

1915 (c) Children’s Extraordinary Needs Waiver 2024–29

application: Summary of public comments and the Office of Developmental Disabilities Services’ (ODDS) responses

ODDS collected public comments on the draft 1915 (c) Children's Extraordinary Needs Waiver from Oct. 5–Dec. 5, 2023. Thank you, all who responded and shared your feedback, ideas, and personal stories or struggles. Your feedback informed our revision of the application.

In each table below, we grouped and summarized similar comments together. We provide a response to each summary. We explain whether we used your suggestions in our revision of the draft waiver. In compliance with federal requirements, we included these data in the [final Children’s Extraordinary Needs Waiver application](#).

Summary of comments received
<p>Audience group: Parents and families receiving ODDS services, advocates for those receiving ODDS services, Advocates for Disability Supports, Pay Family Caregivers — Oregon, and Autism Society of Oregon</p>
<p>Summary of comments: We received many comments asking for parental income disregard to be included.</p>
<p>ODDS response: Based on the comments received, we added the 42 CFR §435.217 financial eligibility group to the revised application. This addition allows for the parental income disregard.</p>

Summary of comments received

Audience group: Parents and families receiving ODDS services, advocates for those receiving ODDS services, Advocates for Disability Supports, Pay Family Caregivers — Oregon, and Autism Society of Oregon

Summary of comments: We received many comments concerned about the current financial eligibility groups in the Children’s Extraordinary Needs waiver. The feedback about those enrolled in the waiver at risk of becoming over income and losing waiver access.

ODDS Response:

Based on the comments received, we added the 42 CFR §435.217 financial eligibility group to the revised application. This addition allows for the parental income disregard.

Summary of comments received

Audience group: Parents and families receiving ODDS services and advocates for those receiving ODDS services

Summary of comments: We received a few comments supporting the exclusion of parental income disregard.

ODDS response:

Many more comments asked for the inclusion of parental income disregard. Based on those, we added the 42 CFR §435.217 financial eligibility group to the revised application. This addition allows for the parental income disregard.

Summary of comments received

Audience group: Parents and families receiving ODDS services, advocates for those receiving ODDS services, Advocates for Disability Supports, Pay Family Caregivers — Oregon, and Autism Society of Oregon

Summary of comments: We received a few comments asking the current 1915 (c) waivers be amended to include the paid parent option.

ODDS response:

We lack legislative authority to incorporate the changes requested to the current 1915 (c) waivers, so we are making no changes to them at this time. We received direction from the Legislature in Senate Bill 91 (SB 91) to create a new waiver to address the needs of children with most significant needs. The new Children’s Extraordinary Needs Waiver will implement SB 91’s directives.

Summary of comments received

Audience group: Parents and families receiving ODDS services, advocates for those receiving ODDS services, Advocates for Disability Supports, Pay Family Caregivers — Oregon, and Autism Society of Oregon

Summary of comments: We received a few comments requesting an 1115 waiver be utilized instead of a 1915 (c) waiver.

ODDS response:

Advocates encouraged us to pursue this program with the utmost urgency. The proposed design of the program would have been the same using an 1115 waiver or 1915 (c) waiver. We chose a 1915 (c) waiver because it is the fastest option available. An 1115 waiver application would likely have taken much longer to develop and get approved. The state already has approved 1915 (c)

waivers that served as a blueprint to expedite the new waiver’s application, development and submission. 1915 (c) waivers also have less burdensome administrative and reporting requirements than 1115 waivers. For example, 1115 waivers require extensive data collection and evaluation plans to assess the effectiveness of proposed projects. They mandate monthly progress calls, quarterly and annual progress report, and other burdensome requirements.

Summary of comments received

Audience group: Parents and families receiving ODDS services, advocates for those receiving ODDS services, Advocates for Disability Supports, Pay Family Caregivers — Oregon, and Autism Society of Oregon

Summary of comments: We received many comments requesting we increase the hour-per-child limitation from 20 to 40 hours per week, per child.

ODDS response: Workgroups that we consulted while drafting the waiver preferred 20 hours per week over 40, as 20 hours doubles the number of children the program can serve within SB 91’s budget. Because of this, the limitation of 20 hours per week remains.

Summary of comments received

Audience group: Parents and families receiving ODDS services, advocates for those receiving ODDS services, Advocates for Disability Supports, Pay Family Caregivers — Oregon, and Autism Society of Oregon

Summary of comments: We received many requests for an increase of the unduplicated count of participants to serve all children who meet the eligibility criteria.

ODDS Response:

We are making no changes at this time. SB 91's legislatively approved budget allows a maximum, unduplicated count of 171 spots per waiver year for the cost of paid parent care at 20 hours per week. After the program is in place, we will track expenditures and based on data may adjust the number of individuals who can be served on the waiver.

Summary of comments received

Audience group: Parents and families receiving ODDS services and advocates for those receiving ODDS services

Summary of comments: We received a few comments asking for the waiver to prioritize those who currently lack access to attendant care.

ODDS Response:

We had this requirement but based on the other feedback received, we removed this requirement from the waiver application.

Summary of comments received

Audience group: Family receiving ODDS services

Summary of comments: We received one request to first prioritize Native and Black families, who face ongoing discrimination and obstacles and then prioritize low-income, unhoused and single-parent families.

ODDS Response:

At this time based on overall feedback we are not making any changes to the waiver application regarding this request. Senate Bill 91 defines eligibility criteria, provider types that are allowed, training requirements, the budget, and the accountability and requirements. The bill also requires us ensure we

implement the program consistently and equitably throughout the state.

Summary of comments received

Audience group: Families receiving ODDS services

Summary of comments: We received two requests that parents not be required to pass a background check.

ODDS response:

Senate Bill 91 requires parents to be direct support professionals (DSPs) employed by provider agencies. Statute requires DSPs to pass a background check. The bill provided no exemptions to this requirement. ODDS is making no changes to the waiver application at this time.

Summary of comments received

Audience group: Parents and families receiving ODDS services, advocates for those receiving ODDS services, Advocates for Disability Supports, Pay Family Caregivers- Oregon, and Autism Society of Oregon

Summary of comments: We received many requests to remove the documentation of inadequate caregivers from the waiver's criteria.

ODDS response:

We intended this requirement to prioritize individuals and families who demonstrate the inadequacy of available caregivers. We did not intend to increase the administrative burden on families. Based on the comments received, we removed this requirement from the waiver application.

Summary of comments received

Audience group: Parents and families receiving ODDS services, advocates for those receiving ODDS services, Advocates for Disability Supports, Pay Family Caregivers- Oregon, and Autism Society of Oregon

Summary of comments: We received many requests for a “simple lottery based on need.” Commenters stated that there are already too many barriers to access this program. Commenters also wrote that the additional requirements are largely subjective and create opportunities for bias.

ODDS response:

Based on received feedback, we are not changing the wavier. The selection process remains the same. We will assign initial applicants for the waiver a randomly drawn number between one and the total number of initial applicants. Those with the numbers one to waiver capacity must meet all eligibility requirements. Those who do, will be able to enroll. We will place initial applicants with numbers that are beyond the program’s capacity on a statewide wait list. The wait list will follow applicants’ initially assigned numbers. Applicants who apply after the initial pool will receive numbers at end of the wait list on a first come, first served basis. As waiver slots open, we will inform the applicant atop the wait list that they may begin eligibility screening.

Summary of comments received

Audience group: Service Employees International Union Local (SEIU) 503

Summary of comments: We received one comment requesting the waiver allow for personal support worker and agency with choice qualified provider types.

ODDS Response:

Senate Bill 91 specifies the qualified provider type as a parent provider who must be employed by an agency and not by the child or the other parent of the child. The parent provider may not be paid to provide attendant care services to the client child by an agency that is owned by the parent, the child or any family member or for which the parent or other family member serves in any administrative or leadership capacity, including as a member of a board of directors and the agency employing the parent provider to provide attendant care services to the client child may not employ a parent provider as an independent contractor. If there are changes to Senate Bill 91, we will implement them as specified. If an agency with choice provider model is created in the future, we will determine whether or not workers employed by these agencies fit within the requirements of SB 91. We are making no changes to the waiver application at this time.

Summary of comments received

Audience group: Parents and families receiving ODDS services, advocates for those receiving ODDS services

Summary of comments: We received many comments expressing gratitude for our work on this waiver.

ODDS response:

We appreciate your gratitude and look forward to our continued collaboration on Senate Bill 91 and the Children’s Extraordinary Needs Waiver.

Summary of comments received

Audience group: Maxim Healthcare Services

Summary of comments: We received one comment expressing concern that private duty nursing would be negatively impacted by this waiver.

ODDS response:

Private Duty Nursing Services are a separate Oregon Medicaid State Plan service for specific populations and with specific eligibility criteria. The Children's Extraordinary Needs Waiver will not negatively impact eligibility for private duty nursing services. We are making no changes to the waiver application at this time.

Summary of comments received

Audience group: Family receiving ODDS services

Summary of comments: We received one request that waiver slots be set aside for children receiving nursing services.

ODDS response:

The additional criteria of children being assigned to the highest service group due to very high medical or behavioral support needs includes those receiving nursing services. There are already slots in the proposed program for these children if they meet all of the eligibility requirements for this program.

Summary of comments received

Audience group: Family receiving ODDS services

Summary of comments: We received one comment suggesting an alternative utilization model be considered of allowing parents to provide support up to the

balance of unused average utilization.

ODDS response:

At this point in time, we are making no changes to the waiver application to adopt alternative utilization models.

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