



Published in final edited form as:

*Child Adolesc Psychiatr Clin N Am.* 2014 January ; 23(1): 143–155. doi:10.1016/j.chc.2013.08.006.

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

**Leann E. Smith, PhD [Assistant Clinical Professor of Pediatrics],**  
Waisman Center Investigator University of Wisconsin-Madison

**Jan Greenberg, PhD [Professor and Director, School of Social Work],** and  
Waisman Center Investigator University of Wisconsin-Madison

**Marsha R. Mailick, PhD [Vaughan Bascom and Elizabeth M. Boggs Professor Director]**  
Waisman Center University of Wisconsin-Madison

### Synopsis

In this review, we report the findings from our longitudinal program of research examining the bidirectional influences of the family environment on the behavioral phenotype of autism, and describe a newly developed family psychoeducation program, titled *Transitioning Together*, designed to reduce family stress, address behavior problems, and improve the overall quality of life of adolescents with autism and their families. In our search for characteristics of the family environment that influence the behavioral phenotype of adolescents and adults with autism, we focus on both positive dimensions of family life, such as warmth and positive remarks that may promote adaptive behavior in individuals with autism, as well as negative dimensions, such as high levels of criticism that may result in an escalation of behavior problems. We find that high levels of maternal warmth and positive remarks are associated with the abatement of behavior problems over time, while high levels of maternal criticism are associated with increasing levels of behavior problems in adolescents and adults with autism. These patterns of relationships have been replicated in a longitudinal study of families of children and adolescents with fragile X syndrome, and are consistent with other studies examining the impact of the family on the behavior of children with developmental disabilities. These findings suggest that the family environment is an important target for interventions not only to reduce family stress but also to improve the behavioral functioning of children, adolescents or adults with ASD.

Building upon a well-developed intervention for families of individuals with psychiatric conditions, we report on the development of *Transitioning Together*, a psychoeducation program targeted to families with adolescents with autism who are approaching high school exit, a difficult transition stage for individuals with autism that is often marked by negative changes in behavior problems. The 8-week *Transitioning Together* program involves education on a variety of topics relevant to ASD and guided practice in helping families better manage problem behavior in adolescents with autism. Preliminary data suggest that the program can improve the parent-child relationship and increase parental expressions of warmth. A case study is presented that illustrates how *Transitioning Together* helps reduce family stress and improve the overall quality of the

---

© 2013 Elsevier Inc. All rights reserved.

Corresponding: Mailick@Waisman.Wisc.Edu.

**Publisher's Disclaimer:** This is a PDF file of an unedited manuscript that has been accepted for publication. As a service to our customers we are providing this early version of the manuscript. The manuscript will undergo copyediting, typesetting, and review of the resulting proof before it is published in its final citable form. Please note that during the production process errors may be discovered which could affect the content, and all legal disclaimers that apply to the journal pertain.

The authors have nothing to disclose

family environment. We conclude the article with a discussion of directions for future research on best practices in working with families of children, adolescents and adults with autism.

## Keywords

autism spectrum disorders; family; stress; psychoeducation; expressed emotion

---

## 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 (6). Although there is evidence of some abatement of autism symptoms and behavior problems over time (7, 8), ASD is a lifelong disability which 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 (9), 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 subsequently 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 GI problems than mothers of adults without disabilities (10). Further, 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 (11). This pattern of a chronic stress response is similar to what has been found in individuals with caregiver burnout and post-traumatic 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 five 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, i.e., 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 paper, we report the findings from our research examining the bidirectional influence between the family environment and the behavioral phenotype of autism, and we 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

In an effort 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; 12). 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 (13). In early studies of the effects of EE on relapse rates in adults with schizophrenia, Brown and his colleagues (14) 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's disease, asthma, diabetes, and Parkinson's disease (15, 16).

More recently the construct of EE has been explored in families of typically-developing children and adolescents (17, 18) and families of individuals with intellectual and developmental disabilities (IDD; 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 (17-18, 21, 23). Parental criticism has likewise been linked with behavior problems in children and adolescents with IDD (20, 24). In a review of studies of EE in families of children with IDD, Hastings and Lloyd (25) 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 in an effort 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 as well as dimensions such 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 autism spectrum disorder who have been followed since 1999 (26, 27). 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; 28) confirmed the parental report of an autism spectrum disorder.

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; 29), which was based on the Camberwell Family Interview, to measure the family environment. For the FMSS, the mother is asked to speak for five 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 (29). 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 five-minute speech sample.

### **Case: Composite Case of Parent Relationship with Autistic Child**

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 one 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 over-involvement occurs when the family member either expresses excessive self-sacrificing or overprotective feelings toward the son or daughter with autism. Since 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 over-involvement requires that the behavior be “excessive.” The following composite transcript captures the meaning of emotional over-involvement 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 (a) tone of voice; (b) spontaneity of expression of sympathy, concern, or empathy, and (c) 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 sub-scale of the Scales of Independent Behavior – Revised (SIB-R; 30) and the Autism Diagnostic Interview-Revised (ADI-R; 28) to the families in our study. These measures were administered repeatedly (at four points of data collection over a seven year period) in order to measure change. Standardized algorithms (30) are used to translate SIB-R frequency and severity ratings into three subscales scores: Internalized Maladaptive Behavior, Asocial Maladaptive Behavior, and 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 (8), the ADI-R yields ratings for the three primary symptom clusters used in the diagnosis of autism: repetitive behaviors and restricted interests, impairment in reciprocal social interaction, and 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 the bidirectional influences between the family environment factors and child functioning, the direction of effects appears to be primarily from the family to the child. In our first study investigating 149 mothers co-residing 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 (31). 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 (32).

We subsequently conducted a parallel longitudinal study of 122 mothers of children (ages 6 to 8) and adolescents (ages 12 to 21) with fragile X syndrome (FXS; 33). 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 (34, 35), 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 (36). This direction of effects was similar to the patterns we found between criticism and behavior problems (summarized above) i.e., from warmth and positive remarks to behavior problems. We did not find evidence for the reverse direction of effects. In other words, 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 sub-set 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 (37, 38). 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 (39). Furthermore, the findings reported above based on Taylor and Seltzer's research (38) 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**

Multi-family group psychoeducation is a well-validated intervention approach for families of individuals with psychiatric conditions (40-42). Psychoeducation interventions for mental health conditions typically provide families with information about what is known about the etiology, 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 (43). 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 (44, 45) and mood disorders (46-48). 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 multi-family psychoeducation model, the *Transitioning Together* program (49) 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. After completing the joining sessions, families attend 8 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.

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, non-critical way. In addition to group problem-solving, families also receive individualized resources and referrals based on needs expressed during sessions (e.g., 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 topics such 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 pre- to post-intervention in parents' understanding of their child's disability and of the service system (49). 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 Five Minute Speech Sample. Further, following 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 pre- to post-intervention (49).

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 year 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, both parent and teen sessions will be more focused and beneficial for families, hopefully with even larger observable gains in quality of life. In this current study, we have increased the sample to include 48 families and broadened the range of outcome measures to include parental well-being, burden, and daily stress (including a measure of salivary cortisol) as well as adolescent social and recreational activities, friendships, and adaptive behavior.

Below we present a 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 autism spectrum disorder. 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.

Prior to beginning the intervention, Becky reported a high level of stress on the Perceived Stress Scale (50) and her responses during the Five Minute Speech Sample 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.”

Following 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 Five Minute Speech Sample 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 following the intervention, although it is important to note that 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.”

Participating in *Transitioning Together* also had a positive impact on John. Over the course of the 8 group sessions he became increasingly more engaged in group interactions, as rated by the intervention staff. There also was noticeable improvement in John's challenging behaviors. Based on an adapted, daily version of the SIB-R, John's level of daily behavior problems dropped by 12% following the intervention. Also, although his CBCL total score was still within the clinical range following the intervention, the general trend was one of improvement. On one sub-scale (conduct disorders), John's scores were in the borderline clinical range prior to the intervention but were in the normal range after the intervention. Unfortunately, John did not show



significant change in autism symptoms (as measured by the Social Responsivity Scale; 51). The lack of change in autism symptoms and the continued high levels of many behavior problems are consistent with our prior findings and highlight the pervasive nature of ASD and the likely need for continuing, intensive interventions for individuals and their families.

During the exit interview, John indicated that he learned better ways to do things like organizing and planning, which he thinks will help him in the future. He particularly appreciated getting to meet other teens his age.

“The thing I liked best was probably just meeting the other guys. We were all juniors so it was neat to meet other people like me going through the same types of things at school. We would share about our weeks. One person might make a joke and then someone else would make a follow up on it and that was just great. Of course I would usually be the one making the jokes!”

In addition to providing humor for the group, John felt that he contributed good ideas: “I was a good observer and listener, and when I did say something it was a good point.” Reflecting on insights he had over the course of the group John also said, “Mostly I’ve been thinking about how far I’ve come since I was a kid. And I think I’ve figured out that my brain works differently from most people. That’s what I’ve been thinking.”

## Conclusion 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 (52), that high school exit marks a time of increased vulnerability with respect to behavior problems and autism symptoms (37), that friendships are scarce in adulthood and social participation is not frequent (53), that vocational outcomes are poor and tend to decline over time (54), and that few live independently (55).

In this paper, we have reviewed 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 earlier 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, physical illnesses as diverse as asthma, ADHD, Parkinson’s 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.

There currently is significant interest in bullying as experienced by children and adolescents with autism (56-58) 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, as well as 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 co-workers, 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. Due to 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. Multi-family 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.

## Acknowledgments

This research is supported by grants from the National Institute on Aging (R01 AG08768, M. R. Mailick, PI), the National Institute on Child Health and Human Development (P30 HD03352, M.R. Mailick, PI), and Autism Speaks (7523, L. Smith, PI). We gratefully acknowledge support from UW-Madison's Clinical and Translational Science Award Program for community intervention research (supported in part by grant U21 RR025011), the Autism Society of Southeastern Wisconsin, the Graduate School, and the Waisman Center at the University of Wisconsin-Madison.

## References

1. Duarte CS, Bordin IA, Yazigi L, Mooney J. Factors associated with stress in mothers of children with autism. *Autism*. 2005; 9:416–427. [PubMed: 16155057]
2. Montes G, Halterman JS. Characteristics of School-Age Children with Autism. *Journal Of Developmental And Behavioral Pediatrics*. 2006; 27:379–385. [PubMed: 17041273]
3. Hastings RP, Kovshoff H, Ward NJ, degli Espinosa F, Brown T, Remington B. Systems analysis of stress and positive perceptions in mothers and fathers of pre-school children with autism. *Journal of Autism and Developmental Disorders*. 2005; 35:635–644. [PubMed: 16177837]
4. Herring S, Gray K, Taffe J, TongeHastings RP, Daley D, Burns C, Beck A. Maternal distress and expressed emotion: Cross sectional and longitudinal relationships with behavior problems of children with intellectual disabilities. *American Journal of Mental Retardation*. 2006; 111:48–61. [PubMed: 16332156]
5. Lounds J, Seltzer MM, Greenberg JS, Shattuck PT. Transition and change in adolescents and young adults with autism: Longitudinal effects on maternal well-being. *American Journal of Mental Retardation*. 2007; 112:401–417. [PubMed: 17963433]
6. Smith, M.; Philippen, LR. Community integration and supported employment.. In: Zager, D., editor. *Autism spectrum disorders: Identification, education, and treatment*. 3rd ed.. Lawrence; Mahwah, NJ US: 2005. p. 493-514.
7. Seltzer MM, Shattuck P, Abbeduto L, Greenberg J. The trajectory of developments in adolescents and adults with autism. *Mental Retardation and Developmental Disabilities Research Reviews*. 2004; 34:41–48.
8. Shattuck PT, Seltzer MM, Greenberg JS, Orsmond GI, Bolt D, Kring S, Lounds J, Lord C. Change in autism symptoms and maladaptive behaviors in adolescents and adults with an autism spectrum disorder. *Journal of Autism and Developmental Disorders*. 2007; 37:1735–1747. [PubMed: 17146700]
9. Smith LE, Hong J, Seltzer MM, Greenberg JS, Almeida D, Bishop S. Daily experiences among mothers of adolescents and adults with ASD. *Journal of Autism and Developmental Disorders*. 2010; 40:167–178. [PubMed: 19655239]
10. Smith LE, Seltzer MM, Greenberg JS. Daily health symptoms of mothers of adolescents and adults with fragile X syndrome and mothers of adolescents and adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders*. 2012; 42:1836–46. [PubMed: 22167342]
11. Seltzer MM, Greenberg JS, Hong J, Smith LE, Ameida DM, Coe C, Stawski RS. Maternal cortisol levels and behavior problems in adolescents and adults with ASD. *Journal of Autism and Developmental Disorders*. 2010; 40:457–469. [PubMed: 19890706]

12. Butzlaff RL, Hooley JM. Expressed emotion and psychiatric relapse: a meta analysis. *Archives of General Psychiatry*. 1998; 55:547–552. [PubMed: 9633674]
13. Leff, JP.; Vaughn, CE. Expressed emotion in families. Guilford Press; New York: 1985.
14. Brown GW, Birley JLT, Wing JK. Influence of family life on the course of schizophrenic disorders: A replication. *British Journal of Psychiatry*. 1972; 121:241–258. [PubMed: 5073778]
15. Hooley JM. Expressed emotion and relapse of psychopathology. *Annual Review of Clinical Psychology*. 2007; 3:329–352.
16. Wearden AJ, Tarrrier N, Barrowclough C, Zastowny TR, Rahill AA. A review of expressed emotion in health care. *Clinical Psychology Review*. 2000; 20:633–666. [PubMed: 10860170]
17. Kwon J, Delaney-Black V, Covington C, Abell SC, Nordstrom-Bailey B, Sokol R, Ager J. The relations between maternal expressed emotion and children's perceived self-competence, behavior and intelligence in African-American families. *Early Child Development and Care*. 2006; 176:195–206.
18. Wedig MM, Nock MK. Parental expressed emotion and adolescent self-injury. *Journal of the American Academy Of Child & Adolescent Psychiatry*. 2007; 46:1171–1178. [PubMed: 17712240]
19. Beck A, Daley D, Hastings RP, Stevenson J. Mother's expressed emotion towards children with and without intellectual disabilities. *Journal of Intellectual Disability Research*. 2004; 48:628–638. [PubMed: 15357682]
20. Chadwick OO, Kusel YY, Cuddy MM. Factors associated with the risk of behaviour problems in adolescents with severe intellectual disabilities. *Journal of Intellectual Disability Research*. 2008; 52:864–876. [PubMed: 18647216]
21. Peris T, Baker B. Applications of the expressed emotion construct to young children with externalizing behavior: Stability and prediction over time. *Journal of Child Psychology and Psychiatry*. 2000; 41:457–462. [PubMed: 10836675]
22. Peris TS, Hinshaw SP. Family dynamics and preadolescent girls with ADHD: the relationship between expressed emotion, ADHD symptomatology, and comorbid disruptive behavior. *Journal Of Child Psychology And Psychiatry*. 2003; 44:1177–1190. [PubMed: 14626458]
23. Baker BL, Heller TL, Henker B. Expressed Emotion, parenting stress, and adjustment in mothers of young children with behavior problems. *Journal Of Child Psychology And Psychiatry*. 2000; 41:907–915. [PubMed: 11079433]
24. Hastings RP, Daley D, Burns C, Beck A. Maternal distress and expressed emotion: Cross-sectional and longitudinal relationships with behavior problems of children with intellectual disabilities. *American Journal of Mental Retardation*. 2006; 111:48–61. [PubMed: 16332156]
25. Hastings RP, Lloyd T. Expressed emotion in families of children and adults with intellectual disabilities. *Mental Retardation and Developmental Disabilities Research Reviews*. 2007; 13:339–45. [PubMed: 17979206]
26. Barker ET, Hartley SL, Seltzer MM, Floyd FJ, Greenberg JS, Orsmond GI. Trajectories of emotional well-being in mothers of adolescents and adults with autism. *Developmental Psychology*. 2011; 47:551–561. [PubMed: 21171753]
27. Seltzer, MM.; Greenberg, JS.; Taylor, JL.; Smith, LE.; Orsmond, GI.; Esbensen, A.; Hong, J. Adolescents and adults with autism spectrum disorder.. In: Amaral, DG.; Dawson, G.; Geschwind, D., editors. *Autism spectrum disorders*. Oxford University Press; New York: 2011. p. 241-252.
28. Lord C, Rutter M, Le Couteur A. Autism Diagnostic Interview-Revised: A revised version of a diagnostic interview for caregivers of individuals with possible pervasive developmental disorders. *Journal of Autism and Developmental Disorders*. 1994; 24:659–685. [PubMed: 7814313]
29. Magaña AB, Goldstein MJ, Karno M, Miklowitz DJ, Jenkins J, Falloon IRH. A brief method for assessing expressed emotion in relatives of psychiatric patients. *Psychiatry Research*. 1986; 17:203–212. [PubMed: 3704028]
30. Bruininks, RH.; Woodcock, RW.; Weatherman, RF.; Hill, BK. *Scales of Independent Behavior – Revised*. Riverside Publishing; Itasca, IL: 1996.
31. Greenberg JS, Seltzer MM, Hong J, Orsmond GI. Bidirectional effects of expressed emotion and behavior problems and symptoms in adolescents and adults with autism. *American Journal on Mental Retardation*. 2006; 111:229–249. [PubMed: 16792426]

32. Baker JK, Smith LE, Greenberg JS, Seltzer MM, Taylor JL. Change in maternal criticism and behavior problems in adolescents and adults with autism across a 7-year period. *Journal of Abnormal Psychology*. 2011; 120:465–475. [PubMed: 21319925]
33. Greenberg J, Mailick MR, Smith L, Hong J, Warren SF, Brady N. Bidirectional effects of the family environment and behavior problems in children and adolescents with fragile X syndrome: A longitudinal study. (under review).
34. Achenbach, T.; Rescorla, LA. *Manual for the ASEBA School-Age Forms & Profile : an integrated system of multi-informant assessments*. University of Vermont, Research Center for Children, Youth, & Families; Burlington, VT: 2001.
35. Achenbach, TM.; Rescorla, LA. *Manual for ASEBA Adult Forms & Profiles*. University of Vermont, Research Center for Children, Youth, & Families; Burlington, VT: 2003.
36. Smith LE, Greenberg JS, Seltzer MM, Hong J. Symptoms and behavior problems of adolescents and adults with autism: Effects of mother-child relationship quality, warmth, and praise. *American Journal on Mental Retardation*. 2008; 113:387–402. [PubMed: 18702558]
37. Taylor J, Seltzer M. Changes in the autism behavioral phenotype during the transition to adulthood. *Journal Of Autism And Developmental Disorders*. 2010; 40:1431–1446. [PubMed: 20361245]
38. Taylor J, Seltzer M. Changes in the mother-child relationship during the transition to adulthood for youth with autism spectrum disorder. *Journal Of Autism And Developmental Disorders*. 2011; 41:1397–1410. [PubMed: 21184158]
39. Cox MJ, Paley B. Families as systems. *Annual Review of Psychology*. 1997; 48:243–267.
40. Hogarty GE, Anderson CM, Reiss DJ, Kornblith SJ. Family psychoeducation, social skills training, and maintenance chemotherapy in the aftercare treatment of schizophrenia: II. Two-year effects of a controlled study on relapse and adjustment. *Archives Of General Psychiatry*. 1991; 48:340–347. [PubMed: 1672589]
41. Klaus N, Fristad MA. Family Psychoeducation as a Valuable Adjunctive Intervention for Children With Bipolar Disorder. *Directions in Psychiatry*. 2005; 25:217–230.
42. Lukens, EP.; McFarlane, WR. Psychoeducation as evidence-based practice: Considerations for practice, research, and policy.. In: Roberts, AR.; Yeager, KR., editors. *Foundations of evidence-based social work practice*. Oxford University Press; Oxford: 2006. p. 291-313.
43. McFarlane, WR.; Hornby, H.; Dixon, L.; McNary, S. Psychoeducational multifamily groups: Research and implementation in the United States. In H.. In: Lefley, P.; Johnson, DL., editors. *Family interventions in mental illness: International perspectives*. Praeger Publishers/Greenwood Publishing Group; Westport, CT US: 2002. p. 43-60.
44. Dixon L, Adams C, Lucksted A. Update on family psychoeducation for schizophrenia. *Schizophrenia Bulletin*. 2000; 26:5–20. [PubMed: 10755667]
45. McFarlane WR, Dixon L, Lukens E, Lucksted A. Family psychoeducation and schizophrenia: A review of the literature. *Journal of Marital and Family Therapy*. 2003; 29:223–245. [PubMed: 12728780]
46. Colom F, Vieta E, Martinez-Aran A, et al. A randomized trial on the efficacy of group psychoeducation in the prophylaxis of recurrences in bipolar patients whose disease is in remission. *Arch Gen Psychiatry*. 2003; 60:402–407. [PubMed: 12695318]
47. Miklowitz DJ, George EL, Richards JA, Simoneau TL, Suddath RL. A randomized study of family-focused psychoeducation and pharmacotherapy in the outpatient management of bipolar disorder. *Archives of General Psychiatry*. 2003; 60:904–912. [PubMed: 12963672]
48. Rea MM, Tompson MC, Milowitz DJ, Goldstein MJ, Hwang S, Mintz J. Family-focused treatment versus individual treatment for bipolar disorder: Results of a randomized clinical trial. *Journal of Consulting and Clinical Psychology*. 2003; 71:482–492. [PubMed: 12795572]
49. Smith LE, Greenberg JS, Mailick MR. Adults with autism: Outcomes, family effects, and multi-family group psychoeducation model. *Current Psychiatry Reports*. 2012; 14:732–738. [PubMed: 23015048]
50. Cohen, S.; Williamson, G. Perceived stress in a probability sample of the United States.. In: Spacapan, S.; Oskamp, S., editors. *The social psychology of health: Claremont Symposium on applied social psychology*. Sage; Newbury Park, CA: 1988.

51. Constantino JN, Davis SA, Todd RD, Schindler MK, Gross MM, Brophy SL, et al. Validation of a brief quantitative measure of autistic traits: Comparison of the social responsiveness scale with autism diagnostic interview-revised. *Journal of Autism and Developmental Disorders*. 2003; 33:427–433.
52. Smith L, Maenner M, Seltzer M. Developmental trajectories in adolescents and adults with autism: the case of daily living skills. *Journal of the American Academy of Child & Adolescent Psychiatry*. 2012; 51(6):622–631. [PubMed: 22632621]
53. Smith LE, Mailick MR, Greenberg JS. Interpersonal relationships and social participation as markers of quality of life of adolescents and adults with autism and fragile X syndrome. (under review).
54. Taylor JT, Mailick MR. A longitudinal examination of 10-year change in achievement outcomes for adults with autism spectrum disorders. (under review).
55. Esbensen AJ, Bishop S, Seltzer M, Greenberg JS, Taylor J. Comparisons between individuals with autism spectrum disorders and individuals with Down syndrome in adulthood. *American Journal On Intellectual And Developmental Disabilities*. 2010; 115:277–290. [PubMed: 20563296]
56. Cappadocia MC, Weiss JA, Pepler D. Bullying experiences among children and youth with autism spectrum disorders. *Journal of Autism and Developmental Disorders*. 2012; 42:266–277. [PubMed: 21499672]
57. Montes G, Halterman JS. Bullying among children with autism and the influence of comorbidity with ADHD: A population-based study. *Ambulatory Pediatrics*. 2007; 7:253–257. [PubMed: 17512887]
58. Van Roekel E, Scholte RHJ, Didden R. Bullying among adolescents with autism spectrum disorders: Prevalence and perception. *Journal of Autism and Developmental Disorders*. 2010; 40:63–73. [PubMed: 19669402]

### 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, multi-family 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.

**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

From Smith, LE, Greenberg, JS, & Mailick, MR (2012). Adults with autism: Outcomes, family effects, and the multifamily group psychoeducation model. *Current Psychiatry Reports*, 14, 732-738; with permission.

\* Indicates content based on published findings of our research group