

TRANSITIONING TO ADULthood: UNIQUE HEALTH CARE CHALLENGES FOR YOUTH WITH INTELLECTUAL/DEVELOPMENTAL DISABILITIES

For the 15 percent of adolescents who have intellectual/developmental disabilities (IDD),¹ transitioning to adulthood can present unique challenges to accessing necessary health care. These young adults are simultaneously leaving the protections of the education and pediatric health systems while expected to make health care decisions independently. These changes can lead to reduced access to essential health services, medications and equipment, and result in poor health outcomes and social isolation in young adulthood and beyond. Additionally, their caregivers are often forced to leave the workforce to make up for the loss of these supportive services and provide full-time care.

PolicyLab researchers have identified specific barriers facing this population and recommended actions that health systems and policymakers can take to help address them. The challenges outlined in this document reflect the patient's journey through the transition process, from gaining adequate coverage, to handling clinical encounters in adult settings, to accessing long-term services needed to maintain as much independence and quality of life during adulthood as possible.

CHALLENGES TO ACCESSING HEALTH CARE FOR YOUNG ADULTS WITH IDD

- **When it comes time to make their own health-related decisions, youth with disabilities may not receive necessary decision-making support.** Few pediatric health systems routinely assess whether adolescents with IDD can make their own health care decisions or will require legal guardianship, and providers often struggle to connect them with appropriate legal resources when needed.
- **Adult Medicaid plans are not as comprehensive or widely accepted as children's Medicaid plans.** Medicaid for children covers all services deemed medically necessary, but transitioning to adult Medicaid plans is not automatic and may discontinue coverage for therapies that had been provided in pediatric health care and school settings. Additionally, fewer adult providers accept new Medicaid patients.²
- **When coverage is available, identifying adult providers can be difficult.** Many adult providers lack enough formal training, comfort and time to adequately assess and treat young adults with IDD. This process is especially challenging for the nearly 35 percent of young adults with IDD who also have a mental health condition given the limited availability of psychiatric services.³
- **Limited services in adult settings may prevent young adults with IDD from receiving necessary tests or treatments.** Children's hospitals offer coordinated sedation and general anesthesia services as well as psychologists to help children tolerate stressful but necessary tests and therapies, such as MRIs and catheter placements.⁴ Adult care settings rarely provide these services.
- **Most states have decades-long waitlists for community-based, long-term care services that many young adults with IDD need once they leave high school.**⁵ Individuals with IDD are often dependent on caregivers their entire lives, require assistance with daily activities (such as toileting or preparing meals) and have limited verbal and social skills. Excessively long waitlists for community-based, long-term care services can force many of these individuals into institutional settings or require their parents to leave the workforce to care for them full-time.

Eugene's Story



My brother, Eugene, is 35 years old and enjoys traveling and being entertained by his young nieces and nephews. He also has a profound intellectual disability, seizures and severe nearsightedness. He doesn't speak, and he needs my parents' help with nearly all aspects of daily care—toileting, bathing, walking. Despite the fact that my father, my sister and I are all doctors, navigating the health care system when Eugene turned 21 was extremely difficult. We were lucky that his school and pediatricians let us know early about our state's developmental disability registry, so that when Eugene turned 21 and left school he could attend an adult day program. Many other families we knew were not able to get this type of care. However, even with the registry, **we had a hard time finding an adult primary care doctor, neurologist, psychiatrist and ophthalmologist who would take Medicaid.** This resulted in higher costs—more than \$250 for most psychiatry visits—and delayed care as we were unable to find an ophthalmologist who could sedate Eugene for eye exams. One day, Eugene suddenly couldn't see. We took him to the hospital and doctors discovered that both of his retinas had detached. Only part of his eyesight was restored. **These consequences may have been avoided if he had access to adequate health care and coordination services to help meet his unique needs.**

—Dr. Sophia Jan

RECOMMENDATIONS FOR HEALTH CARE SYSTEMS

Health care systems can help to ease the burden of transition into adulthood for young adults with IDD.

All health care settings should:

- Routinely assess whether adolescents with IDD can make their own medical decisions or indefinitely need caregiver support
- Develop medical–legal partnerships to work directly with patients and families undergoing the guardianship process, and develop clear pathways for providers to use when facilitating legal aspects of medical decision-making
- Help register individuals for state IDD services at the time of diagnosis to secure a spot on long waitlists

Adult health care settings should:

- Offer sedation services to patients with IDD for common procedures and tests that patients without IDD can generally tolerate without sedation
- Help coordinate procedures and tests across different treatment teams to minimize sedation or general anesthesia
- Provide psychological services to help adult patients cope with difficult clinical experiences
- Ensure that their providers, including mental and behavioral health providers, are trained on best practices for caring for patients with IDD

RECOMMENDATIONS FOR POLICYMAKERS

Policymakers can also take steps to support health systems and providers in offering the best possible care to all people with IDD.

State Medicaid directors should:

- Identify ways to facilitate a seamless transition to adult Medicaid managed care plans for youth with severe disabilities
- Extend habilitative services—services needed to maintain function in daily life—as part of their guaranteed adult benefits for young adults with IDD who depend on such services to minimize loss of function and maintain their ability to participate in school and employment

Federal policymakers should:

- Consider the already excessive waitlists for long-term adult services when shaping any Medicaid reforms that could impact coverage and availability of such services

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The mission of PolicyLab at Children's Hospital of Philadelphia (CHOP) is to achieve optimal child health and well-being by informing program and policy changes through interdisciplinary research. PolicyLab is a Center of Emphasis within the Children's Hospital of Philadelphia Research Institute, one of the largest pediatric research institutes in the country.

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