

The Roles and Needs of Families of Adolescents with ASD

Involving families of students with autism in the transition out of high school is a crucial best practice.

The transition of a student out of high school into the adult world can be a stressful time for many families. This major life transition can be particularly challenging for students with autism spectrum disorder (ASD) and their families. Families of students with ASD must navigate several forms of transition at one time, including: shifting from being a high school student to post-secondary student or employee; beginning new daily family routines; and moving out of the public school system into adult services or losing services and formal supports.

Supporting transition-age students with ASD and their families throughout this process requires a better understanding of the unique roles and needs of families, as well as implementing practices that can best ensure family involvement and enhance post-secondary outcomes.

The Role of Families in Transition

All families play a critical role in their child's development, from early childhood through adolescence and beyond. Research indicates that positive and responsive relationships between caregivers and their children can influence development. Parental expectations and involvement in their child's education can impact achievement and post-secondary success.

Families of adolescents with ASD often have additional roles during the transition process. Families may take on the role as advocates for their son/daughter—finding, organizing, and maintaining post-secondary educational and vocational opportunities. This requires that educators involve families in the transition process and provide adequate information to support them.



Photograph courtesy of Jeff Frye.

The Needs of Families During Transition

Families with children with ASD often experience significant stress, which can increase during adolescence. Child-related challenges, as well as stress associated with transition planning, can lead to increased anxiety and worry for families. Parents indicate concerns about their child's preparedness and skills, as well their expanding role as a coordinator of service and activities after graduation. This stress can lead to risks regarding the health and well-being of some family members. While not all families experience compromised health and well-being during the transition process, all families will benefit from increased social support, improved access to information, and stronger partnerships with schools.



Practices to Support Families

Involving families of students with disabilities in the transition process is a key best practice in transition-focused education. Educators should consider parents as partners and allies. Family involvement can take the form of empowerment, training, and participation in planning.

Unfortunately, even when more broadly including special education literature not specific to autism, there are few studies on specific programs and practices as they relate to transition and families. However, despite the current dearth of evidence-based practices for families of transition-age youth with ASD, there are promising new programs. A recent study of a three-component intervention for transition-age youth with ASD and their families involved group training sessions for families on the transition process, planning meetings, and follow-up with students around career exploration and implementation. Following this intervention, families had higher expectations for the student's future, and students had higher levels of self-determination and decision-making ability.

The Center on Secondary Education for Students with Autism Spectrum Disorders (CSESA) model incorporates the Transitioning Together program, which involves education on a variety of topics relevant to transition planning and ASD, as well as guided practice in helping families to problem-solve around current difficulties and stressors. Families receive two individual joining sessions focused on establishing goals, followed by eight weekly sessions for parents and youth (in separate groups in the same building). In addition to transition planning, topics include risks to independence, community involvement, health and well-being, and legal issues. Data suggest that the program can improve the parent-child relationship and increase parental expressions of warmth, as well as increase parental knowledge of autism and the service system.

Taken together, new studies on interventions for transition-age students with ASD and their families suggest that families are eager for such supports and that there may be multiple benefits to incorporating such family-centered transition programs into school and clinical settings.

Future Directions

Little research has been conducted on how to best support families with children with ASD during the transition process. Future study should promote collaboration between schools, families, and adult service providers to examine how to address the complex issues faced by individuals with ASD and their families. Areas to explore include better understanding how to make secondary and post-secondary environments more "autism-friendly" and the role of technology and virtual learning environments in supporting the transition process. Future work and current practice requires positive partnerships among students, families, and educators to support successful transition for individuals on the spectrum.

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<http://rse.sagepub.com/content/early/2013/12/23/0741932513514616.full.pdf+html>

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