



Using Medicaid to Support Parents with Disabilities

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INTRODUCTION

As people with disabilities have greater opportunities to live and participate fully in their communities, a growing number are choosing to raise families (National Council on Disability, 2012). While prevalence estimates vary, research indicates that approximately 5% to 10% of parents in the United States have disabilities.¹ Although parents with disabilities exist in substantial and growing numbers, community-based services and supports remain scarce for these families. In fact, government-funded home- and community-based services (HCBS), such as personal care attendant (PCA) services, do not generally offer services to assist parents with disabilities with childrearing tasks, because parenting is not considered an activity of daily living. Likewise, there is a dearth of available and affordable adaptive parenting equipment, such as modified cribs and baby carriers. This brief proposes policy solutions for assisting parents with disabilities with childrearing tasks through existing Medicaid-funded services and supports.

BACKGROUND

Parents with disabilities and their families are highly vulnerable to child welfare system involvement. One study, for example, found that 19% of children in the United States child welfare system were removed at least partly because of a parent's disability, and 5% were removed solely because their parent was disabled.² Parents with disabilities also experience higher rates of termination of parental rights.³ Moreover, once involved with the child welfare system, parents with disabilities often do not receive individually tailored services to meet their disability-related needs.⁴ Parents of color with disabilities may experience even more significant child welfare system inequities than parents who are white or disabled because of the intersection of racism and ableism.⁵

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Removing children from their homes is costly. Recent estimates suggest that the government spends almost ten times more on foster care and adoption than it does on services and supports to reunify families.⁶ Accordingly, experts believe that providing parents with disabilities and their children appropriate services and supports will save the government money and lead to better outcomes for families.⁷ Notably, a pilot study from the 1990s in Santa Clara

found that for every dollar the county spent on services and supports for disabled parents, the county saved \$1.72 in federal, state, and county funds allocated for foster care, not counting court costs involved in arranging foster care.⁸ More recently, the Minnesota legislature has introduced a bill that would establish a pilot program to provide state-funded personal assistance for childrearing tasks and prevent removal of a child by the child welfare system solely because of parental disability (Minn. Senate Bill 846, Minn. House Bill 898).

The federal government spends nearly **10 times more** on foster care and adoption than on it does on services and supports to reunify families.

Federal Foster-Care and Adoption Spending



Federal Parental-Reunification Spending



(Brico, 2019)

Parents with disabilities are more likely than nondisabled parents to have household incomes below the federal poverty level and to receive government-funded health insurance. Recent studies indicate that between 16.9% and 38.5% of disabled parents receive Medicaid and/or Medicare.⁹ At the same time, disabled parents report significant challenges accessing necessary services and supports. Medicaid funds PCA services while Medicare does not. Nonetheless, most states' Medicaid programs do not include PCA assistance for childrearing or fund adaptive parenting equipment. For example, in a national survey of 1,200 parents with diverse disabilities, 57% of respondents reported needing assistance with childrearing tasks but only 10% of respondents who needed parenting assistance used government-funded PCA services for parenting tasks.¹⁰ In addition to needing PCA services, many parents with disabilities have reported that cost is a barrier to accessing adaptive parenting equipment to help them with childrearing tasks. In the aforementioned national survey, nearly one-third of respondents expressed a need for adaptive parenting equipment but nearly 50% reported being unable to afford it. Recent studies have similarly documented a need for PCA services and adaptive parenting equipment to assist disabled parents with childrearing tasks.¹¹

Notably, some states have used Medicaid Home and Community-Based Services (HCBS) 1915(c) waiver programs to develop and implement programs for parents with intellectual

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or developmental disabilities. For example, Connecticut provides parenting supports to consumers who are or will be parents in developing appropriate parenting skills.¹² Through the waiver, parents receive individualized training on the health and welfare and developmental needs of their child. Close coordination is maintained with informal supports and other formal supports. Similarly, North Dakota's waiver services also include parenting supports.¹³ Parents receive parenting skills training that is individualized and focused on the health and welfare and developmental needs of their child. Close coordination is maintained with informal supports and other formal supports.

POLICY SOLUTIONS

Parents with disabilities and their families urgently need services and supports. Rather than develop and implement new programs, local, state, and federal government agencies should consider ways to expand existing services and supports to include assistance with childrearing tasks. In particular, we offer the following policy solutions:

- **Allow PCA services to include assistance with childrearing tasks.** PCA services enable many people with disabilities to live independently in their communities. At the same time, many people with disabilities are prohibited from using PCA services to carry out childrearing tasks. The Centers for Medicare and Medicaid Services (CMS) should explore ways to expand PCA services to include helping people with disabilities with taking care of their children. Specifically, CMS should issue guidance to states that clarifies that PCA services can include assistance with childrearing tasks. Additionally, CMS should expand its definition of activities of daily living (ADLs) to include parenting activities so that PCA services explicitly includes assisting with childrearing tasks.
- **States should use Medicaid HCBS authorities to provide services and supports.** Some states have used Medicaid HCBS 1915(c) waiver programs to develop and implement programs for parents with intellectual and developmental disabilities. HCBS waiver programs provide states with a great deal of flexibility to provide services and supports, such as PCA services, adaptive equipment, and peer training. States that maintain waiting lists for their HCBS waivers could also consider prioritizing parents with disabilities at risk of losing their children as priority population. States could also consider utilizing the 1915(i) HCBS State Plan Option to develop programs for parents with disabilities. The same types of services and supports can be provided through this HCBS authority. The advantage of this approach is that services and supports could be provided to individuals who do not meet the strict bar of an “institutional” level of care need. Finally, Managed Long-Term Services and Supports (MLTSS) programs also provide additional flexibilities

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and opportunities for states and managed care organizations to design innovative services and supports for parents with disabilities.

- **Fund adaptive parenting equipment similar to durable medical equipment (DME).** Adaptive parenting equipment, such as lowered cribs and specialized baby carriers, can enable some disabled parents to care for their children. Nonetheless, adaptive parenting equipment remains largely inaccessible because of cost. Accordingly, CMS should expand the definition of DME to include adaptive parenting equipment for parents with disabilities who receive Medicaid or Medicare.
- **States should expand Medicaid eligibility.** Medicaid eligibility varies from state to state, leaving some adults with disabilities unable to earn an income and still receive benefits. Hence, some disabled parents must live in poverty in order to keep their Medicaid. All states should create an HCBS buy-in program for those whose incomes exceed Medicaid eligibility.
- **States should collect data on parents with disabilities.** States should merge their administrative datasets, especially Medicaid and child welfare system datasets, to collect data on the prevalence of parents with disabilities, their involvement with the child welfare system, and the services and supports they receive. Data on race and ethnicity is also crucial to identifying the intersection of racism and ableism. Collected data should inform future policymaking to eliminate disparities and address unmet needs.

CONCLUSION

People with disabilities are increasingly raising families. At the same time, disabled parents encounter substantial bias within the child welfare system and have limited access to services and supports to help them in childrearing. Medicaid services offer cost-effective options for helping these families.

HOW TO CITE THIS BRIEF

Powell, R.M. (2020). Using Medicaid to support parents with disabilities. National Research Center for Parents with Disabilities. Waltham, MA: Brandeis University.

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