Paid Parent Caregiving

It just makes sense

Who am I?

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I’m a writer living in Portland, Oregon. I’m also the mother of twin boys who were born three months early and who have several disabilities. Each Sunday, I publish news and information relevant to people raising disabled children at MedicalMotherhood.com.

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The Problem

There's no getting around it: Disabilities are additional work

Studies show that while disabled children are more expensive than average to raise, families often sacrifice work and sleep for their additional cares, surviving off low incomes or public assistance programs. This intersection of poverty and disability starts early with devastating long-term effects.

Many states have begun to offer these families access to in-home caregiver hours. But this program designed for adults does not work well for children. It makes sense to allow families the option to choose to employ their best-qualified and most readily available caregiver —parents.

The Solution

During COVID, Medicaid temporarily allowed parents to be paid

Under either an Appendix K or 1135 waiver, CMS temporarily allowed states to apply for the right of legal representatives to also be their child’s hired worker. This allowance expires when the Public Health Emergency does —currently set for July 15.

The federal government could continue to offer states the flexibility to hire parents of minor children. This could either be through language similar to the temporary 1135 or Appendix K flexibilities, or by offering clearer guidance that parents of minor children are already allowed this flexibility under 1915(c), 1915 (k) and 1915 (j) as long as they are not also the child’s legal representative. There needs to be a clear solution for single parents, too.

9 out of 10

children in Oregon’s temporary program had fewer mental and physical health problems. Hospitalizations reduced dramatically. There was also much lower reliance on public assistance programs.

More Benefits:

- Children get access to stable and well-qualified support in their own homes with their family
- States get a solution to the labor shortage. CT saw a six-fold increase in their labor force when they allowed family caregivers for adults.
- As individual as planning gets —each family gets to choose what's right for their child's needs
- Taxpayers get bigger bang for buck: The dollars work two ways, providing the child support during shifts, and direct and immediate support in the rest of their lives -- rather than on bureaucracies.
- Parents felt the dignity of being valued for their "silent subsidy" of medical care work. One mother said it helped her escape a 15-year "victim mentality"
- Breaks the poverty cycle, keeps families together

Many states did this temporarily. Some have had permanent programs already:

Colorado

California

Arizona

Minnesota

Programs are idiosyncratic but can be under several different types of Medicaid self-direction authorities, such as 1915 (c), 1915 (k), 1915 (j) and 1115.

There is broad interest across the nation in making permanent this temporary Medicaid allowance, but there is resistance to change and it constitutes a challenge to established powers and flows of money.

Challenges

Funding

This would constitute a shift in investment:

- More money needs to be allocated by states and feds to ensure promised services are delivered. Medicaid is currently underfunding the support needs promised to disabled children.
- In Oregon, children were only able to use half of the hours they were awarded. This creates a mirage of services with already-stressed out parents spending time and energy trying to get a program to work.
- Children would reduce need for expensive hospital, foster care and institutional care.
- Parents would reduce need for wrap-around services.

How can Title V funding help?

I’m not an expert in that, but here are some suggestions:

- Title V programs could convene discussions on this topic among stakeholders in their state
- They could use their connections to educate and disseminate research on the benefits of programs like this
- Could potentially provide staff support to promote policy change, especially at a federal level

Additional Resources

Additional Resources

- Oregon Advocates for Equitable Disability Services has a 112-page proposal for their state, as well as many other documents and resources.
- NASHP has a report on several state plans.
- Medical Motherhood has published many issues related to this topic:
  - Julie Beckett's legacy is honoring the role parents play in raising disabled children
  - Survey says: Paid parent-caregivers mean healthier, happier disabled children
  - The case for paying parents of disabled children