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Medicaid's Role for Children with Special Health Care Needs: A Look at Eligibility, Services, and Spending

MaryBeth Musumeci and Julia Foutz

Key Findings

Medicaid and CHIP covered about half (48%) of all children with special health care needs in 2016. This issue brief describes the role that Medicaid plays for children with special health care needs and includes 50-state data on children with special health care needs covered by Medicaid/CHIP. Key findings include the following:

- Less than one in five (19%) children with disabilities receives Medicaid because they also receive federal Supplemental Security Income (SSI) benefits. Other Medicaid coverage pathways for children with disabilities are offered at state option. Reflecting different state policy choices, the share of children with special health care needs covered by Medicaid/CHIP varies by state from 23% to 67%.
- Medicaid's benefit package for children, Early and Periodic Screening Diagnostic and Treatment, covers physical and behavioral health services as well as long-term care services that enable children with chronic needs to live at home with their families. Medicaid supplements special education services and fills in coverage gaps for privately insured children with special health care needs.
- Annual per enrollee spending is over seven times higher for Medicaid children who qualify through a disability pathway (\$17,831) compared to those who qualify through another pathway, such as family income (\$2,484) as of 2013. This reflects the greater intensity and variety of needs among most children who qualify based on a disability compared to most children who qualify through another pathway.

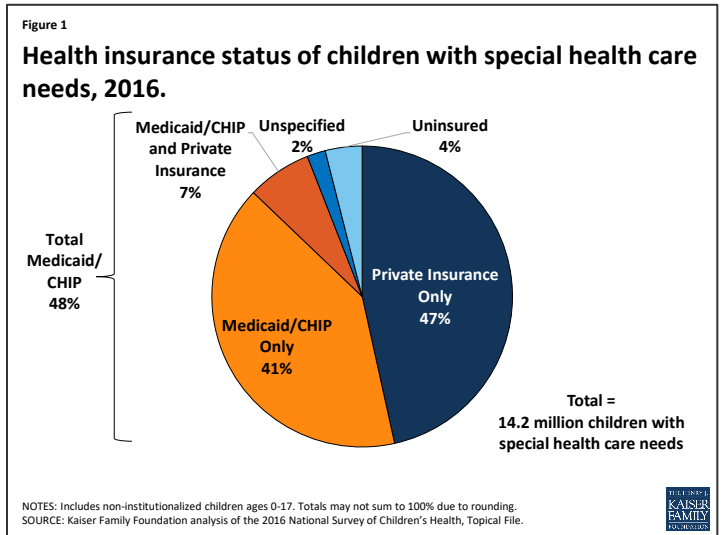
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Introduction

An estimated 14.2 million children, or 19% of all children in the U.S., have special health care needs.¹ According to the U.S. Department of Health and Social Services, these children "have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions and also require health and related services of a type or amount beyond that required by children generally."² Their needs result from a range of conditions, such as Down syndrome, cerebral palsy, and autism. They may require services such as nursing care to live safely at home, therapies to address developmental delays, and mental health counseling.

Medicaid and CHIP covered about half (48%) of children with special health care needs in 2016 (Figure 1).

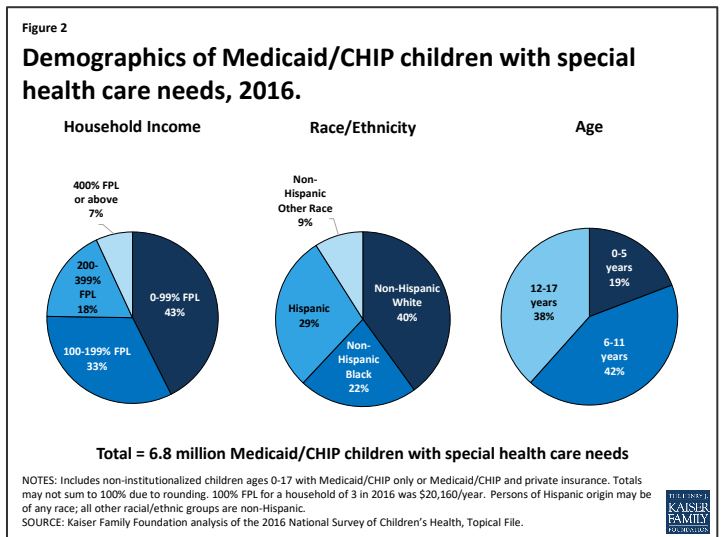
Medicaid provides a wide range of medical and long-term care services, many of which are not covered at all or only available in limited amounts through private insurance, and makes coverage affordable for many children with special health care needs and their families. Legislative proposals that would reduce and cap federal Medicaid funding may pose a particular risk to children with special health care needs. While Congress did not pass such legislation in 2017, similar proposals could be considered in 2018, and the Trump Administration’s FY 2019 proposed budget continues to advance these proposals.



This issue brief describes the role that Medicaid plays for children with special health care needs. It explains common eligibility pathways, covered services, and program spending for these children. The Appendix includes 50-state data on the number of children with special health care needs covered by Medicaid/CHIP. A companion brief compares key characteristics of Medicaid/CHIP children with special health care needs to those covered by private insurance.

Who Are Medicaid/CHIP Children with Special Health Care Needs?

Most Medicaid/CHIP children with special health care needs live in low or middle income families. This is due to program eligibility rules which generally include financial eligibility limits. Just under half (43%) of Medicaid/CHIP children with special health care needs reside in a household with income below the federal poverty level (FPL, less than \$20,780/year for a family of three in 2018). Three-quarters (75%) of Medicaid/CHIP children with special health care needs live in families with incomes below 200 percent of the federal poverty level (less than \$41,560/year for a family of three in 2018) (Figure 2).

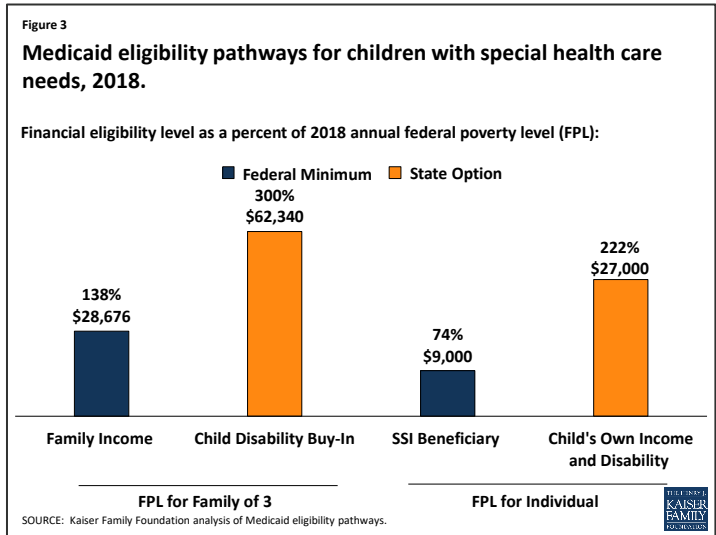


Two in five (40%) Medicaid/CHIP children with special health care needs are non-Hispanic white. About three in 10 (29%) are Hispanic, just under a quarter (22%) are non-Hispanic black, and nine percent are a member of another racial/ethnic group (Figure 2).

Most Medicaid/CHIP children with special health care needs are school-aged (Figure 2). Just under one in five (19%) of Medicaid/CHIP children with special health care needs are age 5 or younger, with the remainder about evenly split between the 6-11 (42%) and 12-17 (38%) age groups.

How Do Children with Special Health Care Needs Qualify for Medicaid?

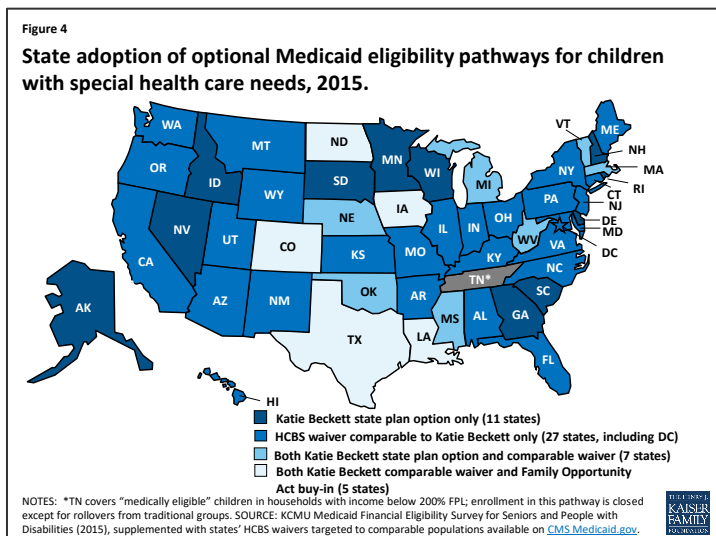
Some children with special health care needs qualify for Medicaid based solely on their family’s low income. Under the Affordable Care Act, states must cover all children in families with incomes up to 138% of the federal poverty level (FPL), \$28,676/year for a family of three in 2018) (Figure 3); although some of these children have special health care needs, their Medicaid eligibility is based entirely on their family’s low income, without regard to their health status.³ States can opt to expand financial eligibility for children above 138% FPL, and all do: [as of January, 2017, the median financial eligibility level for Medicaid and CHIP children nationally is 255% FPL](#) (\$52,989/year for a family of three in 2018).



Other children with special health care needs qualify for Medicaid through a disability-related pathway. States must provide Medicaid to children who receive federal Supplemental Security Income (SSI) benefits; these children live in poor families and have disabilities that result in marked and severe limitations in their ability to function at home, at school, and in the community (Figure 3).

Nearly all states choose to expand Medicaid financial eligibility for children with special health care needs at higher incomes through optional disability-related pathways (Figures 3 and 4).

As of 2015, [50 states opt to cover children with significant disabilities living at home under the “Katie Beckett” pathway](#); this pathway disregards parental income and assets, just as they are for children with disabilities living in an institution, which makes it possible for children with disabilities to receive necessary care while remaining at home with their families. The child’s own income, up to 222% FPL (\$27,000/year for an individual in 2018), and assets (generally limited to \$2,000) are counted. Katie Beckett children also must meet SSI medical disability criteria and otherwise qualify for an institutional level of care according to functional eligibility criteria set by the state. Some states cover

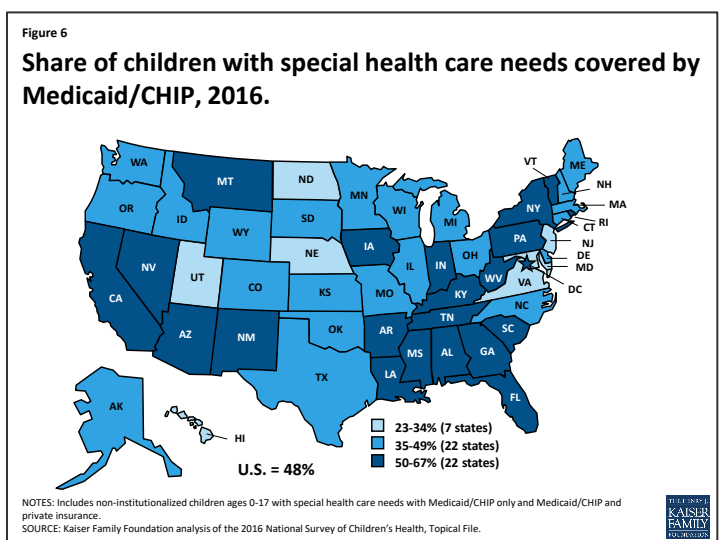
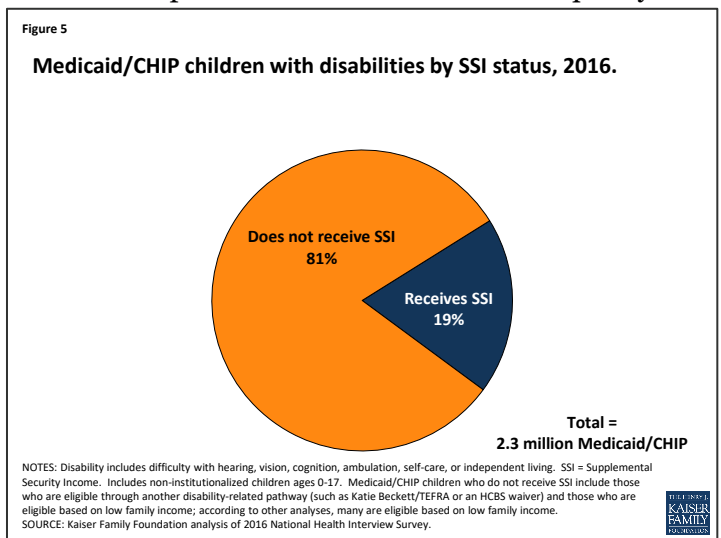


Katie Beckett children as an optional state plan group, while other states use a Medicaid home and community-based services (HCBS) waiver; using a waiver allows states to cap enrollment, which is not permitted under state plan authority.

States also can allow children with special health care needs in middle income families to “buy in” to Medicaid. As of 2015, [five states elect the Family Opportunity Act \(FOA\) option](#), a Medicaid buy-in for children with significant disabilities in families with income up to 300% FPL (\$62,340/year for a family of three in 2018) (Figures 3 and 4). FOA children must meet SSI medical disability criteria, and states may charge them premiums up to 5% of gross countable family income.

Less than one in five (19%) children with disabilities covered by Medicaid also receives SSI benefits (Figure 5).⁴ Children with disabilities are a subset of the larger population of children with special health care needs. Most Medicaid children with special health care needs (81%) do not receive SSI, indicating that they instead qualify for Medicaid on another basis; other data indicate that many of these children are eligible based on low family income.⁵ Some Medicaid children with special health care needs could qualify in a disability-related pathway but are instead enrolled through a poverty-related pathway because it is administratively easier and faster to establish eligibility based on low family income than based on disability. Other Medicaid children with special health care needs still use health services to a greater extent than other children as a result of their health conditions, even though their health needs do not rise to the stringent level of disability required to receive SSI or qualify for an institutional level of care.

As reflected by different state policy choices about optional eligibility expansions for children with special health care needs, the share of children with special health care needs covered by Medicaid/CHIP varies by state (Figure 6). Twenty-two states provide Medicaid/CHIP to between 35% and 49% of the children with special health care needs living in their state. Another 22 states provide Medicaid/CHIP to between one-half and two-thirds of all children with special health care needs living in their state. Seven states cover between 23 and 34 percent of children with special health care needs. Table 1 in the Appendix includes state-level data on the share of children with special health care needs covered by Medicaid/CHIP.



What Services Does Medicaid Provide for Children with Special Health Care Needs?

Medicaid covers a wide range of medical and long-term care services for children with special health care needs. Medicaid’s Early and Periodic Screening Diagnostic and Treatment (EPSDT) benefit includes regular medical, vision, hearing, and dental screenings as well as the services necessary to “correct or ameliorate” physical or mental health conditions. These services must be provided for children, regardless of whether a state chooses to cover them for adults. Medicaid’s benefit package for children covers traditional medical services like doctor visits, hospitalizations, x-rays, lab tests, and prescription drugs. It also includes behavioral health, dental, hearing, and vision care as well as physical, occupational, and speech therapy and medical equipment and supplies. Some children may receive therapy through special education at school, and Medicaid supplements those services by covering additional therapies that are necessary for a child to function outside of school, at home and in the community. For children with chronic needs, Medicaid covers long-term care services, such as private duty nursing, attendant care, and assistive technology, that help children with special health care needs remain at home with their families. It also offers non-emergency medical transportation to appointments and case management through which a social worker coordinates medical, social, and other services for children with multiple needs.

Medicaid fills in coverage gaps for privately insured children with special health care needs.

Private insurance typically is designed to meet the needs of a generally healthy population rather than people with more intensive or chronic needs. As a result, private insurance usually does not cover long-term care services and may offer limited coverage of other services important to children with special health care needs. For example, privately insured children may experience unmet needs for dental care, mental health services, or physical, occupational, or speech therapy. Some privately insured children with special health care needs access Medicaid for wrap-around coverage for the medically necessary services on which they and their families depend to keep them healthy and safe at home and in the community (Figure 1). For an example, see Sam’s story in Box 1 below.

Box 1: Sam, age 6, South Carolina

[Sam](#) was born with Fragile X syndrome, a genetic condition that causes intellectual disability. He also has mild autism. Sam’s mother, Robin, noticed that he was not reaching his developmental milestones around age one. He has difficulty communicating and learning skills such as how to brush his teeth and dress himself. Sam’s private insurance does not cover all of the specialists and services, such as physical, occupational, and speech therapy, that he needs. Medicaid fills these gaps and supplements his private insurance by covering those services. Robin says that the services Sam receives through Medicaid are helping him to learn the skills he needs to “be part of society and with his peers.”

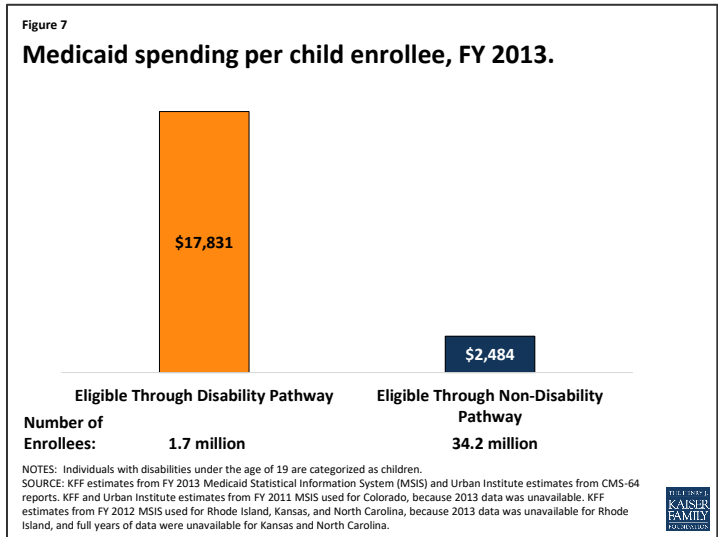


How Much Does Medicaid Spend on Children with Disabilities?

Annual per enrollee spending is over seven times higher for Medicaid children who are eligible through a disability pathway (\$17,831)

compared to those who are eligible through a non-disability pathway (\$2,484) as of 2013 (Figure 7).

This reflects the greater intensity and variety of needs among most children who qualify for Medicaid based on a disability, compared to most children who qualify through another pathway, such as family income. As described above, the Medicaid definition of “disability” is generally more restrictive than the definition of “special health care needs.” As of 2013, 1.7 million Medicaid children qualified through a disability pathway, while 34.2 million children qualified through a non-disability pathway (Figure 7).



Conclusion

Medicaid plays an important role for children with special health care needs. Most Medicaid/CHIP children with special health care needs live in low or middle income families and 40 percent are non-Hispanic white. Nearly all states choose to expand Medicaid eligibility for children with special health care needs at higher incomes through optional disability-related pathways. Reflecting different state policy choices in this area, the share of children with special health care needs covered by Medicaid/CHIP varies by state from 23% to 67%. Medicaid provides a wide range of medical and long-term care services, many of which are not covered at all or only available in limited amounts through private insurance, and makes coverage affordable for many children with special health care needs and their families. These services keep children with intensive and chronic needs living at home with their families.

Legislative proposals that would reduce and cap federal Medicaid funding may pose a particular risk to children with special health care needs. Proposals that would exempt spending for children who are eligible based on a disability would not reach all children with special health care needs, many of whom are eligible based on low family income. While Congress did not pass such legislation in 2017, similar proposals could be considered in 2018, and the Trump Administration’s FY 2019 proposed budget continues to advance these proposals.

Children who use Medicaid long-term care services have higher per enrollee spending than other Medicaid children. Consequently, policies that lead states to limit per enrollee spending or limit costly optional coverage groups could disproportionately affect these children by limiting their access to expensive but necessary services that are unavailable through private insurance. While nearly all medically necessary services for children are mandatory under the EPSDT benefit, states can provide – and may look to scale back – some optional home and community-based long-term care services offered through Section 1915 (c) waivers.

Additionally, many Medicaid eligibility pathways for children with disabilities are optional. All states but one currently choose to expand coverage for these children, but optional pathways are potentially at risk if states must adjust to reduced federal funding. If optional eligibility pathways are not eliminated, budgetary pressures could lead states to scale back provider payments and/or the limited services offered to children through optional waivers, with impacts on these children's access to care and coverage that are less visible than a reduction in eligibility pathways.

Finally, Medicaid is an important source of revenue for children's health care providers, particularly children's hospitals. Reductions to Medicaid payment rates, especially for children's specialty services, or reductions in optional children's coverage pathways, could impact those providers' revenue streams. Because proposals to restructure federal Medicaid financing could have significant consequences for enrollees and the health care system, the potential implications warrant careful consideration for their impact on children with special health care needs.

Appendix

Table 1: Children with Special Health Care Needs Covered by Medicaid/CHIP by State, 2016

State	Total Children with Special Health Care Needs	Share with Medicaid/CHIP*	Share with Medicaid/CHIP as Only Source of Coverage
Alabama	235,500	56%	52%
Alaska	29,900	46%	38%
Arizona	316,700	57%	49%
Arkansas	162,100	65%	60%
California	1,409,500	52%	48%
Colorado	221,000	35%	33%
Connecticut	155,200	40%	37%
Delaware	46,600	47%	33%
DC	21,400	55%	46%
Florida	891,100	52%	50%
Georgia	494,300	60%	51%
Hawaii	42,100	23%	16%
Idaho	75,300	47%	34%
Illinois	572,200	37%	33%
Indiana	355,900	51%	43%
Iowa	128,500	50%	35%
Kansas	147,300	41%	35%
Kentucky	255,900	54%	51%
Louisiana	263,800	56%	50%
Maine	58,700	49%	41%
Maryland	250,000	34%	33%
Massachusetts	286,600	36%	25%
Michigan	444,600	42%	29%
Minnesota	228,700	42%	31%
Mississippi	176,700	67%	57%
Missouri	316,100	38%	30%
Montana	41,800	61%	54%
Nebraska	78,100	33%	27%
Nevada	102,100	52%	38%
New Hampshire	52,200	37%	25%
New Jersey	350,200	32%	28%
New Mexico	98,100	59%	48%
New York	765,100	52%	37%
North Carolina	489,600	49%	44%
North Dakota	30,900	28%	17%
Ohio	598,400	46%	39%
Oklahoma	210,500	48%	37%
Oregon	158,700	42%	32%
Pennsylvania	517,200	54%	43%
Rhode Island	45,500	50%	40%
South Carolina	219,300	61%	51%
South Dakota	32,700	41%	32%
Tennessee	282,600	57%	53%
Texas	1,308,700	49%	40%
Utah	149,000	27%	21%
Vermont	25,200	65%	58%
Virginia	391,400	33%	29%
Washington	299,100	46%	37%

West Virginia	91,100	55%	45%
Wisconsin	245,700	43%	31%
Wyoming	28,100	44%	30%
U.S. Total	14,197,000	48%	41%

NOTES: Includes non-institutionalized children ages 0-17. *Includes those with Medicaid/CHIP as sole source of coverage and those with both Medicaid/CHIP and private insurance.

SOURCE: Kaiser Family Foundation analysis of the 2016 National Survey of Children's Health, Topical File.

Endnotes

¹ Kaiser Family Foundation analysis of the 2016 National Survey of Children's Health, Topical File.

² U.S. Dep't of Health & Human Services, Health Resources & Services Administration, Maternal & Child Health, Children with Special Health Care Needs (Dec. 2016), <https://mchb.hrsa.gov/maternal-child-health-topics/children-and-youth-special-health-needs#ref1>.

³ It may not be possible to easily identify all of these children in the Medicaid administrative data, based on their service use.

⁴ This share is based on data from the National Health Interview Survey which does not identify whether children are eligible for Medicaid in a poverty-related pathway vs. a disability-related pathway, and may be a conservative estimate of the total number of children with SSI. The Social Security Administration reports about 1.2 million child SSI beneficiaries in 2016. Social Security Administration, Annual Statistical Supplement to the Social Security Bulletin (2017), Table 7.A9 (preliminary data), <https://www.ssa.gov/policy/docs/statcomps/supplement/2017/7a.html#table7.a8>. These two sources report differ numbers due to differences in underlying data collection methods, but the difference does not change the overall conclusion that most Medicaid children with special health care needs do not qualify through a disability-related pathway.

⁵ For example, MSIS data show [34.8 million](#) Medicaid children eligible based on low family income as of 2014, and [1.6 million](#) Medicaid children eligible based on a disability (including SSI, Katie Beckett, HCBS waivers, and other disability-related pathways) as of 2011.