U.S. House of Representatives
Committee on Oversight and
Government Reform

Democratic Staff Report

The Republican Bill to Repeal the Affordable Care Act and Slash Medicaid Will Hurt Children with Severe Disabilities and Special Health Care Needs in the District of Columbia

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EXECUTIVE SUMMARY

This report has been prepared by the Democratic staff of the Committee on Oversight and Government Reform to examine the devastating effects that Republican efforts to repeal the Patient Protection and Affordable Care Act (ACA) and slash Medicaid funding would have on children with severe disabilities and special health care needs who rely on these programs to survive.

The report finds that Republican efforts to impose massive cuts to the Medicaid program would have particularly harmful and lasting effects on children with severe disabilities and other special health care needs, despite the fact that these children have done absolutely nothing to warrant such treatment.

The report provides information on the negative effects of these Republican proposals on these children both nationally and in the District of Columbia.

On May 4, 2017, Republicans in the House of Representatives passed the American Health Care Act (AHCA) to repeal the ACA, reverse its Medicaid expansion, and drastically limit future Medicaid funding. The President celebrated the passage of this bill by hosting Republican lawmakers at the White House.

After the bill was passed, the nonpartisan Congressional Budget Office (CBO) reported that the Republican House bill would slash Medicaid funding by $834 billion over ten years and leave 14 million fewer Americans with health insurance through Medicaid. The President reportedly stated that the Republican House bill was "mean" and that he wanted the Senate to pass a bill with "heart."

The Senate bill would harm Medicaid even more profoundly than the House version, by further restricting the growth rate for future federal funding. Even though the Senate bill attempts to disguise these larger cuts by delaying their implementation until later years, CBO released an analysis of the bill on June 26, 2017, showing that even more people would lose their Medicaid coverage under the Senate bill than the House bill.

When he was running for president, Donald Trump promised that he was "not going to cut" Medicaid, but that is exactly what these Republican bills would do.

Republican efforts to repeal the ACA and slash the Medicaid program threaten the ability of children with severe disabilities and special health care needs to access care at home, in school, and at medical facilities throughout the country.

More than 11 million children in the United States—15% of all children—have special health care needs. Many of these children have severe physical and developmental disabilities. Through no fault of their own, these children require intense and often lifelong care so they can live healthy and productive lives. Families of children with severe disabilities and special health care needs face daunting financial and other challenges in caring for their children.

Approximately 18,800 children in the District of Columbia have special health care needs such as cerebral palsy, Down syndrome, and autism. These children come from all backgrounds,

and families with the lowest household incomes have the highest incidence of children with special health care needs. Approximately 15.1% of families in the District of Columbia who have children with special health care needs report facing financial difficulties as a result of their children's health care needs.

Approximately 61.3% of children with special health care needs in the District of Columbia rely wholly or partially on public insurance programs such as Medicaid. Many qualify based on their parents' low household income; a small fraction qualify based solely on their disabilities.

Because children with special health care needs often require intensive long-term care and support services, on average they are about 12 times more costly to state Medicaid programs than children without such needs. In 2011, the District of Columbia spent about $22,000 for each child who qualified for Medicaid based solely on a disability.

Republicans have argued that their legislation does not "cut" Medicaid, but rather slows the rate at which its funding is currently scheduled to grow. However, their proposals do nothing to slow the growth of the costs that the Medicaid program will face during that same period, such as the skyrocketing prices of prescription drugs and the growing opioid epidemic.

Slashing future Medicaid funding while ignoring the actual increase in costs faced by states will result in fewer people being covered and more benefits being cut. Many pathways to enrollment are optional for states, as are many health and support services used by children with severe disabilities and special health care needs. These benefits could be curtailed or eliminated by states facing funding shortfalls.

Senate Republicans have tried to blunt this criticism by claiming that children with disabilities will be excluded from the per capita funding restrictions in their bill. However, it is nearly impossible to identify and protect all children with special health care needs from these funding cuts. A large number of children with special health care needs qualify for Medicaid based on their parents' household income rather than a disability. Limiting the carve-out to children who qualify based on a disability would leave the majority of children with special health care needs vulnerable to these massive cuts.

For many of these same reasons, on June 22, 2017, the Children's Hospital Association—which represents 220 children's hospitals and describe itself as "the voice of children's hospitals"—issued the following statement opposing the bill:

> **Children's hospitals are unified in calling on the Senate to reject the bill. At its core, the bill is a major step backward for children and their health. If enacted, the bill would end Medicaid as an entitlement to coverage and treatment for over 30 million children who would be subject to per capita caps and potential limits on their health care. ... Compared to the AHCA, the new Senate bill calls for even steeper cuts to the Medicaid program by restricting Medicaid's funding to a slower growth rate. ... Children's hospitals across the country call on senators to reject this bill, a bad bill for kids.**

I. CHILDREN IN THE DISTRICT OF COLUMBIA WITH SEVERE DISABILITIES AND SPECIAL HEALTH CARE NEEDS

Each year, thousands of children in the United States are born with or develop severe disabilities and special health care needs. More than 11 million children in the United States currently live with developmental disabilities such as Down syndrome and autism, physical disabilities such as muscular dystrophy and spina bifida, or other health care challenges.[1]

Through no fault of their own, these children—who comprise approximately 15% of all American children—can often need significant ongoing medical care and support services that their families simply cannot pay for by themselves.[2]

In the District of Columbia, about 18,800 children—or 16.6% of all children in the state—have severe disabilities or special health care needs.[3]

In many instances, their disabilities can be severe. For example, about 200 children in the District of Columbia have Down syndrome, about 400 have cerebral palsy, and about 600 have epilepsy or another seizure disorder.[4] Approximately 1,000 children in the District of Columbia have autism, Asperger's disorder, or another pervasive developmental disorder.[5]

District of Columbia families with children who have severe disabilities or special health care needs have household income levels across the spectrum. Those with the lowest income levels are most likely to have children with special health care needs.

Approximately 18.2% of children in the District of Columbia whose families are below 100% of the Federal Poverty Level (FPL) have special health care needs.[6]

In the District of Columbia, approximately 52.5% of children with special health care needs live in low- or middle-income families below 400% FPL.[7]

Table 1. D.C. Children with Special Health Care Needs by Household Income

	0-99% FPL	**100-199% FPL**	**200-399% FPL**	**400% FPL and above**
No. Children w/ Special Health Care Needs	6,498	3,521	3,733	5,066
No. Children w/o Special Health Care Needs	29,262	16,755	18,309	30,482
% Children with Special Health Care Needs	18.2%	17.4%	16.9%	14.3%

Percentages and population estimates are weighted to represent child population in US.

Children in the District of Columbia with severe disabilities or special health care needs come from all backgrounds: approximately 15.6% of Caucasian children, 18.1% of African American children, and 10.7% of Hispanic children have special health care needs.[8]

Table 2. D.C. Children with Special Health Care Needs by Race

	Caucasian	African American	Hispanic	Other
No. Children w/ Special Health Care Needs	3,511	12,937	1,488	882
No. Children w/o Special Health Care Needs	19,029	58,412	12,468	4,899
% Children with Special Health Care Needs	15.6%	18.1%	10.7%	15.3%

Percentages and population estimates are weighted to represent child population in US.

Many children with severe disabilities require intensive daily care. In the District of Columbia, the families of approximately 2,000 children spend 11 or more hours per week providing this care.[9] About 15.1% of families with children who have special health care needs report facing financial difficulties as a result of their children's health care needs.[10] Approximately 17.9% of families of children with special health care needs report spending $1,000 or more on out-of-pocket medical expenses for their children each year, and roughly 24.6% report having a family member cut back or stop working altogether because of a child's health condition.[11]

Many children with severe disabilities and special health care needs lack the medical and support services they need. Approximately 31.2% of District of Columbia families with these children report that their insurance is inadequate to cover their children's health care needs.[12] Approximately 25.4% report that their children have had an "unmet need for specific health services" in the past year.[13]

Many children with severe disabilities and special health care needs rely on public insurance to access health care, including Medicaid and the Children's Health Insurance Program. Approximately 49.1% of children with special health care needs living in the District of Columbia are covered by public insurance. An additional 12.2% of children rely on public coverage to supplement their parents' private insurance, which is often insufficient to meet their health care needs.[14]

Many children with severe disabilities and special health care needs face daunting educational challenges. Approximately 2,700 children in the District of Columbia have disabilities or special health care needs that make it difficult for them to attend school on a regular basis.[15] These children rely on Medicaid to provide the medical care and support services that allow them to remain in their communities and their schools.

II. THESE CHILDREN RELY ON MEDICAID AS A CRITICAL LIFELINE

The Medicaid program provides a critical lifeline to children with severe disabilities and special health care needs, as well as their families. Nearly half of these children in the United States, or 44%, rely on public health insurance, including Medicaid.[16]

Medicaid provides comprehensive and high-quality care. All state Medicaid programs are required to provide children with Early and Periodic Screening, Diagnostic, and Treatment benefits, which include preventive health care services such as dental and vision screenings and routine check-ups, and traditional health care services such as hospitalizations, doctor visits, and prescription drug coverage.[17]

Children with severe disabilities and special health care needs also receive physical and developmental care to address their particular health care needs, including speech therapy, occupational therapy, and medical equipment. Medicaid also meets children's long-term care needs through institutional care when needed, in-home nursing care, and other services.[18]

States can provide optional health care and support services through home- and community-based Medicaid waivers, which allow children to receive care in their own homes rather than in institutional settings.[19] Since these services are not required, they are at the highest risk of being curtailed or eliminated when states face financial constraints.

Under the Patient Protection and Affordable Care Act (ACA), states are required to cover all children with household incomes up to 138% FPL. In 2017, this includes families of three with annual household incomes of about $28,000.[20] In an effort to include more children, all states have raised their financial eligibility thresholds. Currently, the median state income eligibility threshold for children is 255% FPL (or about $52,000 per year for a family of three).[21] Many children with special health care needs qualify for Medicaid based solely on their families' household incomes.

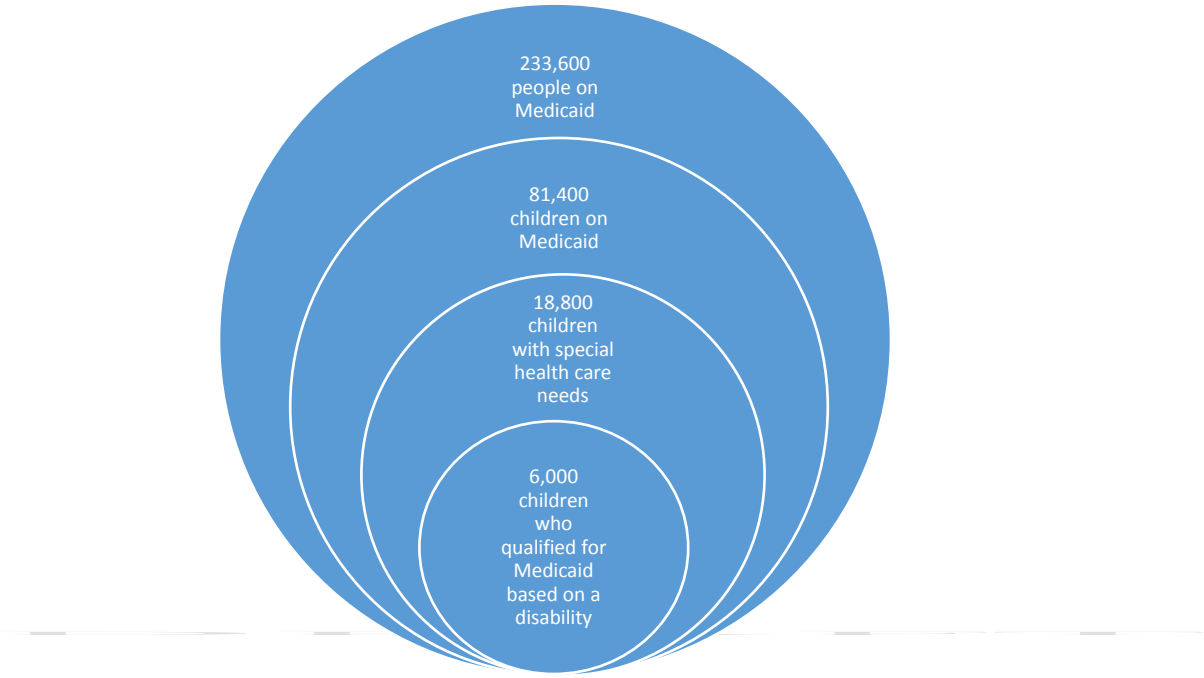
A smaller number of these children qualify for Medicaid through a mandatory disability pathway. Children who qualify for Supplemental Security Income as the result of a disability that results in "marked and severe functional limitations" automatically qualify for Medicaid coverage in most states.[22]

States may also choose to adopt additional pathways to Medicaid eligibility based on a child's disability. One pathway—known as the Katie Beckett option, which President Ronald Reagan created in 1981—allows children with severe disabilities to receive care at home rather than in an institution, without regard to their parents' incomes.[23] As a result of this enrollment pathway, children who otherwise would qualify for Medicaid only in an institutional care setting can receive care at home with their families.

A handful of states also provide a Medicaid "buy-in" option for children with special health care needs whose families have household incomes up to 300% FPL (approximately $61,260 per year for a family of three).[24] Although most are covered by their parents' private insurance plans, they rely on supplemental Medicaid coverage to provide medical services that are not covered by commercial plans.[25]

Children who qualify for Medicaid based on disabilities make up only a small portion of children with special health care needs who rely on Medicaid. Many more children with special health care needs qualify based on their household family income, by virtue of being involved in the foster care system, or by other means.

Figure 1. D.C. Medicaid Enrollment and Special Health Care Needs[26]



According to the Kaiser Family Foundation, only about 6,000 of the approximately 18,800 children with special health care needs in the District of Columbia qualified for Medicaid on the basis of a disability in 2011.[27]

Children with special health care needs are disproportionately more costly to Medicaid than other enrollees because they have more intensive health care needs than the general population. For instance, children with severe disabilities often require long-term care services. In 2011, Medicaid spent about 12 times more nationally on children who received long-term care services than those who did not.[28] Children with disabilities comprised only 2% of Medicaid enrollees in 2011, but they accounted for 7% of Medicaid spending.[29]

The District of Columbia spent about $22,000 for each child enrolled in Medicaid on the basis of a disability in 2011—and a total of roughly $40 million on this same population in 2013.[30] In contrast, in 2014, the District of Columbia spent about $4,400 for each child enrolled in Medicaid through a non-disability pathway.[31]

III. NEGATIVE EFFECTS OF REPUBLICAN BILLS TO REPEAL THE ACA

Republican efforts to repeal the ACA and slash the Medicaid program threaten the ability of children with severe disabilities and special health care needs to access care at home, in school, and at medical facilities throughout the country.

The nonpartisan Congressional Budget Office (CBO) has reported that the Republican ACA repeal bill adopted by the House would slash federal Medicaid funding by $834 billion over ten years and leave 14 million fewer Americans with health insurance through Medicaid.[32]

CBO estimates that the Senate Republican bill would slash federal Medicaid funding by $772 billion over ten years and leave 15 million fewer American with health insurance through Medicaid. According to CBO, the Senate bill would also lead to even more drastic funding cuts in years after 2026, as Medicaid costs are expected to grow at a faster rate than the per capita caps imposed by the Senate bill beginning in 2025. CBO predicts that the difference in Medicaid costs and the Senate bill's funding caps will be "substantial."[33]

Both versions of the Republican ACA repeal legislation would:

- eliminate Medicaid's joint federal-state financing structure and replace it with a lump sum payment to states in the form of block grants or fixed amounts per Medicaid enrollee;
- drastically restrict the growth rate for future federal funding while ignoring the skyrocketing costs of prescription drugs and other medical costs that drive up Medicaid spending over time;
- phase out the ACA's Medicaid coverage expansion;
- lead to funding shortfalls that will likely pressure states to cut or eliminate optional Medicaid benefits such as home- and community-based services, home nursing care for children, and Medicaid buy-in programs; and
- lead to funding shortfalls that will likely pressure states to reduce reimbursement rates for providers, hospitals, long-term care facilities, and schools that care for children with special health care needs.[34]

In addition, President Trump has proposed further Medicaid cuts in his Fiscal Year 2018 budget. Despite his campaign promises to preserve funding for the Medicaid program, the President's budget proposal would cut an additional $610 billion from the Medicaid program over ten years.[35]

Converting Medicaid into Block Grants or Imposing Per Capita Caps

Since its creation in 1965, Medicaid has been funded jointly through a financing structure in which the federal government matches state spending to meet program needs.[36] Matching rates differ across the country, and the average federal match percentage in May 2017 was

64%.[37] The Republican bills would provide states with a lump sum of funding in the form of a block grant or a fixed amount of funding per enrollee. Both approaches are designed to decrease future federal funding for Medicaid, but neither would address the underlying drivers of Medicaid costs, such as rising prescription drug prices and public health emergencies like the growing opioid epidemic.[38]

Limiting Future Funding By Decreasing Medicaid Funding Growth Rate

The Republican bills would decrease future Medicaid funding by imposing artificially low growth rates for future federal Medicaid funding. CBO estimates that per-enrollee Medicaid spending will increase more rapidly than the House and Senate bills' growth rates.[39] As a result, state Medicaid programs will not be able to keep pace with actual increases in medical costs, leaving states to limit benefits, cut payments to providers, or cap enrollment.[40] The Senate bill adopts an even lower growth rate than the House bill—an inflation rate used for basic consumer goods and services—although the bill attempts to disguise it by delaying its implementation to later years. States that already have higher per capita Medicaid costs as the result of offering more benefits or caring for a sicker Medicaid population will be particularly harmed by these lower growth rates.[41]

Reducing Funding for Medicaid Expansion States

The Republican bills would effectively end the ACA's Medicaid expansion, which provided enhanced federal funding for newly eligible Medicaid beneficiaries with incomes up to 138% FPL. Under the ACA's Medicaid expansion, the federal government matched 100% of state spending through 2016. This rate was set to decrease gradually over time.[42]

Under the Republican bills, the federal government would phase out the enhanced matching funds adopted for new expansion enrollees, reverting to the much lower standard federal matching rate.

Seven states that expanded Medicaid under the ACA have laws that effectively require expansion coverage to be rolled back in the event of reduced federal funding, making the end of coverage for some newly eligible Medicaid enrollees virtually inevitable.[43] Approximately 14 million people in 31 states and the District of Columbia who gained coverage as the result of Medicaid expansion stand to lose their health insurance if the ACA is repealed.[44]

Phasing out the Medicaid expansion would be particularly harmful for older children with special health care needs who do not qualify for federal disability payments. These children could face coverage gaps when they turn 19 and are no longer covered by Medicaid, as insurance companies could once again be permitted to charge unaffordable premium rates based on their pre-existing medical conditions.

As of March 2016, approximately 62,600 D.C. Residents had gained coverage as a result of the ACA's expansion.[45] In Fiscal Year 2017, the ACA's enhanced match rate for the District of Columbia was 100%.[46]

Threatening Optional Benefits Such as Home- And Community-Based Services

Most children with disabilities and special health care needs who require nursing and other long-term care receive that care in their homes through home- and community-based services covered by Medicaid. Total Medicaid spending on home- and community based services for individuals of all ages totaled $80.6 billion in 2014—53% of total program spending on long-term care.[47] These benefits are purely optional for states to provide, although most currently do.[48] However, the Republican bills to repeal the ACA and cut Medicaid would create such significant funding shortfalls that states may be forced to cut optional Medicaid benefits, including home- and community-based services.[49]

The Republican bills would have devastating consequences for children with severe disabilities, as many families that otherwise lack the means to care for their children at home may be forced to send their children to live in institutional settings if these optional benefits are eliminated.[50]

In 2013, approximately 12,400 D.C. Residents—including children—received home- and community-based services through Medicaid.[51]

Threatening "Buy-In" Coverage for Children

States also may be forced to do away with an optional Medicaid benefit that allows families to "buy-in" to Medicaid coverage for their children with severe disabilities and special health care needs. Medicaid generally provides a wider range of health services than private insurance, with lower out-of-pocket costs. Buy-in programs allow children with disabilities to purchase Medicaid coverage that "wraps around" or supplements private insurance.[52]

Approximately 8.2% of children with special health care needs rely on a combination private insurance and public insurance like Medicaid, to obtain the medical care they need.[53] For many low-income families, the ability to purchase wrap-around Medicaid coverage allows them to keep their jobs and stay financially stable while providing health care to their disabled child. However, since these buy-in programs are optional, they could be among the first Medicaid benefits to be limited or cut as a result of funding shortfalls, leaving many of these children underinsured.

Threatening Funding for Children's Hospitals

More than half of inpatient care provided by children's hospitals is provided to Medicaid patients, and children on Medicaid with medically complex conditions rely on children's hospitals for about 53% of their hospital stays.[54] Currently, reimbursements from Medicaid cover about 80% of the cost of care provided to these children.[55] Under the Republican bills, states facing budget shortfalls would likely be forced to reduce payments to providers, potentially forcing some facilities to stop accepting Medicaid patients to remain financially sound.[56]

Threatening Funding for Long-Term Care Facilities

Medicaid funding cuts also could strain long-term care facilities that serve the small population of children with the most severe disabilities who require institutional care.

Long-term care facilities are not fully reimbursed for the care they provide to Medicaid patients. In 2015, the average reimbursement rate for these facilities was 89%. The American Health Care Association notes that given the already "razor-thin" profit margins maintained by long-term care facilities, any further decrease in reimbursement rates or total funding could force providers to stop accepting Medicaid patients, creating major access problems for patients like children with severe special health care needs who need advanced institutional care the most.[57]

Threatening Funding for Schools

Medicaid cuts also could harm children with severe disabilities and special health care needs by forcing reductions in Medicaid funding provided to schools. Schools are required to provide children who have disabilities with health and support services they need to pursue their education.[58] Schools rely on Medicaid funding to help provide these services.[59] Without adequate funding, schools would face additional challenges in providing a quality education to children with special health care needs.

V. INADEQUATE CARVE-OUT FOR CHILDREN WITH SEVERE DISABILITIES AND SPECIAL HEALTH CARE NEEDS

Although Republicans have recently begun suggesting that children with special health care needs could be protected from drastic Medicaid cuts, this "carve-out" approach is completely inadequate.

For example, Senate Republicans have tried to blunt this criticism in their bill by excluding "blind and disabled" children from per capita cap restrictions.[60] However, the bill fails to define who is included in that category, instead leaving it up to future rulemaking and state interpretation. A narrow definition from the Trump Administration or onerous documentation requirements could severely impact many children in need.

The population of children with special health care needs is also much broader than those with disabilities as defined by Medicaid. Many children with special health care needs qualify for Medicaid solely on the basis of their families' household incomes. Preserving existing federal funding only for children who qualify for Medicaid through the mandatory disability-related enrollment pathway would drastically undercount children with special health care needs.

For example, although 44% of the 11.2 million children with special health care needs in the United States were enrolled in Medicaid and other public insurance programs in 2011, only 1.6 million of these children were enrolled through a disability-related pathway.[61]

In addition, capping federal funding for one group of Medicaid enrollees likely would affect benefits for all other enrollees—including children with special health care needs—even if these children are not explicitly targeted by funding caps. Finally, phasing out the ACA's

Medicaid expansion all but guarantees that many of these children will face health insurance coverage gaps as they age.[62]

CONCLUSION

For more than fifty years, the Medicaid program has provided essential health care coverage to millions of Americans—including children with severe disabilities and special health care needs. Republican plans to repeal the ACA and impose drastic cuts of more than $1 trillion to the Medicaid program have the potential to disproportionately harm children with severe disabilities and special health care needs at all points of care, including in their homes, in their schools, and at medical facilities.

Any Republican effort to repeal the ACA that proposes to cut Medicaid funding would be especially harmful for the tens of thousands of children with severe disabilities and special health care needs in the District of Columbia who rely on Medicaid to provide them with the critical health care and support services they need to live full and healthy lives.

Republican funding cuts would force states to consider limiting or eliminating many optional Medicaid benefits, including home- and community-based care options and buy-in programs, that allow children with special health care needs—and particularly those with the most severe disabilities—to live comfortably and safely with their families. Medicaid cuts also could inhibit these children from obtaining care at children's hospitals, long-term care facilities, and schools.

ENDNOTES

[1] Kaiser Family Foundation, *Medicaid's Role for Children with Special Health Care Needs* (May 2017) (online at http://files.kff.org/attachment/Infographic-Medicaids-Role-for-Children-with-Special-Health-Care-Needs).

[2] Kaiser Family Foundation, *Medicaid Restructuring Under the American Health Care Act and Children with Special Health Care Needs* (June 22, 2017) (online at www.kff.org/medicaid/issue-brief/medicaid-and-children-with-special-health-care-needs/).

[3] National Survey of Children with Special Health Care Needs, *Demographics and CSHCN Prevalence for All Children ages 0-17* (2009-2010) (online at http://childhealthdata.org/browse/survey/results?q=1792&r=22) (accessed June 16, 2017).

[4] National Survey of Children with Special Health Care Needs, *CSHCN Prevalence and Demographics, Prevalence of Down Syndrome* (2009-2010) (online at http://childhealthdata.org/browse/survey/results?q=2070&r=22) (accessed June 16, 2017); *CSHCN Prevalence and Demographics, Prevalence of Cerebral Palsy* (2009-2010) (online at http://childhealthdata.org/browse/survey/results?q=2065&r=22) (accessed June 16, 2017); *CSHCN Prevalence and Demographics, Prevalence of Epilepsy or Seizure Disorder* (2009-2010) (online at http://childhealthdata.org/browse/survey/results?q=2076&r=22) (accessed June 16, 2017).

[5] National Survey of Children with Special Health Care Needs, *CSHCN Prevalence and Demographics, Prevalence of Autism or Other Autism Spectrum Disorder, Age 2-17 Years* (2009-2010) (online at http://childhealthdata.org/browse/survey/results?q=2060&r=22) (accessed June 16, 2017).

[6] National Survey of Children with Special Health Care Needs, *Demographics and CSHCN Prevalence for All Children ages 0-17, Household Income* (2009-2010) (online at http://childhealthdata.org/browse/survey/results?q=1792&r=22&g=380) (accessed June 16, 2017).

[7] National Survey of Children with Special Health Care Needs, *Demographics and Types of Needs for CSHCN Population Only, Household Income* (2009-2010) (online at http://childhealthdata.org/browse/survey/results?q=2013&r=22) (accessed June 16, 2017).

[8] National Survey of Children with Special Health Care Needs, *Demographics and CSHCN Prevalence for All Children ages 0-17, Race/Ethnicity* (2009-2010) (online at http://childhealthdata.org/browse/survey/results?q=1792&r=22&g=378) (accessed June 16, 2017).

[9] National Survey of Children with Special Health Care Needs, *MCHB Core Outcomes and Key Indicators, CSHCN Whose Families Spend 11 or More Hours a Week Providing Care* (2009-2010) (online at http://childhealthdata.org/browse/survey/results?q=1633&r=22) (accessed June 16, 2017).

[10] National Survey of Children with Special Health Care Needs, *MCHB Core Outcomes and Key Indicators, CSHCN Whose Conditions Cause Financial Problems for Family* (2009-2010) (online at http://childhealthdata.org/browse/survey/results?q=1632&r=22) (accessed June 16, 2017).

[11] National Survey of Children with Special Health Care Needs, *MCHB Core Outcomes and Key Indicators, CSHCN Whose Families Pay $1,000 or More Out-of-Pocket* (2009-2010) (online at http://childhealthdata.org/browse/survey/results?q=1631&r=22) (accessed June 16, 2017); *MCHB Core Outcomes and Key Indicators, CSHCN Whose Conditions Cause Family Members to Cut Back or Stop Working* (2009-2010) (online at http://childhealthdata.org/browse/survey/results?q=1634&r=22) (accessed June 16, 2017).

[12] National Survey of Children with Special Health Care Needs, *MCHB Core Outcomes and Key Indicators, Currently Insured CSHCN Whose Insurance is Inadequate* (2009-2010) (online at http://childhealthdata.org/browse/survey/results?q=1630&r=22) (accessed June 16, 2017).

[13] National Survey of Children with Special Health Care Needs, *MCHB Core Outcomes and Key Indicators, CSHCN With Any Unmet Need for Specific Health Care Services* (2009-2010) (online at http://childhealthdata.org/browse/survey/results?q=1624&r=22) (accessed June 16, 2017).

[14] National Survey of Children with Special Health Care Needs, *Health Insurance Coverage and Program Participation* (2009-2010) (online at http://childhealthdata.org/browse/survey/results?q=1810&r=22) (accessed June 16, 2017).

[15] National Survey of Children with Special Health Care Needs, *MCHB Core Outcomes and Key Indicators, Medical/Behavioral Conditions Interfere with Ability to Attend School, Age 5-17 Years* (2009-2010) (online at http://childhealthdata.org/browse/survey/results?q=1887&r=22) (accessed June 16, 2017).

[16] Kaiser Family Foundation, *Medicaid's Role for Children with Special Health Care Needs* (May 2017).

[17] Center on Budget and Policy Priorities, *House ACA Repeal Bill Puts Children with Disabilities and Special Health Care Needs at Severe Risk* (June 14, 2017) (online at www.cbpp.org/sites/default/files/atoms/files/6-14-17health2.pdf).

[18] Kaiser Family Foundation, *Medicaid Restructuring Under the American Health Care Act and Children with Special Health Care Needs* (June 22, 2017).

[19] Center on Budget and Policy Priorities, *Medicaid Cuts in House ACA Repeal Bill Would Limit Availability of Home- and Community- Based Services,* (May 18, 2017) (online at www.cbpp.org/research/health/medicaid-cuts-in-house-aca-repeal-bill-would-limit-availability-of-home-and).

[20] Kaiser Family Foundation, *Medicaid Restructuring Under the American Health Care Act and Children with Special Health Care Needs* (June 22, 2017); Office of the Assistant Secretary for Planning and Evaluation, Department of Health and Human Services, *U.S. Federal Poverty Guidelines Used to Determine Financial Eligibility for Certain Federal Programs* (Jan. 26, 2017) (online at https://aspe.hhs.gov/poverty-guidelines).

[21] Office of the Assistant Secretary for Planning and Evaluation, Department of Health and Human Services, *U.S. Federal Poverty Guidelines Used to Determine Financial Eligibility for Certain Federal Programs* (Jan. 26, 2017).

[22] Social Security Administration, *Understanding Supplemental Security Income SSI for Children—2017 Edition* (online at www.ssa.gov/ssi/text-child-ussi.htm) (accessed June 19, 2017).

[23] Kaiser Family Foundation, *Medicaid Restructuring Under the American Health Care Act and Children with Special Health Care Needs* (June 22, 2017).

[24] *Id.*

[25] *Id*.

[26] Kaiser Family Foundation, *Medicaid Expansion Enrollment By Age, Timeframe: FY 2011* (online at www.kff.org/medicaid/state-indicator/medicaid-enrollment-by-age/?dataView=1&currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D) (accessed June 26, 2017); National Survey of Children with Special Health Care Needs, *Demographics and CSHCN Prevalence for All Children ages 0-17* (2009-2010) (online at http://childhealthdata.org/browse/survey/results?q=1792&r=22) (accessed June 16, 2017); Kaiser Family Foundation, *Medicaid Enrollment of Children Qualifying Through a Disability Pathway, 2011* (online at www.kff.org/medicaid/state-indicator/medicaid-enrollment-of-children-qualifying-through-a-disability-pathway/?currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D) (accessed June 20, 2017).

[27] Kaiser Family Foundation, *Medicaid Enrollment of Children Qualifying Through a Disability Pathway, 2011* (online at www.kff.org/medicaid/state-indicator/medicaid-enrollment-of-children-qualifying-through-a-disability-pathway/?currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D) (accessed June 20, 2017).

[28] Kaiser Family Foundation, *Medicaid's Role for Children with Special Health Care Needs* (May 2017).

[29] Kaiser Family Foundation, *State Variation in Medicaid Per Enrollee Spending for Seniors and People with Disabilities* (May 2017) (online at http://files.kff.org/attachment/Issue-Brief-State-Variation-in-Medicaid-Per-Enrollee-Spending-for-Seniors-and-People-with-Disabilities).

[30] *Id.*; Medicaid and CHIP Payment and Access Commission, *Enrollment and Total Spending for Children under 21 years who qualify on the Basis of Disability, by State and Eligibility Pathway, FY 2013* (June 22, 2017).

[31] Kaiser Family Foundation, *Medicaid Spending per Enrollee (Full or Partial Benefit)* (online at www.kff.org/medicaid/state-indicator/medicaid-spending-per-

enrollee/?currentTimeframe=0&selectedDistributions=children&sortModel=%7B"colId":"Location","sort":"asc"%7D) (accessed June 19, 2017).

[32] Congressional Budget Office, *Cost Estimate: H.R. 1628, American Health Care Act of 2017, As Passed by the House of Representatives on May 4, 2017* (May 24, 2017) (online at www.cbo.gov/system/files/115th-congress-2017-2018/costestimate/hr1628aspassed.pdf).

[33] Congressional Budget Office, *Cost Estimate: H.R. 1628, Better Care Reconciliation Act of 2017* (June 26, 2017) (online at www.cbo.gov/system/files/115th-congress-2017-2018/costestimate/52849-hr1628senate.pdf).

[34] American Health Care Act of 2017 (115th Cong.); Better Care Reconciliation Act of 2017 (115th Cong.).

[35] Department of Health and Human Services, *Putting America's Health First: FY 2018 President's Budget for HHS* (May 23, 2017) (online atwww.hhs.gov/sites/default/files/Consolidated%20BIB_ONLINE_remediated.pdf).

[36] Kaiser Family Foundation, *Medicaid Financing: How Does it Work and What are the Implications?* (May 20, 2015) (online at www.kff.org/medicaid/issue-brief/medicaid-financing-how-does-it-work-and-what-are-the-implications/).

[37] Center on Budget and Policy Priorities, *House Health Care Bill Ends Medicaid As We Know It* (May 25, 2017) (online at www.cbpp.org/research/health/house-health-care-bill-ends-medicaid-as-we-know-it).

[38] Congressional Budget Office, *Cost Estimate: H.R. 1628, American Health Care Act of 2017, As Passed by the House of Representatives on May 4, 2017* (May 24, 2017).

[39] Congressional Budget Office, *Cost Estimate: American Health Care Act, Budget Reconciliation Recommendations of the House Committees* (Mar. 13, 2017) (online at www.cbo.gov/system/files/115th-congress-2017-2018/costestimate/americanhealthcareact.pdf).

[40] Center on Budget and Policy Priorities, *House Health Care Bill Ends Medicaid As We Know It* (May 25, 2017).

[41] Center on Budget and Policy Priorities, *Medicaid Per Capita Cap Would Disproportionately Harm Some States* (June 15, 2017) (online at www.cbpp.org/research/health/medicaid-per-capita-cap-would-disproportionately-harm-some-states).

[42] Kaiser Family Foundation, *Understanding How States Access the ACA Enhanced Medicaid Match Rates* (Sept. 29, 2014) (online at www.kff.org/medicaid/issue-brief/understanding-how-states-access-the-aca-enhanced-medicaid-match-rates/).

[43] Center on Budget and Policy Priorities, *House Health Care Bill Ends Medicaid As We Know It* (May 25, 2017).

[44] Kaiser Family Foundation, *Medicaid Expansion Enrollment* (Mar. 2016) (online at www.kff.org/health-reform/state-indicator/medicaid-expansion-enrollment/?currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D) (accessed June 26, 2017).

[45] *Id.*

[46] Office of the Assistant Secretary for Planning and Evaluation, Department of Health and Human Services, *FY 2017 Federal Medical Assistance Percentages* (Dec. 29, 2015) (online at https://aspe.hhs.gov/basic-report/fy2017-federal-medical-assistance-percentages).

[47] Centers for Medicare and Medicaid Services, *Medicaid.gov: Home and Community Based Services* (online at www.medicaid.gov/medicaid/hcbs/index.html) (accessed June 24, 2017).

[48] *Id*.

[49] Center on Budget and Policy Priorities, *Medicaid Cuts in House ACA Repeal Bill Would Limit Availability of Home- and Community- Based Services,* (May 18, 2017) (online at www.cbpp.org/research/health/medicaid-cuts-in-house-aca-repeal-bill-would-limit-availability-of-home-and).

[50] Georgetown Center for Children and Families, *Say Ahhh! Medicaid Per Capita Cap Threatens Children with Disabilities* (May 15, 2017) (online at https://ccf.georgetown.edu/2017/05/15/medicaid-per-capita-cap-threatens-children-with-disabilities/).

[51] Center on Budget and Policy Priorities, *Medicaid Cuts in House ACA Repeal Bill Would Limit Availability of Home- and Community- Based Services* (May 18, 2017).

[52] Catalyst Center, *Frequently Asked Questions About the Family Opportunity Act's Medicaid Buy-In Option* (Feb. 2007) (online at http://cahpp.org/wp-content/uploads/2015/04/FAQ-about-FOA-Medicaid-Buy-In12.pdf).

[53] National Survey of Children with Special Health Care Needs, *Health Insurance Coverage and Program Participation* (2009-2010) (online at http://childhealthdata.org/browse/survey/results?q=1810&r=1) (accessed June 19, 2017).

[54] American Academy of Pediatrics and the Children's Hospital Association, *Medicaid Facts: District of Columbia* (Jan. 2017) (online at https://www.aap.org/en-us/Documents/federaladvocacy_medicaidfactsheet_dc.pdf).

[55] *Id.*

[56] *Id*.

[57] National Center for Assisted Living, American Health Care Association, *Medicaid: Funding Long Term Services and Supports for America's Frail, Aged Populations* (Feb. 2017) (online at www.ahcancal.org/advocacy/Documents/Medicaid%20Briefing.pdf).

[58] Center on Budget and Policy Priorities, *House Health Care Bill Ends Medicaid As We Know It* (May 25, 2017).

[59] *Id.*

[60] Better Care Reconciliation Act of 2017 (115th Cong.).

[61] Kaiser Family Foundation, *Restructuring Medicaid in the American Health Care Act: Five Key Considerations* (Mar. 15, 2017); Kaiser Family Foundation, *Medicaid Enrollment of Children Qualifying Through a Disability Pathway, 2011* (online at www.kff.org/medicaid/state-indicator/medicaid-enrollment-of-children-qualifying-through-a-disability-pathway/?currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D) (accessed June 20, 2017).

[62] Center on Budget and Policy Priorities, *Medicaid Cuts in House ACA Repeal Bill Would Limit Availability of Home- and Community- Based Services*, (May 18, 2017).

Appendix A: Children with Special Health Care Needs, and Medicaid Spending, by State

State	Number of Children With Special Health Care Needs[1]	Percent of Children With Special Health Care Needs Living Below 400% FPL[2]	Percent of Children With Special Health Care Needs Covered By Public Insurance[3]	Percent of Children With Special Health Care Needs Covered By A Combination of Public and Private Insurance[4]	Percent of Children with Special Health Care Needs Whose Families Face Financial Difficulty in Providing Care[5]	Percent of Children With Special Health Care Needs Whose Families Spent More Than $1,000 Out-Of-Pocket In A Year[6]	Children Under 18 Qualifying for Medicaid Through a Disability Pathway (FY 2011)[7]	Medicaid Per Enrollee Spending for Children with Disabilities (FY 2011)[8]	Medicaid Per Enrollee Spending for Children without Disabilities (FY 2014)[9]	Total Medicaid Spending for Children who Qualify for Medicaid Through the SSI Disability Pathway (FY 2013)[10]
Alabama	200,367	54.8%	46.4%	6.0%	19.0%	15.2%	36,659	$11,020	$2,085	$142,304,798
Alaska	19,916	31.5%	26.3%	14.5%	23.6%	26.6%	2,490	$32,734	$5,135	$28,544,478
Arizona	241,067	40.8%	35.9%	9.6%	24.3%	24.8%	28,233	$32,303	$2,949	$161,656,995
Arkansas	139,580	61.7%	57.7%	9.4%	21.2%	16.9%	36,357	$14,317	$3,334	$168,553,497
California	997,157	29.5%	28.1%	8.3%	24.2%	21.8%	150,903	$24,909	$2,368	$2,148,902,656
Colorado	167,524	39.2%	25.2%	5.7%	29.2%	30.3%	16,583	$17,834	$2,033	$130,044,188
Connecticut	139,453	53.5%	27.7%	6.9%	18.8%	24.6%	159	$17,273	$3,380	$3,005,880
Delaware	36,143	51.6%	36.4%	7.0%	19.0%	22.5%	5,562	$20,091	$3,799	$34,568,303
District of Columbia	18,819	52.5%	49.1%	12.2%	15.1%	17.9%	5,966	$21,952	$4,442	$40,152,329
Florida	606,215	46.6%	42.6%	4.9%	26.0%	24.3%	112,436	$13,373	$1,822	$598,891,104
Georgia	411,526	47.9%	38.3%	6.1%	22.4%	19.4%	57,791	$7,829	$2,827	$204,230,193
Hawaii	35,022	36.4%	23.5%	4.2%	14.0%	15.5%	2,533	$21,472	$2,577	$19,093,031
Idaho	53,280	38.7%	38.4%	10.7%	22.2%	23.6%	7,894	$23,073	$2,226	N/A
Illinois	452,574	43.7%	37.8%	8.1%	20.6%	22.6%	17,658	$12,534	$2,108	$83,981,365
Indiana	268,717	51.7%	34.7%	9.1%	25.0%	23.5%	17,676	$14,827	$2,145	$72,102,804
Iowa	105,815	50.4%	34.6%	9.5%	20.6%	24.3%	12,980	$21,263	$2,208	$49,417,693
Kansas	120,822	52.4%	25.1%	6.2%	26.3%	29.0%	13,364	$14,282	$2,662	$70,957,627
Kentucky	197,916	61.0%	47.6%	7.0%	20.9%	16.8%	38,217	$12,442	$3,129	$141,372,264
Louisiana	207,840	59.0%	50.0%	8.0%	23.4%	21.0%	44,856	$11,264	$1,933	N/A
Maine	53,122	67.4%	49.6%	10.0%	18.6%	17.4%	6,713	$22,424	$3,161	$49,323,253
Maryland	211,442	49.9%	27.1%	5.0%	18.3%	22.3%	21,081	$20,678	$3,080	$220,483,487
Massachusetts	261,475	57.9%	24.4%	11.2%	19.1%	25.7%	85,954	$10,351	$3,322	$277,869,625
Michigan	430,222	56.2%	40.6%	7.5%	18.2%	19.0%	51,545	$16,994	$2,381	$327,957,659
Minnesota	179,162	45.8%	26.7%	7.2%	23.1%	30.1%	20,608	$25,425	$3,538	$186,418,071
Mississippi	124,905	50.6%	54.0%	8.6%	21.0%	14.6%	30,553	$11,963	$2,580	$108,447,361
Missouri	252,734	54.8%	39.5%	4.7%	19.7%	20.7%	6,462	$20,759	$3,186	$48,596,240
Montana	30,571	43.8%	38.0%	5.3%	29.8%	31.3%	2,948	$21,203	$3,140	$18,845,590
Nebraska	61,071	41.8%	28.7%	6.0%	22.5%	27.2%	4,292	$17,451	$2,163	$39,816,649
Nevada	82,108	36.1%	28.8%	5.1%	25.4%	26.5%	8,961	$12,391	$1,523	$56,171,160
New Hampshire	54,569	65.5%	31.6%	6.9%	19.6%	23.6%	174	$53,557	$2,984	$3,527
New Jersey	294,346	43.0%	23.6%	4.9%	20.3%	29.8%	28,602	$18,759	$2,518	$322,282,445
New Mexico	70,725	41.2%	44.6%	12.3%	23.2%	18.0%	10,819	$21,966	$5,136	$75,518,044
New York	660,565	44.8%	34.7%	9.4%	17.6%	18.0%	120,966	$20,082	$2,627	$1,101,688,196
North Carolina	389,439	52.7%	44.6%	5.4%	22.5%	19.1%	52,614	$17,971	$2,357	$326,090,714
North Dakota	19,748	47.0%	22.3%	12.5%	22.2%	26.7%	1,024	$18,360	$4,370	$12,383,003
Ohio	483,467	58.8%	36.8%	12.2%	18.3%	20.2%	37,845	$15,499	$2,589	$226,938,605
Oklahoma	161,799	52.9%	44.2%	8.0%	22.2%	21.9%	18,250	$14,460	$2,733	$70,307,479
Oregon	119,187	40.2%	31.3%	6.4%	22.7%	24.7%	11,011	$18,737	$2,737	$86,991,422

Appendix A: Children with Special Health Care Needs, and Medicaid Spending, by State

Pennsylvania	469,906	53.4%	35.7%	18.9%	16.5%	16.9%	155,546	$16,634	$2,889	$732,952,390
Rhode Island	39,170	56.9%	34.6%	12.3%	14.7%	16.8%	6,848	$30,043	$3,357	N/A
South Carolina	177,157	50.6%	42.8%	8.6%	22.4%	20.7%	28,449	$13,366	$1,945	$80,637,844
South Dakota	24,415	41.7%	39.6%	11.4%	27.3%	25.9%	3,344	$16,689	$2,336	$18,668,575
Tennessee	255,692	52.5%	42.8%	10.0%	20.1%	21.9%	32,285	$6,945	$3,143	$61,096,687
Texas	919,876	39.0%	36.6%	6.1%	24.2%	23.9%	144,717	$18,261	$2,966	$1,128,992,361
Utah	112,278	38.7%	14.4%	6.8%	28.3%	34.3%	5,847	$21,683	$2,482	$29,120,820
Vermont	21,790	63.4%	48.8%	11.3%	17.3%	20.1%	2,870	$42,030	$4,611	N/A
Virginia	296,668	53.2%	25.0%	5.6%	19.5%	23.2%	24,512	$15,418	$2,843	$182,427,670
Washington	235,920	45.1%	31.5%	8.9%	21.3%	25.5%	21,671	$17,152	$1,969	$216,182,239
West Virginia	70,609	59.6%	48.3%	9.6%	22.0%	16.8%	11,061	$14,045	$2,675	$35,670,565
Wisconsin	201,529	48.1%	30.9%	12.4%	18.4%	24.4%	30,457	$9,950	$1,762	$135,281,607
Wyoming	18,194	46.6%	36.8%	7.9%	23.3%	31.0%	1,750	$18,684	$2,281	$9,996,096

1 National Survey of Children with Special Health Care Needs, http://childhealthdata.org/browse/survey/results?q=1792&r=22

2 National Survey of Children with Special Health Care Needs, http://childhealthdata.org/browse/survey/results?q=2013&r=22

3 National Survey of Children with Special Health Care needs, http://childhealthdata.org/browse/survey/results?q=1810&r=22

4 National Survey of Children with Special Health Care Needs, http://childhealthdata.org/browse/survey/results?q=1810&r=22

5 National Survey of Children with Special Health Care Needs, http://childhealthdata.org/browse/survey/results?q=1632&r=22

6 National Survey of Children with Special Health Care Needs, http://childhealthdata.org/browse/survey/results?q=1631&r=22

7 Kaiser Family Foundation, www.kff.org/medicaid/state-indicator/medicaid-enrollment-of-children-qualifying-through-a-disability-pathway/?currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D

8 Kasier Familiy Foundation, http://files.kff.org/attachment/Issue-Brief-State-Variation-in-Medicaid-Per-Enrollee-Spending-for-Seniors-and-People-with-Disabilities

9 Kasier Familiy Foundation, http://files.kff.org/attachment/Issue-Brief-State-Variation-in-Medicaid-Per-Enrollee-Spending-for-Seniors-and-People-with-Disabilities

10 Medicaid and CHIP Payment Access Commission, Enrollment and Non-Federal Spending for Children under 21 years who qualify on the Basis of Disability, by State and Eligibility Pathway, FY 2013