

**Navigating the Transition to Adulthood:
How Autistic Youth Confront Healthcare Coverage Challenges**

A Commentary Essay

Kaustubh Dilip Pachpande

Northeastern University

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Professor Barry Wolfeld

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Audience Statement: This commentary essay addresses policymakers and advocacy groups involved in shaping policies and initiatives concerning autism and youth empowerment. It aims to provide insights into the healthcare coverage challenges faced by autistic youth during their transition to adulthood and the implications of inadequate insurance coverage on their access to essential services. Furthermore, this essay seeks to advocate for comprehensive reforms to improve access to support systems and healthcare services.

The transition from adolescence to adulthood is a pivotal period filled with uncertainties and opportunities. Autistic youth, however, face unique challenges during this critical phase of life. As they navigate this journey, one significant factor that profoundly impacts their transition is the accessibility and coverage of healthcare services, particularly through government-funded programs like Medicaid and Medicare. In this commentary essay, I aim to delve into the complexities of how Medicaid and Medicare plans affect the support systems available to autistic youth during their transition to adulthood.

Annually, more than 50,000 young individuals diagnosed with autism spectrum disorder (ASD) transition into adulthood in the United States (Malik-Soni et al., 2021). Autistic adults face a range of health issues, spanning from physical conditions like heart disease to mental health challenges such as social disengagement, depression, loneliness and anxiety. Moreover, adults with autism spectrum disorder (ASD) face a heightened risk of premature mortality, with an average age of death at 54 years, contrasting with the general population's average lifespan of 70 years (Malik-Soni et al., 2021).

Although research into interventions aimed at enhancing health outcomes in autistic adults is currently emerging, evidence suggests that healthcare barriers persist, indicating that the existing healthcare services, physician training and funding are insufficient in meeting the needs of this population. Challenges faced by individuals with Autism Spectrum Disorder (ASD) during the transition age (16-25) include the absence of or incomplete implementation of

healthcare transition (HCT) services, ambiguity surrounding the suitable utilization of HCT services for higher functioning individuals, insufficient physician understanding of healthcare requirements specific to individuals with ASD, and a shortage of services coupled with limited insurance coverage to address mental health comorbidities (Malik-Soni et al., 2021).

Medicaid and Medicare are vital healthcare programs in the United States, providing essential coverage to millions of individuals, including children, adults, and seniors. While both programs offer critical support, their impact on autistic youth transitioning into adulthood varies significantly, often presenting both opportunities and challenges.

Medicaid, which operates through a collaboration between federal and state entities, assists in covering medical expenses for individuals with restricted income and resources, which includes essential services for individuals with disabilities like autism (U.S. Department of Health and Human Services, 2022). For autistic youth and their families, Medicaid can be a crucial source of support, covering a wide range of services, including medical care, therapies, behavioral interventions, and assistive technologies. However, despite its extensive coverage options, while the federal government establishes overarching guidelines that all state Medicaid programs must adhere to, individual states administer their own programs. As a result, eligibility criteria and benefits can differ significantly from one state to another (U.S. Department of Health and Human Services, 2022). This leads to inequalities in accessing healthcare for autistic youth across different regions. Eligibility criteria, service limitations, and provider networks may differ significantly, influencing the quality and comprehensiveness of care available to autistic individuals transitioning into adulthood. Additionally, navigating the complex Medicaid enrollment process can pose challenges for families, particularly those with limited resources or language barriers, potentially hindering their ability to access timely and appropriate care for their autistic child.

Furthermore, recent research indicates that new programs implemented by states to serve autistic individuals are often focused on younger age groups, not adequately addressing

the rise in autistic youth transitioning into adulthood (Shea et al., 2021). Unlike children's services, which are often covered comprehensively under Medicaid's Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) program, adult services may be subject to stricter eligibility criteria and coverage limitations. This transition can disrupt continuity of care and access to essential services, leaving autistic youth vulnerable to gaps in care and support during this critical period of transition. For individuals with autism, even brief gaps in healthcare coverage during childhood or adolescence can have a significant impact, because their healthcare requirements are chronic and breaks in services could heighten the likelihood of crisis situations (Shea et al., 2019).

Under Medicaid, states have the flexibility to utilize waivers to provide tailored benefit packages to a specific group of Medicaid recipients, limit enrollees to a designated network of healthcare providers, or expand coverage to populations not explicitly outlined in Medicaid regulations (Waivers, n.d.). This flexibility can significantly impact the healthcare experiences of autistic youth transitioning into adulthood. For instance, living in a state with Medicaid waivers has been linked to a significant decrease, sixfold or more, in the likelihood of autistic adolescents disenrolling upon entering adulthood., highlighting the importance of policy decisions in ensuring access to care. This underscores the correlation between having insurance and experiencing fewer unmet healthcare needs, potentially leading to reduced utilization of inpatient and long-term care services and associated expenses (Carey et al., 2023).

Similarly, Medicare, the federal health insurance program mainly designed for individuals aged 65 and above, plays a role in shaping the healthcare landscape for autistic youth transitioning into adulthood. While Medicare eligibility is mainly based on age or disability status, individuals with disabilities, including autism, may qualify for Medicare coverage under certain circumstances, particularly if they receive Social Security Disability Insurance (SSDI) benefits. Social Security Disability Insurance (SSDI) offers monthly financial assistance to individuals

whose disabilities prevent or restrict their ability to engage in work where after someone has been receiving SSDI for 24 months, they are automatically enrolled in Medicare (Disability | SSA, n.d.). However, similar to Medicaid, Medicare's coverage of services for autistic youth may be limited and may not always meet the diverse and evolving needs of this population.

Moreover, the interplay between Medicaid and Medicare can further complicate the healthcare landscape for autistic youth transitioning into adulthood. Many autistic individuals may be dually eligible for both Medicaid and Medicare, known as "dual-eligible" individuals. While dual eligibility may offer certain advantages, such as expanded coverage options and reduced out-of-pocket costs, navigating the coordination of benefits between Medicaid and Medicare can be complex and challenging, often leading to confusion and administrative burdens for individuals and their families.

Failing to equip children with autism to become self-reliant adults can result in significant costs to both families and society, ranging from \$1.4 million to \$3.2 million over their lifetime. (Molko, n.d.). To combat this, who have intricate educational and health requirements are likely to gain from planning their transition into adulthood and accessing necessary services. Guaranteeing fair access to these services for all individuals with ASD during adolescence and the transition to adulthood would enhance their overall health and quality of life throughout their lifespans. Secondly, advocacy and policymaking efforts for autistic adolescents may have been delayed partly because the focus of outreach and awareness regarding autism has predominantly emphasized early detection and diagnosis. (Shea et al., 2021). Thus, an additional outreach and awareness campaign is necessary to drive the development of new policies and programs aimed at supporting these children as they grow older. Lastly, Numerous programs demand providers to showcase short-term results, like a child's response to their name, frequently disregarding long-term objectives such as cultivating self-care skills for adulthood. Additionally, Insurance companies typically have a limited outlook since they rarely extend coverage beyond the age of 18, concentrating predominantly on childhood in their

approach to children with ASD. Consequently, recent studies on adults with autism have unveiled a deficiency in personal autonomy and quality of life among this demographic.

In conclusion, the transition from adolescence to adulthood is a critical phase for autistic youth, marked by unique challenges and opportunities. The accessibility and coverage of healthcare services, particularly through government-funded programs like Medicaid and Medicare, profoundly impact the journey of autistic individuals during this pivotal period. While these programs offer essential support, their impact varies, presenting both opportunities and challenges. Disparities in access to care, coverage limitations, and complexities in navigating the healthcare landscape can leave autistic youth vulnerable to gaps in care and support, potentially impacting their health outcomes and overall quality of life. Advocacy and policy efforts are crucial to address these disparities and ensure equitable access to services and supports for autistic adolescents transitioning into adulthood. By prioritizing comprehensive healthcare transition services, increasing awareness, and advocating for policy changes that support the diverse and evolving needs of autistic individuals, we can promote better health outcomes and enhance the quality of life for autistic youth across their lifespans.

As we navigate the complexities of healthcare transition for autistic youth, it is essential to note that every individual deserves access to comprehensive and equitable healthcare services that support their unique needs and empower them to thrive. By increasing awareness, and fostering collaboration across healthcare systems, communities, and policymakers, we can work towards a future where all autistic individuals have the opportunity to achieve their full potential and lead fulfilling lives.

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