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A Case Study for Paying Parent Caregivers

Prepared for Advocates for Disability Supports
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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[1] 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

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[1] Name changed for privacy

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.
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> 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.
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> 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.”

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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.