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Medicaid and Children with Special Health Care Needs

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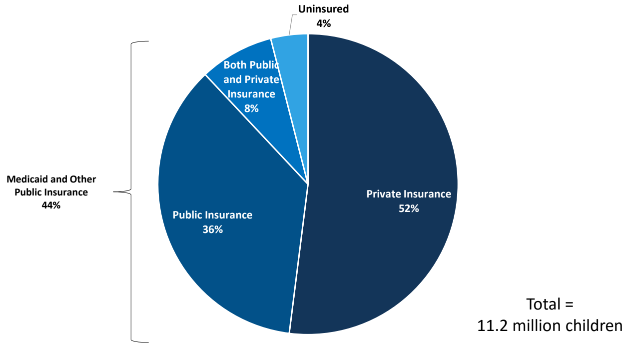
An estimated 11.2 million children, or 15% of all children in the U.S., have special health care needs, based on the most recent data available from 2009-2010. Their needs result from a range of conditions, such as Down syndrome, cerebral palsy, and autism. These children may require services such as 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.

Medicaid, CHIP, and other public health insurance programs cover nearly half (44%) of children with special health care needs (Figure 1). Public insurance, including Medicaid, is the sole source of coverage for over 1/3 (36%) of these children. Another 8% have public insurance 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

Type of health insurance among children with special health care needs



NOTES: Public insurance includes Medicaid, CHIP, 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.

President Trump and Congressional Republicans are considering proposals to restructure Medicaid financing in ways that would cap federal funding through a block grant or per capita limit approach. Under such proposals, states could gain additional flexibility to administer their Medicaid programs but with funding constraints are likely to limit the number of people covered and the scope of benefits available as states use increased flexibility to address less federal funding than under the current financing structure. These changes are particularly relevant to children with special health care needs who use services more intensively than other children.

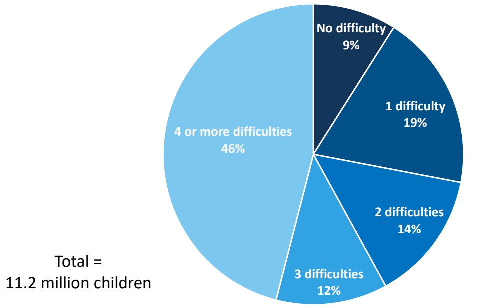
Who are Children with Special Health Care Needs?

As defined by the U.S. Department of Health and Social Services, 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.

Children with special health care needs have multiple needs, with just under half (46%) reporting difficulty functioning in four or more areas (Figure 2). Nearly seven in 10 children with special health care needs have difficulty with bodily functions, such as breathing, swallowing, or chronic pain. Over 60% have difficulty with activities such as self-care, mobility, learning, or communication. Just under 60% have emotional or behavioral difficulties.

Figure 2

Number of functional difficulties reported among children with special health care needs

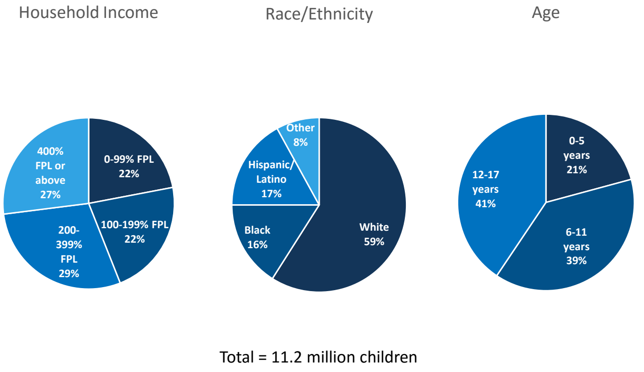


NOTE: Children reporting "no difficulty" did not have one of the 14 surveyed needs or had their needs adequately controlled by treatment. Omits responses reported as "refused," "don't know" or missing (<1%). Includes children ages 0-17.
SOURCE: National Survey of Children with Special Health Care Needs (2009-10), http://childhealthdata.org/learn/NS-CSHCN.

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 (Figure 3). About one in five (22%) resides in a household with income below the poverty level (less than about $20,000/year for a family of three in 2016). Another 22% live in a household with income between 100-199% of poverty (just over $20,000 to just over $40,000/year for a family of three in 2016). About one in three (29%) are in a household with income between 200-399% of poverty (about $40,000 to just over $80,00/year for a family of three in 2016). Nearly six in 10 children with special health care needs are white, and about equal shares are 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.

Figure 3

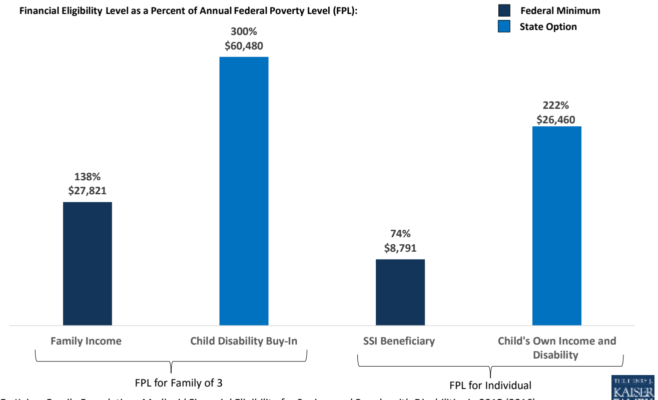
Demographics of children with special health care needs



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.

Figure 4

Medicaid Eligibility Pathways for Children with Special Health Care Needs



SOURCE: Kaiser Family Foundation, *Medicaid Financial Eligibility for Seniors and People with Disabilities in 2015* (2016), http://kff.org/report-section/medicaid-financial-eligibility-for-seniors-and-people-with-disabilities-in-2015-report/.

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

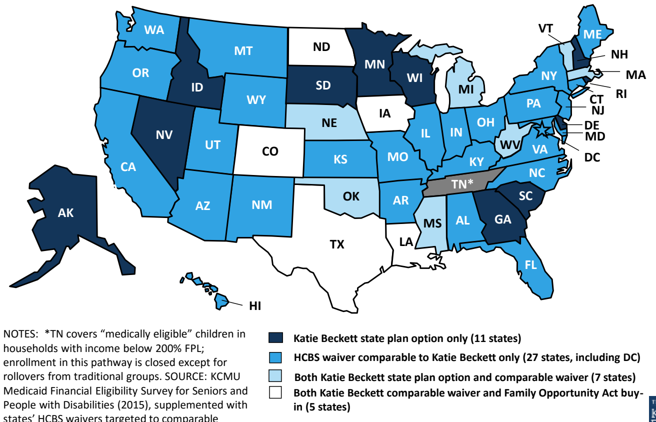
Some children with special health care needs qualify for Medicaid based solely on their family's low income. Under the Affordable Care Act, as of 2014, states must cover all children in families with incomes up to 138% of the federal poverty level (FPL, $27,821/year for a family of three in 2016) (Figure 4); although some of these children have special health care needs, their Medicaid eligibility is based entirely on their family's income, without regard to their health status. 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 is 255% FPL ($51,408/year for a family of three in 2016).

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.

Nearly all states choose to expand Medicaid financial eligibility for children with special health care needs without regard to family income through optional disability-related pathways (Figure 5). 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 ($26,460/year for an individual in 2016), 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 waiver; using a waiver allows states to cap enrollment, which is not permitted under state plan authority.

Figure 5

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.

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 ($60,480/year for a family of three in 2016) (Figure 5). FOA children must meet SSI medical disability criteria, and states may charge them premiums up to 5% of gross countable family income.

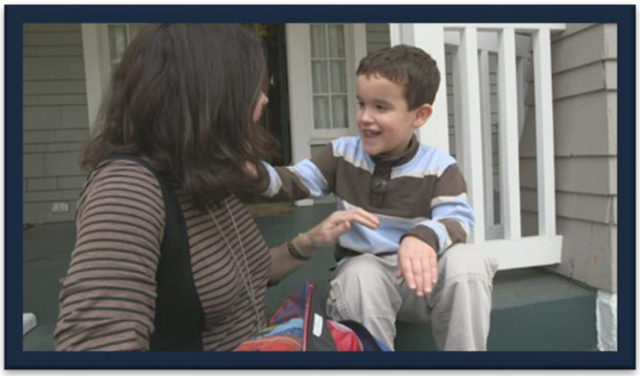
What Services Does Medicaid Provide for Children with Special Health Care Needs?

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 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. Over 1/3 of insured children with special health care needs report that their coverage is inadequate. For example, insured children may experience unmet needs for dental care, mental health services, or physical, occupational, or speech therapy. 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. Privately insured children with special health care needs may 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. For example, see Sam's story below.

Sam, age 6, South Carolina

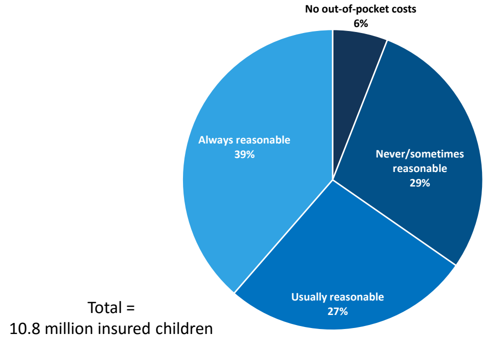
Sam was born with Fragile X syndrome, a genetic condition that causes intellectual disability. He also has mild autism. Sam's mother, Robin, noticed that he was not reaching his developmental milestones around age one. He has difficulty communicating and learning skills such as how to brush his teeth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



Medicaid makes coverage affordable for children with special health care needs. Nearly three in 10 insured children with special health care needs describe their out-of-pocket costs as "never" or only "sometimes" reasonable (Figure 6). Fifteen percent of children with special health care needs experienced delays or difficulty accessing needed care due to costs in the prior year. Out-of-pocket costs under Medicaid are generally 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. For an example of how Medicaid helps make private coverage affordable for children with special health care needs, see Gabriel's story below.

Figure 6

Burden of costs not covered by insurance reported by insured 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.

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.

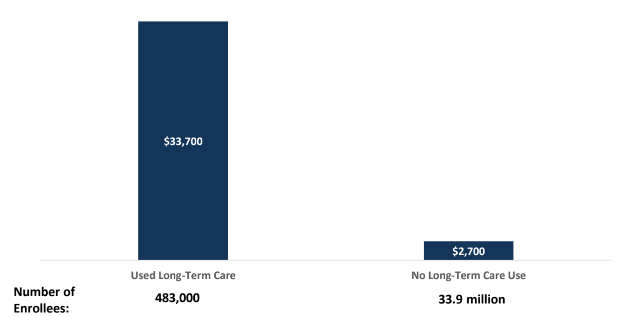
How Much Does Medicaid Spend on Children with Special Health Care Needs?

Child Medicaid beneficiaries 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 2011, nearly 500,000 child Medicaid beneficiaries used long-term care services (Figure 7).

Annual per enrollee spending is over 12 times higher for Medicaid children who use long-term care services ($33,700) compared to those who do not ($2,700) as of 2011 (Figure 7). 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.

Figure 7

Medicaid Spending Per Child Enrollee



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). FY 2010 data is used for 10 states that are missing 2011 data (FL, KS, ME, MD, MT, NM, NJ, OK, TX, and UT).
SOURCE: Kaiser Family Foundation and Urban Institute estimates based on FY 2011 and 2010 MSIS and CMS-64 reports.

Looking Ahead

Changes to Medicaid's financing structure may pose a particular risk to children with special health care needs and their providers. 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.

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 cut costly services could disproportionately affect these children by limiting their access to costly but necessary services that are unavailable through private insurance.

Medicaid also is an important source of revenue for children's health care providers, particularly children's hospitals, and reductions to Medicaid coverage, especially in children's specialty services, 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.

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