June 2019 | Issue Brief

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

MaryBeth Musumeci and Priya Chidambaram

Key Findings

Medicaid and CHIP covered about half (47%) of the 13.3 million children with special health care needs in 2017. These children require medical and long-term care services due to intellectual/developmental disabilities, physical disabilities, and/or mental health disabilities. This issue brief describes the role that Medicaid plays for children with special health care needs and includes 50-state data on those covered by Medicaid/CHIP. Key findings include the following:

- Less than one in six (15%) children with disabilities receives Medicaid because they qualify for 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 15% to 67%.

- Medicaid's benefit package for children, Early and Periodic Screening Diagnostic and Treatment, covers physical and behavioral health services and long-term services and supports that enable children with chronic needs to live at home with their families. Medicaid supplements special education services. It also fills in coverage gaps and makes coverage affordable 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.

Proposals that would reduce and cap federal Medicaid funding may pose a particular risk to children with special health care needs. Although efforts to repeal and replace the Affordable Care Act and cap federal Medicaid funding through a block grant or per capita cap were narrowly defeated in Congress in 2017, some states recently passed legislation to seek capped federal Medicaid funding through a Section 1115 waiver. While all of these state proposals may not include children with special health care needs, Tennessee's legislation does include this population. CMS reportedly is considering issuing guidance to states on these waivers, and program-wide capped federal financing is proposed in President Trump's FY 2020 budget.

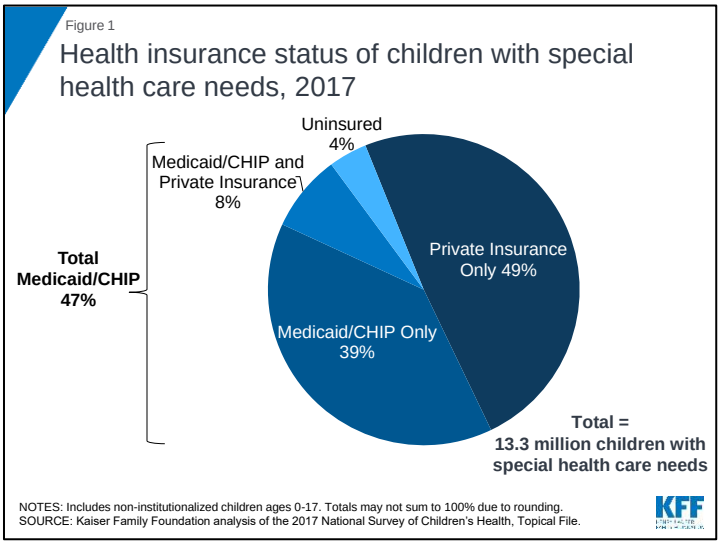
Headquarters / 185 Berry Street Suite 2000 San Francisco CA 94107 / 650 854 9400
Washington Offices and Conference Center / 1330 G Street NW Washington DC 20005 / 202 347 5270
kff.org / Email Alerts: kff.org/email / facebook.com/KaiserFamilyFoundation / twitter.com/KaiserFamFound
Filling the need for trusted information on national health issues, the Kaiser Family Foundation is a nonprofit organization based in San Francisco, California.

KFF
HENRY J KAISER FAMILY FOUNDATION

Introduction

An estimated 13.3 million children, or 18% 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 (47%) of children with special health care needs in 2017 (Figure 1). Medicaid provides a wide range of medical and long-term services and supports (LTSS), many of which are not covered at all or only available in limited amounts through private insurance. Medicaid also makes coverage affordable for many children with special health care needs and their families. Proposals that would reduce and cap federal Medicaid funding may pose a particular risk to children with special health care needs. Although efforts to repeal and replace the Affordable Care Act (ACA) and cap federal Medicaid funding through a block grant or per capita cap were narrowly defeated in Congress in 2017, some states, such as Utah and Tennessee, recently passed legislation to seek capped federal Medicaid funding through a Section 1115 waiver. While all of these state proposals may not include children with special health care needs, Tennessee's legislation does include this population.[3] The Centers for Medicare and Medicaid Services reportedly is considering issuing guidance to states on Section 1115 waivers that would cap federal Medicaid financing. A program-wide federal financing cap also is proposed in President Trump's FY 2020 budget.[4] Depending on how they are structured, these policies could have consequences on Medicaid coverage, services, and access to care for children with special health care needs.



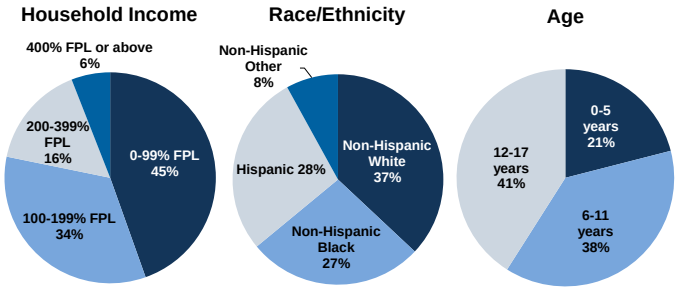
This issue brief describes the role that Medicaid plays for children with special health care needs. It explains common eligibility pathways, covered services, and program spending for these children. The Appendix includes 50-state data on the number of children with special health care needs covered 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 of the 6.1 million 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 (45%) of Medicaid/CHIP children with special health care needs reside in a household with income below the federal poverty level (FPL, less than $21,330/year for a family of three in 2019). Over three-quarters (79%) of Medicaid/CHIP children with special health care needs live in families with incomes below 200% FPL (less than $42,660/year for a family of three in 2019) (Figure 2).

Figure 2

Demographics of Medicaid/CHIP children with special health care needs, 2017



Total = 6.1 million Medicaid/CHIP children with special health care needs

NOTES: Includes non-institutionalized children ages 0-17 with Medicaid/CHIP only or Medicaid/CHIP and private insurance. Totals may not sum to 100% due to rounding. 100% FPL for a household of 3 in 2017 was $20,420/year. Persons of Hispanic origin may be of any race; all other racial/ethnic groups are non-Hispanic.
SOURCE: Kaiser Family Foundation analysis of the 2017 National Survey of Children's Health, Topical File.

Over one in three (37%) Medicaid/CHIP children with special health care needs are non-Hispanic white. About three in 10 (28%) are Hispanic, just over a quarter (27%) are non-Hispanic black, and eight 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 over one in five (21%) Medicaid/CHIP children with special health care needs are age 5 or younger, with the remainder about evenly split between the 6 to 11 (38%) and 12 to 17 (41%) age groups.

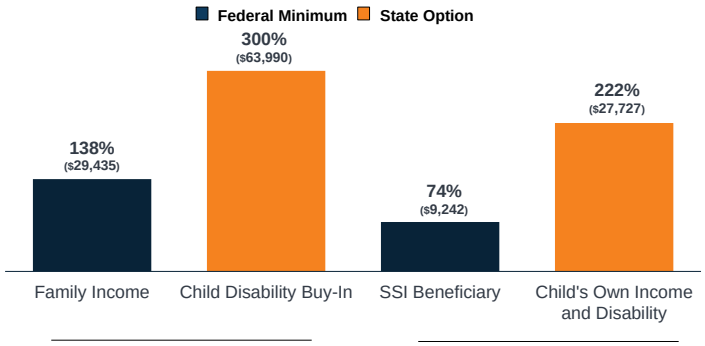
How Do Children with Special Health Care Needs Qualify for Medicaid?

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% FPL ($29,435/year for a family of three in 2019) (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.[5] States can opt to expand financial eligibility for children above 138% FPL, and all do: as of January 2019, the median financial eligibility level for Medicaid and CHIP children nationally is 255% FPL ($54,392/year for a family of three in 2019).

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 (Figure 3); 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

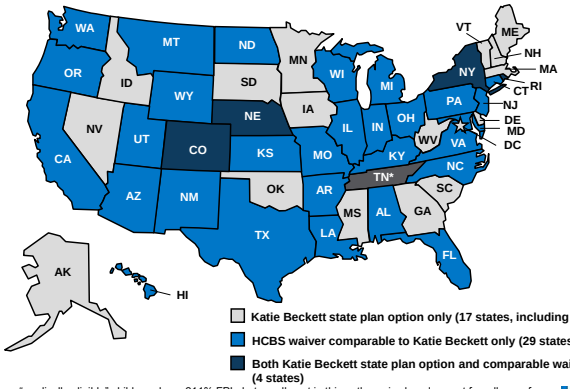
Medicaid eligibility pathways for children with special health care needs, 2019



SOURCE: Kaiser Family Foundation analysis of Medicaid eligibility pathways.

Figure 4

Medicaid Eligibility for Katie Beckett Children with Significant Disabilities, 2018



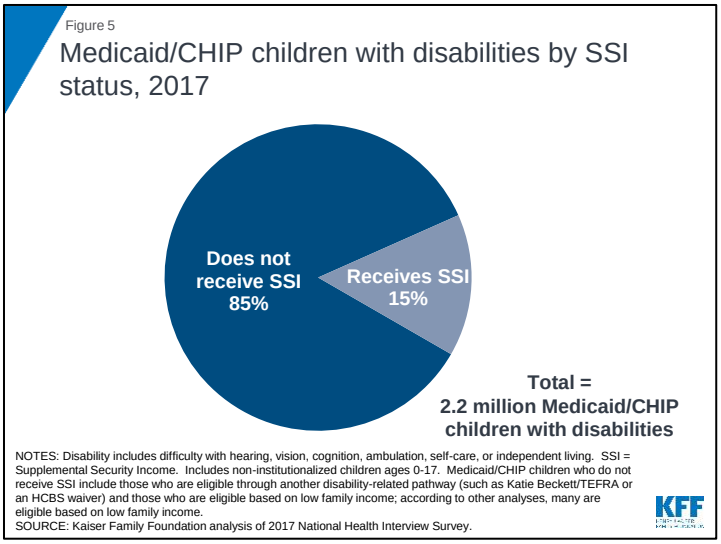
NOTES: *TN covers "medically eligible" children above 211% FPL, but enrollment in this pathway is closed except for rollovers from traditional groups. TN recently passed legislation to establish a new Katie Beckett-like program under its Section 1115 waiver.
SOURCE: KFF Medicaid Financial Eligibility Survey for Seniors and People with Disabilities, 2018.

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 2018, all states but one opt to cover at least some children with significant disabilities living at home under the "Katie Beckett" state plan option or a comparable waiver. 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 (or three times the SSI limit, $27,727/year for an individual in 2019), 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.

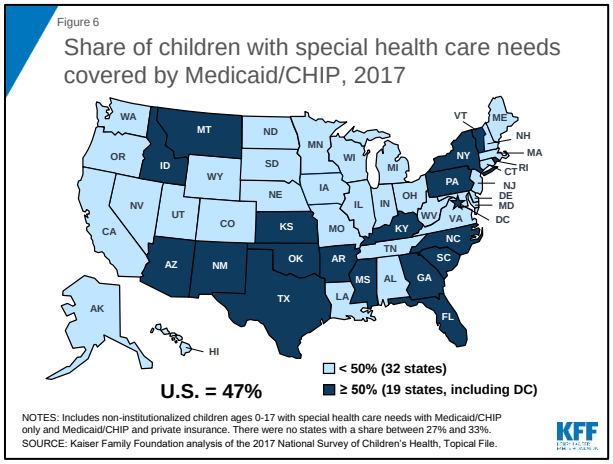
Over half of Katie Beckett states (56%, 29 of 50) cover these children solely through a home and community-based services (HCBS) waiver, under which enrollment can be capped (Figure 4). About one-third (17 of 50) states elect to cover all eligible children under the state plan option; unlike waivers, enrollment caps are not permitted in state plan coverage groups.[6] Four states cover some Katie Beckett children through the state plan option and others through a comparable waiver. The one state that does not currently cover Katie Beckett children, Tennessee,[7] recently passed legislation to establish a Katie Beckett-like waiver program.[8]

States also can allow children with special health care needs in middle income families to "buy in" to Medicaid. As of 2018, five states elect the Family Opportunity Act (FOA) state plan option, and one state offers a comparable waiver. FOA is a Medicaid pathway for children with significant disabilities in families with income up to 300% FPL ($63,990/year for a family of three in 2019) (Figure 3). FOA children must meet SSI medical disability criteria, and states may charge premiums up to 5% of gross countable family income.

Less than one in six (15%) children with disabilities covered by Medicaid also receives SSI benefits (Figure 5).[9] 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 (85%) 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.[10] 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). Thirty-two states provide Medicaid/CHIP to under half of children with special health care needs living in their state. Utah and Maryland provide Medicaid/CHIP to under a quarter of children with special health care needs. The remaining 19 states, including DC, provide Medicaid/CHIP to over half of children with special health care needs living in their state. 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 and supports 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 LTSS, 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 LTSS 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.

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 that 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).

Figure 7

Medicaid spending per child enrollee, FY 2013

NOTE: Individuals with disabilities under the age of 19 are categorized as children.
SOURCE: KFF estimates from FY 2013 Medicaid Statistical Information System (MSIS) and Urban Institute estimates from CMS-64 reports. KFF and Urban Institute estimates from FY 2011 MSIS used for Colorado, because 2013 data was unavailable. KFF estimates from FY 2012 MSIS used for Rhode Island, Kansas, and North Carolina, because 2013 data was unavailable for Rhode Island, and full years of data were unavailable for Kansas and North Carolina.

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."

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 over one-third 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 15% to 67%. Medicaid provides a wide range of medical and LTSS, 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.

Proposals that would reduce and cap federal Medicaid funding may pose a particular risk to children with special health care needs. Notably, 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. Although efforts to repeal and replace the Affordable Care Act (ACA) and cap federal Medicaid funding through a block grant or per capita cap were narrowly defeated in Congress in 2017, some states, such as Utah and Tennessee, recently passed legislation to seek capped federal Medicaid funding through a Section 1115 waiver. While all of these state proposals may not include children, Tennessee's legislation does incorporate children, including those with special health care needs.[11] The Centers for Medicare and Medicaid Services reportedly is considering issuing guidance to states on Section 1115 waivers that would cap federal Medicaid financing. A program-wide federal financing cap also is proposed in President Trump's FY 2020 budget.[12] Depending on how they are structured, these policies could have consequences on Medicaid coverage, services, and access to care for children with special health care needs.

Children who are eligible for Medicaid based on a disability have higher per enrollee spending than other Medicaid children. Consequently, policies that lead states to limit per enrollee spending or cap total Medicaid spending 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 LTSS offered through Section 1915 (c) waivers. Additionally, many Medicaid eligibility pathways for children with disabilities are optional. Tennessee, the one state that does not currently offer the Katie Beckett state plan option or a comparable waiver, recently passed legislation to establish a waiver program. During the same legislative session, Tennessee also passed legislation to pursue capped federal funding in the form of a Medicaid block grant including children with special health care needs. Optional coverage pathways are potentially at risk if states must adjust to reduced federal funding. Even if enrollment in optional eligibility pathways is not capped or eliminated, budgetary pressures could lead states to scale back provider payments and/or limit the community-based LTSS 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, 2017			
State	Total Children with Special Health Care Needs	Share with Medicaid/CHIP*	Share with Medicaid/CHIP as Only Source of Coverage
Alabama	260,000	49%	44%
Alaska	33,400	48%	38%
Arizona	252,900	58%	43%
Arkansas	161,200	63%	54%
California	1,144,500	43%	42%
Colorado	230,400	25%	20%
Connecticut	160,200	45%	38%
Delaware	47,400	33%	28%
DC	21,100	62%	53%
Florida	830,300	51%	46%
Georgia	530,000	54%	49%
Hawaii	40,400	35%	30%
Idaho	79,200	56%	41%
Illinois	575,800	36%	32%
Indiana	328,800	42%	29%
Iowa	144,000	46%	34%
Kansas	148,300	55%	47%
Kentucky	236,800	55%	50%
Louisiana	252,300	46%	36%
Maine	58,200	43%	32%
Maryland	266,400	22%	19%
Massachusetts	276,500	40%	29%
Michigan	453,000	48%	33%
Minnesota	224,000	47%	38%
Mississippi	169,800	67%	61%
Missouri	280,600	47%	45%
Montana	45,300	64%	60%
Nebraska	86,000	38%	37%
Nevada	111,600	47%	47%
New Hampshire	54,600	35%	31%
New Jersey	320,600	37%	31%
New Mexico	89,300	57%	44%
New York	614,200	50%	47%
North Carolina	470,600	50%	42%
North Dakota	29,500	26%	18%
Ohio	547,500	45%	36%
Oklahoma	222,300	54%	46%
Oregon	162,900	49%	38%
Pennsylvania	505,500	55%	33%
Rhode Island	42,600	56%	52%
South Carolina	226,600	61%	44%
South Dakota	35,000	45%	33%
Tennessee	289,200	39%	37%
Texas	1,075,100	57%	38%
Utah	143,000	15%	8%

Vermont	23,500	54%	45%
Virginia	391,500	38%	31%
Washington	305,300	38%	33%
West Virginia	89,600	45%	43%
Wisconsin	212,600	48%	39%
Wyoming	28,000	34%	25%
US Total	**13,327,400**	**47%**	**39%**

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 2017 National Survey of Children's Health, Topical File.

Endnotes

[1] Kaiser Family Foundation analysis of the 2017 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 (Date Last Reviewed: March 2019), https://mchb.hrsa.gov/maternal-child-health-topics/children-and-youth-special-health-needs#ref1.

[3] Tenn. General Assembly, Conference Committee Report on H.B. 1280/S.B. 1428 (May 17, 2019), http://wapp.capitol.tn.gov/apps/BillInfo/Default.aspx?BillNumber=HB1280.

[4] Kaiser Family Foundation, *Medicaid Financing: The Basics* (March 2019), https://www.kff.org/medicaid/issuebrief/medicaid-financing-the-basics/.

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

[6] Louisiana, which currently has a Katie Beckett-like waiver, has passed legislature in both houses to adopt the Katie Beckett state plan option. La. H.B. 199 (2019 Regular Session), http://www.legis.la.gov/legis/BillInfo.aspx?s=19RS&b=HB199&sbi=y.

[7] Tennessee's Section 1115 waiver currently covers "medically eligible" children" in households with income at or above 211% FPL with no asset test, although enrollment in this pathway is closed except for rollovers from those losing coverage in a traditional group. CMS, *TennCare II Special Terms and Conditions*, #11-W-00151/4 at paragraph 20 and Table 1a (Dec. 16, 2016-June 30, 2021), https://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/1115/downloads/tn/tn-tenncare-ii-ca.pdf. Those with income less than 211% FPL are covered with CHIP funds. Tennessee's Section 1115 waiver also provides Medicaid HCBS to a capped number of children up to age 21 with intellectual or developmental disabilities who meet or are at risk of meeting an institutional level of care with incomes up to 300% SSI. *Id.* at paragraph 22 (f), p. 36 and Table 2c.

[8] Tenn. General Assembly, Amendments No. 1-1 and 2 to H.B.0498, http://wapp.capitol.tn.gov/apps/BillInfo/Default.aspx?BillNumber=SB0476.

[9] 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 2017. Social Security Administration, *SSI Annual Statistical Report, 2017*, Table 7 (released Sept. 2018), https://www.ssa.gov/policy/docs/statcomps/ssi_asr/2017/sect02.html#table7. 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.

[10] 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.

[11] Tenn. General Assembly, Conference Committee Report on H.B. 1280/S.B. 1428 (May 17, 2019), http://wapp.capitol.tn.gov/apps/BillInfo/Default.aspx?BillNumber=HB1280.

[12] Kaiser Family Foundation, *Medicaid Financing: The Basics* (March 2019), https://www.kff.org/medicaid/issuebrief/medicaid-financing-the-basics/.