

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

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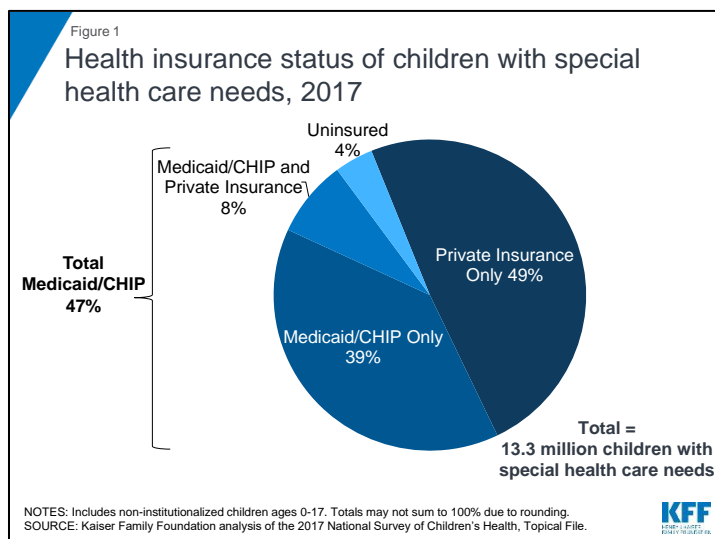
## Key Findings

**Medicaid and CHIP covered about half (47%) of the 13.3 million children with special health care needs in 2017.** These children require medical and long-term care services due to intellectual/developmental disabilities, physical disabilities, and/or mental health disabilities. Medicaid/CHIP is the sole source of coverage for 39% of these children, and another 8% have Medicaid/CHIP to supplement their private coverage. Medicaid plays a key role for children with special health care needs by making coverage affordable and covering services that private insurance typically does not. This issue brief compares key characteristics of Medicaid/CHIP-only children with special health care needs to those with both public and private insurance, private insurance only, and those who are uninsured. For example:

- **Medicaid/CHIP children with special health care needs are significantly more likely to live in low income families compared to those with private insurance only.** Over eight in 10 (83%) Medicaid/CHIP-only children with special health care needs live in families with incomes below 200% of the federal poverty level (less than \$42,660/year for a family of three in 2019), compared to less than two in 10 (17%) of those with private insurance only.
- **Medicaid/CHIP children with special health care needs are significantly more likely to have multiple health conditions and to be in poorer health compared to those with private insurance alone, with children with both Medicaid/CHIP and private insurance having the greatest needs.** For example, children with special health care needs with both Medicaid/CHIP and private insurance (50%) are twice as likely to have four or more functional difficulties compared to those with private insurance alone (25%). Medicaid/CHIP fills in gaps in private insurance and makes coverage affordable for these children.
- **Medicaid/CHIP children with special health care needs are more likely to report that their coverage is affordable compared to those with private insurance alone.** For example, those with Medicaid/CHIP only are four times as likely (78%) to report that their out-of-pocket health care costs are always reasonable compared to those with private insurance alone (19%). Over half (53%) families of Medicaid/CHIP-only children with special health care needs find it somewhat or very often hard to cover basic needs like housing or food since their child's birth, compared to a fifth (19%) of those with private insurance only.

## Introduction

Medicaid and CHIP cover about half (47%, or about 6.1 million) of children with special health care needs in the U.S. as of 2017 (Figure 1).<sup>1</sup> Box 1 below describes these children. Medicaid or CHIP is the sole source of coverage for 39% of these children. Another 8% have Medicaid/CHIP to supplement private insurance. This issue brief compares the demographics, health status, access to care, and coverage affordability of Medicaid/CHIP children with special health care needs to those with private insurance and those who are uninsured.



Medicaid plays a key role for children with special health care needs. It makes coverage affordable by limiting cost-sharing and protecting children from high out-of-pocket costs. Medicaid covers services that private coverage typically does not, including long-term services and supports and Early Periodic Screening Diagnostic and Treatment (EPSDT) services, a comprehensive benefit package of physical and behavioral health services. In addition to covering low income children, states can adopt optional pathways to expand Medicaid coverage for children with significant disabilities. More details about Medicaid's role for children with special health care needs are included in a [companion brief](#).

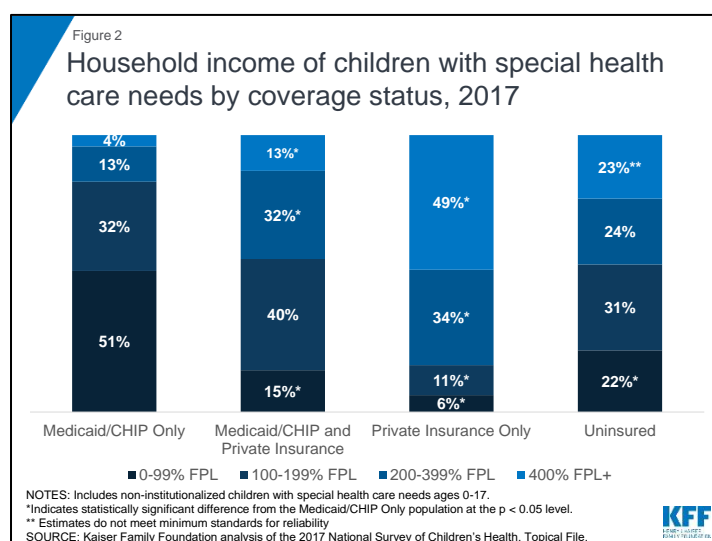
Proposals that would cap and reduce federal Medicaid funding may pose a particular risk to children with special health care needs and their providers. Although efforts to repeal and replace the Affordable Care Act (ACA) and cap federal Medicaid funding through a block grant or per capita cap were narrowly defeated in Congress in 2017, some states, such as [Utah](#) and Tennessee, recently passed legislation to seek capped federal Medicaid funding through a [Section 1115 waiver](#). While all of these state proposals may not include children with special health care needs, Tennessee's legislation does include this population.<sup>2</sup> The Centers for Medicare and Medicaid Services reportedly is considering issuing guidance to states on Section 1115 waivers that would cap federal Medicaid financing. A program-wide federal financing cap also is proposed in President Trump's FY 2020 budget.<sup>3</sup> Depending on how they are structured, these policies could have consequences on Medicaid coverage, services, and access to care for children with special health care needs.

## Box 1: Who are Children with Special Health Care Needs?

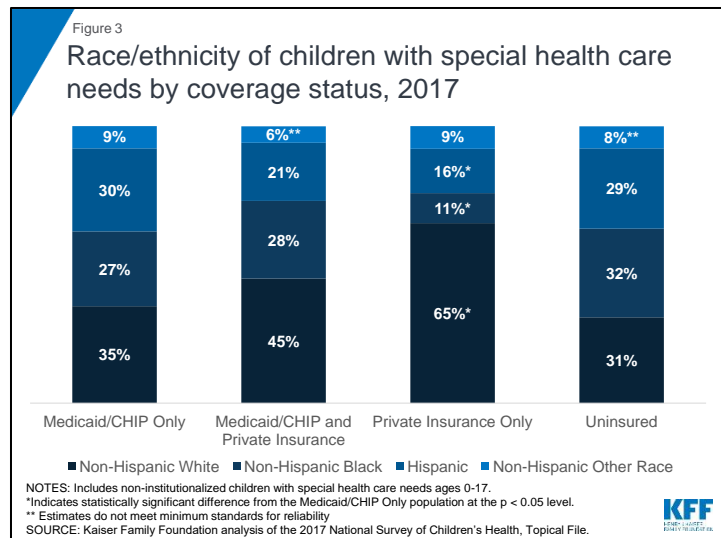
As defined by the U.S. Department of Health and Social Services, children with special health care needs “have or are at increased risk for chronic physical, developmental, behavioral or emotional conditions and also require health and related services of a type or amount beyond that required by children generally.”<sup>1</sup> Their needs arise from a range of conditions such as autism, Down syndrome, and other intellectual and developmental disabilities; 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 physical, occupational, speech or other therapies to address developmental delays. They may have difficulty with bodily functions, such as breathing, swallowing, or chronic pain; difficulty with daily activities such as self-care, mobility, learning, or communicating; and/or emotional or behavioral difficulties, such as anxiety, depression, or difficulty making friends.

## Socio-Demographics

**Among the 13.3 million children with special health care needs, those who have Medicaid/CHIP are significantly more likely to live in low income families compared to those with private insurance only.** Over eight in 10 (83%) Medicaid/CHIP-only children with special health care needs live in families with incomes below 200% of the federal poverty level (FPL, less than \$42,660/year for a family of three in 2019), compared to 17% of those with private insurance only. Over half (55%) of children with special health care needs who have both Medicaid/CHIP and private insurance live in a family with income below 200% FPL (Figure 2).



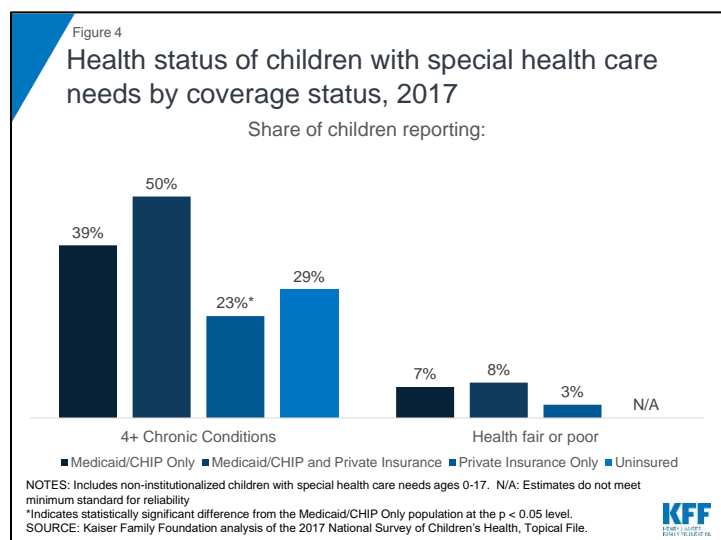
**Medicaid/CHIP-only children with special health care needs are significantly more likely to be a member of a racial or ethnic minority group compared to those with private insurance only.** Nearly two out of three (65%) children with special health care needs with private insurance alone are non-Hispanic white, compared to just over one in three (35%) Medicaid/CHIP-only children with special health care needs (Figure 3).



## Health Status

**Medicaid/CHIP children with special health care needs are significantly more likely to have multiple chronic conditions compared to those with private insurance only.** Almost 4 in 10 (39%) Medicaid/CHIP-only children with special health care needs have four or more chronic conditions, compared to less than a quarter (23%) of those with private insurance only (Figure 4).

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, diabetes, muscular dystrophy, brain injury, heart conditions, and epilepsy.



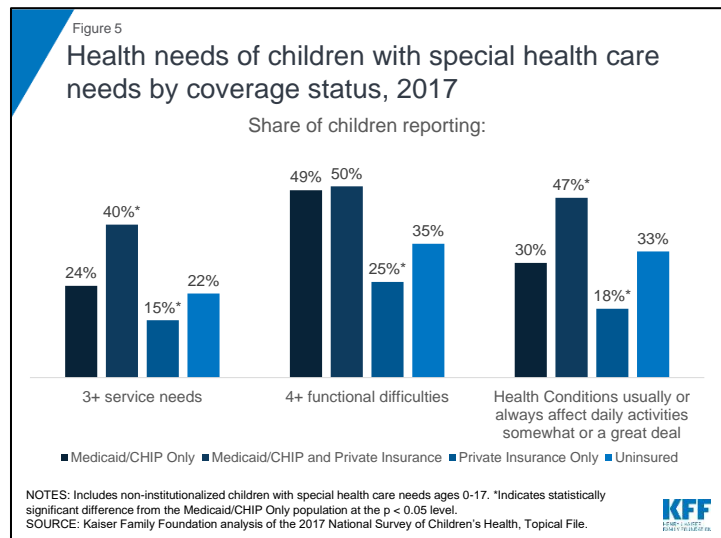
**As a result of their poorer health, Medicaid/CHIP children are significantly more likely to have multiple health care service needs during the course of a year compared to those with private insurance only.** Medicaid/CHIP-only children with special health care needs are significantly more likely (24%) to require three or more health care services, such as specialist care; prescription medication; speech, occupational, or behavioral therapy; or mental health treatment or counseling, compared to those with private insurance alone (15%) (Figure 5).

**Medicaid/CHIP children are significantly more likely to have their daily activities affected by their health compared to those with private insurance only.** Medicaid/CHIP-only children with special health care needs are nearly twice as likely (49%) to have four or more functional difficulties compared to those with private insurance alone (25%).

Functional difficulties experienced by children with special health care needs include problems with bodily functions, such as breathing, swallowing, or chronic physical pain; activities or participation, such as self-care, mobility, learning, or communicating; and emotional or behavioral factors, such as anxiety, depression, or making friends.

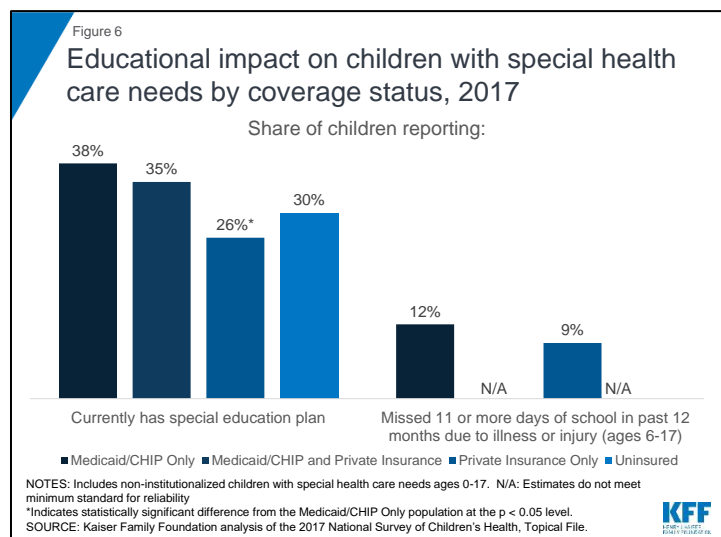
Medicaid/CHIP-only children with special health care needs are significantly more likely (30%) to have health conditions that usually or always affect their daily activities somewhat or a great deal

compared to those with private insurance only (18%) (Figure 5).



**Children with special health care needs who have both Medicaid/CHIP and private insurance have the greatest health care needs compared to other groups.** Forty percent of those with both Medicaid/CHIP and private insurance have three or more health care service needs in the course of a year. Nearly half (47%) of this group have health conditions that usually or always affect their daily activities somewhat or a great deal (Figure 5).

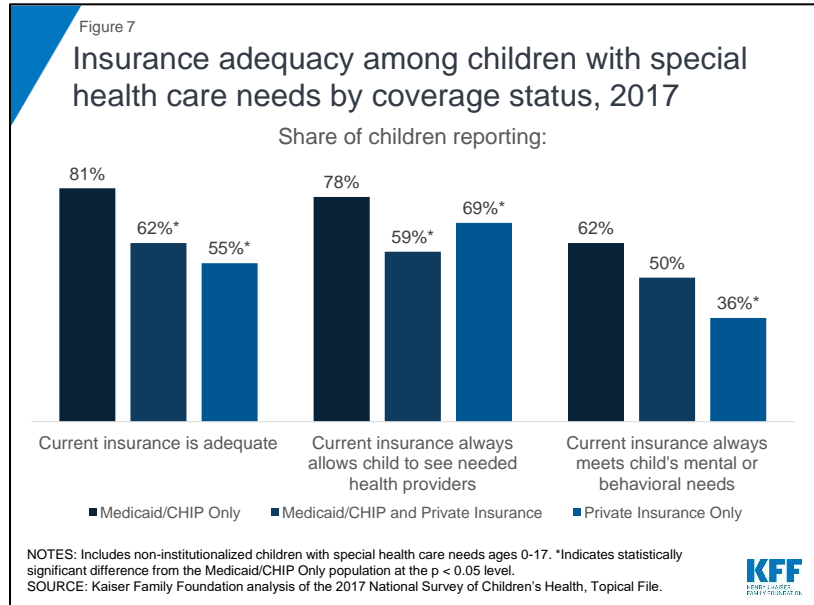
**As a result of their greater health needs and functional limitations, Medicaid/CHIP children with special health care needs are significantly more likely to have their education impacted by their health status.** Those with Medicaid/CHIP only (38%) are significantly more likely to have a current special education plan compared to those with private insurance alone (26%) (Figure 6).



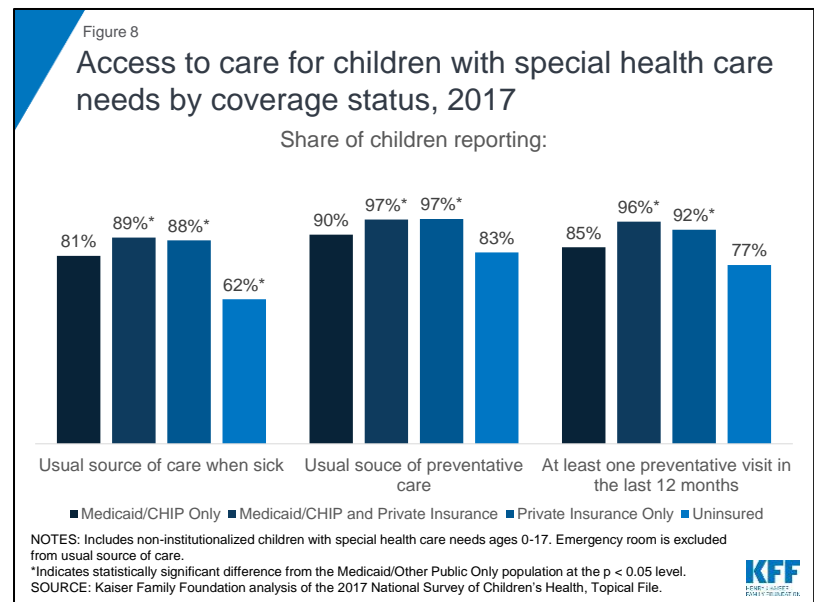
## Access to Care

**Despite their greater needs, Medicaid/CHIP-only children with special health care needs are significantly more likely than those with private insurance alone to report that their coverage**

**meets their needs.** For example, Medicaid/CHIP-only children with special health care needs (81%) are significantly more likely than those with private insurance only (55%) to report that their coverage is adequate. Just under two-thirds (62%) of children with both Medicaid/CHIP and private insurance report that their coverage is adequate, perhaps due to this group’s greater health needs. Medicaid/CHIP-only children with special health care needs also are significantly more likely to report that their insurance always allows them to see all needed health care providers, compare to those with private insurance alone (78% vs. 69%). While access to mental health services can be challenging across payers due to provider shortages, Medicaid/CHIP-only children with special health care needs (62%) are significantly more likely to report that their insurance always meets their mental or behavioral needs compared to those with private insurance alone (36%) (Figure 7).



**Medicaid/CHIP children with special health care needs have high rates of access to care; their access is not as high as those with private insurance alone but significantly better than those who are uninsured.** Over four in five (81%) Medicaid/CHIP-only children with special health care needs report a usual source of care when sick compared to 88% of those with private insurance alone. The rates for access to a usual source of preventative care (90% for Medicaid/CHIP-only vs. 97% for private insurance only) and for at least one preventative visit in the last year (85% for Medicaid/CHIP-only vs. 92% for private insurance only) are high for both groups. Medicaid/CHIP children with special health care needs also experience significantly better access to care when sick compared with those who are uninsured (Figure 8).

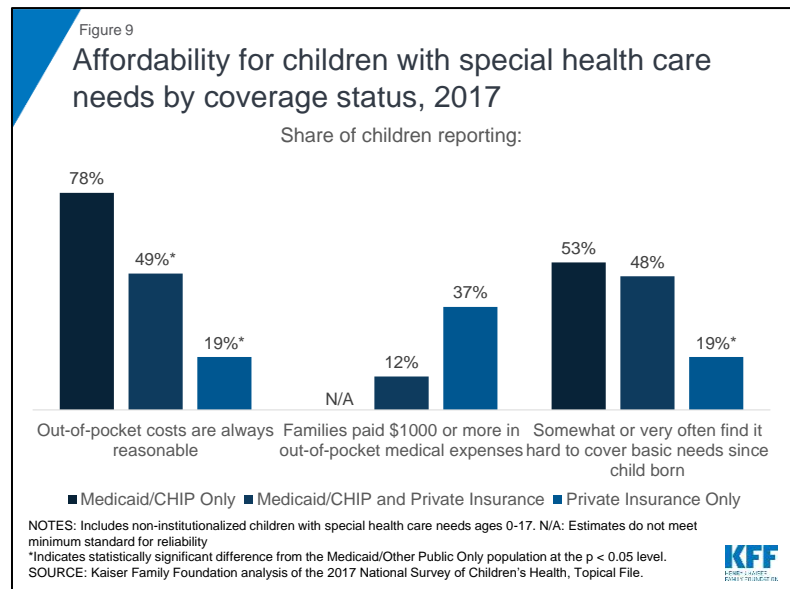


## Affordability

**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-only children with special health care needs (78%) are more than four times as likely to report that their out-of-pocket health care costs are always reasonable compared to those with private insurance alone (19%) (Figure 9).

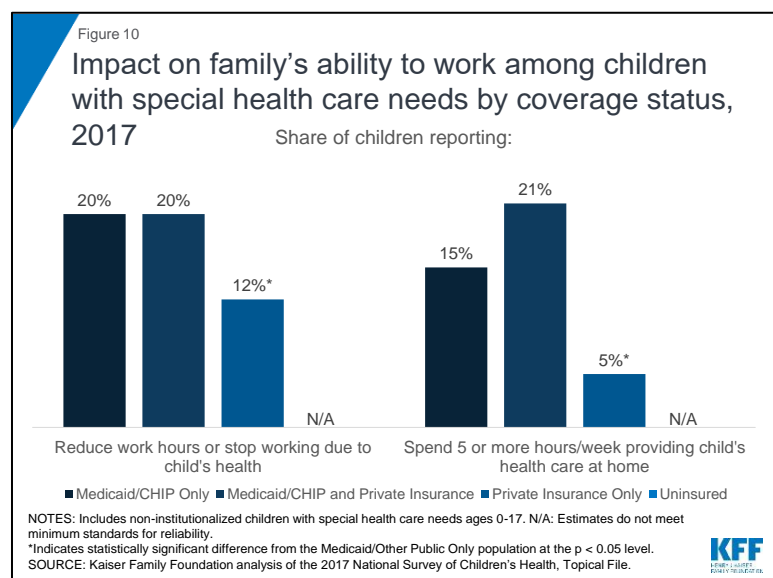
**Insurance affordability may be a particular concern for families of Medicaid/CHIP children with special health care needs because they are significantly more likely to have difficulty covering basic household needs compared to those with private insurance only.** Families of Medicaid/CHIP-only children with special health care needs are almost three times as likely (53%) to find it somewhat or very often hard to cover basic needs like housing or food since their child's birth compared to those with private insurance alone (19%)

(Figure 9). For an example of how Medicaid helps make private coverage affordable for children with special health care needs, see Gabriel's story in Box 2 below.



**Insurance affordability also 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 with special health care needs compared to those with private insurance only.**

Medicaid/CHIP-only children with special health care needs are nearly twice as likely (20%) to live in families who had to reduce their work hours or stop working due to their child's health needs, compared to those with private insurance alone (12%) (Figure 10).



**Families of Medicaid/CHIP children with special health care needs may be less able to work because they are significantly more likely to devote time to meeting their child's health needs compared to those with private insurance only.** They are three times as likely (15%) to have family members who spend five or more hours per week providing their health care at home compared to those with private insurance alone (5%) (Figure 10).

**Box 2: 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.





## Conclusion

Medicaid/CHIP children with special health care needs experience greater health needs and have coverage that is more affordable compared to those with private insurance alone. Their families are more likely to have to limit their work hours or stop working as a result of their health and more likely to devote time providing or coordinating their health care. 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 also fills in the gaps in private insurance and makes coverage affordable for children with some of the greatest health care needs. Medicaid/CHIP children with special health care needs have high rates of access to care and experience significantly better access to care compared with those who are uninsured.

Proposals to cap and reduce federal Medicaid funding may pose a particular risk to children with special health care needs because these children use services more intensively, and often incur greater costs, compared to other children. Although efforts to repeal and replace the Affordable Care Act (ACA) and cap federal Medicaid funding through a block grant or per capita cap were narrowly defeated in Congress in 2017, some states recently passed legislation to seek capped federal Medicaid funding through a Section 1115 waiver, and at least one state (Tennessee) plans to apply this cap to children with special health care needs. A key consideration for families of children with special health care needs, their providers, and policymakers at the federal and state level is how proposed changes could affect Medicaid's role for children with special health care needs.

## Endnotes

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<sup>1</sup> An estimated 13.3 million children, or 18% of all children in the U.S., have special health care needs. Kaiser Family Foundation analysis of the 2017 National Survey of Children's Health, Topical File.

<sup>2</sup> Tenn. General Assembly, Conference Committee Report on H.B. 1280/S.B. 1428 (May 17, 2019), <http://wapp.capitol.tn.gov/apps/BillInfo/Default.aspx?BillNumber=HB1280>.

<sup>3</sup> Kaiser Family Foundation, *Medicaid Financing: The Basics* (March 2019), <https://www.kff.org/medicaid/issuebrief/medicaid-financing-the-basics/>.