

Care for the Caregivers

Thousands of parents of children with special health care needs fall into North Carolina's health insurance "coverage gap."

More than 1 in 5 children in North Carolina have special health care needs – including chronic physical, developmental, behavioral, and emotional conditions. About 300,000 children in our state regularly experience moderate to severe functional limitations that can affect their education, health, and well-being.¹ For many parents, grandparents, and foster parents, caring for a child with special health care needs can be a full-time job. Unfortunately, that job is one that does not usually involve a salary or health benefits.



Financial & Health Impacts on Families

Access to health care has remained top of mind for the hundreds of thousands of North Carolinians caught in the "coverage gap." The inability to get care can have lasting impacts on individuals and families. Not having health coverage increases the likelihood that families will accrue medical debt. This can create a costly cycle that often leads to people skipping the care they need until a condition worsens and requires emergency attention.² For families caring for children with special health care needs, the impact of being uninsured can be far greater than financial, risking the health and well-being of both the parent as primary caregiver, and the child who depends on them.

What is the Coverage Gap?

A family of three that makes \$10,000/year earns too much to qualify for health insurance through Medicaid in North Carolina.

Yet they cannot get a subsidy to buy private insurance in the marketplace until they earn \$21,330.



Preventive care, mental health care, and coverage for specialized services are critical for parents who themselves provide for the care and well-being of a child with special health care needs. Research has shown that caregivers of children with special health care needs are more likely to report poor health status and experience increased rates of depression and anxiety.³

One hallmark of Medicaid includes access to preventive care and services. If North Carolina were to expand Medicaid to low-income adults, many parents taking care of children with special

Care for the Caregivers

health care needs would be able to address their own health and well-being *before* issues become those issues become severe or chronic.⁴

Since Medicaid Expansion was first allowed under the Affordable Care Act in 2014, countless studies have shown how this health coverage for low-income families significantly reduces the burden of emergency and chronic health costs.⁵ Medicaid coverage also creates a sustainable pathway to comprehensive health care that enables people to receive low-cost, preventive care.⁶

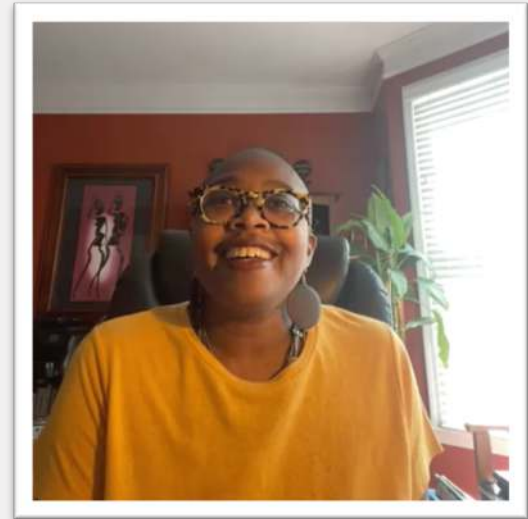
Statewide Survey Results

In June 2021, NC Child conducted a statewide survey asking parents of children with special health care needs about their access to care. In total, 194 parents of children with special health care needs responded. Respondents came from 53 different counties, including urban, rural, and suburban parts of the state.

- 20% of parents in the survey reported that they are uninsured.
- 87% of uninsured parents reported they had skipped needed health care due to cost.
- Over 60% of uninsured parents disclosed that health care issues have interfered with their ability to care for their child.

Closing the coverage gap in North Carolina would provide health coverage to approximately 600,000 currently uninsured adults. The uninsured population in our state is made up of essential workers, students, veterans, and parents, including those taking care of our some of our state's most medically vulnerable children. Expanding Medicaid would support tens of thousands of parents who care for children with special health care needs, by improving health outcomes, increasing family economic security, and making it easier for them to care for children at home rather than in an institutional setting.

Coverage Gap Stories: Candice



Candice Grant is a mother of three in Mecklenburg County. She works from home as a freelancer, and taking care of her 23 year-old son who has been diagnosed with autism, epilepsy, and kidney disease. Because she and her husband are self-employed contractors, they frequently do not have health insurance.

Mrs. Grant is a kidney transplant survivor herself, and has to take medication for the rest of her life. Her family often finds that they struggle to afford that life-saving care out-of-pocket.

"It matters to me in such an incredible sense that caregivers are made whole, so that they can be there for their children."

Care for the Caregivers

Acknowledgments

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Citations

¹ [National Survey of Children with Special Health Care Needs](#), Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. 2021.

² Zewde N, Wimer C. Antipoverty impact of Medicaid growing with state expansions over time. *Health Affairs (Millwood)*. 2019;38(1):132–8.

³ Pilapil M, Coletti DJ, Rabey C, DeLaet D. Caring for the Caregiver: Supporting Families of Youth With Special Health Care Needs. *Current Problems in Pediatric and Adolescent Health Care*. 2017 Aug;47(8):190-199. doi: 10.1016/j.cppeds.2017.07.003. Epub 2017 Aug 10. PMID: 28803827.

⁴ Jennifer C. Spencer, Alex K. Gertner, Pam Silberman. Health Status and Access to Care for the North Carolina Medicaid Gap Population. *North Carolina Medical Journal* Sep 2019, 80 (5) 269-275; DOI: 10.18043/ncm.80.5.269

⁵ Center on Budget and Policy Priorities. [The Far-Reaching Benefits of the Affordable Care Act's Medicaid Expansion](#). 2020.

⁶ Kates, Jennifer. [How the ACA Changes Pathways to Insurance Coverage for People with HIV](#). 2012.