The Family Context of Autism Spectrum Disorders
Influence on the Behavioral Phenotype and Quality of Life

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KEYWORDS
- Autism spectrum disorders • Family • Stress • Psychoeducation
- Expressed emotion

KEY POINTS
- A growing body of research has documented the high level of stress that parents of individuals with ASD experience and the subsequent impact of stress on parental well-being.
- Few have studied the reverse direction of effects: the influence of the family environment on the behavioral phenotype of ASD.
- Reducing levels of criticism and increasing levels of warmth in the family may help prevent the development and escalation of severe behavior problems in children, adolescents, and adults with ASD.
- Transitioning Together, an 8-week, multifamily group psychoeducation program, was developed to improve the family environment and meet the needs of families of individuals with ASD for education and support.
- Future research is needed to identify other best practice models in working with families of persons with ASD.

INTRODUCTION
Parents of children with autism spectrum disorder (ASDs) experience high levels of stress as caregivers.1,2 The challenging behaviors presented by many children on the spectrum is one of the most significant sources of stress for families.3–5 These behavior problems can continue into adulthood, creating barriers for adult
independence and community involvement. Although there is evidence of some abatement of autism symptoms and behavior problems over time, ASD is a lifelong disability that presents multiple challenges for families at each stage of the life course.

Our research has documented significant levels of stress associated with parenting a child with ASD during adolescence and adulthood and the impact of this stress on maternal health and well-being. In a daily diary study of mothers over an 8-day period we 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. These stressful daily experiences had a negative impact on mothers' emotional and physical well-being. Our research has demonstrated that mothers of adults with ASD have significantly more physical health symptoms, such as joint pain, fatigue, headaches, and gastrointestinal problems, than mothers of adults without disabilities. Furthermore, we examined differences in cortisol expression between mothers of adolescents and adults with ASD and mothers of similar-aged children without disabilities and found that mothers of individuals with ASD had significantly hypoactivated cortisol levels. This pattern of a chronic stress response is similar to what has been found in individuals with caregiver burnout and posttraumatic stress disorder. The history of behavior problems in the adolescents and adults in our sample significantly moderated the association between daily stress and cortisol level, with mothers of a son or daughter with clinically significant levels of behavior problems over the previous 5-year period having a blunted cortisol response in the face of daily stress, reflecting a greater hypoactivation of cortisol and a chronic stress response. These findings clearly highlight the significant risks to parental emotional and physical well-being associated with raising a child with ASD.

Perhaps in reaction to the history of blaming families of children with autism, researchers have been reluctant to examine the reverse direction of effects (ie, the influence of the family environment on the behavioral phenotype of autism). Given the centrality of the family in helping maximize the quality of life of persons with autism, there is a need to identify those characteristics of the family environment that are associated with the abatement versus escalation of behavior problems over time. In this article, we report the findings from our research examining the bidirectional influence between the family environment and the behavioral phenotype of autism, and describe a newly developed family psychoeducation program to reduce family stress, reduce behavior problems, and improve the quality of life of adolescents with autism and their families.

EXPRESSED EMOTION AND BEHAVIORAL DIFFICULTIES

To identify characteristics of the family environment that may influence the course of a child's disability, researchers studying persons with psychiatric disorders have paid considerable attention to the phenomenon of expressed emotion (EE). EE was originally conceptualized in terms of five dimensions of the family environment (criticism, hostility, emotional overinvolvement, warmth, and positive remarks), which were initially assessed by the administration of the Camberwell Family Interview. In early studies of the effects of EE on relapse rates in adults with schizophrenia, Brown and colleagues found that it was the criticism dimension that was the crucial variable in predicting symptomatic relapse, with emotional overinvolvement independently predicting relapse in a small number of cases. Consequently, subsequent studies focused on these two dimensions in operationalizing high EE. Since this initial work, a large number of studies have implicated EE in predicting symptom exacerbations across a broad range of mental health disorders and medical conditions, including
schizophrenia, mood disorders, eating disorders, Alzheimer disease, asthma, diabetes, and Parkinson disease.\textsuperscript{15,16}

More recently the construct of EE has been explored in families of typically developing children and adolescents\textsuperscript{17,18} and families of individuals with intellectual and developmental disabilities (IDD).\textsuperscript{19–22} In families of typically developing children, higher levels of parental criticism have been associated with more problematic child behaviors at multiple points in the life course.\textsuperscript{17,18,21,23} Parental criticism has likewise been linked with behavior problems in children and adolescents with IDD.\textsuperscript{4,20} In a review of studies of EE in families of children with IDD, Hastings and Lloyd\textsuperscript{24} argued that although the challenges associated with caring for an individual with IDD may create a family context where some level of EE is to be expected, the presence of high EE in families may exacerbate or maintain behavior problems and that research is needed to understand how to most effectively intervene to help these families.

**FAMILIES OF ADOLESCENTS AND ADULTS WITH AUTISM**

Our longitudinal research, spanning a 13-year period in a large cohort of families of adolescents and adults with ASD, has investigated separate dimensions of EE to identify characteristics of the family environment that influence the behavioral phenotype of adolescents and adults with autism. However, rather than focusing only on the negative dimensions of the family environment, our approach has been to broaden the focus to also include positive dimensions of family life, such as warmth and positive remarks that may promote positive behavior in the son or daughter with ASD and such dimensions as high levels of criticism that may result in an escalation of behavior problems or worsening of symptoms. The data for the analyses reported here come from a larger study of 406 families of adolescents and adults with an ASD who have been followed since 1999.\textsuperscript{25,26} The families met three criteria when initially recruited: (1) the son or daughter was age 10 or older; (2) he or she had received a diagnosis on the autism spectrum from a medical, psychological, or educational professional, as reported by the parents; and (3) administration of the Autism Diagnostic Interview–Revised (ADI-R)\textsuperscript{27} confirmed the parental report of an ASD.

Mothers were interviewed in their homes and also completed standardized self-administered measures. At the beginning of the study, the mothers ranged in age from 32 to 81 and their sons and daughters ranged from 10 to 52. Almost 65% of the individuals with ASD lived at home when the study began, and 49% still live in the family home 13 years later. Of the individuals with autism, 73% were male and 70% had an intellectual disability diagnosis.

As part of the interviews, we administered the Five Minute Speech Sample (FMSS),\textsuperscript{28} which was based on the Camberwell Family Interview, to measure the family environment. For the FMSS, the mother is asked to speak for 5 minutes to describe her relationship with the son or daughter with autism and to express her thoughts and feelings about this individual. The FMSS is coded both with respect to verbal content and vocal tone, and measures of maternal criticism, emotional overinvolvement, warmth, and positive remarks can be derived from this coding based on standard coding procedures.\textsuperscript{28} Hostility cannot be separately coded using the FMSS because of its high correlation with criticism.

Briefly, respondents are rated as “high” on criticism if they describe their relationship with their son or daughter in negative terms, or if they make one or more criticisms about their son or daughter during the course of the 5-minute speech sample.
CASE: COMPOSITE CASE OF PARENT RELATIONSHIP WITH CHILD WITH AUTISM

The following transcript, which represents a composite case, provides an example of how a parent classified as high in criticism speaks about the relationship with her child with autism:

David is a very wonderful, kind-hearted boy. He’s motivated to do what’s expected of him and tries very hard. But he has a lot of limitations. He has no peer relationships. He is very challenging because he needs a lot of input from us. He’s dependent on us to provide his recreation all the time and it gets really difficult. One of the biggest problems is to structure his time. I’ve had to deal with that throughout his life. He may enjoy doing something 1 day and the next absolutely refuse to do it so it is really hard to find things that motivate him. The other difficulty is that he wants many, many material items. His appetite for material items is insatiable and it is constantly a battle to get him to understand that we are not a bottomless money pit.

Emotional overinvolvement occurs when the family member either expresses excessive self-sacrificing or overprotective feelings toward the son or daughter with autism. Because autism requires that many parents make personal sacrifices to care for their child and may need to protect their child from being harmed by self or others, a rating of emotional overinvolvement requires that the behavior be “excessive.” The following composite transcript captures the meaning of emotional overinvolvement in autism.

Susie is the biggest challenge of my life. She can make us cry in a heartbeat and she can make us laugh in a heartbeat. It’s always about her; our life revolves around whatever works for Susie. Everything that affects her affects us. I know my life would be entirely different without her. We don’t go to restaurants; we don’t go to movies; we don’t do family activities, and sometimes my sadness is for the other kids that they never experienced what a lot of their friends have. I care a lot about her, maybe too much, but I feel like I need to protect her to the maximum. I often times wonder how much of my identity is wrapped up in her. Where is the line? Where does Susie end and I begin?

Warmth ratings are based on (1) tone of voice; (2) spontaneity of expression of sympathy, concern, or empathy; and (3) expression of interest in the child with autism. The following transcript represents a composite case of how a mother classified as high in warmth speaks about her child.

My son Steve is a wonderful, loving upbeat beautiful man and I am very, very proud of him. We live out here on our farm. Steve gets up every day faithfully and works diligently in providing care for the animals and it has helped him. He just seems to feel more important because he knows that these animals depend upon him and care. Right now we are in the process of canning and Steve is learning horticulture. We are about to have our first grandchild and Steve is going to be an uncle for the very first time and he’s excited about that. He got to help his brother participate in the naming of the baby.

Positive remarks reflect the number of positive statements the respondents expresses about her child during the FMSS. The following transcript, which represents a composite case, provides an example of a mother high on positive remarks.

He’s so amazing. He’s very kind hearted and he’s honest. And his randomness is such a unique personality. People really just love him. He tries hard to understand what other people are feeling and doing. He doesn’t like to complain about feeling bad or being sick, so if he does you know it’s really bad. He doesn’t mind helping usually and he loves to learn. Since he started Special Olympics, he’s just blossomed. He can run now; he took third place in one of his meets and it was unbelievable because he ran like no one was looking at him.
To investigate the association between the family environment and the behavioral phenotype of ASD, we administer the Problem Behavior subscale of the Scales of Independent Behavior–Revised (SIB-R) and the ADI-R to the families in our study. These measures were administered repeatedly (at four points of data collection over a 7-year period) to measure change. Standardized algorithms are used to translate SIB-R frequency and severity ratings into three subscales scores: (1) Internalized Maladaptive Behavior, (2) Asocial Maladaptive Behavior, and (3) Externalized Maladaptive Behavior. The ADI-R is a standardized investigator-based interview conducted with a primary caregiver (in our case, with the mother of the individual with autism). Based on the items in the diagnostic algorithm the ADI-R yields ratings for the three primary symptom clusters used in the diagnosis of autism: (1) repetitive behaviors and restricted interests, (2) impairment in reciprocal social interaction, and (3) impairments in communication. The repeated measures of the FMSS (to assess the family environment), SIB-R (to assess behavior problems), and ADI-R (to assess autism symptoms) make it possible to examine how aspects of the family environment predict change in the behavior problems and autism symptoms of the son or daughter, and whether the reverse direction of effects (from the child’s behavior problems and autism symptoms to the family environment) is also evident.

Although we find evidence of bidirectional influences between the family environment factors and child functioning, the direction of effects seems to be primarily from the family to the child. In our first study investigating 149 mothers coresiding with an adolescent or adult with autism, we found that family environments marked by high levels of criticism predicted increases in the severity of internalizing and asocial behavior problems and in repetitive behaviors and restricted interests over the 18-month period, controlling for prior levels of behavior problems and autism symptoms. Furthermore, in a follow-up analysis of the same sample, we examined growth curve trajectories of criticism and behavior problems over a 7-year period. We found that increases in criticism over the 7 years were associated with higher levels of behavior problems at the final time point, whereas change in behavior problems did not significantly predict final levels of criticism.

We subsequently conducted a parallel longitudinal study of 122 mothers of children (ages 6–8) and adolescents (ages 12–21) with fragile X syndrome (FXS). In this study, we found similar relationships between high levels of maternal criticism and an increase in internalizing, externalizing, and total problems as measured by the Child (or Adult) Behavior Checklist (A/CBCL), although the patterns were somewhat different in families of children and families of adolescents. Higher levels of maternal criticism were related to a subsequent increase in externalizing and total problems in the children with FXS, and to an increase in internalizing behavior problems, externalizing, and total behavior problems in the adolescents with FXS. Thus, one consistent finding of our research on families of persons with developmental disabilities is the pervasive negative effect that a high level of parental criticism has on child behavior.

We also found evidence that high levels of maternal warmth and positive remarks are associated with reductions in autism symptoms in our longitudinal research on families of adolescents and adults with autism. High levels of maternal warmth and positive remarks were related to declining levels of repetitive behaviors and restricted interests, as measured by the ADI-R 18 months later. This direction of effects was similar to the patterns we found between criticism and behavior problems summarized previously (ie, from warmth and positive remarks to behavior problems). We did not find evidence for the reverse direction of effects. Thus, we did not find that prior levels of behavior problems or autism symptoms affected levels of maternal
warmth or positive remarks 18 months later. In our parallel longitudinal study of families of children and adolescents with FXS, we similarly found that high levels of maternal warmth were related to declining levels of total behavior problems and to declining levels of externalizing problems (as measured by the A/CBCL) for children with FXS (but maternal warmth did not have a significant effect on the behavior of adolescents).

In a related study of a subset of the families in our longitudinal research on autism, we examined how exiting high school affected the behavior of adolescents with autism and also the relationship of the adolescent with his or her mother. For those adolescents with autism who did not have a comorbid intellectual disability, maternal warmth was found to decline after the son or daughter left high school, although this was not the case for mothers of adolescents with intellectual disabilities. This finding suggested that although behavior problems did not directly affect maternal warmth, changes in the daily life of the young adult with autism (i.e., exiting high school) did have an influence on maternal warmth.

Taken together, our findings suggest that reducing high levels of criticism (or maintaining low levels of criticism) and increasing parental warmth may prevent an escalation of behavior problems and autism symptoms. Thus, the family environment is an important target for intervention not only to reduce family distress but also to improve functioning for the child, adolescent, or adult with ASD. From a family systems perspective, transition periods, such as adolescence, may be particularly effective times for interventions, given that reorganizations in the family system are taking place during this stage of life. Furthermore, the findings reported previously based on Taylor and Seltzer’s research suggest that maternal warmth may be disrupted by transitions in the life of the son or daughter with autism, and thus adolescence may be an ideal time to intervene at the family level, which has led our group to develop a family psychoeducational program known as Transitioning Together.

The Transitioning Together Program

Multifamily group psychoeducation is a well-validated intervention approach for families of individuals with psychiatric conditions. Psychoeducation interventions for mental health conditions typically provide families with information about what is known about the cause, course, and outcome of the condition; effective interventions and treatments; community supports and resources; how the family is affected; behavior management; and vocational and residential planning. The effectiveness of psychoeducation interventions in improving the overall family environment and reducing behavior problems and symptoms in individuals with mental health conditions has been demonstrated in multiple studies of conditions, such as schizophrenia and mood disorders. However, such programs had yet to be developed and evaluated for families of children with autism. Our primary goal in developing Transitioning Together was to determine whether a psychoeducational group intervention would reduce family stress and behavior problems, and improve the quality of life of persons with autism and their families.

Consistent with a multifamily psychoeducation model, the Transitioning Together program has two stages of intervention: two individual-family joining sessions and eight multifamily group sessions. The joining sessions allow the family to meet with the intervention staff before the group meetings to develop rapport and clarify family goals. After completing the joining sessions, families attend eight weekly group sessions. 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.

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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 participating families and to focus on addressing problems in a constructive, noncritical way. In addition to group problem-solving, families also receive individualized resources and referrals based on needs expressed during sessions (eg, mental health providers, summer camps). 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, which involves a variety of games and learning activities on such topics as sharing interests, setting goals, social problem solving, and party planning.

Our initial pilot evaluation of the Transitioning Together program included 10 families of adolescents with ASD (aged 15–18 years; M = 16.2; SD = 1.1). Even with this very small sample, we found significant positive changes from preintervention to postintervention in parents’ understanding of their child’s disability and of the service system.48 There were also significant improvements in the parent-child relationship domain. Importantly, parents were rated (by an independent blind rater) as having higher levels of warmth toward their son or daughter, based on coding of the FMSS. Furthermore, after the intervention, parents were more likely to report being happy or proud of their child. Although we did not find significant changes in autism symptoms or in parental report of stress in this small pilot sample, parents increased in their ability to predict when their child would have a behavior problem from preintervention to postintervention.48

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

From Smith LE, Greenberg JS, Mailick MR. Adults with autism: outcomes, family effects, and the multifamily group psychoeducation model. Curr Psychiatry Rep 2012;14:735; with permission.
Currently we are evaluating a refined version of the *Transitioning Together* program with a highly homogenous group of families. Our pilot study was comprised of adolescents with a wide range of verbal and intellectual abilities, including individuals with intellectual disability along with individuals with IQs in the gifted range. The inclusion criteria for our new evaluation study are that participating families have adolescents between the ages of 14 and 17 years who are verbal (speak using complex sentences) and who particulate in general education settings at least 50% of the time. We believe that by creating homogenous groups, parent and teenage sessions will be more focused and beneficial for families, with even larger observable gains in quality of life. In this current study, we have increased the sample to include 40 families and broadened the range of outcome measures to include parental well-being, burden, and daily stress (including a measure of salivary cortisol) and adolescent social and recreational activities, friendships, and adaptive behavior.

**COMPOSITE CASE OF A FAMILY WHO COMPLETED THE TRANSITIONING TOGETHER PROGRAM**

**CASE:** Composite Case of Family in Transitioning Together Program

Becky is a single mother of a 16-year-old son, John, who has ASD. John is a junior in a large public high school and he has two older sisters who no longer live at home. He enjoys videogames and is fascinated with Chinese culture. Although John has above average intelligence (Wechsler Full Scale IQ of 125) and does well in many academic subjects, he has significant delays in adaptive behavior (e.g., difficulties with hygiene; Vineland Standard Score of 67). At time of entry into the *Transitioning Together* study, John had total scores in the clinical range on measures of behavior problems and psychopathology (SIB-R and CBCL) and was taking medication for anxiety. He exhibited a range of challenging behaviors including being hurtful to himself, hurtful to others, disruptive, withdrawn, uncooperative, and having repetitive habits.

Before beginning the intervention, Becky reported a high level of stress on the Perceived Stress Scale and her responses during the FMSS indicated a high level of EE:

> My relationship with John, well, I wish it was better. I wish for more. I try to talk to him about important things and I can’t have a conversation, a real conversation with him. I hope that as he grows older that will change.

After completion of the *Transitioning Together* program, the family displayed positive changes that were consistent with the program’s goals of reducing family stress and improving quality of life. For example, there was an improvement in the parent-child relationship, which was evidenced in the FMSS taken during the exit interview:

> As far as my relationship with John, he has a great sense of humor, and he loves to have intellectual conversation with me. He shares science facts with me and we joke around a lot. His sisters think he’s funny too. I really enjoy that aspect of our relationship.

Becky also reported lower levels of stress after the intervention, although her overall stress levels were still elevated. During the exit interview Becky reflected on her experience in the program, saying:

> I think probably what was most useful to me was just hearing from other families, hearing about the challenges they have with their teens too and getting ideas for handling issues. At times with my kids I’ve felt very isolated and alone. Hearing other families talk about having the same types of experiences was really validating. And it was nice to toss out my ideas that could maybe help others. The group reminded me that some of these things are just a part of autism.
SUMMARY AND FUTURE DIRECTIONS

In other studies based on our ongoing research, we have reported poor outcomes for adults with autism in important areas that determine their quality of life. For example, we have shown that adaptive behavior in adults with autism lags behind their cognitive capacities,\textsuperscript{51} that high school exit marks a time of increased vulnerability with respect to behavior problems and autism symptoms,\textsuperscript{36} that friendships are scarce in adulthood and social participation is not frequent,\textsuperscript{52} that vocational outcomes are poor and tend to decline over time,\textsuperscript{53} and that few live independently.\textsuperscript{54}

In this article reviews our research that has shown that the quality of the relationship between parents and the adolescent or adult with autism can be an important factor shaping trajectories of behavioral functioning in the son or daughter. Our findings are completely consistent with the large body of research summarized previously in this paper showing that the family environment, as indexed by EE, can have a significant effect on the functioning of individuals with mental health problems; developmental problems; and physical illnesses as diverse as asthma, attention-deficit/hyperactivity disorder, Parkinson disease, and schizophrenia, and now autism and FXS. As such, criticism and warmth might best be conceptualized as powerful aspects of intimate relationships that can significantly affect the manifestation and severity of symptoms.

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There currently is significant interest in bullying as experienced by children and adolescents with autism\textsuperscript{55–57} and the effect of bullying on their mental health. Perhaps bullying is a particularly intense form of criticism and may be a factor that affects the gap between the cognitive capacities and adaptive behavior of those who have
autism, and the persistence of their behavior problems and autism symptoms. Furthermore, it would be valuable to ascertain the extent to which criticism in the relationships between adults with autism and other key figures in their lives, such as employers or coworkers, is also implicated in the poor quality of life that such adults typically experience.

Transitioning Together is a promising intervention that may have the effect of reducing family distress during the time when the son or daughter with autism is transitioning to adulthood. Given the centrality of the family in the lives of adults with autism, and their continued need for support, the positivity of their relationships with their parents and siblings may be particularly important for behavioral regulation, social integration, and quality of life. Because of the rapid increase of autism diagnoses since the 1990s, more children than ever before are entering adulthood with an autism diagnosis. Despite a pressing need for research and interventions during this transition period, there currently are very few empirically validated programs for adolescents with autism or their families. Multifamily group psychoeducation, such as Transitioning Together, is one promising approach to address these needs and potentially ameliorate risks for individuals with adults and their families during the transition to adulthood and beyond.

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