

## Acknowledgements

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**Cover Art:** *Flowers and Trees at Sunset* by Philip H. Porter who lives in Madison, Wisconsin. From the Harvey A. Stevens International Collection of Art by People with Developmental Disabilities, sponsored by the Friends of the Waisman Center.

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## **Section 1: Introduction**

When we began our study in 1998, we aimed to understand the impact of autism spectrum disorders (ASDs) on the family as well as the developmental course of ASD during adolescence and adulthood. Ultimately, we hoped to better understand the needs of individuals and families in order to inform the development of appropriate interventions and services. In this report we are excited to describe how we have used the valuable information you have shared with us over the years to develop an intervention for families who are currently going through the transition to adulthood. We hope this report demonstrates to you the truly significant amount of knowledge your participation in this study has provided regarding ASD during adolescence and adulthood.

Over the years, participants in our study have provided us with a vast amount of information on topics ranging from the symptoms of ASD during adolescence and adulthood to the day-to-day experiences of families. Findings from our past waves of data collection have highlighted the significant need for services for families during the transition to adulthood and beyond. These findings also have provided us with evidence regarding what should be targets of intervention and the types of information and supports that might be most useful to families.

This report has three sections. First, we present evidence from our research documenting the need for supports for individuals with ASD and their families during adolescence and adulthood. Next, we highlight a selection of findings from our research that can be directly used as content for intervention curricula for families. Third, we discuss our newly developed education and support program for families of adolescents with ASD entitled, *Transitioning Together*. This intervention is based entirely on the findings we have learned from you and we are excited to share this new project with you.

We are very grateful for the many years that you have given to this research and for sharing your lives with us. We are hopeful that your dedication to and support of this research will result in benefits for many other families of children with ASD.

## **Section II: Findings from the AAA Study---Documenting the Need for Supports and Services for Families Across the Life Course**

Multiple findings from our study have documented the need to provide supports and services to families of children with autism across the life course. Our study is the first to document that (a) parents continue to experience substantially higher levels of stress as their children grow into adolescence and adulthood than parents of similarly-aged children without disabilities and (b) this chronic stress over time may take a toll on parents' health and well-being. Below we highlight findings from the AAA study that underscore the need for family-centered services and policies later in life:

### ***❖ Daily life is often marked by high levels of stress for mothers of adolescent and adult children with ASD.***

- As part of our daily diary study, 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 similarly-aged children without disabilities.
- On average, mothers of a son or daughter with ASD experienced at least one stressful event on *five days* of the eight-day diary study. Stressful events occurred at home and at work, and included arguments, avoided arguments, and stressors happening to close friends and family members. In contrast, mothers of similarly-aged children without disabilities experienced stressful events on *three days* out of the eight-day diary study.

### ***❖ High levels of stress may lead to compromised health and well-being for parents of adolescents and adults with ASD.***

- Both mothers and fathers in our study have reported lower levels of psychological well-being in comparison to parents of similarly-aged children without disabilities as well as in comparison to parents of children with disabilities other than autism (e.g., Down syndrome, fragile X syndrome).
- As part of our daily diary study, mothers provided saliva samples from which we measured cortisol, a biological marker of stress. Our analysis

of these data indicated that many mothers of adolescents and adults with ASD displayed dysregulated patterns of cortisol, suggesting a chronic stress response.

- Mothers in our sample also have reported a higher frequency of health symptoms and conditions, including more frequent headaches, backaches, muscle weakness, and gastrointestinal symptoms compared to mothers of similarly-aged children without disabilities.

❖ *Importantly, many families of adolescents and adults with ASD display resilience later in the life course.*

- Using data collected over the past 10 years, we found that mothers in our study experienced decreases in anxiety symptoms over time, suggesting improvements in psychological well-being as children age.
- Our research also has shown that many mothers in our sample received valuable social support from friends and family and have high levels of marital satisfaction. This support, in turn, is associated with higher levels of positive well-being for mothers over time.

❖ *Adolescence and adulthood may be an especially important time to provide supports to families.*

- Our research has shown that mothers report particularly high levels of anxiety and anger during their son or daughter's adolescence, as mothers anticipate and worry about the transition out of high school.
- We have found that marital patterns of parents of children with ASD are similar to parents of children without disabilities when their children are young. However, there is an elevated risk of divorce for couples of a son or daughter with ASD during adolescence and beyond. Nevertheless, 75% of the mothers in our study remain married to the father of their child with ASD.

Taken together, these findings suggest that caring for a son or daughter with ASD may have long-term impacts on parental health, well-being, and family

functioning. It is especially noteworthy that although our research shows that maternal well-being and child behavior tend to improve over time, mothers of children with ASD still report a higher level of stress and distress during their son or daughter's adolescence and adulthood than mothers of similarly-aged children without disabilities. These key findings provide a strong rationale for providing comprehensive supports for the entire family not only during the childhood years, but also during the transition to adulthood and beyond.

Most encouraging, however, are the findings from our study which point to the types of support that might be most beneficial to families over time. For instance, results from our study indicate that reducing parental stress may be critical for promoting health and well-being later in life. In the next section we present information from the AAA study that we have included in the curriculum of our new intervention program, *Transitioning Together*.

### **Section III: Findings from the AAA Study---Informing Intervention Content**

In addition to highlighting the need for services and supports for families during adolescence and adulthood, findings from the AAA study have provided us with valuable knowledge to share with a new generation of families as they approach their son or daughter's transition to adulthood.

Specifically, we used multiple findings from the AAA study to create the core curriculum for our newly-developed intervention for parents of teenagers with ASD, *Transitioning Together*. Below we highlight a selection of key findings which have informed the new intervention:

#### **❖ *The Developmental Course of ASD***

- Our past findings have indicated that, on average, both behavior problems and autism symptoms of adolescents and adults with ASD tend to improve (become less severe) over time.
- Our recent research also has shown that for many individuals with ASD, patterns of behavior differ before and after they leave high school. Improvement tends to slow down after leaving high school which suggests that access to stimulating daily activities is important for promoting continued developmental gains for young adults on the spectrum.
- Participants in our study have provided us with in-depth profiles of activities and life experiences of individuals with ASD during adulthood. We subsequently have used this information to document a gap in services for many adults with ASD: A significant proportion of young adults with ASD have no regular vocational or educational activities following high school exit.
- The exact percentage of individuals with ASD who do not work, participate in agency-based programs, or attend post-secondary education varies from year to year (based in part on the economy) and from one state or county to another (based on services). Nevertheless, the percentage of adults without daily services, work, or post-secondary education is a significant concern.
- This information on the developmental course of ASD and current trends for adults with ASD is very valuable to parents who are currently going

through transition planning with their school-aged child and can alert parents to the need to prepare for, find, and maintain appropriate and meaningful daytime activities and social opportunities for their soon-to-be adult children.

❖ ***Effective Coping Strategies for Promoting Positive Parental Well-Being***

- Our research has shown that mothers who use problem-focused coping have lower levels of depression and greater feelings of personal growth. Our findings also suggest that mothers may gain skills in using these strategies over time. Examples of problem-focused coping include:
  - Planning → Developing a plan of action to deal with a stressor
  - Active Coping → Directly attempting to remove or reduce effects of the stressor
  - Positive Reinterpretation and Growth → Reframing a problematic event in a positive light
- As part of the intervention program, we help parents practice these coping strategies that have been shown to be beneficial for mothers in the AAA study.

❖ ***Strategies for Reducing Stress in the Family Environment and Promoting Behavioral Improvements for Individuals with ASD***

- Our research has found that when mothers remain positive, even in the face of stress, their son or daughter gains in terms of reductions in behavior problems and autism symptoms. Criticism of the son or daughter has the opposite effect. Positivity also has benefits for mother's own physical health.
- The effects of a warm parent-child relationship are very powerful. Our research has shown that parenting style at one point in time influences the severity of behavior problems and autism symptoms as long as eight years later.
- Parents can be empowered by knowing that having a strong, positive relationship with their son or daughter has value throughout their child's adult life. This knowledge may be particularly important to share with parents who are approaching the high school transition, as this is often a time of stress and worry for families.

## **Section IV: Transitioning Together**

### **Developing the Intervention**

With a grant from the University of Wisconsin's Clinical and Translational Science Award Program for community intervention research (supported in part by grant U21 RR025011), we developed and pilot tested an education and support program for families of adolescents with ASD entitled, *Transitioning Together*. First, based on findings from the AAA study over the past decade, we created a detailed outline of the potential curriculum. Next, we held three focus groups comprised of families of adolescents and young adults with ASD and professionals working with these families to gain their feedback on the curriculum.

Notably, focus group participants were universally enthusiastic about a program for families of adolescents. There was strong interest in our proposed curriculum topics. Parents told us that families would be likely to maintain participation if there were activities for the adolescent with ASD (as such activities would provide both respite for the parents and a social outlet for the teen) and if real solutions would be offered (in contrast with only venting problems). Based on focus group feedback, our research team refined the intervention curriculum and finalized the special program components.

### **Pilot Testing the Intervention**

After finalizing the curriculum, we recruited 11 families of adolescents with ASD (aged 15-18 years) to participate in the 8-week program. Families were randomly assigned to an initial treatment group or wait list control group. After the initial treatment group completed the intervention, families in the wait list control group had their opportunity, resulting in two groups of families who ultimately completed the intervention program.

The *Transitioning Together* program had two stages of intervention: two individual-family joining sessions and eight multi-family group sessions. The joining sessions allowed each family to meet with the intervention staff prior to the group meetings in order to develop positive relationships with the team and clarify family goals. For Joining Session 1, parents had the opportunity to discuss their family history and express their hopes and worries for their child with ASD. For Joining Session 2, parents discussed the types of connections they have with various individuals, services, and community organizations. At the close of

Joining Session 2, parents worked with the facilitator to create a list of goals for the *Transitioning Together* program. Each joining session lasted approximately 1.5 hours.

After the completion of joining sessions, families attended 8 weekly group intervention sessions together with other families. For each week of the intervention, mothers, fathers, and other parent figures attended parent group sessions which lasted approximately 1.5 hours each. While parents attended the parent group sessions, the adolescents with ASD participated in a social group with other adolescents on the spectrum.

Parent group sessions involved education on a variety of topics relevant to ASD as well as guided practice with problem-solving for difficulties that individual family members were facing. Examples include sleep problems for both teens and their parents, trouble finding appropriate health professionals and respite providers, and challenges related to locating social activities for teens. The session topics included:

Session	Topic	Session	Topic
1	Autism in Adulthood*	5	Addressing Risks for Adult Independence*
2	Transition Planning*	6	Community Involvement*
3	Problem-Solving	7	Risks to Parental Health and Well-being*
4	Family Topics*	8	Legal Issues

*Note: Sessions marked with an asterisk (\*) were based on findings from the AAA study.*

Parent sessions typically began with 15 minutes of socializing, followed by approximately 30 minutes of teaching on a topic and 45 minutes of discussion and problem-solving. The adolescent social group involved activities such as interactive games, cooking, and skits. All sessions took place at the Waisman Center at the University of Wisconsin-Madison.

## Outcomes of the Intervention

We conducted telephone interviews with all parents prior to the intervention (pre-test) as well as after the intervention (post-test) to collect data on parental knowledge and attitudes and adolescent behavior. We also collected data on the parental satisfaction with the intervention at conclusion of each group session and during the post-test interviews.

Overall, parents were highly enthusiastic and satisfied with the weekly sessions. As an example, in reflecting on her experience in the program, one parent said,

*“It was very nice to sit back and learn from other people and also put our two cents into the conversation. We’re absorbing and we’re sharing. Sometimes just doing that is a great stress reliever.”*

There were significant positive changes in parental knowledge and attitudes from pre- to post-intervention, particularly for mothers.

- After completing the intervention, both mothers and fathers reported having a significantly better understanding of their son or daughter’s autism condition.
- Mothers also reported significant improvements in their ability to anticipate their adolescent’s behavior problems from pre- to post-intervention.
- Following the intervention, mothers reported significantly higher levels of feeling happy and proud of their son or daughter’s behavior both at home and in public. These positive changes are encouraging given that parental positivity has been shown in our research to be associated with improvements in both parental well-being and child functioning over time.

In summary, these findings suggest that, despite high levels of stress, parents of teenagers with ASD are (a) eager to participate in an 8-week family-based intervention and (b) feel that they benefited from participating in our education and support intervention. This project is the first step in the development of a comprehensive intervention to improve adolescent functioning and reduce family stress during the transition years. We were able to develop this program because of the AAA research study and the data you and other families provided to us so many times over the past decade. We are in possession of this unique knowledge because of you.

## **Section V: Summary and Conclusions**

This report has highlighted ways in which findings from the AAA study have influenced the development of an intervention for families of adolescents with ASD. We also have presented a short summary of our activities to date related to the *Transitioning Together* intervention. Importantly, your participation in the AAA study has allowed us to document multiple findings regarding adult life for individuals with ASD and their families. This knowledge has served not only as a call for better services and interventions across the life course, but also as a roadmap for what types of education and supports might be most beneficial to families in the future. In summary, this report has shared the following information:

- ❖ The AAA study has documented that having a child with ASD is a profoundly stressful experience for many parents. This stress remains high even as children grow into adolescence and adulthood. Chronic stress may place parents at risk for health problems as they age.
- ❖ The AAA study has provided us with detailed knowledge that can be used to inform other parents of children with ASD. Past work has demonstrated that behavior problems and autism symptoms of individuals with ASD generally improve over time, particularly while individuals receive educational services. The study also has indicated that (a) using problem-focused coping strategies and (b) maintaining warm, positive relationships among family members can promote better well-being for parents and their son or daughter with ASD.
- ❖ Based on findings from more than 10 years of the AAA study, we developed and pilot-tested an education and support program for families of teenagers with ASD entitled *Transitioning Together*. The intervention involved eight weeks of group sessions for both parents and teens. Families who participated in the *Transitioning Together* program reported high levels of satisfaction with the program and displayed gains in knowledge about their child's disability. Parents also were more likely to report feeling happy and proud of their child after completing the program. This pilot study is the first step in developing a comprehensive intervention for transition-aged youth and their families.

We hope that this report has shown you how much we have learned from your participation in our study and how you have made significant contributions to the lives of other parents. We wish to once again express our gratitude for your

continued support of our research. We especially thank you for all of the insights and detailed observations you have provided to us over the years. This information made the *Transitioning Together* intervention possible. We are currently in the process of refining and expanding this intervention program to benefit even more families.

In addition to our intervention work with the *Transitioning Together* curriculum, we are excited to continue conducting research to understand factors that promote a high quality of life for all individuals with ASD. We aim to inform policies, interventions, and services for individuals with ASD and their families, not only during young adulthood, but also in mid-life and old age. We thank you again for your partnership in this work.

Finally, you can expect to receive another family report in about one year that will focus on plans that families in our study have made for their adult son or daughter's future. Many families worry about the future, and we hope that families can benefit from learning about the plans that others have put into place.