (36%), and Supplemental Security Income (SSI) (27%). Other programs such as rental assistance, Temporary Assistance for Needy Families (TANF), and Section 8 housing are relatively unused.

Program Name	**Utilize- Yes**	**Utilize- No**
OHP/Medicaid for health insurance (for the family)	88 (71%)	36 (29%)
Supplemental Nutrition Assistance Program (SNAP)	44 (36%)	80 (64%)
Supplemental Security Income (SSI)	33 (27%)	91 (73%)
Women Infants Children (WIC)	15 (12%)	109 (88%)
Utility assistance (LIHEAP)	12 (10%)	112 (90%)
Rental assistance	6 (5%)	118 (95%)
Temporary Assistance for Needy Families (TANF)	4 (3%)	120 (97%)
Section 8	1 (1%)	123 (99%)

There were no statistical differences in public assistance program usage by families who were given a lottery spot compared to families who weren’t $\chi^2(1, N = 124) = .01, p = .93$

Of all families who are using some type of public assistance, 66% (*N* = 61) thought they would be or may be able to leave at least one public assistance program as a result of getting into the CEN program. 28% (*N* = 26) did not anticipate being able to leave any program.

Of the families specifically who were selected for CEN and use some type of public assistance, 54% (*N* = 7) thought they would be or may be able to leave at least one public assistance program as a result of getting into the CEN program. 39% (*N* = 5) did not anticipate being able to leave any program.

In their own words:

- I was in the paid parent program during COVID, and we were able to leave SNAP, utility assistance, unemployment, and housing subsidy
- Thanks to the [COVID] waiver we no longer needed SNAP or SSI. Unfortunately, we may end up back on both.
- The income would provide income enough to make our family ineligible for SSI and SNAP. OHP will be a secondary insurance for life based on cost vs income
- We wouldn't need TANF assistance anymore
- We will no longer use the foodcard/SNAP
- We would no longer need TANF at least, possibly others

- When it was available during the pandemic we no longer needed SNAP or SSI. If it was permanent we would qualify for different insurance due to increased income as well.
- I would not need food stamps if I had an income for taking proper care of my child

However, other families point out that even though the program is a good first step, it is not sufficient

- At 20 hours per week, we would still need supplemental income, which may not be possible, or public assistance.
- The income would likely place me over the limits and I'd lose some benefits. But the waiver income would still not fully support family at 20 hours a week.
- Only 20 hours a week would still qualify me for assistance programs. Full-time, I would be able to get off the programs.
- I have to be with my child 24/7 whether there's a caregiver or not because of her extremely high needs there is no possibility for me to make an income to support my family any other way so I have to rely on all the help that I can get in order to support my family

Current Support

70% of families (*N* = 87) had some form of paid caregiver who was not a parent, however only 9% (*N* = 11) of families had full-time caregiving. Looked at it another way, **91% of families were not utilizing all of the hours allotted to them.**

Of the families not receiving any paid caregiver support, 57% (*N* = 21) state it is because it is due to workforce issues (e.g. lack of available workers). 41% (*N* = 15) cite safety concerns, meaning that in their experience, the pool of available workers are not sufficiently trained to safely address all of their high-needs child's care.

Family Perspectives

As a result of their parent(s) being able to stay home as paid caregivers….

88% of families (*N* = 109) believe or strongly believe that their child would be **healthier** and their child's physical health would improve

90% of families (*N* = 112) believe or strongly believe that their child would be **happier** and their child's mental health would improve

90% of families (*N* = 111) believe or strongly believe that their child would experience more **inclusion** in the wider community

Having parents as a paid caregiver is either favored or a non-issue for the majority of children.

35% of parents (*N* = 43) say their child understands and **likes it**
64% (*N* = 79) of parents say their child **can not understand** the concept due to age or disability
17% (*N* = 21) of parents say that their child **does not want any nonparent caretakers**
0% (*N* = 0) of parents say their child understands and **does NOT like it**.

What will families do with the extra funds?
Families have very modest and practical goals for the extra funds. The three major themes of expenditures are meeting universal basic needs, helping with additional expenses related to their child's diagnosis, and improving their child's quality of life. Few families expressed the extra money would be set aside for savings.

52% of families say they will direct funds to meet **universal basic needs** such as paying utility bills, rent/morgage, food, clothing, and gas.

48% of families say they will direct funds to **medical expenses** not typically experienced by other families such as paying down extensive medical debt, paying for therapies, equipment or supplies that are not covered by insurance, or for costs associated with adapting homes or vehicles for their children's needs.

42% of families say will direct funds toward getting their child out more into the community and improving their child's **quality of life**.

7% of families say the additional income will allow them to start **saving** and building a safety net for future unanticipated needs, or for care once parents pass away.

In their words (a representative selection):

- I would spend it on basic needs like mortgage, food, and utilities.
- I would pay for basic living expenses. The lack of worry regarding paying bills would enable my focus to solely be on my child. We would be able to do "extras" for him like visit new places and pay for additional therapies
- We would be able to pay for transportation to get to and from medical appointments, to pay for housing costs, and potentially keep up with small maintenance needs for our home and transportation.
- This will help us to breathe easier. Living paycheck to paycheck is so stressful and scary at times. The extra funds will also allow us to buy more items to help her that are not covered through DD services. We hope to do more activities in the community.
- Groceries, bills, transportation, etc. The time would be the most essential gain. Could spend more time meeting the goals actually written on ISP, that never get met.
- I would use the income to help pay rent, pay for gas to take my child to her weekly appointments (speech, OT, etc). I would purchase sensory items (fidget toys, sensory activities like painting supplies, swimming at our local pool, sensory swing, etc.) I would buy new clothes/shoes for her when she outgrows her clothes/shoes and other costs like baby wipes/diapers that are not covered by insurance.
- It would make a huge impact by lightening the financial burden our family faces as a single-income home since only one of us can work outside of the home due to our son's disability.
- We would be able to pay for therapies like feeding therapy and buy a special needs car seat. We could pay for things like groceries and utilities that we currently struggle with.
- I would be able to buy a wheelchair that allows my daughter to play on grass with other children.

- We could pay down medical bills, pay our insane primary insurance premiums and co-pays, pay for therapies that we know work that aren't covered by insurance or OHP.
- Community inclusion, social opportunities
- Right now my son only knows doctor appointments, therapies, and surgeries. There's no income available to let him experience life. There are no free hours in the day for me to get a paying job outside the home. Our last nurse provided by the state abused my son so this is the main reason I will struggle financially to keep my son safe.
- Provide extra funds for more community involvement as well as home improvements and equipment to make the home and the community more accessible
- My son's school is too far away, so the paid parent program helped with gas. Also gas for the hour drive to see specialists. We would be able to participate more in community activities. We can also afford more adaptive toys, and medical equipment, and our world would open up to take him to more places.
- We will be able to purchase equipment and treatments for our son that aren't covered/fully covered by insurance to improve his health and quality of life. We will be able to be present at medical appointments/hospitalizations instead of worrying about missing work and thus be able to advocate more effectively for his health.
  It would greatly reduce stress in our house which would have a huge impact on my child's physical and mental health
- We try to save this money for family needs for our home, providing additional therapies and equipment that is not covered, maintenance on the wheelchair van we have, and allowing me to stay home from and not work outside the home so I can tend to his needs. This impacts us and our son, allowing our home and lives to be more accessible, so he can have as close to the same experiences as other nondisabled peers.

Should we expand CEN?

100% of families participating in the survey believe we should expand the CEN program!

In their words (a representative selection):

- Yes! The program should, at minimum, include all eligible children. It should be expanded to all Level 5 and CIIS children (at minimum), and allow children to have their parent caregiver for 40 hours/week. Twenty hours is just not enough to get off of public assistance, to provide sufficient care for children who cannot have outside DSPs, or for a parent to leave a job to provide their child full-time care with their best caregiver. The program is so limited it's hard to imagine how impactful it can really be as it currently stands, but it has the potential to be so much more.
- Yes. So many families desperately need this program. It's insanity that strangers can be paid caregivers, but not parents, who actually know their own kids, their kids are comfortable around, and don't have to worry about the safety issues associated with bringing a stranger into your home.
- Yes! It feels backward to pay parents to care for 18+-year-old children (who would perhaps prefer age-appropriate independence from family), and not allow paying parents of young children. Needs are also 24 hours a day and parents are the best caregivers for those needs. But so many are forced to forgo working to care for kids. My kid's needs make it impossible to imagine not having a parent available 24/7 even when DSPs are available.
- Yes! I cannot work! We can't pay our bills because I'm stuck being a full-time caregiver. It would be life-changing for our family. Not to mention, I would finally feel valued for the work that I do and the sacrifices I make.

- Absolutely! Paid parent opportunities have always been the missing link that our family has needed. It makes no sense to prohibit parents from being a paid parent caregiver. There is so much abuse and neglect in the news that happens in the state's care. Parents are the absolute best caregivers unless shown otherwise. Outside caregivers don't work for all families due to many reasons. In 11 years of being a parent of highly disabled children, I haven't worked a single day at a paid job because I am doing the extraordinary caregiver duties my children require. Families that leave a paid job especially to provide this care should be able to be paid for at least a portion of the work they are doing. SB 91 chose the eligible children and the 155 spots should be expanded to all eligible kids 1500 or whatever it currently is. All 1500 kids eligible should have equal access to the program. I want to see all the eligible kids have equal access. I am so disappointed families are having to carry all the heavy lifting for 3 legislative sessions straight. Oregon needs to remove these systemic barriers keeping up from Medicaid services our kids need. I support paid parents and always will.
- Yes. Our families so desperately need it. Anyone who talks to me, even casually, says oh you have a full-time job. I do, and then some, and I love taking care of my son. But the time I devote to him prevents me from being able to work for pay, keeping our family well below the poverty line.
- Absolutely. There is so much of a need to provide care for the kids that can't be done by a stranger. It would be life-changing and improve the quality of life for the child.
- Yes, there are so many parents that can't work due to supporting their child full time and this would be a huge help to their family.
- Yes. The funds were already there during COVID-19 and was it proven how well kids improved health and behavior and less trauma and hospitalization. It also saved crisis events and made our children feel safer.
- Yes. It's not only cheaper for parents to stay home, but it improves the quality of life for children. There are no justifications for parents to not be paid. We are often overlooked by people because most don't know how few resources are available. There are no nurses available to help so we can work. I have not had a nurse in almost four years due to a lack of nurses available. Since I have no nurses, I can't work. I depend on selling everything I ever owned including the house I once owned to survive. I depend on assistance from the government which isn't much. My husband is the sole provider for our family and we only have enough to get by every month. Being a paid parent would be cheaper because they're paid less than a nurse and we can get off assistance. Our disabled child would have better care since I know him best and work directly with all his specialists. There are fewer hospitalizations when I watch my son full-time. Having paid parents would improve quality of life, be better for families, and be cheaper for the government. No one should be left behind because they have a disabled family member.
- Absolutely yes. It literally helps families AND the government, by keeping kids healthier and out of institutions.
- YES! Parent care is by far the most invaluable for our kids. We provide them with nurture and care that no one else will. It's a fundamental need for children with these needs to strive and grow. These children need love and nurturing more than typical children because they are so developmentally behind. My children are both level 5 needs with CIIS and we are so restricted with what we can do trying to work opposing schedules and the burnout of DSPs is real. Constantly having to come home from work due to incidents has really strained our work reliability. Also, my children cannot speak for themselves which adds an entire set of concerns as a parent leaving their children.
- YES! Especially now that public schools are cutting back on services and support for disabled children. Families and their special needs children are falling through the cracks

and further into poverty. This would address both issues and be a cheaper solution than the county and state being sued for not offering FAPE and accommodations to children when they need to be homeschooled or use alternative educational settings.

Additional data or analysis is available upon request

Appendix: Excluded Data

16 survey responses were not included in this analysis. 5 responses were excluded because they indicated their child didn’t qualify for CEN. In some of these cases, their child was assessed to be in highest needs service group (Level 5) but did not additionally have a medical or behavioral designation. At this time the CEN program is only available to children with these additional designations. 11 responses were excluded because they were unsure if their child qualified for the CEN program. Although the 16 families either do not, or may not qualify for CEN, their dependence on social services, their care needs, and the way they would spend the CEN income (basic needs, medical needs) are very similar to the families that were included in the initial CEN lottery.

Of these 16 families:

81% of families (*N* = 13) are using at least one public assistance program *in addition* to Medicaid for their high-needs child. This is not a statistically significant difference in service usage compared to families who were deemed to qualify for the CEN program $\chi^2(1, N = 139) = .25$, $p = .62$. Looked at it another way, despite either being deemed ineligible or not receiving adequate outreach and assistance enrolling in the lottery, these families have similarly high needs.

56% (*N* = 9) are utilizing some sort of paid caregiving but only 13% (*N* = 2) are using all of their allotted hours. Of the seven families that are not using any paid caregiving, 57% (*N* = 4) say it is primarily due to bureaucratic red tape. Although sample sizes are too small to conclude statistical significance, the high social services needs and unmet caregiving needs in this group, which mirror the patterns of families that were deemed eligible, suggest that it may be prudent for the program’s existence and eligibility requirements to be better communicated to the public.

In their words (a representative selection):

- Had we been selected we could have gotten off SSI.
- I was paid during the pandemic and we were left off CEN because we don’t have a (b) designation. My child is very close to institutionalization. The parent’s efforts are all that is keeping him in a home, and one of the parents has to work full time.
- Currently, my child is level 5, but not behavioral or medical. General needs level 5 children are left out. Most of my child’s needs are at night and it’s impossible to find a caregiver/let alone a night caregiver in Central Oregon. It takes a severe toll on our family.
- I have not been able to use even half of our allotted hours for the majority of the time we have had access to them. My son needs 24/7 supervision for his safety and I have about 20 hrs a week of help and am a divorced parent who has the majority of caregiving responsibility which makes work outside the home impossible.

On what the extra income would mean for them:

- Income would be spent on monthly bills, such as mortgage and food.

- Medical bills, wheelchair-accessible vehicle
- Be able to afford life essentials-groceries/mortgage/medical bills/utilities
- I would use it to take time off work to take my kid to more therapies and appointments and could get connected with services more easily due to increased availability. This would also allow me to implement strategies on her IFSP and ISP that her daycare provider cannot accommodate and that the school district and DD services aren’t able to help with via their staff. I could spend more time helping her learn skills, find recreation and social activities for her, and keep a better eye on her physical health.
- It would help us afford food and bills we struggle with every month. It would allow us to pursue classes and activities for our son that we cannot currently access.