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