Secondary Medicaid: Why Privately Insured Children Rely on Medicaid, Too

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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.*

I am a pediatrician who cares for children who have been hospitalized. Most of my patients are among the 20% of children and youth with special health care needs (CYSHCN), who are more likely to be hospitalized than other children. Many have one or more common conditions, like asthma or autism. Others have rare genetic syndromes or, like, 10% of U.S.-born infants, were born prematurely. Some are getting ready to go home for the first time. For these patients, the transition from the hospital to home, while exciting, is fraught with worry.

Children with these conditions often need medical support at home, like daily medications, feeding tubes, or home-based services to live full, healthy lives like their peers. Unfortunately, getting all these essential life-saving supports covered by insurance is challenging. Even families with existing private insurance—most commonly through a parent's employer—are often surprised to learn that it may not cover needed services, such as physical therapy, medical daycare or home nursing.

Not having access to these services can result in a longer stay in the hospital; sometimes it means paying exorbitant out-of-pocket costs. It can also mean going home without services, to the detriment of a child's health and development.

As discussed in other posts in this series, children with disabilities, youth with eating disorders, or those who live in rural areas rely on Medicaid for health care coverage and access to services. In this post, I make the case for the importance of Medicaid even for CYSHCN who already have private insurance.

How secondary Medicaid works

Secondary Medicaid, also known as “wrap-around Medicaid,” means that a child has both private insurance or TRICARE (from a parent’s military service), and they are simultaneously eligible for Medicaid through non-income-based eligibility pathways available to CYSHCN. In these cases, Medicaid serves as a payer of “last resort”—only paying for services not covered by the child’s primary, private insurance.

About 1 in every 10 children with more complex health care needs is dual-enrolled in private insurance and secondary Medicaid. Many more children are likely eligible, but the complexity of enrollment and state-by-state variability make secondary Medicaid difficult to access. This may contribute to the high prevalence of underinsurance in CYSHCN, a patient population which already requires their caregivers spend significantly more time coordinating services.

Every state has at least one secondary Medicaid program that does not consider parental income when determining a child’s eligibility. This means eligible children in any state can enroll based on their disability or medical need alone. There are 4 types of programs or waivers through which states may offer secondary Medicaid: Tax Equity and Financial Responsibility (TERFA)/Katie Beckett, Home and Community Based Services (HCBS) Waivers, 1115 Waivers, and State-Based Programs.

Both between states and within a given state, these options vary in their eligibility criteria and service offerings. Some programs focus on a certain condition, while others focus on the degree of need. **HCBS** waivers are the most common and include services beyond what is typically offered by Medicaid. **TERFA/Katie Beckett** or TERFA-like waivers extend standard Medicaid coverage to include children with disabilities but may not offer additional services.

Why secondary Medicaid is so important

Secondary Medicaid can provide coverage for services that would otherwise be inaccessible to families because they are not covered by private insurance and are expensive. These services often include respite care, long-term home nursing, medical daycare, transportation to-and-from appointments, home or vehicle modifications, or equipment like adaptive seating or hearing aids. Fortunately, caregivers of dual-enrolled children are more likely to report adequate insurance coverage for their children.

Without these services, some children may need to live in institutions. Avoiding unnecessary, expensive and damaging institutionalization is what first prompted the development of secondary Medicaid waivers in the 1980s, named after a young patient named Katie Beckett.

Potential cuts to Medicaid would impact access to important services and/or drastically increase out-of-pocket costs for CYSHCN, including among families with employer-sponsored insurance. Having these services in place also enables parents to retain their own employment and the source of their primary health insurance.

When a child has special health care needs, secondary Medicaid supports families of all income levels. My patients rely on this coverage to safely go home from the hospital—and hopefully, stay home—where they can live the full lives they deserve.

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