

Developmental Disabilities Worker's Guide

Office of Developmental Disabilities Services

Topic:	Guide to Children's Extraordinary Needs (CEN) Program
Date Issued:	

Overview

Description: This worker guide (WG) describes the Children's Extraordinary Needs program. This program allows a limited number of parents to be paid attendant care providers for their minor child.

Purpose/Rationale: To assist services coordinators in understanding, authorizing, approving, and monitoring Phase 1 of the Children's Extraordinary Needs (CEN) program.

Phase 1 refers to the initial start-up of the CEN program and includes the initial random selection of participants for this waiver. Phase 1 will also establish a waitlist for those who are not initially offered a chance to enroll in this program.

There will be a permanent worker guide available for **Phase 2** of the CEN program that will assist service coordinators through the requirements of the on-going, established, program. Most of the information found here will also appear in the permanent worker guide.

Applicability: Services coordinators who support children.

Background: In 2023, the Oregon Legislature passed Senate Bill 91 (SB 91) into law which directs ODDS to start and operate a program that will pay some parent/guardian to provide attendant care services to their own minor child who has very high medical or very high behavioral needs.

Summary of Senate Bill 91 (SB 91):

- Directs ODDS to start and operate a waiver that will allow payment to parent/guardian to provide attendant care services to their own child who has very high medical or very high behavioral needs.
- For a parent/guardian to be paid through this program, the parent must work for an agency and cannot be involved with the agency in any way other than as a Direct Support Professional (DSP). This means a parent/guardian cannot own an agency, be a board member, or be related to anyone in a similar role in the agency.
- The agency cannot hire the parent/guardian as a contractor.
- The agency cannot pay for any attendant care services during regular school hours, when a child attends a reduced school day, is homeschooled, or is enrolled in a private school with fewer school hours than public school.
- The parent/guardian cannot provide paid attendant care if they are responsible for a child under 10-years of age or vulnerable adult at the same time.
- The parent/guardian cannot perform typical household tasks while being paid to provide attendant care unless the tasks are included on the child's individual support plan and the tasks are related to the child's disability.
- ODDS may require the parent/guardian provider to assign another person to make decisions about the child's individual support plan while the child has a parent/guardian provider.
- Parent/guardian providers are mandatory abuse reporters, 24/7.
- Requires ODDS to adopt rules for the program related to workforce and training of parent/guardian providers, children, and case managers.
- Rules must address parent/guardian-child relationship impacts when parents/guardians are paid caregivers.
- Must allow child to be able to object to parent/guardian as provider.
- Must ensure consistent, equitable implementation across Oregon.

Included in this Worker Guide:

- Initial Enrollment in CEN program
- Parent/Guardian Considerations
- DSP Role vs Parent Role Example Chart
- Parent/Guardian Decision
- Eligibility Determination
- eXPRS
- Parents/Guardians Hired as DSP's
- Complaints
- Frequently Asked Questions (FAQ's)
- Appendix
- Resources

Initial Enrollment in CEN waiver:

For equity purposes, all children on the referral list for a CIIS medical waiver and all children who are assessed by the Oregon Needs Assessment (ONA) with a Service Group of 5b/5m on May 2nd, 2024, will form the group of children for potential enrollment in the CEN program. This includes children in residential, foster care, and host home settings.

ODDS will send a letter on May 13th through the mail (USPS) to all families of children who are in the ONA Service Group 5b/5m and to children who are not DD eligible on the CIIS waitlist for one of the medical programs. You will find a copy of this letter in the appendix below.

There will be more children who qualify for the CEN program than the program can accommodate. For that reason, the list of children selected and offered initial enrollment will be identified through a randomized selection process.

All children who meet the criteria for the initial group of eligible participants will be part of the randomized selection process and every child will be assigned a number. The children with the randomized assignment of numbers 1 through 155 will be included in the initial offer to enroll in the CEN waiver program.

The children whose names are not selected initially will be added to a waitlist, retaining their assigned number. eXPRS is designed to

automatically move children “up” on the waitlist as children move off, so that the child at the top of the waitlist will always be assigned the number one.

Beginning in August, a waitlist report will be sent to managers at each CDDP, CIIS, and Children’s Residential program to help services coordinators know where children on their caseloads are on the waitlist.

Following the randomized number assignment to each child, ODDS will mail two different letters to families (the letter template can be found in the appendix below):

- a. One letter will be sent to the first 155 families the week of May 20th who are being offered enrollment in the waiver explaining next steps and letting them know that they should hear from their SC soon.
- b. A different letter will be sent to families whose children have been added to the waitlist the week of May 27th.

By May 24th, 2024, ODDS will send the manager(s) of CDDPs, CIIS and ODDS Children’s Residential programs, the names and parent or guardian contact information of children selected in the initial group to be offered enrollment who are in their county or program.

Once the initial group of children is selected, the CME is responsible for:

1. Within 5 days of ODDS sending information to the CDDP, CIIS or ODDS Children’s Residential programs, contact the family to let them know that their child has an opportunity to participate in the CEN program. Discuss “Parent/Guardian Considerations” (below) or set-up time to discuss in detail.
2. Work with ODDS to inform families who may not have received the letter telling them that their child was selected as part of the initial group to choose whether to be part of the CEN program.
3. Make multiple attempts (3 to 4 minimum and through various formats) to contact the family directly and offer choice advising. Document

each attempt in case notes.

4. Explain in detail what being a paid provider to their child means so that parents can make an informed decision on whether they would like to participate in the CEN program. You will find this information detailed below in **“Parent/Guardian Considerations”**.

This **timeline visual (in process)** will walk you through the initial eligibility and enrollment process. You may want to refer to this timeline while using this guide.

***HELPFUL HINT*: Medicaid only allows a person to be on one waiver at a time. If a child is removed from the CEN waiver, they may transition to another waiver that is appropriate, if they choose and are eligible.**

See Children’s Waiver Explanation Chart (in process).

For Phase 1, after the initial selection and offer of the CEN waiver program, ODDS will identify the number of children/families who opted out of the CEN waiver program or who did not respond.

For every child who declines enrollment on the waiver, that same number of children will be selected in order by the assigned number from the waitlist. When applicable, ODDS will notify the family by mail (USPS) and the CDDP manager(s) via email.

This process will continue, using the assigned order of the waitlist, until the maximum number of children allowed are enrolled and being served in the CEN program. The SC’s responsibilities for these children and families are the same as for the initial group of children.

Parent /Guardian Considerations:

There are very important factors for families to consider when choosing whether to be paid to provide attendant care to their minor child:

- A child may receive no more than 20 hours per week of attendant care from a parent/guardian. There are no exceptions. More than one

parent/guardian can be their child's DSP. eXPRS will lock at 20 hours per week per child regardless of the number of parents/guardians providing attendant care.

- SB 91 states that the eligible child must “learn to advocate for themselves with respect to choosing and managing direct support professionals before and after reaching 18-years of age “. . . and the empowerment of the client child to have a meaningful voice in the selection of the client child's direct support professionals”.

ODDS has developed a learning module for children to meet these criteria. The SC will assist the child with accessing the learning module. The module can be found here: [learning module \(in process\)](#)

About the learning module for children:

- a. The information is meant to be flexible to the child's age and specific learning needs.
- b. It is okay to modify the information to meet the child's communication and learning needs if the specific objectives in SB 91 (above) are met.
- c. Parents/guardians are encouraged to participate in this discussion if they choose.
- d. The parent/guardian of a minor child has authority to choose who will provide attendant care to their child.

***HELPFUL HINT: When a child indicates that they do not want their parent/guardian as their paid provider 1. Ask clarifying, open-ended questions and explore the reasons why 2. Use the Charting the Life Course (CtLC) [Trajectory](#) tool to better understand what the child wants and doesn't want from a paid provider 3. Problem-solve with the parent/guardian and child together to try to resolve the issue. 4. Document these conversations in case notes.**

- A parent/guardian may not be paid for attendant care delivered to their child until the parent/guardian is hired by a provider agency and has met all the agency requirements and received required training related to the CEN program. This training will be made available by ODDS. Parents/guardians have 90-days to be hired as a DSP. A paid

parent/guardian must work as a DSP at least once every 90-days for the child to remain enrolled in CEN.

- Parents/guardians must be eligible to work in the United States.
- The parent/guardian is subject to a background check and will become a 24-hour [mandatory reporter](#).
- Parents/guardians must understand that when they are being paid to provide support to their child, they are required to follow all applicable state and federal rules and laws that pertain to the paid attendant care of children receiving ODDS services.

***HELPFUL HINT: One or more of these rules may conflict with how someone chooses to parent. For example, DSPs may not be authorized to place a child in “time out” or send them to their room (to be alone). This may be considered involuntary seclusion and, in some cases, might fall under the category of abuse while working as a DSP.**

- The parent/guardian CANNOT work or be paid to provide attendant care to the child enrolled in CEN under the following circumstances:
 - a. If they are also responsible for a child(ren) under the age of 10 or a vulnerable adult who requires physical care or monitoring.
 - b. During a child’s assigned public school’s regular instructional hours.
- During activities not for the primary benefit of the child in CEN, such as:
 - a. Grocery shopping for the parent/guardian provider’s household.
 - b. Housekeeping not required for the disability-related support needs of the client child; and,
 - c. Transporting and/or accompanying any person to activities or appointments, including the child enrolled in CEN. Transportation is not attendant care.

***HELPFUL HINT*: It may help the parent/guardian to explain that they are entering into an employee/employer relationship with the provider agency and every employer has rules (policies and procedures) and job duties that are a condition of their employment.**

When a parent/guardian “clocks in” they are being paid to provide attendant care like every other DSP in the agency. It may help the parent/guardian to think of it as wearing two hats that they take off and on when being paid: a parent/guardian hat or a DSP hat.

- As the employer, the provider agency may have policies and procedures that address specific situations that come up when a parent/guardian is providing attendant care for their child.
- Parents/guardians may not do remote work or operate a home business while providing attendant care to their child.
- Unless there is an unpaid parent/guardian in the child’s life, the paid parent/guardian must choose a designated representative (defined below in FAQ) to direct the ISP. An unpaid parent/guardian does not need to become a designated representative. Otherwise, the designated representative might be an adult family member or close family friend who knows the child well.
 - a. The parent/guardian not being paid to provide attendant care, or the designated representative will become responsible for signing the ISP and related documents.
 - b. For the monthly case management contact requirement to be fulfilled, the SC must contact the unpaid parent/guardian or designated representative. The paid parent/guardian may or may not be present.

DSP Role vs. Parent/Guardian Role Examples:

Role as Direct Support Professional	Role as Parent/Guardian
Mandatory Abuse Reporter 24/7	Still Mandatory Abuse Reporter 24/7

Only provide ADL/IADL services as directed by provider agency in alignment with ISP and/or service agreement	No restrictions in the care provided
Cannot provide care for any children under the age of 10 while providing ADL/IADL services to the child in the CEN program	No restrictions in the care provided
Cannot provide care for a vulnerable adult while providing ADL/IADL services to the child in the CEN program	No restrictions in the care provided
Cannot do household duties that do not directly benefit the child in the CEN program	No restrictions with any household duties
Behavior supports only allowed as authorized in the ISP	How to address behavior is not restricted by an ISP
Remote work or self-employment is not allowed	No restrictions around remote work or self-employment
Paid provider cannot direct ISP due to conflict of interest	Must have designated representative who is not a paid provider for authorizing/signing and monitoring ISP services if another parent/guardian is not available for this role.

Parent/Guardian Decision:

1. CME's should collect family responses and send one email to ODDS with all responses that are known at the time on **June 14th** and then with all other responses and non-responses **July 19th**.
 - a) Send the first 'accept' and 'decline' responses from families to ODDS at: [CEN Program Questions](#) Subject Line: Parent/Guardian Decision **on June 14th**.
 - b) Work with ODDS to assure that families who have not responded by **June 14th** have received the offer letter.

- c) The parent/guardian of a child selected for initial enrollment must let the SC know that they agree to the requirements of the CEN program and would like to move forward with the enrollment process **no later than July 19th**.
 - d) Notify ODDS of all family decisions **on July 19^h**, or that they have not responded after multiple attempts to contact, by email: [CEN Program Questions](#) Subject Line: Parent/Guardian Decision **on July 19th**.
- 2. If the family agrees to participate in the CEN program, ODDS will verify the child's eligibility. For a non-DD eligible child on the referral list for a CIIS waiver, this means an ONA will be completed by ODDS and possibly a hospital or nursing facility level of care determination, also completed by ODDS.
 - 3. The SC should advise the parent/guardian to begin the process of becoming a direct support professional (DSP) through a provider agency ([link to provider list in process](#)) as it might take some time to complete this process. This list is not exhaustive. If the parent/guardian or services coordinator knows of other provider organizations, they should feel free to reach out.

***IMPORTANT* A parent/guardian may NOT be paid to provide attendant care for their child until they are hired by a provider agency and have met all the agency requirements and not before July 1st.**

The parent/guardian must be hired within 90-days of the offer to enroll in the CEN program for the child to remain eligible. This can be extended by the Department for good cause.

Schedule a time to meet with the child in person for the required children's learning module found here: [link in process](#)

If the family declines to participate in CEN by July 19th, the parent/guardian must be given a choice:

- a. to be added to the bottom of the waitlist (the child may not retain their assigned number on the waitlist); or
- b. be removed from the waitlist.

If the family does not respond to the SC by July 19th the child will not be considered for the CEN waiver and will be moved to the end of the waitlist.

Eligibility Determination

For children randomly selected from the initial group of eligible children whose parent/guardian has agreed to the requirements of the CEN program, ODDS will review the following to determine the child's eligibility:

Eligibility Requirements for the child:

1. Must be a resident of Oregon.
2. Meet ICF/IID, Hospital, or Nursing Facility Level of Care.
Be receiving Medicaid Title XIX benefit package through OSIPM or HSD medical programs.
3. Be assigned to the highest service group due to their very high medical (5m) or very high behavioral (5b) support needs according to a current, valid Oregon Needs Assessment.

If a child is found to be not eligible for the waiver, they will be given a Notice of Planned Action (NOPA) by ODDS and the SC will be notified.

eXPRS:

The following describes how eXPRS will be updated to implement the CEN program:

- 1) The **View Client Page** will have a new section added called **Extraordinary Needs Eligibility**, where a child's referral to this program will be documented and processed by State Staff.
- 2) A new page has been added to eXPRS so that a link can be established between a child approved for the program and an identified parent/guardian caregiver. This link will appear in the **View Client > Relationship** section, which will be updated to have a section for **Parent/Child Relationships**.
- 3) A new Service Procedure Code (**OR525 - Parent Attendant Care**) will be added to eXPRS. When a parent/guardian who is a paid

caregiver is providing Attendant Care to their minor child, this will be authorized using OR525/NA, ZE, or ZC.

- 4) Parents/guardians can be enrolled as a DSP in the eXPRS by means of a new User Enrollment Form. This form will be made available closer to the implementation of the program. Being enrolled as a DSP allows the parents/guardians to log into eXPRS Mobile-EVV and select the new OR525 Procedure Code when delivering service to the minor child that they have an established **Parent/Child Relationship** with in eXPRS (see point #2).
- 5) A new search page named **Children's Extraordinary Needs Waiver Enrollment** will be created. This page will allow CME staff to search for and see all children associated with their CME that have been referred to the CEN program, along with the status of their CEN eligibility. It will also show if they are currently enrolled in the Extraordinary Needs Waiver, and if so, the start and end dates.

For more information, see the [eXPRS Train Email: Section #1 – Children's Extraordinary Needs \(CEN\) Program](#). At a later time, more eXPRS-related emails and how-to guides will be made available in the eXPRS Help Menu.

Parent/Guardian Hired as a DSP:

The provider agency will notify the CME and ODDS that the parent/guardian has completed all the requirements and has been hired as a DSP.

1. The SC will complete a change form to indicate the new service element and update the Freedom of Choice form. Both should be signed by the unpaid parent/guardian or designated representative. The paid parent/guardian is no longer able to sign the ISP and related documents.
2. ODDS will complete the parent/guardian training module **(in process)** with the parent/guardian DSP's.

Complaints

Complaints related to the administration of the program described in these

rules may be made orally, in writing at [ODDS Complaints](#), or by using a Department-issued Complaint form 0946 (appendix below **in process**) and must be made directly to the Department.

***Remember*: Every person and family member of a person receiving ODDS services has the right to file a complaint and should never be discouraged from doing so.**

Frequently Asked Parent/Guardian Questions (FAQ's):

Who is the CEN program for?

The program is for parent/guardian caregivers of minor children assessed as having very high medical or behavioral support needs.

How many children can be served in the CEN waiver program?

The CEN program can serve no more than 155 children at a time. It will support no more than a total of 171 children every 12 months. Only serving 155 children at a time allows for turnover over the 12-month waiver period. As children leave the program throughout the year, for example, because of moving out of state, additional children will be added to fill open slots.

What is the child's role in choosing their parent/guardian to be their paid provider and participate in the CEN program?

A parent/guardian has the authority to choose their minor child's paid caregivers. There is also an expectation that the SC discuss options with the child, explore their preferences, and work on addressing and resolving any issues that arise in choice advising conversations.

What is the difference between a parent/guardian role and a paid provider role?

There are significant differences between these two roles. One important difference is that paid providers are mandatory reporters of abuse 24 hours a day, 7 days a week. If you are a [mandatory reporter](#), you must report all suspicions of abuse or neglect to authorities.

- Call the abuse hotline at 855-503-SAFE (7233) to make a report. The hotline is open 24 hours a day, 365 days a year.

What is the Designated Representative Role?

A designated representative is chosen to direct ISP planning and monitoring when a parent/guardian is being paid to provide attendant care and there isn't another parent/guardian to take on this role. This person cannot be a paid provider due to conflict-of-interest considerations.

- See role chart (above) for more information on the differences between DSP roles and parent/guardian roles.

How many hours can a parent/guardian provide for their child enrolled in the CEN program?

A child may have a maximum of 20 hours per week provided by a parent/guardian. More than one parent/guardian can be their child's provider. Regardless of the number of parents/guardians providing attendant care, the maximum total is 20 hours per week. There are no exceptions.

How does a parent/guardian sign up as a DSP with a provider agency?

Services Coordinators should help a parent locate provider agencies who have already identified themselves as interested in hiring parents/guardians of minor children. However, this does not mean that other provider agencies have declined to hire parents/guardians of children.

A list of participating provider agencies can be found [here](#).

What services can a provider agency be reimbursed for when a paid parent/guardian is acting in the role of a DSP?

An agency provider may bill for attendant care services. In general, attendant care services assist an individual in accomplishing activities of daily living (ADL), instrumental activities of daily living (IADL) and health related tasks through hands-on assistance, supervision, or cueing. ADL is a term used to refer to daily self-care activities such as eating, using the restroom, grooming, dressing, bathing, and transferring. Activities of daily living are defined in [OAR 411-317-0000](#). Please review the rule for additional information.

Some tasks that are not billable because they are considered general parental/guardian responsibilities or are available through other resources such as school or medical systems. An example of a non-billable task would include transportation to and from school or medical appointments. Providers should follow the policies and procedures of the agency where they are employed. Provider agencies must direct their DSPs in providing supports in alignment with a child's ISP and/or service agreement.

If an unexpected situation outside of the provider responsibilities needs to be addressed while the parent/guardian is providing paid attendant care, the parent/guardian provider should follow their agency's policies and procedures.

Q. What should a parent/guardian provider do if they make a timesheet/EVV login mistake?

The paid parent should notify the provider agency as soon as possible to address the error. This is important to address because incorrect billing may be considered Medicaid fraud.

Q. What can a parent/guardian expect from their case manager if selected for the CEN program?

Medicaid rules say that an individual can only be enrolled in one waiver at a time. If a child is selected for the CEN program, the SC will engage in choice advising discussions to help a family understand how the CEN program differs from the child's current services, learn what their case management options are, and understand important requirements such as monthly case management contact.

Q: Can a parent/guardian be paid to provide transportation for their child if it is related to the PBSP?

No. The CEN waiver does not allow ODDS to reimburse an agency for transportation of a child receiving in-home services.

Appendix:

Letters to families (in process)

Complaint form

Reference(s):

Senate Bill 91:

<https://olis.oregonlegislature.gov/liz/2023R1/Downloads/MeasureDocument/SB91>

Children's Extraordinary Needs program web page:

<https://www.oregon.gov/odhs/idd/Pages/sb-91-implementation.aspx>

Charting the LifeCourse Nexus: <https://www.lifecoursetools.com/>

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