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Editorial

New Data, Persistent Barriers: Transition Plans are Common but Miss the Mark for Many Autistic Youth

The current issue of the Journal of Adolescent Health includes research that leverages an exciting new dataset generated from the Centers for Disease Control and Prevention (CDC) Autism and Developmental Disabilities Monitoring (ADDM) network following children diagnosed with autism through age 16 [1]. It is worth applauding the ADDM Network for extending their surveillance efforts to include adolescents in this crucial transitional period in one of the only United States autism-specific surveillance initiatives. The CDC ADDM network examined within this new age group the presence and dimensions of transition plans focused in the education system (including individualized education plan [IEPs]). In the following commentary, we discuss these findings and make recommendations regarding education and cross-system transition planning for autistic children and youth.

Several findings revealed that health inequities observed among children continued into adolescence, including gaps in transition planning. Notably, several groups of children were diagnosed between the ages of 9–16 years. This is well beyond age two when experienced and qualified professionals would provide a reliable diagnosis. The children who were documented receiving an initial diagnosis at a later age were more often Hispanic as well as those who were verbal or scored more proficiently on developmental tests [2]. Additionally, adolescence frequently coincided with concurrent developmental diagnoses and co-occurring conditions, with more than half receiving attention deficit hyperactive disorder and anxiety diagnoses. Moreover, autistic youth identified as females experienced the most substantial growth in co-occurring anxiety by age 16 and had increased rates of epilepsy. Almost one in five youth (16.8%) had documented suicidal behavior. These findings underscore the utility of linking mental health and educational supports in transition planning, particularly for underrepresented groups of autistic individuals, including youth identified as female and Hispanic children. This is critical because services through the education system end in late adolescence and may not focus on mental health.

Additional inequities emerged for those with co-occurring intellectual disabilities (ID). Specifically, although most (94%) autistic youth had a transition plan documented in their records, youth with ID represented a greater share of those who did not. This begs important questions about if and how this group may be less represented or prioritized for transition planning than their counterparts or if they may require more intensive services that delay or crowd out intentional transition planning. It may be that education system personnel require training related to the benefits of transition planning for optimizing life course outcomes. Transition plan mandates may need to include enhanced, nationwide, monitoring to guarantee that these individuals experience an easy service-to-service hand-off and to reinforce that transition planning is fundamental for all groups.

Additionally, the presence of a transition plan was measured, as was if the transition plan included an IEP. IEPs are vital for transition planning because they are familiar to families of youth with disabilities, lay the groundwork for service needs, and are used to track goal progress in the education system. Alternative forms of transition plans, including 504 plans, which are common for youth who do not need specially designed instruction, were not indicated as included in the documentation of a transition plan. ADDM network tracking of 504 plans would be an added resource to education-focused policymakers and help determine if options available to students across a range of needs are present. This tracking may show more comprehensively if or how transition planning is in place for youth. Given the heterogeneity of autism and multifaceted potential needs for services and support, it would be beneficial to measure alternative transition plan types, including health care or vocational transition plans as well [3]. Other critical measures that propel successful transitions include self-advocacy or the intentional involvement

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of youth in their transition plan and goals, and could significantly bolster nationwide capacity to improve transition planning.

Important components of transition plans were documented across the assessment of transition needs, postsecondary and education and training goals, career and employment goals, and independent living and daily living skills as well as community participation. Critically, one third of youth did not have a goal for independent or daily living skills, or community participation. This finding represents an important element in the construction of transition plans. It makes plain the missed opportunities for supporting youth to prepare for adulthood.

Transition planning should be in place in high school years and be a hallmark requirement and function of the education system. Recommendations for transition planning range from encouraging implementation as early as possible, providing specific adolescent ages (such as ages 14 and 16 or at least one year before the age of majority/legal adulthood). However, transition planning presence or absence and quality have significant downstream impacts for autistic youth outside the education system. Once youth lose their entitlement to services in the education system, Medicaid is a likely default for service coverage since it is the largest behavioral health insurer in the United States and among the only insurers available to individuals with disabilities, including autism, across the lifespan. Medicaid is facing a sea change in how it requires supports to be delivered to individuals enrolled through programs specifically designed for those with disabilities, such as 1915(c) Medicaid waivers, which allow states to build programs for specific populations to expand coverage or improve care for certain groups. Medicaid is in the throes of implementing a mandate to increase the proportion of time that individuals spend receiving services in the community. Given that a large proportion of youth served in schools will transition to support through Medicaid, transition plans that document goals and set the stage for developing community participation, daily living, and independent living skills are a crucial top priority and should be solidified early on in adolescence. Medicaid has committed to supporting individuals, regardless of their needs, in communities. Additional funds have been allocated through the American Rescue Plan Act of 2021 to increase the capacity for services aimed at autonomy and community participation, through specific state plans, resources to alleviate the direct support workforce crisis that was worsened through the COVID-19 pandemic, and ensure that support plans include control over personal resources and preparation for independent living [4].

The findings from Hughes, et al., indicate that there is work to do within the education system to ensure that transition plans are robust and prioritize independent living and community participation [1]. To improve outcomes across systems, building linkages within transition plans to ease autistic youth aging out of the education system into Medicaid-funded long-term services and supports is urgently needed. Transition plans are critical determinants of life course outcomes for autistic individuals. Data from the CDC ADDM Network gives us a solid framework and starting point for transition plan improvements.

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Lindsay Shea, M.S., Dr.P.H.
Kyle Chvasta, M.S.W.
Policy and Analytics Center, A.J. Drexel Autism Institute
Drexel University
Philadelphia, Pennsylvania

Emily Hotez, Ph.D.
UCLA David Geffen School of Medicine
Los Angeles, California

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