

Autism Spectrum Disorders

Challenges and Opportunities for Transition to Adulthood



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KEYWORDS

- Autism • Autism spectrum disorder • College mental health • Young adults
- Adults with disabilities

KEY POINTS

- Owing to good outcomes, individuals with autism spectrum disorder (ASD) are increasingly transitioning to adulthood with diverse goals regarding their education, vocation, and degree of independent living.
- These individuals may experience substantial challenges during this period owing to the decreased availability of supports, particularly regarding their educational goals.
- Although programs exist to support these individuals, they are, for the most part, limited and without significant evidence.
- Providers need to have both an understanding of the challenges for transition age youth with ASD and an awareness of their unique needs in clinical settings.

INTRODUCTION

The transition to adulthood presents a broad range of challenges and opportunities to individuals with ASD. The nature of the transition experience depends on the levels of functioning of the individual and includes goals as diverse as entry in to the labor force,¹ attending college,² and achieving a degree of independent living.³ A significant increase in the provision of supports to children and adolescents with ASD has broadened the scope of potential opportunities² and also provided new impetus for services that support the optimal transition of youth into adulthood.⁴ The diversity of individual capacities, resource availability, and family and individual preference significantly complicate the task of providing support during the transitional period, requiring that services be pitched at a range of levels and operate in several contexts. During childhood, school systems frequently serve to organize and provide the necessary

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supports to optimize learning outcomes for individuals with ASD—by contrast, colleges and other postsecondary educational programs do not have a federal mandate to act in this capacity.⁵ Furthermore, many individuals with ASD may not be able to, or may choose not to, access postsecondary education programs at all. This underscores the need for both research and service development that extend across multiple settings.

Existing research has raised awareness of the diversity of outcomes for individuals with ASD entering adulthood.⁶ Furthermore, some more recent work has explored employment outcomes,⁷ and the small body of research pertaining to social, behavioral, and cognitive outcomes has been the subject of systematic review.⁸ Emerging understanding is that overall, adaptive functioning may improve in adulthood but that there are risks for deterioration across other domains.⁸ Psychiatric comorbidity has been found more common in adults with ASD,^{9,10} although these findings are from small samples, and there is significant complexity in appropriately framing comorbidity within an ASD population.^{11–13} Even less research involves evaluation of specific programs to support these individuals. Although the literature increasingly contains helpful recommendations for specific contexts, there is a limited understanding of the overall needs of this population and how they can be met most effectively. From a neuroscience perspective, although some work has identified the ongoing presence of cognitive deficits in specific domains, such as theory of mind, understanding of brain development into adulthood for individuals with ASD is extremely limited.¹⁴ Adding a final layer of complexity, preliminary research has identified the inadequacy of training in ASD and developmental disabilities in child and adolescent psychiatry residents¹⁵—although there are no data available, it is reasonable to assume that training is even less adequate for adult psychiatry residents, who frequently are tasked with the care of these individuals.

This article describes the unique challenges faced by transitional age youth with ASD. It focuses on both less and more cognitively able young adults and highlights existing research and approaches to psychosocial support. Specific legal issues that are pertinent during this period are discussed further and tentative best practice recommendations for clinicians working with these individuals are offered. Finally, the most critical areas for future research are highlighted, which will improve understanding and capacity to deliver effective supports.

CHALLENGES FOR INDIVIDUALS WITH AUTISM SPECTRUM DISORDER ENTERING COMMUNITIES AND WORKPLACES

As for all young adults making the transition from high school to adulthood, there are several challenges for individuals with ASD—in particular, the less cognitively able. With earlier diagnosis and intervention, more students are functioning at higher levels; unfortunately, some students remain in need of substantial supports.⁴ For these students, support from state departments of developmental disabilities are usually available; depending on the state/jurisdiction, eligibility may be arbitrary, often centering around full-scale IQ rather than individual needs. This is particularly unfortunate given that individuals with relatively normal full-scale IQ but significant deficits in certain domains—such as adaptive functioning—may be particularly responsive to a range of supports. In addition to cognitive disability, difficulties in adaptive skills pose real obstacles for daily functioning.¹⁶ As Howlin⁴ notes, it is important to underscore that what adults with ASD might prefer in terms of living arrangements may differ from societal or parental expectations. Societal ideals might emphasize independent living, whereas for some a sense of privacy and safety may be more important.⁴

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