

Budget benefits of a paid parent caregiver program

Across the nation, states are seeking to make permanent paid family caregiver programs, such as were unintentionally piloted to great effect during the COVID-19 federal Public Health Emergency. In fact, the Kaiser Family Foundation recently [reported](#) that 48 states are now allowing “legally responsible relatives” to be paid caregivers, up from 36 in 2020.

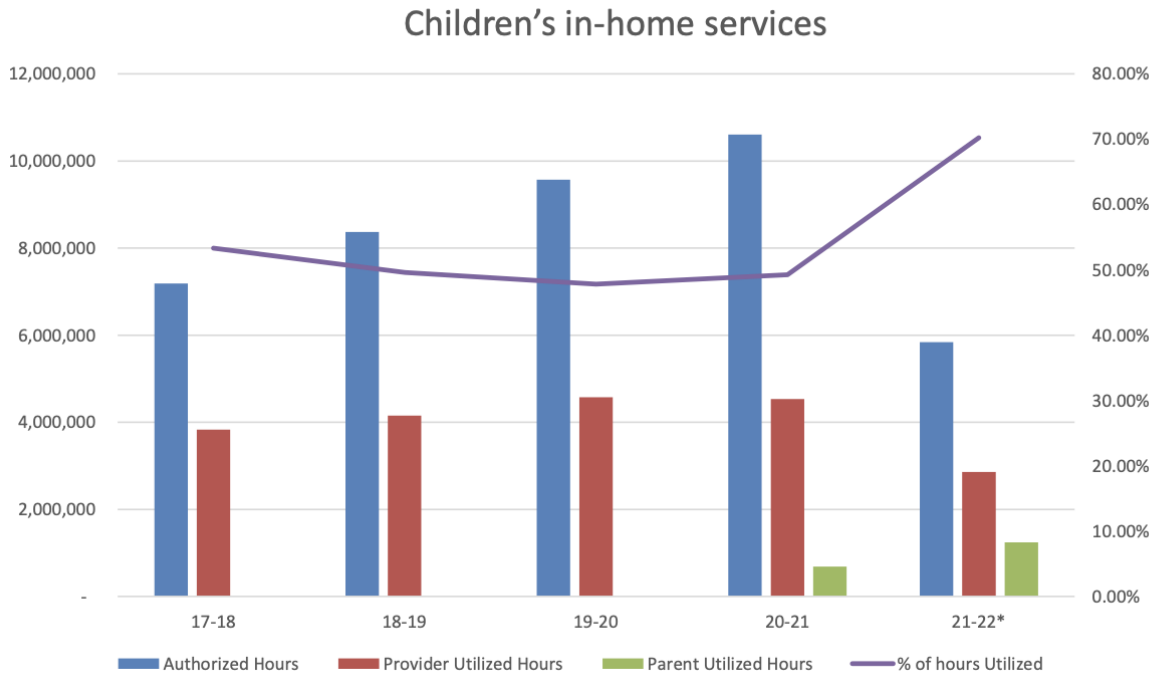
As the nation struggles with a care worker crisis with no end in sight, there is growing recognition that providing this option is the right thing to do. The National Council on Disability, a federal agency, also [recently recommended](#) continuing the temporary programs (both 1135, which Oregon uses, and Appendix K) permanently.

When considering aid to the vulnerable population of children with complex care needs, we **must** take into consideration the variety and overlapping nature of different silos of government. The National Center for Complex Health and Social Needs [sharply criticized](#) government programs for not recognizing their collective impact on the end user. “Our health and social systems typically focus narrowly on an individual’s single need and are not designed to work together to address multiple needs, often leading to costly and avoidable care. Many causes of poor health are best addressed through non-medical interventions that require cross-sector and community collaboration.” This is what parents do every day for their children.

The average monthly hours of paid parents in Oregon’s temporary program was 24,186 (Source [ODDS July 2022](#)).

Time Periods	Total average monthly hours provided per non-parent caregivers	Total average monthly hours provided per parent caregivers
3/1/2019-2/29/2020 Pre COVID	31,392	0
3/1/2020-12/31/2020 Pre Parents as Providers	37,672	0
1/1/2021-12/31/2021 Post Parents as Providers	38,801 avg monthly hours	24,186 avg monthly hours

At \$41/hr (Source: ODDS Jan 25, 2023 Senate Human Services hearing)(Note: **This is taxpayer cost.** PSW/DSP wages for minors range from \$18-\$24/hr) that would be a total fund cost of roughly \$1 million/month (\$991,626) and a general fund cost of \$337,152/month. When we divide by the 330 families utilizing the temporary paid parent program, that equals \$1,021 general fund dollars per month per family for paid parents of the **highest-needs** kids. (Children with fewer authorized hours would cost far less than the stated average of 447 hours/month.) For a program the size of the temporary one, that would be \$4.045M per year or \$8.09M per biennium (GF) for increased hours utilization. That’s still not full use of authorized hours. Use of children’s in-home services, and therefore authorized hours, dropped dramatically from 2020-21 to 2021-22. Parent hours comprised only a small fraction of authorized hours. The total cost to the state of the program remained steady to previous years.



Source: [ODDS, June 2022](#)

Also consider:

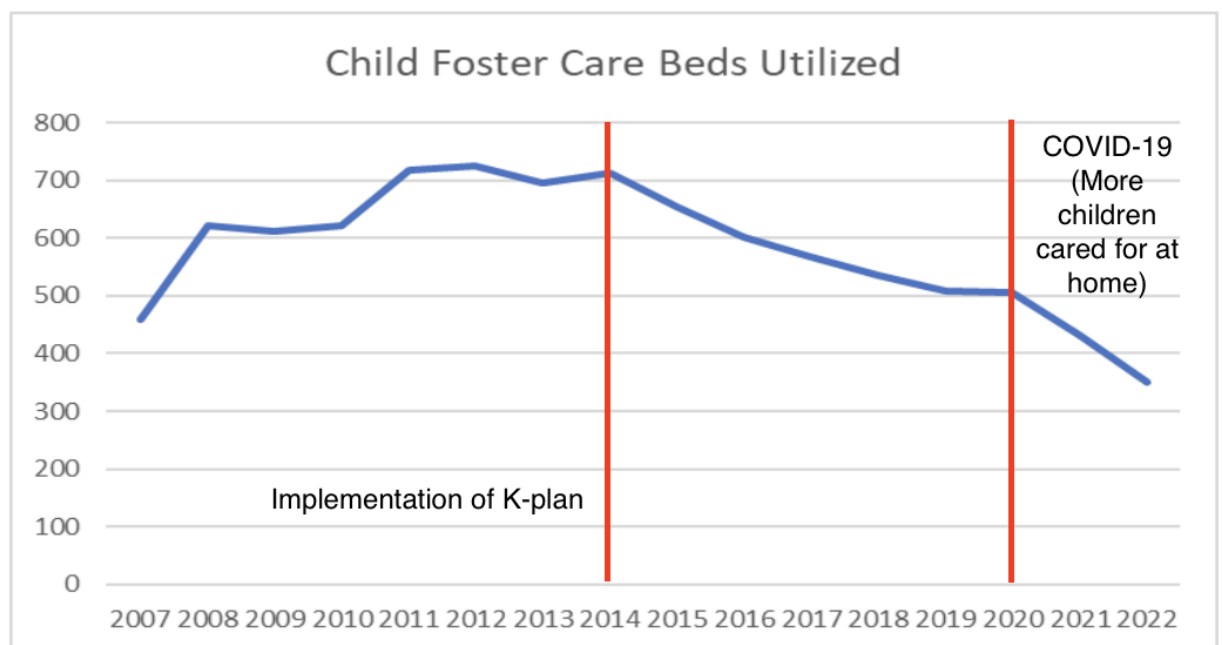
1. Beginning in 2025, the Oregon Needs Assessment ([Compass Project](#)) will cut assessed hours **IN HALF** for minor children. (Source: Anna Lansky, Jan 2023) This will dramatically reduce the cost of any paid parent program.

2. During the pandemic, a portion of the federal match for Medicaid services (an increase of 6.2 percent, representing millions of dollars) was diverted out of DD services. It's time to repay that sacrifice. (Source: Lilia Teninty, [May 19 2022](#), 1:09:00)
3. SB 91's many restrictions and limitations will add to the cost of administering the program.
 - a. The Office of Developmental Disabilities Services would need to develop a tracking system for agency hours, parent activities and mediate disputes.

Cheaper for the state

Paying parent caregivers to provide care for minor disabled children would be cheaper for the government and more effective overall. Some on-the-ground benefits include:

1. Cost-effective: The paid parent caregiver program has a relatively low cost compared to other options, such as institutional care or foster care, and could lead to cost savings for the government and families when the entire system of care is considered.
 - a. Foster care for I/DD children costs about \$70,000/yr per case. Foster care for I/DD children dropped dramatically after children were able to be cared for at home.



Source: ODDS chart of I/DD children in foster care July 2022

- b. See chart below for cost of foster care as well as 24-hour residential homes. There are 135 children in 24-hour residential homes for a total annual cost FY 2022 of \$30.6 million (\$8.4M GF)

Childrens Residential Settings for Fiscal Year 2022		
	24 Hour Residential Homes	Foster Homes
Average Monthly Cost Per Child	\$23,839	\$5,784
Monthly Cost All Children	\$3,397,333	\$1,587,480
2022		
General Fund	\$8,376,696	\$3,915,792
Federal Fund	\$22,199,301	\$10,371,530
Total Fund	\$30,575,997	\$14,287,322

Notes -
The Total Costs do not include ARPA Funds Costs from 7/1/2021 - 3/31/2022

- c. Providence Child Center is administered through the APD budget and not ODDS. It costs \$17,246 per child per month which would be a total expenditure of \$5.6 million per year (TF) for 27 children. PLEASE NOTE: PCC is at capacity and only offering short-term respite stays as spots become available. There is NO safety net for children requiring this sort of care. Source: ODDS, May 13, 2022

7/1/19-6/30/21	\$ 10,575,396.35
Avg Per Mo:	\$ 465,648.14
Avg # of children:	27
Avg/child	\$ 17,246.23

2. Good for the workforce.
 - a. In a [webinar](#) on family caregivers, Connecticut noted a six-fold increase in the caregiver workforce when they allowed family caregivers to work these jobs, from 2,477 to 14,680 workers. A paid parent program would help with the system-wide shortages and bring flexibility.
 - b. The Kaiser Family Foundation [reports](#) that 45 states have a significant caregiver workforce crisis. Paying parent caregivers would add to the labor force, training thousands of new workers, giving families the bandwidth to find and train non-parent providers and lessening the demand on non-parent providers.
 - c. The state's current unemployment rate is 4.5 percent.

3. Budget-neutral: The paid parent caregiver program is expected to increase utilization rates, but the federal government's match (60-66 percent) would also

increase. A paid parent caregiver program would be budget-neutral **to any other program that is designed to increase utilization.**

- a. SB 1548 (2022) — which was a boon to the in-home care system by increasing self-determination and reimbursement rates under an “agency with choice” model — was projected to cost just \$766,789 (GF 2021-23 biennium) but that bill’s [fiscal analysis](#) failed to project costs for increased reimbursement rates to agencies nor increased utilization.
 - i. “DHS notes that this bill will impact the cost per case, but the total fiscal impact is indeterminate at this time because it is unknown how many individuals would switch to the new provider type, and what the rates for this provider type will be.” -- The same would be true for a paid parent program. It’s unknown how many would use this provider type.
- b. HB 2457 (2023) Would guarantee 150 percent of minimum wage for providers. This measure would also benefit the workforce and increase utilization.
- c. *“There is a crucial need to address family caregiver under- and unemployment and home health care workforce shortages for CMC [children with medical complexity]. Policy makers, advocates, providers, and health care systems should become familiar with Colorado’s paid family CNA model for potential adoption locally and nationally as a budget-neutral way to address those critical issues.”*

[Employing Family Caregivers: An Innovative Health Care Model](#), American Academy of Pediatrics, May 5, 2022

4. Reduced reliance on other government assistance programs: By paying parent-caregivers for the extraordinary labor they provide to their disabled children, a paid caregiver program would likely reduce the need for families to rely on other government assistance programs, such as food stamps or housing assistance.
 - a. *“They don’t care that you have a disabled child and you have to stay home all day. They don’t care. If you don’t have an income, you don’t matter.” — Cyndy Campobasso-LeDoux*

[Single mom escapes 'victim mentality' through paid parent-caregiving but will it last?](#) (Medical Motherhood, May 2022)

5. Lower healthcare costs: Providing a paid caregiver program could lead to lower healthcare costs for both the government and families, as it could allow children to receive higher quality care and potentially avoid or reduce the need for hospitalizations or other expensive medical procedures.
 - a. Parents reported in [a survey](#) of 94 participants in Oregon’s temporary program that their children had been hospitalized far fewer days than before the program and twice as many said their children had stayed out of the hospital entirely.
 - b. *“We support this type of solution because it drives significant cost reductions — and that’s so important at a time when states desperately need support due to their revenue shortfalls from COVID-19. National attention is really needed at this point.”* — Team Select Home Care President and CFO Fred Johnson
 - c. A study of 700 participants in Colorado’s program found a six-fold reduction in hospitalization rates. Source: [Home Health Care News](#)
6. Increased productivity and improved quality of care: By paying parent caregivers for their extraordinary labor, a paid caregiver program could allow parents to focus more on caring for their disabled children. This continuity of care is safer and better for children’s health, success and skills acquisition. This could increase the potential productivity of parent caregivers and soon-to-be adult children, as they would be on a better trajectory and potentially participate more in other work or education.
7. Lower costs of care to family caregivers.
 - a. Family caregivers experience extreme amounts of stress and they overwhelmingly report that being paid for their labor lowers burnout.
 - b. The White House has put out a [National Caregiver Strategy](#) calling on government agencies to increase their support to this vital population.
8. Better K-12 outcomes: Family income and stability are important factors in student outcomes, and the paid parent caregiver program could help to stabilize and support families, potentially leading to improved K-12 outcomes for disabled children.

- a. Accountability in IDEA services comes from the parents. When parents don't have the bandwidth to advocate, schools and children suffer.
9. Advocacy: The ability of parent caregivers to advocate for their children's needs may be improved if they are able to focus more on caring for their children and have the financial resources to do so. This could lead to improved outcomes for disabled children and potentially reduce the need for more costly interventions.
10. Economic generator: The federal government funds these hours with a 2:1 match. Particularly in service deserts, this would help lift families out of poverty and positively impact their communities.

It's worth noting that these potential benefits would need to be carefully evaluated in the context of a specific paid caregiver program, as the specific design and implementation of the program could impact the extent to which these benefits are realized. **A program that is overly restrictive or complex could lessen its impact as fewer families would benefit and only those with the privileges to reach the end of a maze of restrictions would qualify.**

Finally, if Oregon doesn't have the budget to pay parents as caregivers then neither does it have the budget to fix the workforce crisis and fill the promised clients hours with non-parent providers. This would amount to a shameful mirage of services to families in desperate need. Parents are asking for access to the same hours their children have been assessed to need — above and beyond the care of a neurotypical child their age — not an additional benefit.

Thank you for your time and attention to these important issues. We are ready to discuss any of the above in further detail at your earliest convenience.

[Advocates for Disability Supports](#)