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Adults with Autism: Outcomes, Family Effects, and the Multi-Family Group Psychoeducation Model

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Abstract

Although an increasing number of individuals with autism spectrum disorders are entering adulthood, currently there are few evidence-based programs for individuals later in the life course. In this paper we present an overview of recent research on outcomes for adolescents and adults with ASD and highlight the role of the family for individuals with ASD during the transition to adulthood. We also discuss multi-family group psychoeducation as a promising model for use with individuals with ASD transitioning to adulthood.

Keywords

Autism; Autism spectrum disorders; ASD; Adolescence; Adulthood; Transition; Psychoeducation; Family; Intervention; Outcomes; Psychiatry

Introduction

Autism spectrum disorders (ASDs) are developmental disabilities that affect an estimated 1 in 88 children in the US [1]. ASDs are lifelong conditions characterized by difficulties in communication and social interaction, and repetitive behaviors and restricted interests. While there has been high interest and investment on the part of researchers in understanding and treating ASD during early childhood, there remains a dearth of research on ASD during adolescence and adulthood [2, 3]. This lack of knowledge is particularly evident in the area of intervention; very few programs are available to families as children move into adolescence and adulthood. The 2010 U.S. Department of Health and Human Services' [4] Interagency Autism Coordinating Committee strategic plan for autism research indicated the important need for strategies to increase quality of life and improve functioning of individuals with ASD later in the life course. In this paper we present an overview of recent research on outcomes for adolescents and adults with ASD, highlight the role of the family for individuals with ASD during the transition to adulthood, and discuss multi-family group psychoeducation as a promising model for use of transition-aged individuals with ASD.

Outcomes for Adolescents and Adults with ASD

For individuals with ASD, the normative challenges associated with the transition to adulthood [5] are compounded with multiple difficulties unique to ASD. The emergence of adulthood often involves transitions in educational, occupational, residential, and relational

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arenas and the development of new roles and identity formation [6]. These transitions are particularly stressful for adolescents with ASD and their families because difficulty coping with change is part of the behavioral phenotype of ASD, and the heterogeneity of ASD may make it challenging for families to develop clear expectations for the future. Families of individuals with ASD also face special challenges related to changes in the service system following high school exit, which exacerbates the normal stresses associated with supporting a child's transition to adulthood.

Past research has demonstrated that anxiety is high for mothers of children with ASD during their child's adolescence as they anticipate their child's transition out of school and worry about the future [7]. Unfortunately, in many cases, the high level of parental concern is merited. There is a significant loss of services for individuals with ASD upon exiting the school system and the picture of adult services can be bleak, with long waiting lists and few opportunities for maximum independence [8–10]. In many cases, individuals with ASD will lose insurance coverage and access to therapies during the transition to adulthood [11]. Even individuals with ASD who initiate services in adulthood are more likely to have difficulty maintaining those services than adults in other disability groups [12]. For example, using a well-characterized, longitudinal sample of young adults with ASD who recently exited the school system, Taylor and Seltzer [13] found very high rates of unemployment, with only 18% of the sample reporting competitive or supported employment. Notably, of the young adults in this sample who were competitively employed, the vast majority was engaging in low-paid, menial work and nearly all were working less than 30 hours per week. Additionally, over 25% of the young adults with ASD *without* intellectual disability (ID) had no daytime activities of any kind compared to only 8% of young adults with ID, suggesting a disparity between those with and without ID in the availability and/or appropriateness of adult day services [13].

Similarly, a recent analysis of national survey data by Shattuck and colleagues [14] revealed that after young adults with ASD left the public school system, 80% continued to live at home, only 32% attended postsecondary education, just 6% had competitive jobs, and 21% had no employment or education experiences at all. Further, 40% reported having no friends. Consistent with the findings of Taylor and Seltzer [13], a number of postsecondary outcomes were worse for individuals with ASD without ID. For example, they were three times more likely to have no daytime activities (e.g. employment, post-secondary education, day services; [14]). This lack of services and day time activities following high school exit may place young adults with ASD at risk for increased behavioral and mental health difficulties [14, 15] and decreased functional independence [16].

Taken together, these findings demonstrate the significant, continuing need for targeted interventions during the adolescent and adult period for individuals with ASD. Programs that help families of individuals with ASD find appropriate local services and daytime activities for their soon-to-be young adult may be particularly beneficial. In the absence of an adequate adult service system, increasing empowerment and advocacy skills of parents is a potential mechanism by which to help families access and develop supports and community activities for their children as they move into adulthood [17]. Furthermore, given the current economic climate and the dearth of appropriate *formal* services for young adults with ASD, it becomes all the more imperative to offer interventions that increase a family's capacity to find and create *informal* supports and activities. Thus, interventions are needed that help parents and teens learn new skills and promote empowerment during the transition to adulthood.

In the next section, we further delineate the central role of the family in the lives of adolescents and adults with ASD, with particular attention given to past research on the

bidirectional effects between individuals with ASD and their families. Later we highlight multi-family group psychoeducation as one intervention method with promising applications for families of teens with ASD.

Families of Individuals with ASD during Adolescence and Adulthood

Raising a child with an ASD is a profoundly stressful experience [18, 19]. Particularly stressful for families is the high level of challenging behaviors presented by many children on the spectrum [7, 20, 21]; these behavior problems can continue into adulthood and remain a barrier for adult independence and community involvement [22]. Although there is some abatement of autism symptoms and behavior problems over time [2, 23], as noted above, there is also evidence that improvements in behavioral functioning slow down once the young adult leaves school [15], suggesting potential risk for maladjustment during young adulthood.

Parenting a child with ASD during adolescence and adulthood is associated with significant stress. In an examination of the day-to-day experiences of mothers over an 8-day period, Smith and colleagues found that mothers of adolescents and adults with ASD were three times more likely to experience a stressful event on a given day than mothers of children without disabilities. Daily stressful experiences subsequently were associated with mothers' emotional well-being [24]. The high level of stress experienced by parents of adolescents and adults with ASD also takes a toll on the physical well-being of parents. Recent work indicates that mothers of adults with ASD have significantly more physical health symptoms including fatigue, joint pain, gastrointestinal problems, and headaches than mothers of adults without disabilities [25]. Seltzer and colleagues [26] recently examined differences in cortisol expression between mothers of adolescents and adults with ASD and mothers of similarly-aged children without disabilities and found that mothers of individuals with ASD had significantly hypoactivated cortisol levels; this pattern of low cortisol is similar to what has been found in individuals with caregiver burn-out and post traumatic stress disorder. These findings clearly highlight the significant risks to parental emotional and physical health associated with raising a child with ASD and underscore the need for appropriate intervention services to help reduce stress for the entire family system across the life span. Indeed, the profile of poor health and physiological dysregulation manifested by mothers of individuals with ASD constitutes a public health challenge of considerable magnitude, given the prevalence of ASD.

It is important to note that within any family system, transactions among family members are bidirectional. As such, in addition to risks for parental health due to stressful caregiving, high levels of family distress also can create difficulties for the individual with autism. In a review of studies of families of children with intellectual and developmental disabilities (IDD), Hastings and Lloyd (2007) argued that the challenges associated with caring for an individual with IDD may create a family context where some level of negative emotional intensity, referred to as *expressed emotion* (EE), is to be expected. The presence of high EE in families may in turn exacerbate or maintain behavior problems [27]. For instance, high levels of EE, namely criticism of the son or daughter by the parent, have been associated with elevated levels of maladaptive behaviors in individuals with intellectual disabilities [28]. Other studies in child populations have likewise found parental criticism of the child to be a particularly salient aspect of the family emotional environment in predicting child behavior problems [29].

Consistent with the general literature on EE, past longitudinal work among families of adolescents and adults with ASD has demonstrated that high levels of EE, particularly criticism, can lead to increases in child behavior problems and autism symptoms over time

[30, 31]. In contrast, research shows that when parents of adolescents and adults with ASD continue to remain warm and positive toward their children, the behaviors of their children improve [32]. As such, intervention services that reduce family stress and support family-wide positivity can promote well-being not only for parents, but also for adolescents and young adults with ASD.

Notably, from a family systems perspective, transition periods for family members and family systems, such as adolescence, may be particularly effective times for interventions given that the family system is more fluid and reorganizations in the system are taking place [33]. As such, adolescence may be an ideal time for interventions that reduce the level of stress and EE, and promote positivity, within the family. Below we discuss prior research on psychoeducation interventions in clinical populations and highlight our work to adapt this model of intervention for use among families of adolescents with ASD.

Multi-Family Group Psychoeducation Interventions

Multi-family group psychoeducation is a well-developed intervention approach with proven efficacy among families of individuals with psychiatric conditions such as schizophrenia [34, 35] and mood disorders [36, 37]. Findings for this type of intervention for schizophrenia are particularly well-documented, with more than 30 randomized clinical trials reporting benefits including lower rates of relapse and reduced symptoms for the individual with schizophrenia as well as improved well-being for family members [35]. The positive effects of psychoeducation groups also have been seen in samples of children and adolescents with psychiatric disorders. For example, in a study of families of children with mood disorders, families in the multi-family psychoeducation group reported increased knowledge of symptoms, increased positive family interactions, and increased service utilization than the waitlist control group [38]. Similarly, in a study of family psychoeducation with adolescents with major depression, adolescents in the experimental group displayed more gains in social functioning and greater improvements in parent-child interactions relative to the control group [39].

Although the content and components of psychoeducation interventions vary by study and type of mental health condition, they have several key common elements: *The intervention involves weekly group sessions wherein multiple family members are together provided with education on the nature, course, and management of the condition as well as training in and activities for practicing problem-solving.* In sum, the multi-family psychoeducation model emphasizes education and problem-solving strategies, with a focus on reducing family stress, lowering EE, and increasing empowerment. This model of intervention delivery holds promise for applications in multiple populations, including families of individuals with disabilities. Below we outline our work in developing and pilot testing a multi-family group psychoeducation model for families of adolescents with ASD.

Given the significant positive effects of multi-family group psychoeducation interventions found in studies of families of individuals with mental health conditions, we designed a psychoeducation curriculum for families of adolescents with ASD based on evidence from longitudinal research and feedback from families of individuals with ASD. First, using past multi-family psychoeducation interventions as a model, we drew from the research literature on autism during adolescence and adulthood to create a detailed outline of a potential intervention curriculum. Next, we held three focus groups composed of families of adolescents and young adults with ASD as well as professionals working with these families and individuals. During each focus group, we asked for feedback on curriculum content and intervention delivery. Notably, focus group participants were universally enthusiastic about a program for families of adolescents. Comments solidly converged with the empirical

literature on families of children with ASD and our proposed psychoeducation model. Specifically, participants noted needs including (1) increasing community activities and connections, (2) help with problem-solving, and (3) training in advocacy, highlighting the relevance of our research-based intervention goals for the end-users of the treatment. There also was strong interest in our proposed informational topics, particularly transition planning, self and family care, and legal issues. Families reported that they would be more likely to maintain participation if there are activities for the adolescent with ASD (as it provides both respite for the parents and a social outlet for the teen) and real solutions are being offered (in contrast with only opportunities to vent). Based on focus group feedback, the research team refined the intervention curriculum and finalized the specific program components, resulting in the *Transitioning Together* program.

Consistent with a multi-family psychoeducation model, the *Transitioning Together* program has two stages of intervention: two individual-family joining sessions and eight multi-family group sessions. The *joining sessions* allow the family to meet with the intervention staff prior to the group meetings in order to develop rapport and clarify family goals. For Joining Session 1, parents have an opportunity to discuss their family history and express their hopes and worries for their child with ASD. For Joining Session 2, parents complete an “Ecomap” depicting the type of connection (strong, weak, stressful, or hoped for) they have with various individuals, services, and community organizations. At the close of Joining Session 2, parents work with the facilitator to create a list of goals for the *Transitioning Together* program. Joining sessions are an essential aspect of the treatment as they lay a foundation of trust and collaboration for articulating and achieving family goals, and increase family commitment and attendance, and reduce attrition. After completing the joining sessions, parents attend 8 weekly group sessions. Both parents are encouraged to attend. Group sessions involve education on a variety of topics relevant to ASD and guided practice with problem-solving for individual family problems. The topics and goals for each session are presented in Table 1. *Sessions based on published findings of our research group are marked with an asterisk.*

Sessions last approximately 1.5 hours each. Sessions begin with 15 minutes of socializing, followed by 30 minutes of presentation on a topic and 45 minutes of discussion and problem-solving. For each problem-solving activity, one family’s problem is chosen by the group. Next, the group works together to select strategies that the family can implement to address that problem. The family is able to share updates on strategy implementation the following week. This process provides an opportunity to gain from the vast experiences of the multiple families present and to focus on addressing problems in a constructive, non-critical way.

At the same time and location (but in a different room) as the parent group sessions, the adolescents with ASD participate in a social group. Based on feedback from community partners during our development work, we know that it is important to tailor the activities of the social group to meet the needs of the specific youth in the group. As such, the social group involves a variety of games and learning activities such as skits, role plays, cooking, crafts, and music.

Pilot Results

In order to pilot test the intervention, we recruited 11 families of adolescents with ASD (aged 15–18 years; $M = 16.2$, $SD = 1.1$) to participate in the 8-week *Transitioning Together* program, resulting in two groups of families who completed the intervention program. For each week of the intervention, parents attended group sessions which lasted approximately 1.5 hours. While parents attended the parent group sessions, the adolescents with ASD

participated in a social group with other adolescents. Variables related to feasibility and acceptability were measured at the conclusion of each group session as well as during exit interviews. Additionally, before and after the intervention, data were collected from parents regarding (1) parental knowledge and empowerment, (2) parent-child relationship quality, (3) child behavior, and (4) parent stress. To measure parental knowledge, parents rated their agreement with statements such as “I have a good understanding of my child’s disability” on a 5 point scale ranging from *not at all true* to *very true*. Parent-child relationship quality was assessed using the Positive Affect Index [40]. Five self-report items were drawn from this scale that reflected the parent’s feelings toward his or her son or daughter (e.g. “How much affection do you have toward your son/daughter?”). Additionally, the *Five Minute Speech Sample* was used to code EE based on the coding manual developed by Magaña et al. [41]. For this study we were interested in criticism, warmth, and positive remarks. Four items were used to measure the behavior of the adolescent with ASD. Parents rated the severity of autism symptoms on a 10 point scale (10 being the most severe). On a five point scale (*never to all the time*) parents also rated how often they were walking on egg shells around their child, how often their child had a behavior problem come out of nowhere, and how often they felt happy or proud of their child.

Notably, all families remained in the *Transitioning Together* program for the course of the study. One family, however, did not participate in exit interviews due to a family tragedy. Outcome data were subsequently available from 10 families (10 mothers and 8 fathers). Satisfaction data indicated that parents were highly satisfied with the weekly sessions and felt that sessions were useful. To explore possible change from pre- to post-intervention, we conducted 1-tailed paired samples t-tests on variables in the following domains: parent knowledge, parent-child relationship quality, child behavior, and parent stress. Given statistically nonsignificant intraclass correlations on most variables of interest, mother and father data were considered as independent observations. As shown in Table 2, there were significant positive changes from pre- to post-intervention in parents’ understanding of their child’s disability and of the service system. There were also significant improvements in the parent-child relationship domain. Most notably, parents were rated (by an independent blind rater) as having higher levels of warmth toward their son or daughter. Further, although we did not find significant changes in autism symptoms or in parental report of stress, following the intervention parents were more likely to report being happy or proud of their child. Parents also increased in their ability to predict when their child would have a behavior problem from pre- to post-intervention.

Conclusions

In this paper we discussed current research on outcomes for individuals with ASD during adulthood as well as highlighted the important role families play in the transition to adulthood for their son or daughter. There is mounting evidence that few adults with ASD achieve traditional markers of adult independence and many individuals have limited to no regular day time activities following high school exit [8, 13, 14]. Not surprisingly, the transition to adulthood is a time of high stress for families of children with ASD; this stress, in turn, has been associated with compromised health and well-being in parents who continue to be the primary caregivers for their children well into adulthood [26]. Further, negative emotional intensity (and a lack of positivity) in the family home has been associated with increases in symptoms and problem behaviors in individuals with ASD over time [30–32]. All these findings converge to indicate the transition to adulthood is a time of elevated risk for families of individuals with ASD, creating a need for target interventions during this period. Currently there is a paucity of such programming.

We also argued in this paper that multi-family group psychoeducation is a potentially powerful intervention model for reducing family distress during the transition to adulthood. Our pilot study of the *Transitioning Together* program demonstrated the feasibility and acceptability of an 8-week group-based psychoeducation curriculum. Participating parents displayed positive changes in knowledge as well as their attitudes about their son or daughter. Particularly promising was evidence of parental positive reframing about the child's behavior and an increase in parental warmth. Past research has documented that parental positivity (and lower criticism) is associated with improvements in child behavior problems and autism symptoms in samples of adolescents and adults with ASD [30–32]. These findings also highlight that, while certain aspects of the family system are amenable to change over an 8-week period, other, more negative dimensions such as behavior problems are more deeply entrenched and warrant direct psychological or psychiatric intervention.

Given the rapid increase of autism diagnoses since the 1990s [42], more children than ever before are entering adulthood with an ASD diagnosis. Despite a pressing need for research and interventions during this transition period, there currently are very few empirically-validated programs for adolescents with ASD. In the absence of appropriate transition services, the burden of care falls on the family. Multi-family group psychoeducation is one promising approach to address these needs and potentially ameliorate risks for individuals with ASD and their families during the transition to adulthood.

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Table 1

Summary of Intervention Session Topics

Session	Topic	Goals
Group Meeting 1	Autism in Adulthood	Meet other families *Learn about developmental course of ASD
Group Meeting 2	Transition Planning	*Learn about education, occupational, residential, service system, and health transition
Group Meeting 3	Problem Solving	Learn and practice problem-solving method
Group Meeting 4	Family Topics	*Learn about how family environment impacts behaviors
Group Meeting 5	Addressing Risks to Adult Independence	*Learn strategies for behavior management during late adolescence and early adulthood *Discuss advocacy strategies when behaviors are misunderstood by community
Group Meeting 6	Community Involvement	*Finding community activities and social opportunities Discuss safety concerns for adults with ASD
Group Meeting 7	Risks to Health	*Learn about risks to parental health and well-being
Group Meeting 8	Legal Issues	Receive information on long-term planning: guardianship, wills, trusts, etc

Table 2

Paired Samples T-Tests Comparing Pre-Intervention to Post-Intervention Scores

	Pre-Intervention	Post-Intervention	t (df; 1-tailed sig)	Effect size (Cohen's D)
PARENT KNOWLEDGE				
I have a good understanding of my child's disability	3.17 (.86)	3.50 (.71)	t(17)= 2.06; p=.03	.49
I understand how the service system is organized	1.78 (1.11)	2.22 (1.00)	t(17)= 1.72; p=.05	.40
I tell people in agencies how services for children can be approved	2.00 (1.37)	2.06 (.94)	t(17) =.25; p=.40	.06
PARENT-CHILD RELATIONSHIP				
Relationship Quality	22.89 (2.95)	24.00 (3.27)	t(17) = 1.64; p=.06	.39
Warmth	2.61 (.92)	3.00 (1.14)	t(17) = 1.94; p=.03	.46
Positive Remarks	2.33 (2.06)	2.17 (1.79)	t(17) =.36; p=.36	.09
Criticism	.94 (.80)	.89 (.76)	t(17) =.27 p=.40	.06
CHILD BEHAVIOR				
Autism severity rating	5.06 (1.73)	5.33 (2.09)	t(17) =.61 p=.28	.14
Walking on egg shells around s/d	1.39 (.92)	1.44 (.98)	t(17) =.33 p=.37	.08
Behavior problems seem to come out of nowhere	1.89 (.96)	1.50 (.71)	t(17) = 2.12; p=.02	.50
My s/d makes me happy/proud	2.00 (.77)	2.39 (.61)	t(17)= 2.36; p=.02	.50
PARENT STRESS				
Parent stress rating	6.22 (2.69)	6.50 (1.98)	t(17)=.70; p=.25	.17