



# Allow Oregon's Disabled Kids to Have Paid Parent-Caregivers

## Senate Bill 646

"Family caregivers should be paid, and CMS should make this a permanent (program) to support the nation's need for a strong HCBS system." - National Council on Disability

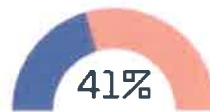
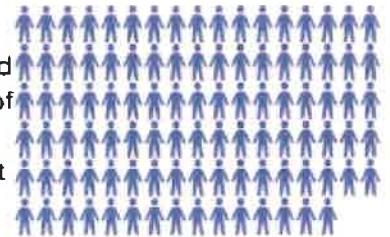
### Key Data

- **89%** of families surveyed reported their children's health improved after participating in the program
- **Twice as many** children had zero hospitalizations after the paid parent program was implemented
- A sample of over 700 participants in Colorado's similar program found there was a **six-fold reduction** in rehospitalization rates
- During the temporary program, **two-thirds** of families increased work hours for non-parent providers, helping solve the caregiver workforce crisis.

### Workforce Challenges

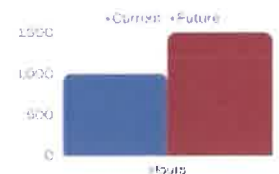
#### Unmet Need

The four agencies surveyed showed a combined total of 181 children currently waiting for a direct support professional placement.



#### Unfilled Hours

A review of the total attendant care hours actually utilized in 2018 showed 41% went unused.



#### Unstaffed Nursing Hours

One in-home nursing agency expects to see a 50% increase in unfilled hours when parents are no longer eligible to fulfill them

### Program Facts

- **Cost savings:** The program is a cost-saver when compared to institutional and foster care. Reduces healthcare costs for government and families with lower rates of hospitalizations.
- **Budget-neutral:** The program is budget-neutral if Oregon intends to allow disabled children to use the full supports allotted to them by the Department of Human Services.
- **Reduced reliance on government assistance programs:** Paying parent-caregivers for the extraordinary labor they provide to their disabled children can reduce reliance on programs such as food stamps and housing assistance.
- **A solution to the workforce crisis:** Parent providers add to the labor force, while data indicate hours worked by non-parent providers also increased during the temporary program.
- **Federal match:** SB 646 is a waiver amendment that can be enacted quickly by CMS, making use of the 2:1 Federal Match, and saving Oregon from the costly stop-gap of continuing the current program on General Fund dollars.

"In addition to the Federal integration mandate, it is well established that living in one's home with supports is safer than living in an institutionalized setting, costs less, and is the desire of most individuals."

- Andrés J. Gallegos, J.D., Chairman of the National Council on Disability



**Cost Effective**



**System Stabilizing**



**Equitable**

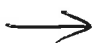


Jan. 18, 2023

To the policymakers of Oregon,

We have a number of concerns about SB 91, a proposed paid parent caregiver program to minor children. It's important to carefully consider the potential impacts and unintended consequences of such a program, and to ensure that it is designed in a way that is fair, inclusive, and effective in meeting the needs of the disabled children it is intended to serve. It's also important to involve parents and client children in the design and implementation of the program to ensure that it is equitable and accountable.

1. **Exclusive eligibility:** The "very high" level of needs does not appear to even cover many of the very small number of people in the temporary program. More inclusive eligibility would expand this benefit to children whose needs are still high enough above their nondisabled peers to qualify for aides.
2. **Agency hours cap:** The 30 percent cap on agency hours would create a subset, within a subset, within a subset of the number of disabled children who would qualify. This could lead to a chilling effect and the best-qualified caregivers being denied due to limited available spots, particularly in service deserts.
3. **Effect on other programs:** The rule allowing the department to shrink the paid parent program if it affects other programs pits adult services against children's services in a way that is not helpful or productive, and divorces children's identified needs from the supports they are allowed to receive.
4. **Creating a new waiver solely for this program instead of amending a current one:** The use of a new 1915(c) instead of amending the current program could be problematic in several ways. Additionally, it could become a state-level barrier if the federal government continues the COVID-19-era program, as the National Council on Disability has [recommended](#).
5. **Unfair to client children with siblings who also require this one-to-one support.** The per household cap on hours, rather than per employee, would unnecessarily discriminate against families with more than one disabled child who would otherwise qualify for a paid parent provider.
6. **Institutionally biased advisory committee:** The rules advisory committee appears to be mostly composed of non-parents, which could limit the perspective and input of those who have direct, lived experience with the issues being addressed during the implementation phase.
7. **Protectionist policies for non-parent providers:** The protectionist policies for non-parent providers could thwart self-determination in ways that the Centers for Medicare and Medicaid (CMS) could possibly disallow and could certainly be detrimental to client children.
8. **Overbroad parent limits:** The limits on parent activities are overly controlling of parent providers while ignoring the potential for harm that also exists from non-parent providers. Parents and non-parent providers should be given the same benefits, limits and trainings while staying within [CMS guidelines](#) that the services be provided for



“extraordinary care” — which is defined by each child’s Individual Service Plan and annual assessments.

We would be happy to discuss these concerns in further detail at your earliest convenience.

Thank you,

[Advocates for Disability Supports](#)

