



Cuts to Medicaid Would Harm Young Children with Disabilities

By Rebecca Ullrich

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Kim and Rich Rankin of St. Louis, Missouri, are among the millions of Americans who are worried about what changes to Medicaid could mean for their family.¹ Their 4-year-old son Nathaniel was born with birth defects, resulting in significant developmental delays and health problems. Right now, Medicaid helps cover Nathaniel's medical supplies, surgery, and therapy, but the Rankins worry that cuts to Medicaid could mean his care soon will no longer be covered.²

Parents like the Rankins have reason to be concerned as the discussion about decreasing funding for Medicaid intensifies. Refinancing Medicaid would gut funding by putting a limit on the amount of money that the federal government contributes to states' health care spending.³ Cuts to Medicaid would have significant implications for many children under age 5.⁴ However, changes to how the federal government finances Medicaid would be particularly harmful to the young children with disabilities who rely on Medicaid to help them learn and grow in their homes and communities.

Medicaid provides a lifeline for children with disabilities and their families

More than half of all children with a disability or other special health care need rely on public insurance coverage for a wide range of services and supports.⁵ Because Medicaid extends eligibility in multiple ways to children with disabilities, it reaches a broad range of families and children with special needs.

Compared to other children, children with disabilities are more likely to live in low-income households.⁶ Many qualify for Medicaid based on their families' income alone⁷—without it, they would likely have no other affordable insurance options. All states—except Tennessee⁸—have additional disability-specific eligibility criteria, which allow some children with disabilities to qualify for Medicaid even if their parents' income exceeds the state-established threshold.⁹ Five states allow certain eligible parents of children with disabilities to “buy in” to Medicaid.¹⁰ For many of these families, Medicaid is the difference between being able to comfortably access comprehensive care for their child and falling into debt due to medical expenses.

Medicaid covers comprehensive health and developmental services for children with disabilities

Children with disabilities and their families rely on Medicaid for a range of services that support their health and development. While the services covered by Medicaid reimbursement, as well as the individuals eligible for services, can vary widely from state to state, they generally include:¹¹

- **Early and periodic screening, diagnostic, and treatment, or EPSDT, services:** Medicaid's EPSDT benefit ensures that children have access to preventive health care, including developmental screenings; vision, dental, and hearing services; diagnostic evaluations; and services to treat any identified physical or mental health conditions.¹² States are required to cover services deemed "medically necessary" to "treat, correct or reduce" health or developmental conditions, even if those services are not otherwise covered by a state's Medicaid plan. States determine which services are medically necessary.
- **Home- and community-based services:** Children with intellectual and developmental disabilities who would otherwise require an institutional level of care can receive services in their homes through home- and community-based services waivers.¹³ The services and

resources available through these waivers vary by state but can include respite care to give parents a break from caregiving, habilitative therapies, and medical equipment.

- **Prescription drugs:** Some children's disabilities require prescription drug treatment to eliminate or offset symptoms that affect their ability to function. Children with disabilities commonly take medication for conditions such as anxiety, hyperactivity, asthma, and seizures.¹⁴ Some disorders also make children more likely to have ear infections, eczema, gastrointestinal problems, and heart defects.¹⁵
- **Speech, occupational, and physical therapy:** Some states may choose to cover these habilitative therapies to support children's healthy development, help them meet developmental milestones, and support children's participation in their schools and communities. These therapies are critical for children but are not always deemed "medically necessary" and therefore may not fall under the EPSDT benefit.¹⁶ Some children can access these services through home- and community-based service waivers.

Capping federal funds for Medicaid would be harmful to children with disabilities and their families

Reforms to Medicaid would put every Medicaid service—and the children who need them—potentially at risk. At present, the federal government covers a fixed percentage of states' Medicaid costs—57 percent on average—meaning that states receive funding for that proportion no matter the cost of care.¹⁷ Under the financing structure known as a per capita cap, the federal government would instead pay a fixed dollar amount per person.¹⁸ Caps would differ for each subpopulation that Medicaid serves. States would then be responsible for 100 percent of any costs above this fixed amount.

Capping federal funds for Medicaid would put states under significant budgetary strain. This would have direct consequences for the services available to children with disabilities through Medicaid, as well as the other state systems that support them and their families.

Children with disabilities would lose access to health and developmental services

Because individuals with disabilities account for a large proportion of Medicaid costs,¹⁹ the federal funding caps for individuals with disabilities would presumptively be higher than for other children or for the elderly. That said, these caps would likely fall far short of the cost of providing comprehensive care for young children with special needs, and children could lose access to the services they depend on in several ways.

First, one of Medicaid's current advantages is that it is a federal-state partnership, and states have incredible flexibility in how they choose to meet their constituents' needs.²⁰ There is considerable variability in how states extend their eligibility criteria beyond those required by federal regulations, as well as the types of services and resources that are eligible for reimbursement. However, under the budget constraints imposed by fixed federal funding, states could potentially use this flexibility to eliminate reimbursement for optional services.²¹ Many of the resources on which families of children with disabilities rely—such as costly prescription medication and habilitative therapies—are not required by the federal government and, therefore, could be among the first to go under budgetary pressures.²²

Second, fixed funding may also make it harder for children with significant disabilities to receive home- and community-based services.²³ While these services can be costly, they are generally preferred by families over institutions, as they allow children to remain in their homes, attend school, and participate in their communities.²⁴ In some states, there are already enormous waiting lists to receive this type of in-home support through Medicaid waivers.²⁵ With federal funding capped, states would be even more limited in their ability to reimburse for home- and community-based care.²⁶

Finally, per capita caps may remove the guarantee for coverage of certain services, such as those under the early and periodic screening, diagnostic, and treatment, or EPSDT, benefit.²⁷ Low-income children are at greater risk for disabilities and developmental delays.²⁸ Medicaid and the EPSDT benefit help ensure that problems with children's development are identified and addressed as early as possible. Removing the guarantee of the EPSDT benefit—or, worse, denying some low-income children health care coverage altogether—would likely mean that many more children's developmental delays or disabilities could go unidentified and unaddressed in early childhood, leading to adverse health effects or the need for more intensive special education or therapeutic services in the future.²⁹

Parents may be required to pay more for their children's care

Reforms to Medicaid could cause parents to assume a larger share of the cost of their children's care, which would have significant consequences for children's development and their families' economic well-being.

Most immediately, if states choose to reduce or eliminate reimbursement for habilitative services—such as speech, occupational, and physical therapy—parents would be responsible for paying for these services on their own. Therapy services can be incredibly expensive. One parent reported to CNN that the average cost of therapy for her 4-year-old son with autism was \$90 per one-hour session.³⁰ At eight sessions per week, the total cost of her son’s therapies exceeds \$36,000 per year—well beyond what most families can afford without substantial help from insurance. Without support from Medicaid, the costs of therapeutic services would put significant financial strain on many families. Others may be forced to forgo these services, potentially hampering children’s developmental progress.

A recent letter from U.S. Secretary of Health and Human Services Tom Price and Centers for Medicare and Medicaid Services Administrator Seema Verma³¹ indicates that the federal government is preparing to encourage states to increase cost-sharing and premiums for Medicaid beneficiaries. Although initially targeted at nondisabled adults, future policy changes in this direction could negatively affect families of children with disabilities. The cost burden for services that states are required to provide—such as physician visits—could then also increasingly fall on parents.

Rising costs could be financially devastating for families of children with disabilities and even put important services out of reach. They are already economically vulnerable: On top of the costs associated with specialized care, parents of children with special needs typically work fewer hours and earn less income due to their child’s increased caregiving needs.³² Nationally, 25 percent of parents of children with special health care needs report having to cut back on their hours or stop working altogether.³³ One analysis found that families lose an average of \$3,200 per year in wages.³⁴ This amount is likely even higher among families of young children who are not yet in school.

Children with disabilities in some states would be permanently worse off than others

Per-person funding caps effectively lock states into the level of care they provided for a given population during the year that they are established. This means that children with disabilities who live in states offering less comprehensive benefits through their Medicaid program would be perpetually disadvantaged.³⁵ For example, in 2011, New York spent \$30,221 per Medicaid enrollee with a disability—more than four times as much as Alabama, which spent just \$7,989.³⁶

Proponents argue that Medicaid financing reform would support state flexibility, but it is well-established that Medicaid is already quite flexible.³⁷ By basing the federal funding limit on prior-year spending levels, Medicaid refinancing minimizes states’ flexibility rather than enhancing it. For example, if states want to expand coverage to certain services to address an increasing need or public health crisis in the future, the federal government’s contribution would not expand in kind.

Early intervention and special education services would be under threat

Medicaid plays a significant role in ensuring that children with disabilities receive early intervention and special education services. Providers must attempt to use Medicaid funds to pay for health-related services for Medicaid-eligible children—such as speech, occupational, and physical therapy—before using funds from the Individuals with Disabilities Education Act, or IDEA.³⁸ Capping federal funds poses unique threats to states' early intervention and special education programs.

Early intervention

Part C of the IDEA provides early intervention services to eligible infants and toddlers in participating states and determines how, when, and from whom children receive early intervention services.³⁹ At present, all 50 states and the District of Columbia have an early intervention program and receive federal funds, but most states bear a large cost burden to provide these services. Medicaid is the largest reported federal funding source for early intervention systems.⁴⁰

States have long depended on Medicaid's flexibility to continue serving vulnerable children and families—in some cases, even increasing the number of children served—as state budgets are under pressure and federal funds for IDEA Part C remain flat.⁴¹ However, if Medicaid is refinanced, declining federal funds would create a gap in early intervention funding that states would inevitably struggle to fill. States may cope with funding pressures by further narrowing their Part C eligibility criteria, imposing fees on parents, or withdrawing from Part C altogether.⁴²

The IDEA is a discretionary grant, meaning that states can opt out of Part C and forgo IDEA funds if they choose. At least a handful of program administrators surveyed by the IDEA Infant and Toddler Coordinators Association each year report that they were asked to prepare documents that justify continuing participation in Part C.⁴³ Given that most states already pay the majority of early intervention costs, they may choose not to continue their programs with even fewer federal resources. States that opt not to participate would no longer be required to have an early intervention program to serve infants and toddlers with developmental delays and their families.⁴⁴

Special education

Part B of the IDEA guarantees children ages 3 to 21 access to special education services in their public schools.⁴⁵ Similar to Part C, federal funding for Part B falls well below the cost for services, and school districts use a combination of other local, state, and federal funding sources to meet children's needs.⁴⁶ One school leader recently said that Medicaid “closes the resource gap” between the IDEA and other funding sources.⁴⁷

Each year, school districts collectively rely on \$4 billion to \$5 billion in Medicaid funds to support special education services for children eligible for Medicaid.⁴⁸ Schools use these funds to pay critical personnel such as speech-language pathologists and occupational therapists, as well as to provide assistive technology and transportation for children with special needs.⁴⁹ Many schools also provide developmental screenings to students through Medicaid’s EPSDT benefit.

Under funding restrictions, schools would compete against other providers for limited Medicaid dollars. Compared to hospitals, physicians, and other health care providers, schools receive a relatively small proportion of Medicaid funds—an estimated 1 percent of total Medicaid funding as of 2014—and for that reason, they could be an easy target if state budgets were stretched thin.⁵⁰ The consequences for education budgets would be devastating if Medicaid funding were significantly reduced.⁵¹

The American Association of School Administrators recently surveyed school administrators regarding the impact that a 30 percent reduction in Medicaid funding would have on their schools. Leaders reported that reduced Medicaid funding would undermine their ability to educate children with disabilities in inclusive classrooms; force them to lay off staff; and reduce the availability of mental health services in schools.⁵² Schools in states that receive a relatively higher proportion of Medicaid funds per student with a disability—such as Idaho, Michigan, Montana, Texas, and Wisconsin⁵³—would be particularly affected by a reduction in Medicaid funds.

Conclusion

Rather than strengthening health care coverage for those who need it most, cutting federal funding for Medicaid would put some of the most vulnerable Americans at risk—all to provide tax breaks to the wealthy few.⁵⁴ Children with disabilities and their families deserve health care coverage that supports them, enabling children to grow up healthy, meet their developmental milestones, and thrive in their schools and communities. Significant cuts to Medicaid would represent a step in the wrong direction and must be opposed.

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