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Medicaid Restructuring and Children with Special Health Care Needs

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Executive Summary

Medicaid and CHIP cover 44% of children with special health care needs, providing access to a broad range of medical and long-term care services that enable many to live at home with their families and making coverage affordable. This brief includes state-level data on the share of children with special health care needs covered by Medicaid and describes Medicaid's role for these nearly five million children to help inform the debate about current proposals in Congress to reduce federal Medicaid funding under a per capita cap or block grant.

Nearly ¾ of all children with special health care needs live in low or middle income families, below 400% of the federal poverty level (FPL). About one in five are below 100% FPL (<$20,420/year for a family of three in 2017), and another one in five are between 100-199% of poverty.

Medicaid/CHIP children with special health care needs have significantly greater health needs compared to those with private insurance alone, with children covered by both Medicaid/CHIP and private insurance having the greatest needs. Medicaid/CHIP children with special health care needs are nearly two and one-half times as likely (24%), and those with both Medicaid/CHIP and private insurance are three times as likely (30%), to have four or more chronic conditions, compared to those with private insurance alone (10%). Medicaid/CHIP children are more than one and one-half times as likely (58%), and those with both Medicaid/CHIP and private insurance are nearly twice as likely (63%), to have four or more functional difficulties compared to those with private insurance (33%). Medicaid/CHIP cover 60% of the 2.9 million children with special health care needs whose health conditions consistently and often greatly affect their daily activities, with Medicaid/CHIP as the sole source of coverage for nearly half of these children.

Medicaid/CHIP children with special health care needs have access to care on par with those with private insurance alone. For example, Medicaid/CHIP children (92% for both those with and without private insurance) are about equally as likely to have had a preventive care visit in the last year compared to those with private insurance alone (91%). Medicaid/CHIP children are significantly more likely than those with private insurance to report that their coverage is adequate to meet their needs (69% vs 64%).

Medicaid/CHIP children with special health care needs are significantly more likely to report that their coverage is affordable compared to those with private insurance alone. Medicaid/CHIP children are more than five times less likely (6%), and those with Medicaid/CHIP and private insurance are half as likely (16%), to incur out-of-pocket costs of $1,000 or more, compared to those with private insurance

alone (32%). Medicaid/CHIP is a safety net, covering 59% of the 2.7 million children with special health care needs whose families have had to reduce their work hours or stop working altogether due to their child's health status, and serving as the sole source of coverage for nearly half of these children.

Medicaid children with special health care needs may be particularly affected by changes currently being considered by Congress, including the shift to per capita capped federal financing. Per enrollee spending for Medicaid children who use long-term care services is over 12 times higher ($37,084) compared to those who do not ($2,836), due to these children's greater health needs and reliance on Medicaid for expensive but necessary services that are generally unavailable through private insurance and too costly to afford out-of-pocket. Many Medicaid coverage pathways for children with disabilities, and some community-based long-term care services provided through waivers, are offered at state option, making them subject to potential cuts as states adjust to substantial federal funding reductions under a per capita cap. While the Better Care Reconciliation Act proposed in the Senate would exempt Medicaid children who are eligible based on a disability from the per capita cap, most Medicaid children with special health care needs are eligible based on their family's low income and not based on a disability and therefore would be subject to the per capita cap.

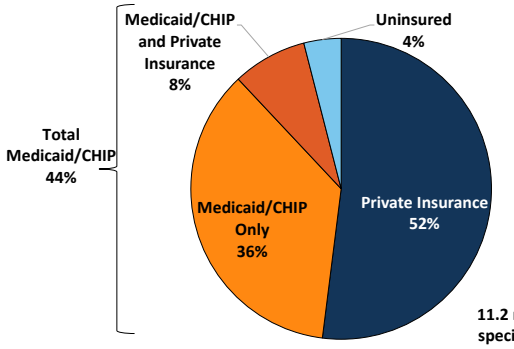
Introduction

An estimated 11.2 million children, or 15% of all children in the U.S., have special health care needs, based on the most recent data available from 2009-2010. Their needs result from a range of conditions, such as Down syndrome, cerebral palsy, and autism. These children may require services such as nursing care to live safely at home, therapies to address developmental delays, and mental health counseling. This issue brief describes the role that Medicaid plays for children with special health care needs. It presents data comparing the health and functional needs, coverage adequacy and access to care, and affordability of coverage for Medicaid/CHIP children with special health care needs and those with private insurance. The Appendix includes state-level data on the distribution of children with special health care needs by household income (Table 1), the share of children with special health care needs who are covered by Medicaid (Table 2), and the share of Medicaid children with special health care needs who receive SSI (Table 3).

Medicaid and CHIP cover nearly half (44%, or nearly five million) of children with special health care needs (Figure 1). Medicaid or CHIP is the sole source of coverage for over 1/3 (36%) of these children. Another 8% have Medicaid or CHIP to supplement their private coverage. 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.

Figure 1

Health insurance status of children with special health care needs, 2009-2010.



NOTES: Medicaid/CHIP also includes Medicare and Medigap. CDC, Design and Operation of the National Survey of Children with Special Health Care Needs, 2009-2010, https://www.cdc.gov/nchs/data/series/sr_01/sr01_057.pdf. Omits responses reported as "refused," "don't know" or missing (<1%). Includes children ages 0-17.
SOURCE: National Survey of Children with Special Health Care Needs (2009-10), http://childhealthdata.org/learn/NS-CSHCN.

Limits and reductions in federal Medicaid financing, as currently being considered by Congress, are particularly relevant to children with special health care needs because these children use services more intensively, and often incur greater costs, than other children. Both the American Health Care Act (AHCA) as passed by the U.S. House of Representatives and the Better Care Reconciliation Act (BCRA) as proposed in the Senate fundamentally restructure Medicaid financing by changing the current guarantee of federal matching funds without a pre-set limit to a per capita cap or block grant. While the BCRA would exempt Medicaid children who are eligible based on a disability from the per capita cap, most Medicaid children with special health care needs are eligible based on their family's low income and not based on a disability. The change in federal Medicaid financing (together with eliminating the enhanced federal matching funds for the Affordable Care Act's Medicaid expansion) is estimated to reduce federal Medicaid funds to states by $772 billion from 2017 to 2026 under the BCRA, according to the Congressional Budget Office. Given the magnitude of these funding cuts, states are likely to look to limiting provider payment rates, the number of people covered, and the scope of benefits available, which could impact Medicaid children with special health care needs.

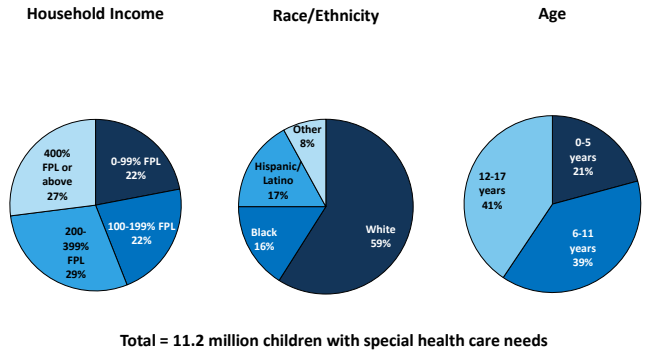
Who are Children with Special Health Care Needs?

As defined by the U.S. Department of Health and Social Services (HHS), children with special health care needs "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." Their needs arise from a range of conditions such as autism, Down syndrome, and other intellectual and developmental disabilities (I/DD); physical disabilities such as cerebral palsy, spina bifida, and muscular dystrophy; mental health needs such as depression and anxiety; and complications arising from premature birth. They may need nursing care to live safely at home with a tracheotomy or feeding tube; attendant care to develop community living skills; medical equipment and supplies; mental health counseling; and/or regular therapies to address developmental delays. They may have difficulty with bodily functions, such as breathing, swallowing, or chronic pain; difficulty with activities such as self-care, mobility, learning, or communication; and/or emotional or behavioral difficulties.

Nearly three-quarters (73%) of children with special health care needs live in low or middle income families, below 400% of the federal poverty level (FPL) (Figure 2). About one in five (22%) resides in a household with income below the poverty level (less than $20,420/year for a family of three in 2017). Another 22% live in a household with income between 100-199% of poverty ($20,420-$40,636/year for a family of three in 2017). About one in three (29%) are in a household with income between 200-399% of poverty ($40,840-$81,396/year for a family of three in 2017). Table 1 contains state-level data on the distribution of children with special health care needs by household income. Nearly six in 10 children with special health care needs are white, and about equal shares are

Figure 2

Demographics of children with special health care needs, 2009-2010.



Total = 11.2 million children with special health care needs

NOTE: Percentages may not sum due to rounding. Omits responses reported as "refused," "don't know" or missing (<1%). Includes children ages 0-17.
SOURCE: National Survey of Children with Special Health Care Needs (2009-10), http://childhealthdata.org/learn/NS-CSHCN.

black (16%) and Hispanic/Latino (17%). Just over 20% of children with special health care needs are age 5 or younger, with the remainder about evenly split between the 6-11 and 12-17 age groups.

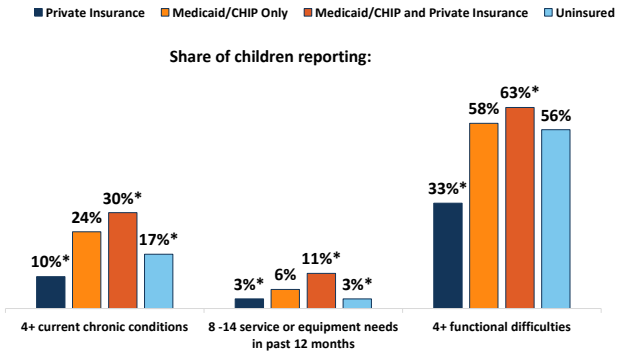
How Do Medicaid Children with Special Health Care Needs Differ from Those with Private Insurance?

Greater Health Needs and Functional Limitations

Medicaid/CHIP children with special health care needs have significantly greater health needs compared to those with private insurance alone, with children covered by both Medicaid/CHIP and private insurance having the greatest needs. Medicaid/CHIP children with special health care needs are nearly two and one-half times as likely (24%), and those with both Medicaid/CHIP and private insurance are three times as likely (30%), to have four or more chronic conditions, compared to those with private insurance (10%) (Figure 3). Some of the chronic conditions reported by children with special health care needs include autism, intellectual disability, asthma, depression, anxiety, attention deficient hyperactivity disorder, cerebral palsy, cystic fibrosis, muscular dystrophy, brain injury, heart problems, and epilepsy. As a result of their greater health needs, Medicaid/CHIP children are twice as likely (6%), and those with both Medicaid/CHIP and private insurance are nearly four times as likely (11%), to have eight to 14 health care service or equipment needs in a year, compared to those who are privately insured (3%) (Figure 3). These include the need for preventive, specialist, or dental care; prescription medication; physical, occupational, or speech therapy; mental health counseling; mobility or communication aids; home health care; and durable medical equipment, among others.

Figure 3

Health status of children with special health care needs, by coverage status, 2009-2010.

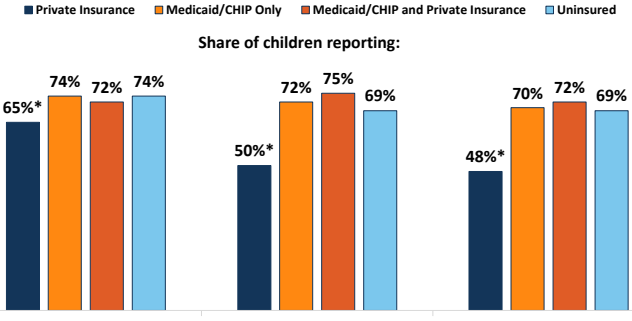


NOTE: Medicaid/CHIP also includes Medicare and Medigap.
* Indicates statistically significant difference from the Medicaid/CHIP population at the p < 0.05 level.
SOURCE: National Survey of Children with Special Healthcare Needs (2009-10), http://www.childhealthdata.org/learn/NS-CSHCN.

Medicaid/CHIP children with special health care needs also are significantly more likely to have multiple functional limitations compared to those with private insurance. Specifically, Medicaid/CHIP children are more than one and one-half times as likely (58%), and those with both Medicaid/CHIP and private insurance are nearly twice as likely (63%), to have four or more functional difficulties compared to those with private insurance alone (33%) (Figure 3). Medicaid/CHIP children, including those with and without private insurance, are more likely than children with private insurance alone to have difficulty with bodily functions, such as breathing, swallowing, or chronic physical pain; activities or participation, such as self-care, mobility,

Figure 4

Functional difficulties of children with special health care needs, by coverage status, 2009-2010.



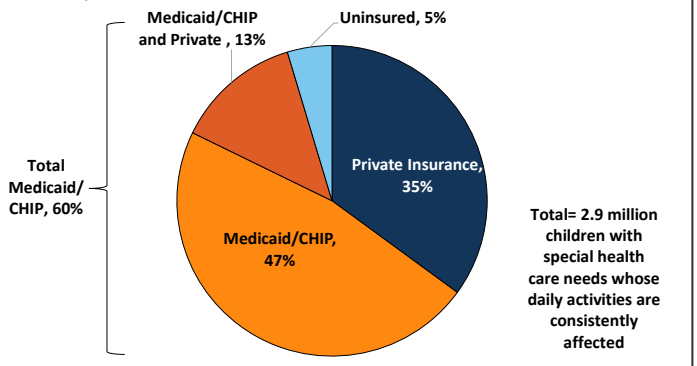
NOTE: Medicaid/CHIP also includes Medicare and Medigap.
* Indicates statistically significant difference from the Medicaid/CHIP population at the p < 0.05 level.
SOURCE: National Survey of Children with Special Healthcare Needs (2009-10), http://www.childhealthdata.org/learn/NS-CSHCN.

learning, or communicating; and emotional or behavioral factors, such as anxiety, depression, or making friends (Figure 4).

Medicaid and CHIP cover many of the children with the greatest needs, including 60% of the 2.9 million children with special health care needs whose health conditions consistently and often greatly affect their daily activities (Figure 5). Medicaid/CHIP is the sole source of coverage for nearly half (47%) of these children (Figure 5). Medicaid/CHIP children are twice as likely (36%), and those with Medicaid/CHIP and private insurance are nearly two and one-half times as likely (43%), to have health conditions that consistently and often greatly affect their daily activities, compared to those with private insurance alone (18%) (Figure 6).

Figure 5

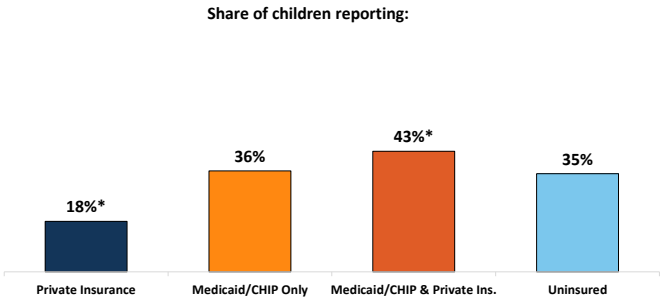
Insurance status of children with special health care needs whose health conditions consistently and often greatly affect their daily activities, 2009-2010.



NOTE: Medicaid/CHIP also includes Medicare and Medigap.
SOURCE: National Survey of Children with Special Healthcare Needs (2009-10), http://www.childhealthdata.org/learn/NS-CSHCN.

Figure 6

Children with special health care needs whose health conditions consistently and often greatly affect their daily activities, by coverage status, 2009-2010.



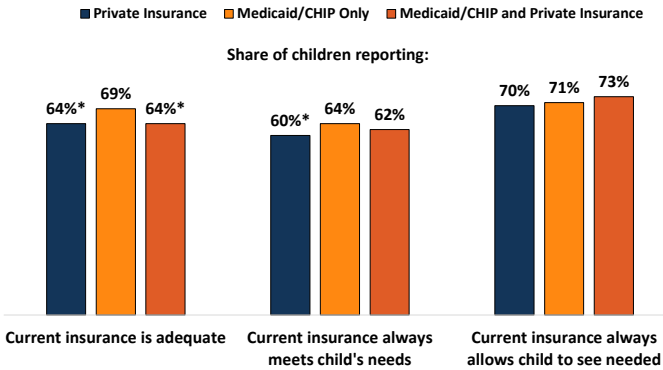
NOTE: Medicaid/CHIP also includes Medicare and Medigap.
* Indicates statistically significant difference from the Medicaid/CHIP population at the p < 0.05 level.
SOURCE: National Survey of Children with Special Healthcare Needs (2009-10), http://www.childhealthdata.org/learn/NS-CSHCN.

Comparable Coverage Adequacy and Access to Care

Despite their greater needs, Medicaid/CHIP children with special health care needs are significantly more likely than those with private insurance to report that their coverage is sufficient to meet their needs. For example, Medicaid/CHIP children with special health care needs (69%) are significantly more likely than those with private insurance alone (64%) to report that their coverage is adequate (Figure 7). Medicaid/CHIP children with special health care needs (64%) also are significantly more likely to report that their insurance always meets their needs, compared to those with private insurance alone (60%) (Figure 7). Comparable shares of Medicaid/CHIP children, those with Medicaid/CHIP and private insurance, and those with private insurance alone report that their insurance allows them to see all needed providers (71% vs. 73% vs. 70%) (Figure 7).

Figure 7

Adequacy of insurance among children with special health care needs, by coverage status, 2009-2010.

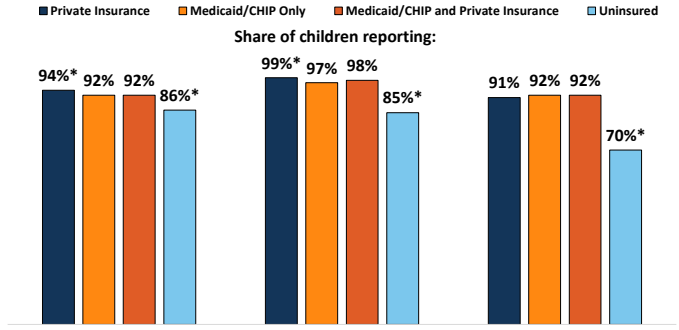


NOTE: Medicaid/CHIP also includes Medicare and Medigap.
* Indicates statistically significant difference from the Medicaid/CHIP population at the p < 0.05 level.
SOURCE: National Survey of Children with Special Healthcare Needs (2009-10), http://www.childhealthdata.org/learn/NS-CSHCN.

Medicaid/CHIP children with special health care needs have access to health care services on par with those who are privately insured. Medicaid/CHIP children with special health care needs (92%), those with Medicaid/CHIP and private insurance (92%), and those with private insurance alone (91%) are about equally as likely to have had a well-child check-up in the last 12 months (Figure 8). Other access to care rates are high among all three groups. For example, 92% of both Medicaid/CHIP children and those with both Medicaid/CHIP and private insurance report having a usual source of care when sick, compared to 94% of those with private insurance alone (Figure 8). The rates for access to a usual source of preventive care also are high among the three groups (97% for Medicaid/CHIP, 98% for Medicaid/CHIP and private insurance, 99% for private insurance alone) (Figure 8). Medicaid/CHIP children with special health care needs also experience significantly better access to care on these measures compared with those who are uninsured (Figure 8).

Figure 8

Access to care among children with special health care needs, by coverage status, 2009-2010.



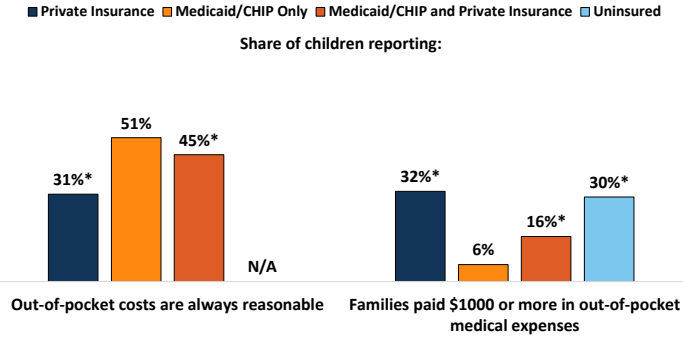
NOTE: Medicaid/CHIP also includes Medicare and Medigap.
* Indicates statistically significant difference from the Medicaid/CHIP population at the p < 0.05 level.
SOURCE: National Survey of Children with Special Healthcare Needs (2009-10), http://www.childhealthdata.org/learn/NS-CSHCN.

Greater Affordability

Medicaid/CHIP children are significantly more likely to report that their coverage is affordable compared to those with private insurance. Medicaid makes coverage affordable for children with special health care needs by limiting out-of-pocket costs. Medicaid/CHIP children with special health care needs (51%), and those with Medicaid/CHIP and private insurance (45%), both are more likely to report that their out-of-pocket health care costs are reasonable compared to those with private insurance (31%) (Figure 9). Medicaid/CHIP children are more than five times less likely (6%), and those with Medicaid/CHIP and private insurance are half as likely (16%), to incur out-of-pocket costs of $1,000 or more, compared to those with private insurance alone (32%) (Figure 9). Out-of-pocket costs under Medicaid generally are limited to nominal amounts, and most children are exempt from cost-sharing, which protects families from the financial burdens often associated with special health care needs. Affordability is a particular concern for families of children with special health care needs because, as discussed above, nearly three-quarters have household incomes below 400% of poverty, and nearly half (44%) are below 200% of poverty (Figure 3). For an example of how Medicaid helps make private coverage affordable for children with special health care needs, see Gabriel's story in Box 1 below.

Figure 9

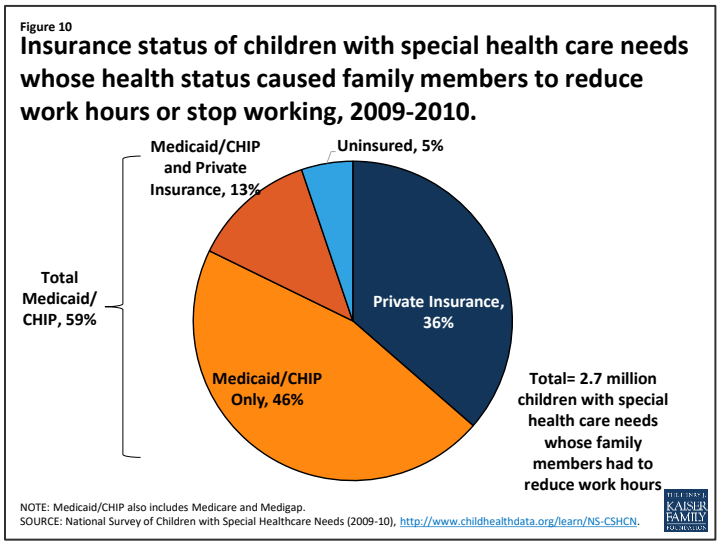
Affordability for children with special health care needs, by coverage status, 2009-2010.

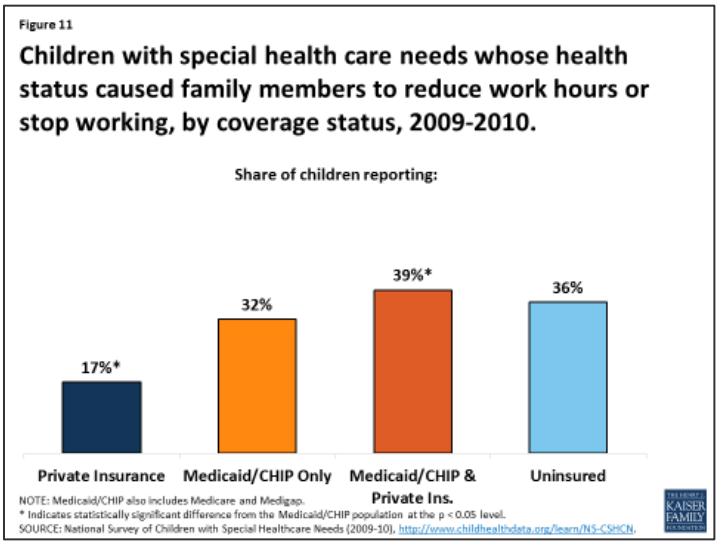


NOTE: Medicaid/CHIP also includes Medicare and Medigap.
* Indicates statistically significant difference from the Medicaid/CHIP population at the p < 0.05 level.
SOURCE: National Survey of Children with Special Healthcare Needs (2009-10), http://www.childhealthdata.org/learn/NS-CSHCN.

Affordability is important because the demands of caring for children with special health care needs can impede their families' ability to work, an outcome that is significantly more likely

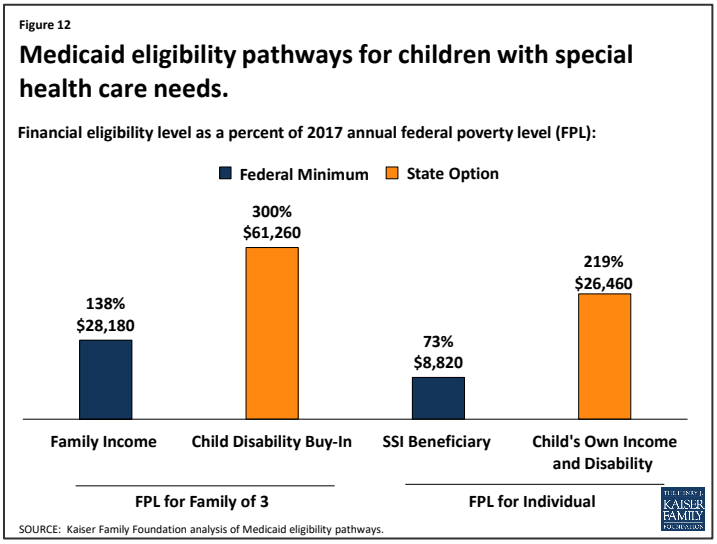
among Medicaid/CHIP children. Given Medicaid/CHIP children's greater health care needs and functional limitations compared to those with private coverage (Figures 3-6), it is not surprising that Medicaid and CHIP cover 59% of the 2.7 million children with special health care needs whose families have had to reduce their work hours or stop working altogether due to their child's health status (Figure 10). Medicaid/CHIP is the sole source of coverage for just under half (46%) of these children (Figure 10). Medicaid/CHIP children with special health care needs are more than one and one-half times as likely (32%), and those with Medicaid/CHIP and private insurance are over twice as likely (39%), to live in families who had to cut back on outside employment due to their child's health needs, compared to those with private insurance alone (17%) (Figure 11).





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, as of 2014, states must cover all children in families with incomes up to 138% of the federal poverty level (FPL, $28,180/year for a family of three in 2017) (Figure 12); 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.[1] States can 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 ($52,071/year for a family of three in 2017).



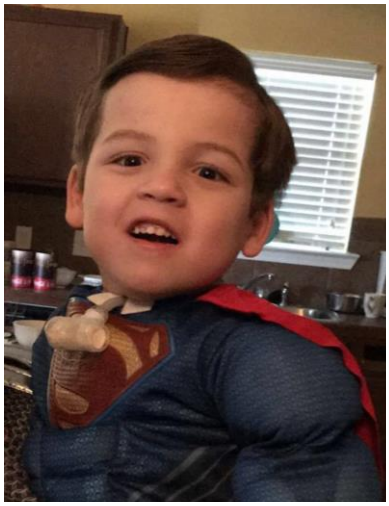
Box 1: Gabriel, age 4, Louisiana

Gabriel was born prematurely at 27 weeks and spent a little over his first year of life in the hospital. When he was ready for discharge, his parents were told that he would have to go to a nursing home because the services that he needed to be safely cared for at home were not offered by his private insurance through his father's job as a tugboat pilot. Medicaid covers these services, and because Gabriel qualified based on the extent of his health care needs, he was able to come home.

Although Gabriel has significant developmental delays and chronic lung diseases, his mother, Jessica, says he is "thriving at home." Jessica attributes Gabriel's progress to the Medicaid services he receives to care for his tracheotomy and gastrostomy tube and monitor his oxygen supply and ventilator. Gabriel requires close attention because he can decompensate quickly, and Jessica credits his Medicaid home nursing services with helping him stay as healthy as possible – he has only been hospitalized for illness once since his discharge. He plays outside with the support of his direct care workers, and Medicaid provided a generator that enabled him to remain at home during recent flooding and power outages instead of going to a shelter or hospital.

Jessica says the private insurance copayments for all of Gabriel's care would be "outrageous" without Medicaid. Medicaid helps with medical supplies, prescriptions, visits with seven specialists and a pediatrician, and eight outpatient occupational and speech therapy sessions per month. Medicaid also supplements Gabriel's special education services, which, for example, do not address feeding issues.

Jessica studied social work in college and says she was used to helping connect others with resources but never thought that she would be "on the other end of needing support" herself. She believes that Medicaid helps Gabriel to "reach his maximum potential" and maintain his quality of life.

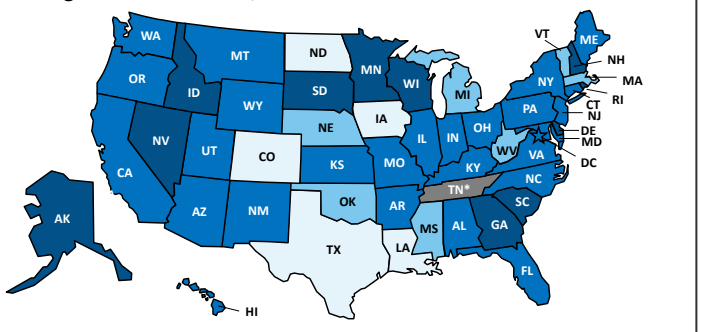


Other children with special health care needs qualify for Medicaid through a disability-related pathway. States must provide Medicaid to children who receive federal Supplemental Security Income (SSI) benefits; these children live in poor families and have disabilities that result in marked and severe limitations in their ability to function at home, at school, and in the community (Figure 12).

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 12 and 13). As of 2015, 50 states opt to cover children with significant disabilities living at home under the "Katie Beckett" pathway; this pathway

Figure 13

State adoption of optional Medicaid eligibility pathways for children with significant disabilities, 2015.



NOTES: *TN covers "medically eligible" children in households with income below 200% FPL; enrollment in this pathway is closed except for rollovers from traditional groups. SOURCE: KCMU Medicaid Financial Eligibility Survey for Seniors and People with Disabilities (2015), supplemented with states' HCBS waivers targeted to comparable populations available on CMS Medicaid.gov.

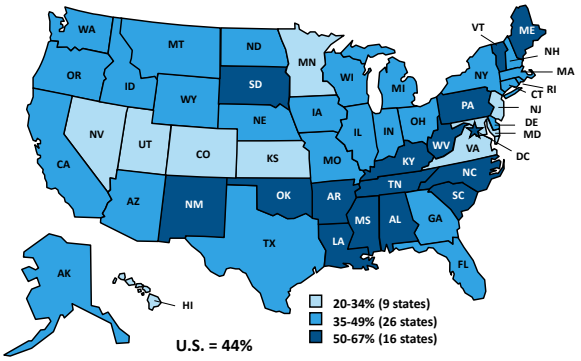
disregards parental income and assets, just as they are for children with disabilities living in an institution, which makes it possible for children with disabilities to receive necessary care while remaining at home with their families. The child's own income, up to 219% FPL ($26,460/year for an individual in 2017), 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 ($61,260/year for a family of three in 2017) (Figures 12 and 13). FOA children must meet SSI medical disability criteria, and states may charge them premiums up to 5% of gross countable family income.

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 14). Twenty-six states (26) provide Medicaid/CHIP to between 35% and 49% of the children with special health care needs living in their state. Another 16 states provide Medicaid/CHIP to between one-half and two-thirds of all children with special health care needs. For most of these children, Medicaid/CHIP is their sole source of coverage, while a smaller share have both Medicaid/CHIP and private insurance (Figure 1 and Table 2).

Figure 14

Share of children with special health care needs covered by Medicaid/CHIP, 2009-2010.

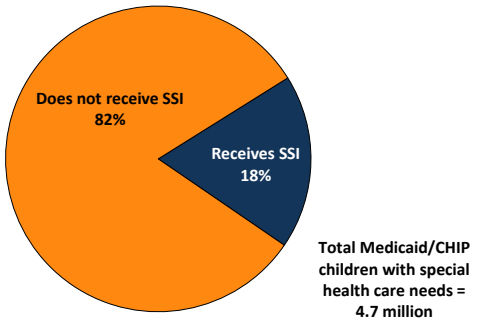


NOTE: Medicaid/CHIP also includes Medicare and Medigap. Includes children with special health care needs with Medicaid/CHIP only and Medicaid/CHIP and private insurance.
SOURCE: National Survey of Children with Special Healthcare Needs (2009-10), http://www.childhealthdata.org/learn/NS-CSHCN.

Few children with special health care needs (18%) qualify for Medicaid because they receive SSI benefits (Figure 15 and Table 3).[2] Most Medicaid children with special health care needs (82%) do not receive SSI and instead qualify for Medicaid on another basis, such as a disability-related pathway other than SSI (such as Katie Beckett or an HCBS waiver) or a poverty-related pathway based on their family's low income, as described above; most of these children are eligible based on low family income, according to other analyses.[3] Some Medicaid children with special health care needs could qualify in a disability-related

Figure 15

Medicaid/CHIP children with special health care needs by SSI status, 2009-2010.



NOTES: SSI = Supplemental Security Income. Medicaid/CHIP children who do not receive SSI include those who are eligible through another disability-related pathway (such as Katie Beckett/TEFRA or an HCBS waiver) and those who are eligible based on low family income; according to other analyses, most of this group are eligible based on low family income. Only those eligible through disability-related pathways are exempt from the BCRA per capita cap. SOURCE: Kaiser Family Foundation analysis based on published data from the 2009/10 National Survey of Children with Special Health Care Needs.

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. Under the BCRA, only Medicaid children who are eligible through a disability-related pathway would be exempt from the per capita cap on federal program financing. Medicaid children with special health care needs who are not enrolled through a disability-related pathway would be included in the per capita cap.

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 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 and Table 2). For an example, see Sam's story in Box 2 below.

Box 2: Sam, age 6, South Carolina

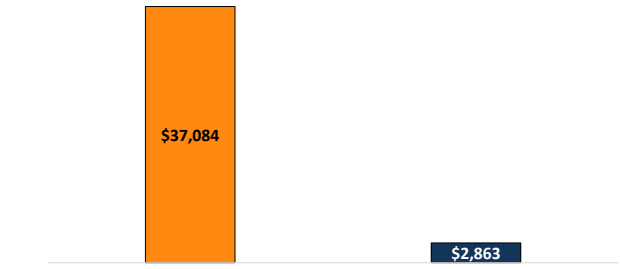
Sam was born with Fragile X syndrome, a genetic condition that causes intellectual disability. He also has mild autism. Sam's mother, Robin, noticed that he was not reaching his developmental milestones around age one. He has difficulty communicating and learning skills such as how to brush his teeth 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 Special Health Care Needs?

Medicaid children who use long-term care services are likely to have special health care needs. Medicaid spending data do not separately distinguish children with special health care needs but do identify children who use long-term care services. Medicaid long-term care services include institutional care, such as nursing facilities, intermediate care facilities for people with I/DD, and intermediate care facilities for children with mental health needs (ICF/IMDs), and community-based services, such as home health, personal care, and home and community-based waiver services. As of 2013, nearly 400,000 child Medicaid beneficiaries used long-term care services (Figure 16).

Figure 16

Medicaid spending per child enrollee, FY 2013.



NOTES: Includes children under age 21 eligible through poverty-related pathways and children under age 18 eligible through disability-related pathways. Includes fee-for-service spending for institutional services (nursing facilities, ICF/IDD, ICF/IMD) and HCBS (home health, personal care, and home and community-based waiver services).
SOURCE: KFF estimates based on analysis of data from the FFY 2014 MSIS and Urban Institute estimates from CMS64 reports. Because 2013 data was unavailable, 2011 data were used for CO and 2012 data were used RI, both having been adjusted to 2013 spending.

Annual per enrollee spending is over 12 times higher for Medicaid children who use long-term care services ($37,084) compared to those who do not ($2,863) as of 2013 (Figure 16). This reflects the greater intensity and variety of needs among children who use long-term care services as compared to children who rely on Medicaid for only acute and preventive care services.

Looking Ahead

Capping and reducing federal Medicaid funding as provided in the AHCA and BCRA may pose a particular risk to children with special health care needs and their providers. While the BCRA would exempt Medicaid children who are eligible based on a disability from the per capita cap, most Medicaid children with special health care needs are eligible based on their family's low income and not based on a disability.

Children with special health care needs rely on Medicaid for its broad scope of medical and long-term care benefits that are typically not covered by private insurance. These services keep children with intensive and chronic needs living at home with their families. In addition to filling gaps in private insurance and making coverage affordable, Medicaid is the sole source of coverage for many children with special health care needs in low and middle income families. Medicaid children with special health care needs have greater health needs and functional limitations, comparable coverage adequacy and access to care, and greater affordability compared to those with private insurance alone.

Children who use Medicaid long-term care services have higher annual 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 Medicaid services for children are mandatory under the EPSDT benefit, states can provide – and may look to scale back – some optional home and community-base 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 eligibility pathways are potentially at risk as states 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 current proposals to restructure the Medicaid program 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: Distribution of Children with Special Health Care Needs by Household Income, 2009-2010.

Table 2: Share of Children with Special Health Care Needs Covered by Medicaid/CHIP, 2009-2010.

Table 3: Medicaid/CHIP Children with Special Health Care Needs by SSI Status, 2009-2010.

Table 1: Distribution of Children with Special Health Care Needs by Household Income, 2009–2010

State	Total Children with Special Health Care Needs	Federal Poverty Level (FPL) Range:			
		0–99% FPL	100%–199% FPL	200%–399% FPL	400% FPL or more
Alabama	200,367	32%	22%	26%	19%
Alaska	19,916	16%	25%	39%	19%
Arizona	241,067	23%	21%	29%	24%
Arkansas	139,580	36%	25%	25%	12%
California	997,157	17%	16%	30%	37%
Colorado	167,524	17%	13%	38%	31%
Connecticut	139,453	15%	15%	25%	44%
Delaware	36,143	13%	26%	30%	31%
DC	18,819	35%	17%	18%	28%
Florida	606,215	23%	27%	29%	21%
Georgia	411,526	24%	23%	25%	26%
Hawaii	35,022	15%	23%	37%	25%
Idaho	53,280	23%	28%	32%	16%
Illinois	452,574	20%	19%	29%	30%
Indiana	268,717	24%	19%	35%	21%
Iowa	105,815	22%	24%	32%	21%
Kansas	120,822	18%	23%	34%	24%
Kentucky	197,916	34%	25%	25%	16%
Louisiana	207,840	28%	23%	28%	20%
Maine	53,122	27%	29%	26%	18%
Maryland	211,442	14%	16%	28%	42%
Massachusetts	261,475	14%	16%	28%	42%
Michigan	430,222	26%	24%	25%	23%
Minnesota	179,162	17%	17%	34%	31%
Mississippi	124,905	40%	24%	21%	14%
Missouri	252,734	23%	27%	28%	20%
Montana	30,571	23%	30%	31%	16%
Nebraska	61,071	16%	24%	34%	25%
Nevada	82,108	15%	25%	37%	22%
New Hampshire	54,569	11%	21%	33%	34%
New Jersey	294,346	15%	14%	29%	42%
New Mexico	70,725	30%	27%	26%	18%
New York	660,565	24%	19%	25%	32%
North Carolina	389,439	23%	28%	25%	24%
North Dakota	19,748	15%	24%	37%	23%
Ohio	483,467	28%	24%	26%	21%
Oklahoma	161,799	24%	26%	29%	19%
Oregon	119,187	19%	23%	33%	25%
Pennsylvania	469,906	21%	21%	30%	28%
Rhode Island	39,170	24%	19%	31%	25%
South Carolina	177,157	27%	26%	26%	19%
South Dakota	24,415	24%	30%	32%	14%

Tennessee	255,692	30%	25%	23%	21%
Texas	919,876	22%	24%	25%	29%
Utah	112,278	13%	26%	37%	23%
Vermont	21,790	18%	23%	37%	21%
Virginia	296,668	19%	18%	28%	33%
Washington	235,920	18%	21%	31%	29%
West Virginia	70,609	32%	25%	28%	14%
Wisconsin	201,529	18%	22%	32%	26%
Wyoming	18,194	12%	29%	33%	24%
U.S. Total	**11,203,616**	**22%**	**22%**	**29%**	**27%**

NOTES: Totals may not sum due to rounding. 100% FPL for a family of 3 in 2017 = $20,420/year. Medicaid/CHIP also includes Medicare and Medigap. SOURCE: National Survey of Children with Special Healthcare Needs (2009-10).

Table 2: Share of Children with Special Health Care Needs Covered by Medicaid/CHIP, 2009–2010			
State	Total Children with Special Health Care Needs	Share with Medicaid/CHIP Only	Share with Medicaid/CHIP and Private Insurance
Alabama	200,367	45%	6%
Alaska	19,916	25%	14%
Arizona	241,067	33%	9%
Arkansas	139,580	56%	9%
California	997,157	27%	8%
Colorado	167,524	24%	5%
Connecticut	139,453	27%	7%
Delaware	36,143	35%	7%
DC	18,819	47%	12%
Florida	606,215	41%	5%
Georgia	411,526	37%	6%
Hawaii	35,022	23%	4%
Idaho	53,280	36%	10%
Illinois	452,574	36%	8%
Indiana	268,717	34%	9%
Iowa	105,815	33%	9%
Kansas	120,822	24%	6%
Kentucky	197,916	45%	7%
Louisiana	207,840	48%	8%
Maine	53,122	49%	10%
Maryland	211,442	26%	5%
Massachusetts	261,475	24%	11%
Michigan	430,222	39%	7%
Minnesota	179,162	26%	7%
Mississippi	124,905	52%	8%
Missouri	252,734	38%	4%
Montana	30,571	36%	5%
Nebraska	61,071	28%	6%
Nevada	82,108	27%	5%
New Hampshire	54,569	31%	7%
New Jersey	294,346	23%	5%
New Mexico	70,725	43%	12%
New York	660,565	34%	9%
North Carolina	389,439	43%	5%
North Dakota	19,748	21%	12%
Ohio	483,467	35%	11%
Oklahoma	161,799	42%	8%
Oregon	119,187	29%	6%
Pennsylvania	469,906	35%	18%
Rhode Island	39,170	33%	12%
South Carolina	177,157	41%	8%
South Dakota	24,415	37%	11%

Tennessee	255,692	41%	10%
Texas	919,876	35%	6%
Utah	112,278	14%	6%
Vermont	21,790	47%	11%
Virginia	296,668	24%	5%
Washington	235,920	30%	8%
West Virginia	70,609	47%	9%
Wisconsin	201,529	30%	12%
Wyoming	18,194	35%	7%
U.S. Total	**11,203,616**	**36%**	**8%**

NOTE: Medicaid/CHIP also includes Medicare and Medigap. SOURCE: National Survey of Children with Special Healthcare Needs (2009-10).

Table 3: Medicaid/CHIP Children with Special Health Care Needs by SSI Status, 2009-2010			
State	Total Medicaid/CHIP Children with Special Health Care Needs	Share Receiving SSI	Share Without SSI
Alabama	102,630	19%	81%
Alaska	7,708	8%	92%
Arizona	102,127	17%	83%
Arkansas	90,428	30%	70%
California	348,461	18%	82%
Colorado	48,673	12%	88%
Connecticut	46,353	14%	87%
Delaware	15,291	13%	87%
DC	10,974	22%	78%
Florida	275,726	20%	80%
Georgia	175,744	18%	82%
Hawaii	9,325	11%	89%
Idaho	24,811	19%	81%
Illinois	195,785	17%	83%
Indiana	113,576	22%	78%
Iowa	44,160	14%	86%
Kansas	36,222	15%	85%
Kentucky	101,350	27%	73%
Louisiana	116,360	17%	83%
Maine	31,161	12%	88%
Maryland	65,537	*	*
Massachusetts	90,137	12%	88%
Michigan	198,266	14%	86%
Minnesota	58,084	11%	89%
Mississippi	74,998	21%	79%
Missouri	106,676	20%	80%
Montana	12,647	18%	82%
Nebraska	20,454	18%	89%
Nevada	26,536	*	*
New Hampshire	20,534	10%	90%
New Jersey	81,067	16%	84%
New Mexico	39,196	17%	83%
New York	282,675	20%	80%
North Carolina	189,666	18%	82%
North Dakota	6,512	13%	87%
Ohio	222,117	20%	80%
Oklahoma	80,877	12%	88%
Oregon	42,259	21%	79%
Pennsylvania	250,033	19%	81%
Rhode Island	17,521	15%	85%
South Carolina	87,409	19%	81%
South Dakota	11,707	*	*
Tennessee	130,388	14%	86%
Texas	373,041	23%	77%
Utah	22,447	15%	85%
Vermont	12,727	10%	90%
Virginia	87,246	26%	74%
Washington	89,744	17%	83%
West Virginia	39,422	17%	83%
Wisconsin	84,559	19%	81%
Wyoming	7,716	*	*
U.S. Total	**4,729,061**	**18%**	**82%**

NOTES: *Data not reported because estimates based on sample sizes too small to meet standards for reliability or precision (relative standard error > 30%). Omitted states are included in U.S. total. Medicaid/CHIP also includes Medicare and Medigap. SSI = Supplemental Security Income. Medicaid/CHIP children who do not receive SSI include those who are eligible through another disability-related pathway (such as Katie Beckett/TEFRA or an HCBS waiver) and those who are eligible based on low family income; according to other analyses, most of this group are eligible based on low family income. Percentages may not sum due to rounding. SOURCE: National Survey of Children with Special Healthcare Needs (2009-10).

Endnotes

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

[2] This share is based on data from the National Survey of Children with Special Health Care Needs 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 2009 and 2010. 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.

[3] 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.