



Medicaid

How Medicaid Protects Children with Special Health Care Needs

Over 14 million children in the U.S. have special health care needs—about one in five children under 18 years of age.^{1,2} These are children who have one or more ongoing health conditions that require more than routine medical services.³ This includes children with significant conditions that range from autism spectrum disorders to vision or hearing loss, diabetes, ADD/ADHD, cancer, or cerebral palsy.⁴

While their underlying medical conditions may vary, these children share a continuing need for complex, often costly medical care that frequently requires connections across multiple clinicians and services.

Another commonality among these children is that they get their coverage through the Medicaid program. Half of U.S. children with special health care needs, nearly 7 million children, rely on Medicaid/Children’s Health Insurance Program (CHIP) for health insurance to cover some or all of their medical care. Medicaid and CHIP cover 48 percent of children with special health care needs. CHIP, which covers low-to-moderate-income children above the Medicaid income limit, is administered by states sometimes as a separate program, but often through state Medicaid programs.⁵

While Medicaid is a major source of health care insurance for all children in the U.S., covering 40 percent of children, it is particularly vital for children with special health care needs.⁶

There are many reasons why—and each of these is discussed in greater detail on the following pages.

- » Compared to private insurance, Medicaid offers more comprehensive coverage for the types of services and supplies these children need. In fact, the services and supplies many of these children need are not generally covered by private insurance at all, or coverage is very limited.
- » Medicaid makes ongoing medical care more affordable, especially for families with children who have ongoing or lifelong medical needs. By law, Medicaid cost sharing, deductibles, and premiums are low. That’s critical, given the high cost of caring for a child with special health care needs, which would bankrupt many families in the absence of Medicaid.
- » The comprehensive range of services that Medicaid offers includes services and supports that can help parents or other caregivers to continue working. Medicaid ensures a path for families to maintain income stability and avoid medical bankruptcy, risks that they might otherwise face as they care for a sick or disabled child. In that way, Medicaid supports entire families.

Both state Medicaid cuts and federal efforts to restructure or cut program spending inherently impact the health of these children, as well as their, and their families’, financial well-being.

Parents or family caregivers of children with special health care needs report more hours providing care at home, and more trouble paying medical bills, than parents or caregivers of non-special needs children.

Who Are Children with Special Health Care Needs?

The formal government definition of children with special health care needs is as follows: “children who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.”⁷ Behind that definition are millions of children and families confronting complex, difficult, and often costly long-term medical needs.

There are differences in prevalence by region, race, and ethnicity

While nearly 20 percent of all U.S. children under age 18 have a special health care need, prevalence varies somewhat between states, from a low of 14 percent in Hawaii, to a high of 25 percent in Kentucky.⁸

There is also variation by race and ethnicity. Prevalence is highest among black, non-Hispanic children, with nearly 25 percent of children under age 18 having a special health care need, followed by 20 percent for white non-Hispanic children, and 18 percent for Hispanic children.⁹

The percent of children with special needs is increasing

In 2001, 13 percent of all children were reported as having a special health care need. It is nearly 20 percent today.^{10, 11}

This increase has been attributed to a combination of factors, including medical advances improving survival

rates from congenital conditions, better diagnostics, increased awareness of the need for early intervention, parental age at birth, increasing exposure to environmental toxins, and environmental stresses associated with poverty.¹² There is no indication that the trend toward more children with special health needs is reversing.

Most have complex, and often costly, medical needs

Most children with special needs (69 percent) have complex medical conditions that cannot be managed with medication alone.¹³ They rely on multiple services to manage their health conditions, beginning with pediatric sub-specialist physicians, but often also including physical, occupational, or speech therapies; in-home nursing; comprehensive services for children with intellectual and developmental disabilities; specialized wheelchairs; and pediatric mental health care.

More than one in four such children has a condition that consistently affects their daily life—and that percent has increased in recent years.^{14, 15}

Children’s needs can place a strain on family caregivers

Not surprisingly, parents or family caregivers of children with special health care needs report more hours providing care at home, and more trouble paying medical bills, than parents or caregivers of non-special needs children. Many reported that caregiving had affected their ability to maintain a job outside their home.

- » Over 20 percent of parents/family caregivers spent five or more hours a week providing care at home;
- » 16 percent have trouble paying medical bills, compared to 9 percent for families of other children; and
- » 15 percent of parents/family caregivers reported that they had stopped working or cut back on work hours to provide care.¹⁶

As described below, all of these problems would be significantly worse if Medicaid did not provide comprehensive benefits and expanded eligibility for children with special health care needs.

Medicaid is a critical source of health insurance for these children

Medicaid/CHIP cover about half of all children with special health care needs. Most of these children live in lower income families. However, recognizing the high medical costs confronting families of children with medically complex needs and the fact that private insurance does not cover many services these children need, most states offer Medicaid eligibility to middle- and higher-income families for children with significant health issues.

Medicaid/CHIP cover nearly 7 million children with special health care needs. For roughly 1 million of those children, this coverage supplements private insurance, paying for costs and services private insurance does not.^{17,18}

- » Three-quarters of children with special health care needs live in families with incomes below 200 percent of poverty (\$41,560 for a family of 3 in 2018).¹⁹
- » Forty percent of these children are non-Hispanic white; 29 percent Hispanic; and 22 percent non-Hispanic black.²⁰

Medicaid Fills the Gaps in Private Coverage

Medicaid is so important to children with special health care needs because it is affordable for families and provides comprehensive coverage.

Medicaid covers services vital to children with special health care needs that private insurance often doesn't cover

Private insurance coverage varies across insurers, but plans generally do not cover (or offer only limited coverage for) many items critical to special needs children. Private insurance, and in particular employer-sponsored insurance, is designed around its dominant customer base: the relatively healthy working-age population and their children (also typically healthy). Private insurance is not designed with the needs of a child born with lifelong medical needs in mind. These medical needs can include round-the-clock nursing care; medical equipment, like feeding tubes, wheelchairs, catheters, and lifts; and physical, occupational, and speech therapy services (which are often limited to a set number of visits in commercial coverage). These are items that Medicaid does cover and that employer coverage usually does not.

Although the services Medicaid covers can vary from state to state, federal law requires that all state Medicaid programs cover certain services. Two of those services—early and periodic screening, diagnostic, and treatment (EPSDT) services and long-term services and supports—address the unique needs of special needs children in ways other insurance does not.

EPSDT services. All state Medicaid programs are required to cover these services for children under age 21. EPSDT services include:

Pathways to Medicaid Coverage for Children with Special Health Care Needs

In broad terms, Medicaid is the state and federally funded health care program for low-income individuals. For children with special health care needs, however, states generally offer ways to qualify for Medicaid coverage based on their disability, even if their family income is above the state's standard Medicaid cut-off. States make these options available because they recognize that private insurance often doesn't cover the services these children need, and that the expense of chronic and acute care for special needs children is beyond the means of even moderate- to high-income households.

Ways children with special health care needs can become eligible for Medicaid

Based on Family Income. Federal law requires that all states provide Medicaid coverage to children in families with incomes below 138 percent of poverty, which is \$28,676 for a family of three in 2018.²¹ Medicaid income eligibility for children varies across states and by child age, but in most states was above 138% of poverty for at least some age groups.²² Many children with special health care needs qualify for Medicaid coverage because of their family income.

Based on their Disability. There are additional programs that extend Medicaid coverage to children with special needs based on their disability.

» **Katie Beckett Programs.** This is an optional program for states—started during the Reagan administration—that has opened up opportunities for families with incomes above the Medicaid cut-off to care for severely disabled children at home and have that care covered by Medicaid. Before this option became available, Medicaid policy was to count parents' income against a child's

Medicaid eligibility if the child lived at home, but not if the child was institutionalized. Katie Beckett programs changed that. For severely disabled children, these programs base Medicaid eligibility on the child's, not the family's, income.²³ As a result, families no longer are forced to institutionalize their children in order to ensure their child has access to Medicaid services. Forty-nine states and DC have Katie Beckett programs. They can be operated as part of a state's regular Medicaid program or through a special program waiver; waiver programs can cap enrollment and create a waiting list.

» **Home and Community-Based Services (HCBS) Waivers.** This is another option for states to extend Medicaid coverage to children with special needs. Like Katie Beckett programs, this option, available under section 1915(c) of the Social Security Act, lets states disregard family income and count only the child's financial resources for Medicaid eligibility. But states electing the 1915(c) option have more latitude in setting clinical eligibility criteria, either in terms

of making eligibility broader or more restrictive. For example, some state 1915(c) programs allow children to enroll if they are "at risk" for institutional care but not necessarily qualifying for that level of care. Some states have 1915(c) programs limited to narrow clinical criteria, such as individuals (including children) with brain injuries or developmental disabilities. States can cap enrollment and create waiting lists in these programs. Twenty-eight states operate at least one HCBS waiver that is targeted at children, and most remaining states operate one or more HCBS programs that can enroll children and adults.

» **Family Opportunity Act—Buying into Medicaid.** This is also an optional program for states. It allows families with incomes below 300 percent of poverty (\$62,340 for a family of three in 2018) to buy into Medicaid coverage for severely disabled children. Families can be charged premiums up to 5 percent of income. Five states offer this option: Colorado, Iowa, Louisiana, North Dakota, and Texas.

Private insurance is not designed with the needs of a child born with lifelong medical needs in mind. Medicaid covers services that employer coverage usually does not.

- » Early and age-appropriate periodic screening (at medically prescribed intervals) to identify health conditions early. Screenings have to include an assessment of physical, mental, and emotional development; dental, hearing, and vision screenings; and other evaluations considered necessary (such as lead screening).
- » Diagnostic services when screening indicates a potential problem.
- » Medically necessary services to treat any conditions discovered, or reduce the burden of the illness. The treatment plan and medical necessity are determined on a case-by-case basis. As long as federal law allows Medicaid to pay for a service, if medically recommended it must be provided, even if it is generally not covered by the state's Medicaid program.

Under EPSDT requirements, states cannot set limits on medically necessary pediatric benefits. For example, unlike commercial coverage, states cannot limit the number of speech or physical therapy sessions they will cover, as long as they are medically necessary.²⁴ These services are essential for children with special health care needs who might require months or years of these services in order to gain or maintain function.

Long-term services and supports. Medicaid covers long-term services both in facilities and at home. This benefit includes long-term home care services, assistive technologies, nursing services, and other supports. But children using Medicaid long-term services and

supports often also have highly medically complex needs, requiring an extraordinary level of specialized care, including ventilators and/or feeding tubes. These are some of the most complex and high-cost patients in our entire health care system. Medicaid helps these children to remain living at home and helps parents of profoundly disabled or ill children to care for their children and/or keep working.

Medicaid has affordable cost-sharing and premiums for families

Federal law requires that Medicaid is provided to families with low out-of-pocket costs: cost-sharing and premiums cannot be more than 5 percent of family income.²⁵

As a result, families of children covered by Medicaid or CHIP alone are four times more likely to report that their out-of-pocket costs are always reasonable compared to those with private insurance alone (82 percent versus 19 percent, respectively).²⁶

Medicaid's financial protection is critical for families with children who have special health care needs, where medical costs are often high and long-term.

Children with Special Health Care Needs, their Families, and Medicaid

The program descriptions above regarding Medicaid law and policy show how the program provides unique support to children with special health care needs. But the real testament to Medicaid's importance is how it works for the children who depend on it and their families. On the following pages, meet Natalie and Josephine.

NATALIE, 11 YEARS OLD

Sandpoint, Idaho



Natalie is a beautiful girl, who has a smile and laugh that light up a room. Medicaid helps us provide for her—and her other siblings—as best we can.

—Jessica

Natalie is living with multiple disabilities. Her mom, Jessica, contracted cytomegalovirus, an often deadly virus, during her pregnancy. As a result, Natalie's in-utero development was profoundly impacted—she was born with cerebral palsy, has regular seizures, and is deaf. The family learned of Natalie's diagnosis when she was two-and-a-half months old.

Developmentally, Natalie is around 4-to-6 months old and, because of the severity of her condition, she requires round-the-clock care, multiple interventions and kinds of services, many of which would not be covered by private insurance. This family relies on Medicaid to ensure Natalie gets the medical services she needs to survive.

These services include access to a caregiver, durable medical equipment, and specialized therapies.



Medicaid provides a nurse to come to the house 55 hours per week, implementing a complex set of medical services. Natalie's equipment includes feeding tubes, catheters, and an oxygen concentrator, cough assist and vest machine for breaking up mucus, and nebulizer, as well as assistive devices such as a bilateral cochlear implant, standing frame, and a wheelchair. Most recently, Medicaid paid for the family to install a ceiling

track system used to safely lift and transfer Natalie in her home. She receives regular speech, physical, and occupational therapies, as well.

While Jessica and her husband are both uninsured, Natalie and her three siblings are eligible for Medicaid because of the family's income level. Says Jessica, "Natalie is a beautiful girl, who has a smile and laugh that light up a room. Medicaid helps us provide for her—and her other siblings—as best we can."

JOSEPHINE, 2 YEARS OLD

Fairfax, Virginia



Medicaid has helped Josephine thrive and stay at home.

—Samantha

Josephine was born at 24 weeks, weighing 1 pound, 12 ounces. Because she was so premature, she experienced numerous complications, including chronic lung disease as a result of severely underdeveloped lungs.

Josephine and her mom, Samantha, were initially covered through an employer-based plan, but after 30 days of continuous hospitalization following her birth, Josephine automatically qualified for institutional Medicaid, this became her secondary insurance. She remained in the hospital for the first 407 days of her life and, for much of that time, she was on different forms of respiratory support, including full intubation and ventilation.

Samantha estimates that the total cost of Josephine's care for that time was just under \$4 million.

Following her discharge, Josephine has continued to need a high level of care. Medicaid pays for the skilled nurses who help provide round-the-clock care and for the equipment that keeps Josephine alive. While she has made significant developmental gains since coming home, she

continues to require some respiratory support with the help of a ventilator, supplemental gastric tube feeds overnight, and she struggles to move around on her own due to being connected to equipment. She needs to be ventilated overnight and during



periods of the day and has a tracheotomy; she is waiting approval for a special wheelchair.

Josephine also takes several costly medications, sees nine specialists and requires multiple

therapists to aid her development. Samantha says that her physical and occupational therapists are helping her grow by leaps and bounds—with their help, Josephine can now sit up, crawl, and meet other developmental milestones that would not be possible without Medicaid services.

Samantha estimates that without private insurance and Medicaid, her monthly medical expenses would be about \$26,000.

Samantha says, “Her doctors say that she was born when she was discharged from the hospital, because that is when she began to be developmentally on track. Without Medicaid, I would have had to quit my job or put Josephine in an institution. Medicaid has helped Josephine thrive and stay at home. We are proud to say that with the help she's received through Medicaid, she is closer to being developmentally on track, and she will begin preschool in the fall of 2018, with additional accommodations.”

Medicaid provides a broad range of support for children with special health care needs, ranging from life-sustaining medical care, to therapeutic care and caregiver support.

These stories are representative of families' experiences across the country. Their stories include common themes, themes that show that Medicaid provides a broad range of support for children with special health care needs, ranging from life-sustaining medical care, to therapeutic care and caregiver support. These services are essential to keep children out of an institutional setting and to prevent financial disaster. The stories show how the Medicaid *policies* outlined above are working on the ground to support America's families.

Medicaid covers services that are not covered by private insurance. Families describe how Medicaid covers services that private insurance does not—services that are critical to the health, development, and sometimes even survival of their children. Families also mention things like feeding tubes, walkers, orthotics, home care nurses, and injections among the many services Medicaid covers that private insurance does not cover.

Medicaid keeps a child's diagnosis from destroying a family's finances. Josephine's family uses Medicaid to supplement employer-based coverage. For families like Josephine's, Medicaid covers copayments and fills in gaps in his family's private insurance coverage. Those gaps can be because a service isn't covered, or because there are limits on how often or for how long insurance will pay for the service. Medicaid extends their private insurance and covers a broader range of essential services, protecting these families from the unsustainable financial burden of having to pay thousands of dollars in annual

health care costs due to the limits of their traditional insurance. Beyond Medicaid's critical coverage for their children, parents noted that Medicaid's home nursing services have helped them avoid the financial disaster of dropping out of the workforce. That helps families stay strong.

Among the common sentiments from parents sharing stories were that they wondered how they could possibly afford to care for their child without Medicaid.

For special needs children covered by Medicaid, the themes captured in these stories are repeated over and over again. For families with children with special health care needs, Medicaid is truly a lifeline.

What Threats to Medicaid Funding Mean for Children with Special Health Care Needs and their Families

In 2017, federal efforts to radically restructure and cut Medicaid funding and repeal the Affordable Care Act failed. But that does not close the door on threats to Medicaid funding. President Trump's FY 2019 budget includes dramatic Medicaid cuts.²⁷ While that budget is not going to become law this year, it shows the administration's priorities, leaving open the possibility that some of the proposals in the budget could be taken up by Congress in the future. Serious federal threats to Medicaid are not over.

Medicaid is funded by states as well, and state funding affects the program. States facing budget shortfalls frequently look to Medicaid as an area to cut. The

complex and intensive health needs of these children mean that they cost Medicaid more to cover, and states faced with Medicaid cuts may look to cutting high-cost services as a way to save money.

Broad Medicaid cuts at either the state or federal level would put services for special needs children at serious risk.

Conclusion

Children with special health care needs are a unique population with distinctive health insurance coverage requirements. Medicaid provides them with critical support. Medicaid's EPSDT benefit ensures that kids get comprehensive services that go beyond what private insurance pays. Because of special flexibilities

in Medicaid income eligibility for children with disabilities or serious illness, for millions of families, Medicaid can be used to wrap around employer-sponsored insurance. For many children, Medicaid is literally life-sustaining. Medicaid also enables children with congenital conditions to receive medically-complex care at home so that they don't spend their childhood in a hospital or nursing home. Medicaid also protects families of children with special health care needs from financial devastation by reimbursing for major ongoing costs such as home-based medical equipment, nursing services, and physical therapy. Medicaid's comprehensive coverage of children with medically complex needs allows millions parents to keep their jobs.

Policymakers must bear in mind the millions of families with special needs children who depend on Medicaid, and the important role that Medicaid plays—a role private insurance cannot replace.

Endnotes

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¹⁴ National Survey of Children with Special Health Care Needs, 2005/2006 and 2009/2010. Available online at <http://childhealthdata.org/browse/survey/results?q=1621&r=1>.

¹⁵ In the National Survey of Children with Special Health Care Needs' 2005/06 findings, 24 percent of children with special health care needs reported that their medical condition consistently affect their daily activities; in 2009/10, that number had increased to 27 percent. This question was rephrased in the 2016 survey, so continued evaluation of the trend is not possible.

¹⁶ National Survey of Children's Health, 2016. Available online at <http://childhealthdata.org/browse/survey/results?q=4799&r=1&g=619>.

¹⁷ Families USA calculation based on Musumeci and Foutz, *Medicaid's Role for Children with Special Health Care Needs*, *op cit*.

¹⁸ Musumeci and Foutz, *Medicaid's Role for Children with Special Health Care Needs*, *op cit*.

¹⁹ *Ibid*.

²⁰ *Ibid*.

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Publication ID: MCD060618

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