Executive Summary

Prepared for Advocates for Disability Supports

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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[1] 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.

[1] 16 families were excluded from the analysis. More information about the reason for the exclusion and a description of the needs of these families are included in the appendix.

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 χ^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 χ^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.