# H.R. 1 Complicates Coverage Transitions for Youth With Special Health Care Needs

Adolescent Health & Well-Being

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*Editor's Note: This post is part of our* ***Blind Spots series****, exploring how current and potential future policy changes will affect children, families, and communities, and what can be done to mitigate harm.*

All young people deserve consistent access to supportive and inclusive health systems and social supports that meet their unique needs. However, many adolescents lose access to health insurance coverage when they become adults, resulting in disruptions in their routine care.

At the same time, many young adults who qualify for supports like Medicaid and the Supplemental Nutrition Assistance Program (SNAP) don't consistently receive them—often due to administrative hurdles. The 2025 budget reconciliation bill, or H.R. 1, adds new work reporting requirements and more frequent eligibility checks that may lead to more coverage interruptions. For youth with special health care needs (YSHCN), even brief gaps can disrupt medication regimens, specialist care and monitoring.

As health researchers who study the challenges young people, particularly those with special health care needs like sickle cell disease (SCD), face as they become adults, we are concerned these changes will add new hurdles at a pivotal moment in young adults' lives. In this post, we explore these changes and what they could mean for the youth we serve.

## Why Coverage Gaps Hit Youth With Special Health Care Needs Harder

YSHCN rely on consistent access to specialists, medications and monitoring to manage their chronic conditions. For these young people, gaps in coverage during their transition from pediatric to adult care can mean that a manageable health condition could quickly become difficult and costly to control.

This transition is riddled with additional systems-level considerations for YSHCN. Adult care is often not structured to provide the same level of coordinated, multidisciplinary support available in pediatric settings. Insurance coverage is often inconsistent. Research shows that uninsurance is about three times greater among young adults with disabilities compared to youth without disabilities. Together, these factors can contribute to disrupted care, greater reliance on emergency departments, and worse health outcomes.

## Sickle Cell Disease and Coverage Transitions in Young Adulthood

A disease that around 100,000 primarily Black and Hispanic Americans live with, SCD has serious implications for these individuals' life chances. PolicyLab research finds that the transition to adult care and coverage further impacts how youth with SCD engage with care.

Our research with the COMETS project has explored how these transition-related challenges unfold for young adults with SCD seeking health care in adult settings.

Beyond the baseline difficulties of navigating this transition to adult care, many young adults with SCD also encounter stigma in adult care settings, particularly around pain management, requiring them to advocate for themselves. Young people who experience marginalization in health care spaces may find it difficult to relinquish their relationship with a trusted pediatric provider and to find an adult provider who can provide consistently affirming and competent care.

In another PolicyLab study, caregivers, pediatricians, and adult providers of young adults with SCD all emphasized that barriers to insurance coverage are one of several factors strongly influencing patients' ability to engage in care. Participants also described how insurance coverage and access to care indirectly shape the transition and transfer process by affecting the readiness of patients, caregivers and providers. These findings align with prior work suggesting that successful transition to adult care depends not only on the readiness of individual young adults and care teams, but also on the equity of the surrounding health system.

## How H.R. 1 Could Complicate Coverage Transitions for Young Adults

The process of moving from pediatric to adult-centered health care, typically occurring between the ages of 18 and 21, requires young people to independently manage their health care for the first time. This can be an exciting but overwhelming process as young adults learn and practice skills like identifying and building relationships with new providers, communicating their medical history, navigating transportation to and from health care appointments, and coordinating insurance coverage, to name a few.

Simultaneously, many young adults must also meet and navigate new eligibility requirements for public benefit programs like Medicaid and SNAP as they move out of their parents' home. These benefits have meaningful short- and long-term payoffs: insurance coverage supports consistent engagement in care and overall well-being, and cash and food assistance can help stabilize basic needs that make it easier to stay on track with school or work.

### *Medicaid*

H.R. 1 changes eligibility and enrollment requirements for some of these programs starting in 2027. For example, some young adults will need to report work, school, or volunteer activities to get or keep their Medicaid coverage or complete necessary administrative processes to qualify for a medical frailty exemption to get or keep their Medicaid coverage. On top of this, eligibility will be checked every six months for most adults, rather than the previously established yearly review.

These changes could have serious implications for young adults with chronic conditions like asthma or SCD who may experience losses in coverage, delayed care and problems accessing medications due to the increased administrative burden. This new provision is particularly concerning since young adults are already more likely than other age groups to be periodically uninsured.

### *SNAP*

Separately, starting in the fall of 2025, H.R. 1 also revised the SNAP program to add a three-month month time limit on benefits if young adults do not meet the existing work requirements. But young adults are more likely to have variable work hours and relocate frequently, complicating their ability to meet reporting requirements and access benefits. Over half of eligible young adults currently miss out on benefits they qualify for.

## What Health Systems & Communities Can Do for Young Adults in Transition

Our research points to clear opportunities to mitigate harm. Through the COMETS project and other research with youth with other special health care needs, like type 2 diabetes, we are learning that successful transitions require coordinated support at many levels. Supports that address the structures and systems of power that make it challenging to ensure care continuity for young people are particularly important.

Health systems, pediatric and adult providers, families, and community partners play a role in successful transitions to adult care. Meaningful actions include investing in structured transition programs, integrating community-based support, and prioritizing continuity of coverage wherever possible.

Ultimately, what we know and are continuing to learn is that young people do their best when decision-makers design systems around their needs. Ensuring stable coverage, coordinated care, and early preparation for transition is essential to supporting adolescents and young adults with chronic conditions as they move into adulthood and may help buffer the potential harms of the major policy changes coming to critical public programs.

## Stats Atwood
## PhD, MA

Stats Atwood
PhD, MA
Email: atwoods@chop.edu

## Tanisha Belton
## DrPH, MPH

### Senior Manager of Research Initiatives

Tanisha Belton
DrPH, MPH
Email: BeltonT@chop.edu