Children's Hospital of Philadelphia PolicyLab

What Coverage Uncertainty Means for Young Adults With Type 2 Diabetes

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.*

Emerging adulthood, or the period between ages 18 and 29 years, is a life stage defined by changes: new schools, new jobs, new housing and—for adolescents and young adults with chronic disease—new responsibilities managing all aspects of their health.

Emerging adults need access to health care and coverage that will support them and their quickly changing needs, including as they age out of pediatric and into adult care. But navigating these changes while managing a chronic disease like Type 2 diabetes presents a range of challenges, particularly in the context of federal

policy changes to supportive programs like Medicaid.

As a health services researcher and a physician trained to care for both children and adults who cares for young people with Type 2 diabetes, I am watching the forthcoming changes to Medicaid eligibility with an eye to my patients and my research.

I am both a general pediatrician and an adult diabetologist. In primary care pediatrics, I care for youth with obesity, prediabetes, and some who have developed Type 2 diabetes. In my adult diabetes practice, I care for emerging adults with Type 2 diabetes, many of whom unfortunately already face complications from the disease, such as dyslipidemia, nephropathy and peripheral neuropathy.

In this post, I describe trends with youth-onset Type 2 diabetes, how forthcoming changes to Medicaid may impact youth with chronic conditions, including Type 2 diabetes, and what I'm hoping to learn through my research.

The Rising Threat of Type 2 Diabetes in Youth

Type 2 diabetes used to be a disease we associated only with adults. Unfortunately, now we are seeing it at much younger ages. Youth with Type 2 diabetes require insulin and develop complications such as kidney disease, diabetic retinopathy, and neuropathy, sooner than adults with Type 2 diabetes, if they do not get the care they need. This can lead to limb amputation, blindness, kidney failure and death.

While the overall prevalence remains low, it is rising rapidly, with 0.34 cases per 1,000 U.S. youth in 2001 nearly doubling to 0.67 cases per 1,000 youth in 2017. When broken down by demographic factors, there is a disproportionate impact on low-income youth, racial/ethnic minorities, and older adolescents, with the most cases among Black, Hispanic, Native American, and Asian/Pacific Islander youth between the ages of 15-19.

Youth-onset Type 2 diabetes is an especially aggressive form of diabetes. It is more severe than Type 2 diabetes that adults develop. However, if properly treated, including through regular care and a chronic disease management plan, youth who develop Type 2 diabetes can live long and full lives, making it all the more critical to ensure that we support them through what can be difficult transitions in young adulthood.

Medicaid Changes and Young Adulthood

Most youth who develop Type 2 diabetes do so in late adolescence, just before the transition from pediatric to adult care, when health care coverage can change. Upcoming changes to Medicaid eligibility stand to make that transition in coverage even more challenging, with potential for serious health consequences.

By January 2027, to enroll and maintain eligibility in states that have adopted Medicaid expansion, individuals age 19 and older must report work, school, or volunteer activities to get or keep their coverage. There are certain exemptions defined for Medicaid work reporting requirements, including for those defined as 'medically frail' and having special medical needs. However, states are still working on their definitions and ways of identifying those eligible for these exemptions as they roll out these new requirements. So there's much that remains unclear, including what this all means for those with Type 2 diabetes.

The additional administrative step of reporting participation in work or school is likely to result in loss of coverage for many, especially young adults who may be newly navigating Medicaid enrollment as adults. Many factors may contribute to their difficulties in managing these steps, including lack of awareness of this new policy, limited experience with bureaucracy, lack of stable employment, and housing mobility.

Even before these changes to Medicaid go into place, research shows that many emerging adults with Type 2 diabetes are lost to follow up in the transition from pediatric to adult care. The SEARCH for Diabetes in Youth

study found that 15% of youth with Type 2 diabetes leave pediatric care without establishing adult care. The TODAY2 Study found that two years post-transition, roughly one-third of participants reported not attending outpatient adult diabetes visits.

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The changes to Medicaid eligibility make supporting the transition to adult care even more critical for youth with chronic conditions, including Type 2 diabetes.

Community Health Workers as a Bridge to Adult Care

In my work as an adult diabetologist, I care for patients who have required limb amputations and hemodialysis for kidney failure as early as their 30s. Many were cared for in emergency departments or urgent care settings for years after leaving pediatric care and before establishing care at an adult diabetes center or with an adult primary care practice. During this time, they went without necessary medications and screening exams for complications, and unfortunately many experienced major organ damage because of this lapse in care.

Community health workers (CHWs) are members of the health care team who can support emerging adults in the transition to adult care. There is a large body of evidence that CHWs can improve diabetes outcomes in adults, but little work has been done evaluating the impact of CHWs on emerging adults or in the transition to adult care.

Given the grave consequences of Type 2 diabetes going untreated, and the promise of CHWs as a way to link pediatric and adult health systems and ensure appropriate adult follow up care is established, I designed a study to test whether utilizing CHWs could improve transfer from pediatric to adult care for emerging adults with Type 2 diabetes.

In this study, emerging adults with Type 2 diabetes who are transitioning out of pediatric care are randomized to either continue with usual care or be linked with a CHW to support their transition to adult care. To assess the impact of the CHW program, we'll measure whether young people successfully transfer care from a pediatrician to adult provider; the level of distress associated with their diabetes; how ready they feel to make the transition; and how well-controlled their blood sugar levels are. The program may set them up for success in ongoing management and screening for complications from this serious disease and may help prevent significant morbidity and mortality.

We will also interview participants and care team members to understand the barriers and facilitators to implement this CHW program to inform scaling up the program in the future for other patient populations.

As youth-onset Type 2 diabetes continues to emerge as an epidemic, more affected young adults will face the transition from pediatric to adult care and coverage in a rapidly shifting policy environment. This presents both challenges and opportunities. To understand the challenges, we are adding new questions to our research to understand how changes to programs like Medicaid are affecting young people.

Navigating an Uncertain Future

Creating a program that helps link young adults with Type 2 diabetes with adult care is a potential opportunity but also requires us to address policy questions such as payment policy for community health workers.

We're hopeful to add to the body of work focused on easing the transition from pediatric to adult care and to do so in the context of this changing policy environment.

Ensuring that young adults maintain coverage and are not lost navigating our increasingly complicated health systems will allow them to have more healthy years ahead of them, free from preventable complications. As states implement upcoming changes to their Medicaid programs, amid the many demands on them, there are also best practices and strategies to consider that may help support coverage for young people as they transition their Type 2 diabetes care.

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