

SB 91 feedback received via email August and September 2023

Theme: Number of Hours Per Week	
Feedback Summary	Response
<p>Due to the lack of available nurses, it would be ideal to have a 60-hr. work week for the paid parent caregivers. 40 hours isn't a livable wage in Oregon.</p>	<p>In September 2023, ODDS issued a state-wide survey to gather feedback from families and community partners encouraging them to share their thoughts and preferences on implementing SB 91. In that survey, 20 hours per week was the most popular response. In our community partner workgroups, there was an equal split between groups and individuals who support a 60-hour weekly cap and those who support a 20-hour cap. Those who chose a 20-hour cap cited the ability for SB 91 to reach as many children as possible within the budget constraints. ODDS is proposing a 20-hour weekly cap in the draft waiver application.</p>
<p>I support a 60-hour weekly cap on work hours. This measure is crucial to ensure that single parents with disabled children can adequately support their families with the income they earn.</p>	<p>In September 2023, ODDS issued a state-wide survey to gather feedback from families and community partners encouraging them to share their thoughts and preferences on implementing SB 91. In that survey, 20 hours per week was the most popular response. In our community partner workgroups, there was an equal split between groups and individuals who support a 60-hour weekly cap and those who support a 20-hour cap.</p>

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<p>There should be a 60-hour work week cap.</p>	<p>In September 2023, ODDS issued a state-wide survey to gather feedback from families and community partners encouraging them to share their thoughts and preferences on implementing SB 91. In that survey, 20 hours per week was the most popular response. In our community partner workgroups, there was an equal split between groups and individuals who support a 60-hour weekly cap and those who support a 20-hour cap. Those who chose a 20-hour cap cited the ability for SB 91 to reach as many children as possible within the budget constraints. ODDS is proposing a 20-hour weekly cap in the draft waiver application.</p>
<p>Please consider 60 hours for a living wage, instead of spaces for children who are in hospitals consider spots for children who have nursing hours. It can both bring kids home from hospitals and keep them out.</p>	<p>In September 2023, ODDS issued a state-wide survey to gather feedback from families and community partners encouraging them to share their thoughts and preferences on implementing SB 91. In that survey, 20 hours per week was the most popular response. In our community partner workgroups, there was an equal split between</p>

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<p>ADS would propose a 60 hours per week maximum.</p> <ul style="list-style-type: none"> -For those in the metro area under \$50k a year is not a living wage. Most of our families do live in the metro area where a living wage is \$74k. The closer we can get to that, the better. We are building a program for the future. Even if we limited parents to an absurd 10 hours a week, the \$4 million annual budget would cover fewer than 100 families. (The cost to the state is \$41/hour.) -Overtime does not cost the state additional money. It is an agency decision to offer and spend with the overhead that they get. -Parents in Arizona agreed to a 40-hour cap and have come to regret it. -The coming shift in ONA hours means very few children could qualify for more than 60 hours per 	<p>In September 2023, ODDS issued a state-wide survey to gather feedback from families and community partners encouraging them to share their thoughts and preferences on implementing SB 91. In that survey, 20 hours per week was the most popular response. In our community partner workgroups, there was an equal split between groups and individuals who support a 60-hour weekly cap and those who support a 20-hour cap. Those who chose a 20-hour cap cited the ability for SB 91 to reach as many children as possible within the budget constraints. ODDS is proposing a 20-hour weekly cap in the draft waiver application.</p>

<p>week anyway, but it is reasonable to have some cap.</p> <p>-Parent caregivers of adult children are allowed to use unlimited hours. There is precedent in Oregon for paying a living wage. We are asking for considerably less.</p>	
<p>I would agree with capping weekly hours at NO LESS than 40 per week. Although our caregiving for our children with this high level of need is often done all hours of day and night, well over 100 hours in a week, the 40-60 hours cap could allow more families access while still mitigating the financial difficulties of not being able to work outside the home at all or work enough to meet basic needs such as food and housing.</p>	<p>In September 2023, ODDS issued a state-wide survey to gather feedback from families and community partners encouraging them to share their thoughts and preferences on implementing SB 91. In that survey, 20 hours per week was the most popular response. In our community partner workgroups, there was an equal split between groups and individuals who support a 60-hour weekly cap and those who support a 20-hour cap. Those who chose a 20-hour cap cited the ability for SB 91 to reach as many children as possible within the budget constraints. ODDS is proposing a 20-hour weekly cap in the draft waiver application.</p>
<p>By implementing a 60-hour weekly cap and utilizing the ONA point system, we can ensure that single parents with disabled children have a better chance of surviving on their income by considering the unique challenges these families face so they receive the support they need.</p>	<p>In September 2023, ODDS issued a state-wide survey to gather feedback from families and community partners encouraging them to share their thoughts and preferences on implementing SB 91. In that survey, 20 hours per week was the most popular response. In our community partner</p>

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<p>Theme: Support for SB91</p>	
<p>Feedback Summary</p>	<p>Response</p>
<p>I am writing to share my thoughts about senate bill 91. First off, I am so thankful and grateful that Oregon is moving in the direction of really supporting children who are disabled.</p>	<p>ODDS recognizes the tremendous parent advocacy that went into this legislation.</p>
<p>Theme: Priority Enrollment/Eligibility in SB91</p>	
<p>Feedback Summary</p>	<p>Response</p>
<p>Please strongly consider self-injurious behaviors as a qualifier. DSPs have prompted more anxiety which leads to self-injurious behaviors either in the moment, or later as a coping mechanism. Please raise self-injurious behaviors to the top of your considerations.</p>	<p>SB 91 describes eligibility as children in the highest service group due to medical or behavioral needs, based on the Oregon Needs Assessment. Children with self-injurious behaviors in the highest service group due to behavioral needs will be included.</p>
<p>I would like to suggest that children who engage in self-injury behavior be included in the program. My daughter when stressed injures herself, she experiences great amounts of stress when around people she doesn't know.</p>	<p>SB 91 describes eligibility as children in the highest service group due to medical or behavioral needs, based on the Oregon Needs Assessment. Children with self-injurious behaviors in the</p>

	highest service group due to behavioral needs will be included.
<p>I am writing this letter to ask ODDS to consider adding additional means criteria to SB 91.</p> <ol style="list-style-type: none"> 1. Poverty is common amongst our families and the most at risk. 2. I would also like to ask ODDS to consider adding additional criteria such as for children in rural communities. There are children in rural areas that have zero or very little access options to caregivers. yet the parent is filling these supports unseen and unrecognized and have exited the work force to care for these children. These are children that have shown history of not receiving HCBS. 3. I would ask that families with multiple eligible children be considered, it is incredibly difficult for one parent to do all the care with no help. I would ask that CIIS children be considered as they have shown to have very high needs. I am asking that a 40-hour cap per eligible child is what is placed on this parent caregiver program to stretch the funding further to more kids. I ask that ODDS apply to the E Board for more equity in the funding to serve the 	<p>ODDS is proposing that this waiver contain Medicaid eligibility groups based on the family income. This waiver is available statewide, so cannot prioritize one part of the state over another.</p>

<p>eligible children. I ask that ODDS ensure no empty seats to this program at any time. We need to keep this program operating at full capacity because there are many kids who need this opportunity. Because the program is so small, I would ask that we don't reserve spots and instead always fill them.</p>	
<p>Thank you for your time on SB 91. My concern is with income eligibility. It would be difficult to determine an appropriate income cap without discriminating against families with different circumstances and without encouraging families to fall or stay in poverty to retain eligibility. Ultimately, I think if income eligibility is attached to SB 91 it should be well above poverty level (\$100,000 or \$150,000?) to account for extenuating expenses families may bear such as student loans. Ideally income would not be an eligibility factor as it is not in any other state allowing for parent pay givers. This is to address the critical lack of support workers not a financial assistance program.</p>	<p>You will find current income guidelines and links to more eligibility tools here: Combined Standards Financial Eligibility</p>
<p>Set spots aside for nursing hours. It would help so much and keep our kids out of long-term care hospitals. Nurses are so hard to find, and these kids are often the most complex and can't use regular DSP's.</p>	<p>This waived service is specific to attendant care and not nursing hours.</p>

Lottery for initial entry into the program. Eligible and interested parties would sign up for the first drawing. Any children not selected would be placed on a waitlist, which would also make use of a lottery system. For the empty spots, each would need to be filled within 30 days with a name randomly chosen from the waitlist. There would also be a required annual notification of eligibility during the ISP, which would include the requirement of a signature verifying that the family/representatives have been notified. Once a child is “in” the waiver program, they stay in. Empty spots would happen when a child ages out, moves out-of-state, dies or improves to the point of no longer meeting the “very high medical” and “very high behavioral” score.

- Because the eligibility described in the bill — “very high behavioral needs” and “very high medical needs” — already limits the population, a lottery among those interested would be the only equitable way to select the kids who get the very few initial spots.
- A lottery would provide researchers a golden opportunity to study the effects of the program. We believe it would show numerous advantages — giving legislators the data they need to expand their investment.

In September 2023, ODDS issued a state-wide survey to gather feedback from families and community partners encouraging them to share their thoughts and preferences on implementing SB 91. In that survey, a utilizing a lottery system for potentially eligible children was the most popular option and is proposed in the draft waiver application.

<p>-Providing a permanent spot once “in” the waiver is a way to give that family stability and predictability. We learned during the pandemic how amazing this support is — but we also learned how terrible it is to be taken away.</p> <p>-A lottery would avoid people “gaming” the system by checking boxes that don’t apply.</p> <p>Oppose adding yet another assessment to the process of applying for the paid parent caregiver program.</p>	
<p>Oppose a means test.</p> <p>-Means tests become poverty traps — people are unable to get the support they need or stay in poverty unnecessarily to keep benefits.</p> <p>-A means test would require regular checks of tax returns, increasing administrative burden to families and the administrative cost to the state.</p> <p>-A means test would tie services to something outside of the child's needs.</p> <p>-Not having a means test is the basis for all other HCBS programs in the state.</p> <p>-Not having one has saved the state money because families don’t have to be bankrupted by medical costs first and then the whole family is on Medicaid anyway.</p>	<p>Medicaid is a low-income program with federally established income eligibility requirements. ODDS is proposing that this waiver contain Medicaid eligibility groups based on family income. You will find current income guidelines and links to more eligibility tools here: Combined Standards Financial Eligibility</p>

<p>The children with the highest point scores (on the Oregon Needs Assessment ONA) should be the children first eligible for paid parent caregivers.</p> <p>A point system based on the Oregon Needs Assessment be utilized to determine qualifying children. Children with the highest points would have priority for receiving service</p> <p>A point system based on the Oregon Needs Assessment be utilized to determine qualifying children. Children with the highest points would have priority for receiving services.</p> <p>It would be efficient, fair and practical to incorporate the ONA into the determination of eligibility for benefits.</p>	<p>The Oregon Needs Assessment assigns children into service groups. Only children in the highest service group due to medical or behavioral needs will be potentially eligible for this waiver.</p>
<p>A lottery system relies on chance and does not consider individual circumstances, potentially leading to unfair outcomes.</p> <p>A lottery seems the least unfair given the disproportionate number of kids that will be given access out of the much larger number who qualify.</p>	<p>Only children who, based on the ONA, have been assessed to have the highest need in medical and behavioral support will be included in the proposed lottery system.</p>
<p>I believe an equally proportionate percentage of medical and behavioral qualifying children should be granted access.</p>	<p>In our proposed waiver application ODDS is projecting an equitable distribution of eligible</p>

	children in the highest service group based on medical or behavioral needs.
(Child) has over 400 hours available. I find it hard to have a person in my home during the night and I find it uncomfortable having too many PSW in my house. Our (foster children) all have trauma issues and different people coming and going is not healthy for them. Please consider letting parents use hours to help with the children's anxieties and trauma.	This waived service will only be assessed to ADL/IADL supports.
Theme: Clarifying Questions	
Feedback Summary	Response
Does SB 91 apply to parents working with children over the age of 18? Or is it just for minors?	This proposed waiver will support minors aged 17 and younger.
I am a mother of a medically fragile 11-month-old. I am interested in becoming a paid parent caregiver of my child. How can I become part of this program please?	Please sign-up for updates: SB 91 web page Information on applying for this waiver will be communicated on this dedicated web page.
The two questions I would like responses to are: 1. Why won't ODDS modify the existing waivers to allow more children to have the most qualified caregivers possible?	1. The limited budget of SB 91 would not allow modifying existing waivers. To meet requirements of SB 91 and its budget, new 1915(c) waiver was determined to be the best and most expedient approach.

<p>2. Why is ODDS creating barriers to growing the pool of caregivers amid a nation-wide shortage of workers in this field?</p>	<p>2. ODDS is following the direction of the legislature and the instructions of SB 91.</p>
<p>I am very interested in being a part of this discussion. Please let me know how to participate.</p>	<p>Find updates on SB 91 here: SB 91 web page Future opportunities to give input on SB 91 will be announced on this dedicated web page.</p>
<p>My team had two suggestions for the form.</p> <ol style="list-style-type: none"> 1. It asks if we are seeing an increase or decrease in SI types. It would be helpful to have a “no change” option. 2. It asks, “Please provide reasoning for the late closures: What actions is your CME taking to remediate this, please list”. It would be helpful if it asked, “What actions, if any, is your CME taking to remediate this?” as there really could be no issues to report. 	<p>Thank you for the suggestions. They are not directly related to SB 91 and it is unclear what form you are referring to.</p>
<p>I ask the ODDS is very considerate with what is required of the child, and sensitive to what is said to the child and make sure its child centered. I am concerned how this will work for children who can't communicate?</p>	<p>ODDS strives to apply person-centered and trauma-informed practices when communicating with all people who receive services.</p>
<p>We have asked ODDS to come prepared with the numbers for how many qualify as highest needs in both categories as well as a third “general</p>	<p>SB 91 describes eligibility as children in the highest service group due to medical or behavioral needs, based on the Oregon Needs Assessment.</p>

<p>support” category that is also considered “very high.”</p>	<p>A minor child is in the "Very High" service group due to medical needs based on how many specific medical treatments or therapies a child receives and how often. As of August 2023, there were 324 children in this group.</p> <p>A minor child is in the "Very High" service group due to behavioral needs based on the type of behavior they exhibit and the support they receive. As of August 2023, there were 1026 children in this group.</p> <p>As of August 2023, there were 16 minor children who meet criteria in both categories.</p>
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Theme: Program Oversight	
Feedback Summary	Response
<p>First, we believe parents should take care of their children and do not need support to do so. Added to this mess is the belief that disabled people do not deserve community supports to have stability in their homes and lives. This is ableist. Our group and many others are working toward challenging these long-held beliefs.</p> <p>The second issue is that children aren't legally able to self-direct their own supports. Therefore,</p>	<p>SB 91 directs ODDS to apply for a waiver using specific criteria. The provider type allowed is a parent who meets the qualifications of a direct support professional based on Oregon Administrative Rule 411-055-0335. The bill also directs ODDS to collect and report on specific data points. ODDS will administer this waiver as directed by the legislature.</p>

we have a situation where their chosen paid safe adult (parents often) are also their legal representatives. This creates the appearance of a self-serving conflict of interest.

The gov is addressing conflict of interest by assigning a different adult to represent the child on the ISP and for authorizing payroll. It makes sense for the gov to also address the appearance of being self-serving too.

I'd picture that process as a balancing test of sorts completed every six to 12 months with the ISP where paid parent provider status is examined and compared to DSPs to document why one is better than the other for the disabled person.

- examine the pros and cons of a DSP vs paid parent when it comes to respecting privacy,
- ask my child's preferences and compare them to the common assumed preferences of a non-disabled child at the same stage of development.

In many cases a child assigning a paid parent as a care provider is making a self-care decision which is consistent with the child developmental stage, they're in.

- examine the qualifications and training needs of both DSPs and parents to meet the child's needs.

Also explore the difficulties for the DSP to reach a minimum amount of competency.

<p>- compare the cost of a DSP to observe my child sleeping with the cost of paying a parent to respond when the medical need arises and when observed sleeping is prudent. The savings of not funding the support all should not be considered.</p>	
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