The Heart of the Matter: Why Medicaid Is Crucial for Children With Congenital Heart Disease

Population Health Sciences

Date Posted:

Jun 13, 2025

Editor's Note: This post is part of a series exploring the role Medicaid plays in the health of children, families and communities. Our experts will examine the data, share timely research, and outline policy details related to the importance of the program for different populations. Click here to explore more posts in the series.

While Medicaid is the largest insurer of children nationwide, it plays an even more significant role in the coverage of children with chronic illnesses and complex needs, including those with asthma, autism, congenital heart disease (CHD), spina bifida and more. Nearly half of children with complex needs are covered by Medicaid (or the Children's Health Insurance Program), with many qualifying for it related to their condition. This population has high and potentially life-long health care needs, and cuts to Medicaid funding are particularly concerning for these children, their families, and doctors like me who care for them. Medicaid cuts may destabilize health care systems, increase disparities in access to prenatal care critical for early diagnosis, or further limit Medicaid provider networks, causing ripple effects that will disproportionately impact children with complex needs.

CHD is the most common birth defect in the United States, impacting 40,000 births annually. As a pediatric cardiologist, I witness firsthand the hardships families with a child with CHD face. They must ensure their children have insurance to receive life-saving care, but also suffer the consequences of missed work and the economic and emotional burden of being away from home and other children to care for their child with CHD. PolicyLab research has emphasized these hardships, highlighting the employment challenges faced by parents of children with medical complexity.

The protective effects of Medicaid for children with CHD

Between one-third and one-half of families of children with CHD experience household material hardship or financial hardship from medical bills. Our research has demonstrated that Medicaid was protective against adverse outcomes like food insecurity and medication non-adherence in families of patients with CHD who experience financial hardship from medical bills. This was in comparison to families with private insurance (private insurance plans have more variability in the robustness of coverage than Medicaid). Additionally, other PolicyLab work has demonstrated that children with public insurance, particularly children and youth with special health care needs, are less likely to experience underinsurance.

Medicaid coverage can be protective for the CHD population, both by providing adequate insurance and by protecting against financial hardship. Yet, children with chronic illnesses and complex needs require health care throughout the duration of their lives and CHD is a prime example of this. It is a life-long diagnosis, often without a definitive cure. Providing adequate care for children with CHD begins with ensuring access to prenatal care

for fetal diagnoses and continues with providing care for adults with CHD.

Uninsured infants with CHD have a three times higher mortality risk as compared to those with insurance. With over 50% of the CHD population insured by Medicaid, the program is critically important for this population. While Medicaid is protective for children, we also know that proposed policy changes to the program will weaken its ability to support children and families with CHD. Children with Medicaid with CHD already have less access to care than their privately insured counterparts, due to low Medicaid provider reimbursement rates and geographic concentration of cardiac centers. Any cuts to provider reimbursement rates, which may be one way that states react to federal budget cuts, would further exacerbate the issue of fewer providers accepting Medicaid-insured patients, increase the regionalization of care, and reduce access to life-saving treatments.

The importance of Medicaid in supporting fetal diagnosis

Medicaid plays a major role in prenatal care throughout the country, covering more than 40% of births. Though I care specifically for children after birth, the majority of my patients are identified through fetal diagnosis. Prenatal diagnosis is correlated with improved outcomes for the child, yet the rates of prenatal diagnosis vary immensely across the United States. While public insurance is associated with lower probability of diagnosis, it is still an important determinant of access to prenatal care and therefore, any changes to Medicaid coverage for pregnant people may impact early detection of CHD among some families, particularly in rural areas. This could result in more infants being born with undiagnosed CHD, leading to worse outcomes and higher health care utilization and costs.

Adults with CHD are a growing population with specialized needs

Finally, due to improved medical care and technology, children with CHD are surviving into adulthood at rapidly growing rates. This achievement represents a new, medically fragile population that requires specialized care. We know that coordinating transitions for adolescents from pediatric to adult care can be especially challenging for youth with chronic conditions. Studies have demonstrated that between 18% and 36% of patients are lost to follow up during this transition period. Furthermore, not all those who do transition to adult care are seen by the appropriate adult CHD specialists. Yet individuals who seek care at accredited adult CHD specialty centers were more likely to have Medicaid insurance, again highlighting the protective effects of the program.

A good portion of the patients I care for are Medicaid participants. Having this coverage means that my patients—infants and children who are born with CHD—receive life-saving surgeries and are increasingly surviving into adulthood. While Medicaid on its own is not enough to protect their families from all of the financial and socioeconomic hardship associated with having a child with CHD, it is a start, and a crucial part of the safety net for these families.

Avital Ludomirsky
Avital Ludomirsky
MD, MPP, MHS
Faculty Member