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The Roles and Needs of Families of Adolescents With ASD

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Abstract

The transition of a student out of high school and into the adult world can be a stressful time for many families of high school students. This major life transition can be particularly challenging for students with autism spectrum disorder (ASD) and their families. In this article, we first discuss the roles of families in the transition process for their son or daughter with ASD. Next, we present literature on the unique needs of families of adolescents with ASD during the transition to adulthood. Finally, we highlight current research on best practices for supporting transition-age students and their families as well as discuss future directions for research and practice.

Keywords

autism, exceptionalities, families/parents, transition

The transition of a student out of high school and into the adult world can be a stressful time for many families of high school students. It is a period marked by reorganization of the family system as youth take on new roles and experience changes in educational, relational, occupational, and living domains (Arnett, 2000). For families of students with an autism spectrum disorder (ASD), there are additional challenges during the transition to adulthood that are unique to having a child with a disability. Families of students with disabilities must navigate several forms of transition at one time including status transitions (e.g., getting a job, entering post-secondary education), family life transitions (e.g., new daily family routines), and bureaucratic transitions (e.g., moving from public school services to the adult service systems; Blacher, 2001). These transitions are particularly stressful for students with ASD and their families, as difficulty with change is a hallmark of the autism phenotype, such that even small changes in routines can be incredibly problematic. ASD-related challenges in social interactions and communication further compound these problems. In addition, many students with ASD experience a significant loss of services and formal supports following high school exit that is greater than students with other disabilities (Lawer, Brusilovskiy, Salzer, & Mandell, 2009; Shattuck, Wagner, Narendorf, Sterzing, & Hensley, 2011).

In this article, we discuss the roles of families in the transition process for their son or daughter with ASD. Next, we present literature on the unique needs of families of adolescents with ASD during the transition to adulthood. Finally, we highlight current research on best practices for supporting transition-age students and families as well as discuss future directions for research and practice.

The Role of Families in Transition

The long-lasting impact that the family has on children's development is well-documented (Borkowski, Ramey, & Bristol-Power, 2002; Bornstein & Bradley, 2003). The benefits of positive parenting practices for the socio-emotional and cognitive-linguistic outcomes for children have been observed in numerous studies, including many studies of children with disabilities (Dyches, Smith, Korth, Roper, & Mandleco, 2012; Slonims, Cox, & McConachie, 2006; Warren & Brady, 2007; Warren, Brady, Sterling, Fleming, & Marquis, 2010). Links between early family interactions and child development also have been found specifically in samples of children with ASD. For example, in a small intervention study of young children with ASD, maternal responsivity predicted improvements in children's socio-emotional functioning and social interaction skills (Mahoney & Perales, 2003). Responsive, sensitive parenting likewise has been associated with better language trajectories for children with ASD (Siller & Sigman, 2002, 2008) as well as for infant siblings of children with ASD (Baker, Messinger, Lyons, & Grantz, 2010).

The critical role of the family in children's lives is not limited to the early childhood and elementary years, as bidirectional influences continue in the parent–child relationship across the life course (Zarit & Eggebeen, 2002). In

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studies of individuals with ASD, the family environment has been shown to impact developmental trajectories across adolescence and into adulthood. For example, in a longitudinal study of mother–child dyads of adolescents and adults with autism, high initial levels of maternal warmth and positive remarks were associated with reductions in autism symptoms and behavior problems 18 months later, even after controlling for earlier levels of symptoms (Smith, Greenberg, Seltzer, & Hong, 2008). In contrast, high levels of criticism were found to predict increases in behavior problems and autism symptoms in the same sample (Greenberg, Seltzer, Hong, & Orsmond, 2006). Furthermore, in a follow-up analysis, increases in criticism over a 7-year period were associated with higher levels of behavior problems at the end of the study, whereas change in behavior problems did not significantly predict final levels of maternal criticism (Baker, Smith, Greenberg, Seltzer, & Taylor, 2011). Findings from these studies highlight the enduring impact that the family environment has on the behavioral development of individuals with ASD across the life course as well as suggest that persons with ASD may benefit from reductions in the emotional intensity of their surroundings.

The family context also has implications for the educational outcomes of students. Parental expectations and involvement in education is strongly predictive of children's academic achievement (Fan & Chen, 2001; Hill & Tyson, 2009; Spera, 2005). Parental acceptance and support for independence of adolescent children has been associated with higher levels of self-esteem and better adult relationships following high school exit (Khaleque & Rohner, 2012). Importantly, parental expectations for their son's or daughter's education have been found to predict involvement in post-secondary education for students with ASD (Doren, Gau, & Lindstrom, 2012). Also during the transition to adulthood, families often take on a role of advocating for post-secondary educational and vocational opportunities for their son or daughter. In the absence of school supports, the family becomes primarily responsible for finding, organizing, and maintaining services and educational/employment activities for their children with ASD. As such, parents are often the driving force in securing vocational and educational placements and promoting a high quality of life for youth with ASD after high school.

Given the multiple, significant roles that families play in the lives of their children and the fact that parents continue to be primary caregivers for individuals with ASD well into adulthood (Barker, Mailick, & Smith, in press; Seltzer et al., 2011), it is paramount that educators involve families in the transition planning process to promote positive transition outcomes for students (Kohler & Field, 2003). However, many families find interacting with school professionals stressful (Bezdek, Summers, & Turnbull, 2010; Fish, 2006) and would like to be more engaged in the planning process (Wagner, Newman, Cameto, Javitz, & Valdes, 2012). For instance, in an earlier study by McNair and Rusch (1991), almost 70% of parents surveyed indicated that they would like to be involved in formalized transition programming for their transition-age child who was receiving special education but were currently uninvolved. Specifically, parents indicated that they would prefer to receive more information about work options, adult service agencies, professional support, and support groups in addition to more information on their son's/daughter's specific skills and to have generally increased emotional support from other family members (McNair & Rusch, 1991).

There is also evidence that students would like the family to have more involvement in the transition planning process. In a qualitative analysis of focus group data of families of students with various disabilities, Morningstar, Turnbull, and Rutherford (1995) found that students desired their families to be involved in the process of helping them plan for the future and attending Individualized Education Program (IEP) meetings; specifically, teens indicated that their family members (both parents and extended family) should be involved by helping students (a) stay in school, (b) find housing and a job, and (c) plan for college. Students also noted potential barriers to family involvement in future planning, including potential disagreements between students and parents as well as a general lack of awareness on the part of students regarding IEP meetings and their potential role in them (Morningstar et al., 1995). In the next section, we discuss in greater detail the specific needs of families of students with ASD during the transition from high school to post-secondary life.

The Needs of Families During Transition

Before practitioners can address the goals of students and families during the transition process, it is necessary to first understand the context of daily life experienced by many families of adolescents with ASD. The significant stress associated with parenting a child with ASD is very well documented (for a review, see Hayes & Watson, 2013). For example, in a large, population-based study, mothers of children with ASD reported higher levels of parenting stress as well as higher rates of mental health problems compared with mothers of children without disabilities (Montes & Halterman, 2006). Parenting a child with ASD also can be more stressful than parenting a child with other disabilities. Several studies have shown that parents of children with ASD report greater negative impact of having a child with a disability and poorer well-being in comparison with parents of children with other developmental disorders including Down syndrome, fragile X syndrome, cerebral palsy, and undifferentiated developmental disability (Blacher & McIntyre, 2006; Eisenhower, Baker, & Blacher, 2005). This high level of caregiving burden for parents of children with ASD has been observed not only during early childhood but also during adolescence and adulthood (Abbeduto et al., 2004; Cadman et al., 2012).

Past research has explored possible reasons for the elevated levels of psychological distress observed among parents of children with ASD, documenting several contributing factors including the core symptoms of autism (e.g., social difficulties, communication difficulties, and repetitive behaviors), delays in adaptive behavior, and co-occuring physical and mental health problems (Bishop, Richler, Cain, & Lord, 2007; Cadman et al., 2012; Kring, Greenberg, & Seltzer, 2008, 2010; Tomanik, Harris, & Hawkins, 2004). The majority of studies have consistently found that challenging behavior problems are among the most significant sources of stress for families (Hastings et al., 2005; Herring et al., 2006; Lounds, Seltzer, Greenberg, & Shattuck, 2007), highlighting how educational interventions to address child behavior likely will have cascading benefits for family life and parent stress.

In addition to the child-related challenges, families of children with ASD also face factors external to the family system that contribute to parental stress. Notably, the financial burden for families raising children with ASD can be very high, particularly in states where Medicaid spending for children with disabilities is low (Kogan et al., 2008; Parish, Thomas, Rose, Kilany, & Shattuck, 2012). Having unsupportive social networks, such as family members and friends who criticize and blame parents for their child's difficulties also can add to the psychological distress of parents (Smith, Greenberg, & Seltzer, 2012). Given these multiple stressors faced by many families of children with ASD, by the time children are in the adolescent period, families are at a greater risk of divorce than families with children without ASD (Hartley et al., 2010).

We also note that the stresses associated with parenting a child with ASD are particularly high during adolescence. Although there is a general trend for reduction of autism symptoms and behavior problems for individuals with ASD in a variety of domains across adolescence and into early adulthood (Shattuck et al., 2007; Smith, Maenner, & Seltzer, 2012; Taylor & Seltzer, 2010), the overall level of challenging behaviors remains high, creating continuing stress for parents. For example, in a daily diary study, 94% of adolescents and adults with ASD exhibited at least one episode of behavior problems over an 8-day period and 35% displayed at least one such episode on all 8 days (Seltzer et al., 2010). In addition, exiting high school may usher in a period of increased risk for mental health difficulties and behavior problems for students with ASD, which in turn adds to parental stress. Major life changes, such as the transition out of high school, are associated with increased risk of mood disorders in individuals with ASD (Lainhart, 1999). Relatedly, in a longitudinal study of students with ASD, Taylor and Seltzer (2010) observed a slowing of improvement in challenging behaviors and autism symptoms following high school exit as well as a slowing of improvement in parent–child relationship quality (Taylor & Seltzer, 2011), suggesting that the lack of structured activities takes a toll on the behavioral development of the young adults which in turn presents challenges for families. Those from low-income families in this study were at heightened risk, showing increases in behavior problems after high school exit.

Families also experience stress associated with educational and transition planning for their son or daughter with ASD. In general, parents of students with disabilities feel less comfortable with the transition process than parents of students without disabilities (Whitney-Thomas & Hanley-Maxwell, 1996). For example, parents of children with ASD report higher levels of anxiety prior to high school exit as they anticipate what will happen in the future (Lounds et al., 2007). In a qualitative study of high-functioning adolescents with ASD and their parents, worries about the future were clear. Adolescent students with ASD indicated concerns about post-secondary education including the level of coursework in college and potential problems in social arenas. Parents indicated concerns about student preparedness and skills, the college's ability to provide appropriate accommodations, and how their child would be able to navigate social situations (Camarena & Sarigiani, 2009). Parents also may worry about having to take on a larger role of coordination for their children's activities and services once school services end (Lawrence, Alleckson, & Bjorklund, 2010). These worries are not without merit, as accessing services after high school can be particularly challenging for individuals with ASD compared with individuals with other types of disabilities (Lawer et al., 2009), adding to parental stress in their role as advocates and locators of supports for their children. In short, parenting an adolescent with ASD is highly stressful as parents must address challenges common to all parents of adolescents in addition to difficulties specific to the autism.

The support needs for parents of adolescents with ASD are not only psychological (Smith et al., 2010) but also physiological. The stress of parenting a child with ASD is associated with compromised physical health for parents (Johnson, Frenn, Feetham, & Simpson, 2011). In a study of daily health symptoms, mothers of adolescents and adults with ASD had higher levels of fatigue, gastrointestinal (GI) problems, and headaches compared with mothers of similarly aged children without disabilities (Smith, Seltzer, & Greenberg, 2012). Mothers of adolescents and adults with ASD also have been found to have dysregulated patterns of cortisol, a stress hormone, compared with mothers of children without disabilities; these atypical patterns are associated with their children's behavior problems (Seltzer et al., 2010). Stressful events not specifically linked to the child with autism also contribute to cortisol dysregulation in mothers (Wong et al., 2012). These intense, stressful experiences accumulate across the life course, forming a chronic parenting stress trajectory and placing parents at risk for physical health problems (Barker et al., 2014). Importantly, the psychological and physiological consequences of chronic parenting stress, in turn, can limit the ability of parents to effectively carry out their critical role as advocate and organizer of their son's or daughter's services and activities during the transition to adulthood.

Finally, it is important to highlight that not all parents experience compromised health and well-being in response to the stresses associated with caring for their child with ASD (Barker et al., 2014). Factors that contribute to adaptation in the face of stress for parents of adolescents with ASD include the presence of social supports (Boyd, 2002; Smith, Greenberg, & Seltzer, 2012), the use of problem-focused coping strategies (Smith et al., 2008), high levels of family adaptability (Baker, Seltzer, & Greenberg, 2011), and age-related improvements in child in behavior problems (Barker et al., 2010; Lounds et al., 2007). Increasing malleable protective factors for families, such as coping and social support, is a promising focus for intervention. As we have noted above, the roles and needs of families of students with ASD are multifaceted and complex, as are the factors associated with resiliency. As such, successful programming to support families as they support their students through the transition process likely will need to include approaches that are intensive, comprehensive, and multidisciplinary. In the next section, we will review the literature on practices to support families during the transition period.

Practices to Support Families

Involving families of students with disabilities in the transition process is a key aspect of best practice in transition-focused education; this involvement can take the form of empowerment, training, and participation in planning (Kohler & Field, 2003). However, even though family involvement in transition planning for all students with disabilities is expected, little attention has been given in the research literature to the specific ways in which schools can support and involve families in the transition process, particularly families of students with ASD. In the absence of a large literature on intervention programming for families of transition-age students with ASD, it can be valuable to consider research on families of students with other developmental disabilities and how those findings may apply to families of students with ASD (Taylor, 2009).

Unfortunately, even when looking at the special education literature not specific to autism, there are few studies on specific programs and practices as they relate to transition and families. For example, in a comprehensive review of evidence-based practices (EBPs) in secondary transition for students in special education by Test and colleagues (2009), of the 32 identified EBPs, only 1, teaching parents about transition, was related to family involvement and the evidence for that practice was based on one study conducted over 20 years ago (Boone, 1992). In the Boone (1992) study, families of students with mild to moderate disabilities attended a training session prior to a transition conference covering topics such as rationale for transition planning, major areas for planning, and the role of the parent in the planning meeting. Compared with families who did not receive the preconference training, parenting with the training had higher levels of knowledge on the transition process; however, parental communication during the conference was similar between the two groups of parents (Boone, 1992). Although this study provided preliminary evidence that parents can benefit from education on the transition process, it explored only one short-term outcome.

Despite the current dearth of EBPs for families of transition-age youth with ASD, there are promising new programs emerging in the literature, suggesting that more attention is being given in research and practice to this group of students and their families. For example, Hagner and colleagues recently published a study of a three-component intervention for transition-age youth with ASD and their families. The intervention involved three group training sessions for families on the transition process, three to five person-centered planning meetings, and follow-up with students around career exploration and implementation. Results indicated that following intervention, families had higher expectations for the student's future and students had higher levels of self-determination and decision-making ability (Hagner et al., 2012).

In our own work, we have taken a well-established intervention approach originally developed for families of individuals with psychiatric conditions and adapted it for families of adolescents with ASD. The *Transitioning Together* program is a multi-family group psychoeducation model 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 stress. Families receive two individual joining sessions focused on establishing goals followed by eight weekly sessions for parents and youth (youth meet separately in the same building). Session topics include transition planning, risks to independence, community involvement, health and well-being, and legal issues. Data from pilot work suggest that the program can improve the parent–child relationship and increase parental expressions of warmth as well as increase parental knowledge of disability and the service system (Smith, Greenberg, & Mailick, 2014; Smith, Greenberg, & Mailick, 2012). Taken together, these 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. The timing and dosage of such programs, as well as an understanding for whom such programs are most beneficial, will be important areas of future research. In addition, it will be valuable for future work to understand how programs can support the role of families in advocating for systems change, as access to services for adults and their families is often limited by the design of the systems and structures involved in the provision of services.

Future Directions for Research and Practice

As noted above, research on best practices to support for families of transition-age youth with ASD is in its infancy. As such, there are several key areas in which the field will need to advance to accomplish better post-secondary outcomes for the diverse population of students with ASD and their families. As Taylor (2009) posited, in the future researchers on transition and ASD will need to further incorporate developmental constructs such as identity, autonomy, and intimacy into theoretical models and research designs, as the presence of ASD does not negate the experience of these normative developmental processes for individuals and the larger family system. For example, as with all emerging adults, it will be important to understand the factors that promote adaptation to new adult rules such as how individuals with ASD develop their personal identity and form relationships (including intimate ones) separate from their family of origin. In addition, the next phase of research in this area will need to move toward a better integration of research across school, family, and services research (Taylor, 2009). Collaboration across disciplines is needed to address the complex issues faced by individuals with ASD and their families during the transition to adulthood, as academic, psychological, occupational, and medical domains are all impacted.

As an example of integration across research areas, it is useful to consider how the literature on families of children with ASD has implications for research and practice in secondary school settings. Studies of families of adolescents and adults with ASD suggest that family environments marked by low levels of emotional intensity (e.g., noncritical, stably warm contexts) are best for individuals on the spectrum in terms of minimizing behavior problems and autism symptoms (Greenberg et al., 2006; Smith et al., 2008). It is likely that the presence of positivity and the absence of criticism from key figures (e.g., teachers, employers) are beneficial in other environments such as school and work, as similar processes are likely at play across contexts. For example, students with ASD unfortunately are often targets of bullying, which in turn can negatively impact their mental health (Cappadocia, Weiss, & Pepler, 2012; Montes & Halterman, 2007; van Roekel, Scholte, & Didden, 2010). Similarly, work in the area of quality of life for adults with ASD has suggested that certain environments are more "autism-friendly" than others, and these factors should be included in the evaluation of adult outcomes (Billstedt, Gillberg, & Gillberg, 2011). Considering these studies from family and adult services research highlights the potential value in exploring the unique milieu of secondary experiences for individuals with ASD across the spectrum and in varying educational settings. It may be that variables measuring school-wide climate (and the climate in community settings) are predictive of not only concurrent well-being and quality of life, but also of post-secondary outcomes. Measures that have been used successfully in the rehabilitation literature may be particularly valuable in this work (see Yasui & Berven, 2009, for a review). Understanding the factors and processes that promote autism-friendly climates will be an important next step for transition research, as the development and evaluation of comprehensive conceptual models of how teachers, staff, and peers influence, and are influenced by, students on the spectrum can inform individual and school-wide intervention strategies.

Another area of future research at the intersection of school, family, and services fields is the emergence of virtual learning environments and its impact on transition planning, services, and outcomes for students with ASD. Families now increasingly have many options in terms of educational settings for their children including public virtual schools, private schools funded by public voucher programs, and homeschooling in addition to public education provided in the local high school building. Given the high frequency of peer victimization experienced by many students with ASD, it is not surprising that virtual schooling might be appealing to parents. Some research also suggests that parents may select to have learning take place in the home environment if they perceive that educators at the local school are either unwilling or unable to provide effective, individualized programming (Hurlbutt, 2011). It is virtually unknown, however, how virtual learning approaches may influence learning trajectories and transition outcomes for students with ASD. As the use of technology and asynchronous learning and work models expand, it will be important to understand how parental choice of learning environment may influence transition outcomes for their youth with ASD, particularly in social and occupational domains, and what the role of special educators will be within these new educational models. It also will be valuable to study the use of technology (e.g., smart phones, tablet computers) by individuals with ASD and how families integrate technology into family routines. Although from an educational perspective certain technologies may be valuable for addressing communication, behavioral, and learning needs, from the perspective of families, the same device (e.g., iPad) may be more useful for recreational purposes. Also, given the natural appeal of technology for many students with ASD, increased access to technology at home may lead to new challenges for families such as navigating how to encourage appropriate technology use (e.g., monitoring, limiting, transitioning to other tasks). As such, more research is needed regarding the benefits and barriers of technology for adolescents with ASD, particularly in family settings.

We close with a focus on how what is already known from research can inform current practice in secondary education settings for students with ASD and their families. First, it is important for practitioners to be aware of the unique challenges confronting families of children with ASD during the transition to adulthood and to maintain a strengths-based perspective with families (Neely, Amatea, Echevarria-Doan, & Tannen, 2012). As noted above, parents of teenagers with ASD have intense daily lives marked by ongoing, chronic stress from a variety of sources (e.g., unpredictable, challenging behaviors in the child; financial strain; difficulties associated with adolescence; exposure to bullying). Some of these difficulties are chronic and not easily remediated; thus, education and support programming for families which encourages problem-focused coping and provides mechanisms for expanding social support networks will be particularly valuable (Smith et al., 2014). Next, given the powerful, continuing impact that parents have on the developmental trajectories of adolescents, professionals can support the continuation of positive parent–child relationships during this period as well as encourage non-critical environments across contexts for students. Finally, educators should consider parents as partners and allies in the transition planning process. Parental expectations and involvement are important predictors of post-secondary outcomes and many parents would like to have a better partnership with school personnel. In sum, strong, positive partnerships among students, family members, and educators are needed to support successful transition for students on the autism spectrum.

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