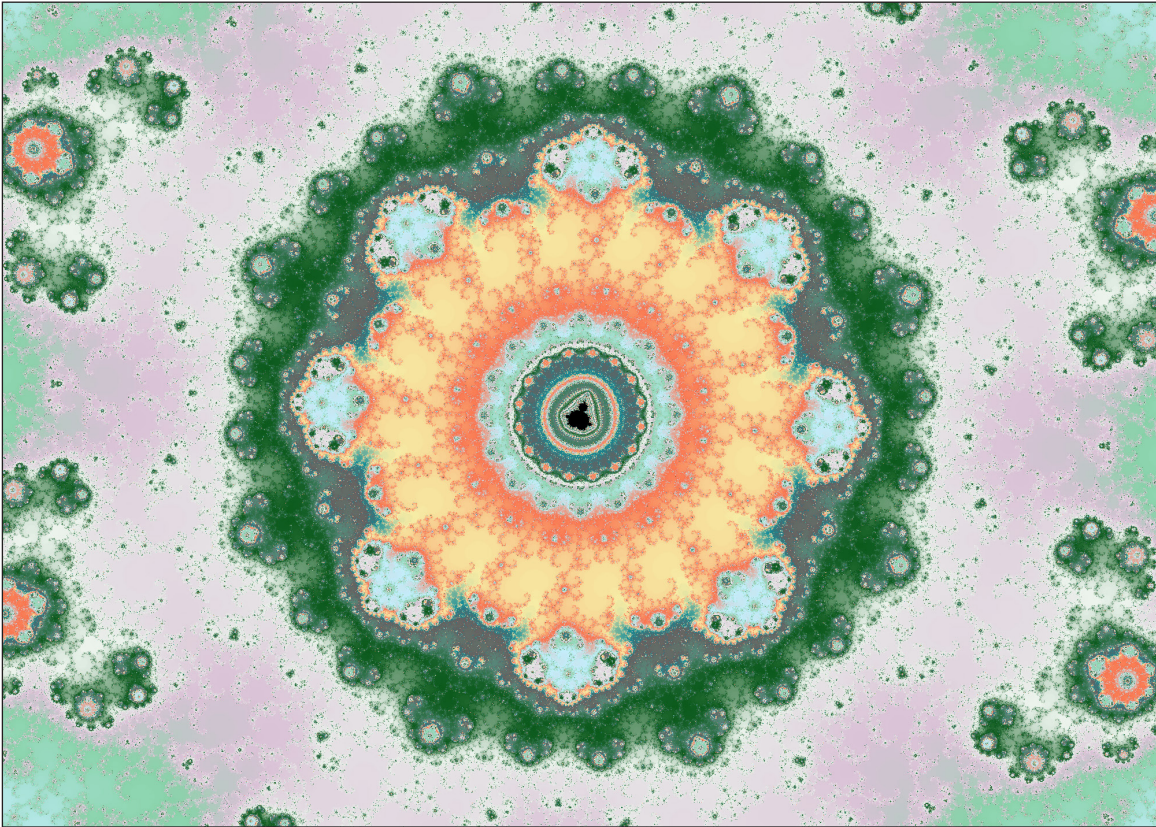


AAA

Adolescents & Adults with Autism A Study of Family Caregiving



Report #17

Transitioning Together: An Update on an Education and Support Program for Families of Adolescents with ASD

- Principal Investigators -

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Cover Art: *Asian Pillow 18*, by Matt Ward who lives in Madison, Wisconsin.

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Section 1: Introduction

Beginning in 1998, and continuing through 2014, your participation in our Adolescents and Adults with Autism (AAA) study has given us insight into the impact of autism spectrum disorder (ASD) on the family, as well as the developmental course of ASD during adolescence and adulthood. Through this study we have learned a great deal about the needs of individuals with ASD and their families across the life course.

In this report, we describe how we have used the valuable information you have shared with us over the years to develop an intervention for families whose son or daughter is currently going through the transition to adulthood. Your participation in this study has enabled us to take what we learned from your experiences and translate it into ways to help a new generation of families who are navigating the transition to adulthood.

Specifically, this report will discuss our education and support program for families of adolescents with ASD entitled, *Transitioning Together*. The intervention is based on the findings that we have learned from you over the years, and we are excited to share the results of our research on the effectiveness of the intervention as well as our ongoing success in sharing the program with families nationally and internationally.

We are very grateful for the many years that you have given to this research and for sharing your lives with us. As we discuss in this report, our hope is that your dedication to, and support of, this research will result in benefits for many other families of children with ASD.



Section II: Development and Pilot Test of the *Transitioning Together* Study

Developing the Intervention

As we discussed in Family Report #14 (*Transitioning Together: Developing an Education and Support Program for Families*), findings from the AAA longitudinal research led our team to develop *Transitioning Together*, an education and support program for families of adolescents with ASD. We began by conducting a development study where we reviewed our research findings, outlined a curriculum, and received feedback from focus groups. Consistent with what we have learned from you over the years, focus groups encouraged us to address the following family needs:

- Increasing community activities and connections
- Helping with problem solving
- Training in advocacy

The *Transitioning Together* intervention uses a multi-family group psychoeducation approach. Multi-family group psychoeducation emphasizes education and problem-solving, with a focus on reducing family distress and increasing capacity for advocacy. There is also a goal of improving the behavioral functioning of the individual with the disability. The program involved weekly group sessions for parents and a separate group for their teens. Parents were provided with education about ASD as well as training and practice in problem-solving issues that families raising children with ASD face. Teens participated in structured activities such as social role plays and independent living skills, and practiced various transition skills as part of a social group.

Pilot Study

Next, we conducted a small pilot study of *Transitioning Together*. We started small to learn whether the program was feasible for families, and also to determine whether the curriculum was potentially effective in improving outcomes for families. A total of 10 families of adolescents with ASD (age 15-18 years) participated in the 8-week pilot *Transitioning Together* program. Families were randomly assigned to either receive the intervention right away or to receive the intervention following a three-month waiting period. The second group of families

served as a control group prior to the time they received the training. All families participated in research interviews at the beginning and at end of the three month period.

In the pilot study, we observed the following outcomes from families who participated in the group:

- Mothers gained a better understanding of ASD
- Mothers reported improved ability to anticipate their child's behavior problems
- Mothers reported higher levels of happiness and pride in their child with ASD

We also learned that the intervention was feasible, as families reported high satisfaction with the program, and all families completed the program.



Section III: What is *Transitioning Together*?

The pilot findings suggested that the multi-family group psychoeducation approach had promise for families with ASD. Based on the pilot findings, we developed an intervention curriculum for *Transitioning Together* which we describe in detail below.

Intervention Components

- Two individual family “joining sessions”
- Eight concurrent weekly parent and teen group sessions
- Ongoing information about resources and referrals.

Joining sessions are scheduled at a mutually agreed upon location that is both comfortable and convenient for the participating family. The purpose of joining sessions is to build rapport and partnership with participating families, and to clarify family goals for the program. Each family can include family members of their choosing to attend the joining sessions (e.g., some families invited a sibling or grandparent to attend), although most joining sessions are comprised of participating parents and the adolescent with ASD. Joining sessions last approximately one hour.

After families complete the joining sessions, the *eight weekly group sessions* are held at the same time and place for both parents and teens, but in separate rooms. Group sessions last approximately ninety minutes. In both groups, facilitators teach and encourage the use of positivity and problem-solving strategies across all sessions.

Throughout the course of the program, families also receive *information about resources* in the local community that are relevant to the specific interests and concerns of the adolescents with ASD and their families (e.g., community events, local college fairs). Similarly, on an ongoing basis, families are given referrals to other community providers, services agencies, etc. based on specific family needs.

As shown in Table 1 on the next page, parent group sessions involve education focused on a variety of topics relevant to ASD as well as guided practice in problem-solving.

As you'll notice, most sessions have goals marked with an asterisk (*), which indicates that the content is based on the research results of the AAA study in which you participated.

Table 1. Parent Session Topics and Goals

Session	Goals
<u>Session 1:</u> Autism in Adulthood	Meet other families Learn about developmental course of ASD*
<u>Session 2:</u> Employment Planning	Learn about employment services and strategies*
<u>Session 3:</u> College Planning and Problem Solving	Learn about post-secondary services and planning strategies*
<u>Session 4:</u> Family Topics	Learn about impact of autism on family and the environment on individuals with ASD*
<u>Session 5:</u> Risks to Adult Independence	Learn strategies for behavior management during late adolescence and early adulthood* Discuss advocacy strategies when behaviors are misunderstood by community
<u>Session 6:</u> Community Involvement	Finding community activities and social opportunities* Discuss safety concerns for adults with ASD
<u>Session 7:</u> Legal Issues	Receive information on long-term planning: guardianship, wills, trusts, etc.
<u>Session 8:</u> Risks to Health and Wealth-Being	Learn about risks to parental health and well-being*

As shown in Table 2 below, the teen social group involves activities on topics such as sharing interests, goal setting, problem solving, and social planning.

Table 2. Teen Session Topics and Goals

Session	Goals
<u>Session 1</u> : Introductions	Practice asking questions of others Establish structure and ground rules
<u>Session 2</u> : Goal Setting	Create a goal and outline steps to achieve goal
<u>Session 3</u> : Social Problem Solving	Discuss how to use problem solving strategies to address social issues
<u>Session 4</u> : Coping Strategies	Determine potential coping strategies for stressful situations
<u>Session 5</u> : Flex Week	Session activities determined by needs and interests of group
<u>Session 6</u> : Conversation	Practice different types of conversations
<u>Session 7</u> : Party Planning	Learns steps for planning a party and prepare to implement next week
<u>Session 8</u> : Party/Graduation	Execute party plan and receive graduation certificates

Section IV: Randomized Controlled Trial (RCT) of *Transitioning Together*

In order to carefully test the effectiveness of *Transitioning Together* program, we next conducted a randomized waitlist control trial with a new, larger group of families of adolescents with ASD using the fully-manualized curriculum.

Our primary research question was whether families who received the *Transitioning Together* intervention would have greater improvements in key parent and adolescent outcomes compared to families who were in the control group. Specifically, we hypothesized that the intervention group would show improvements in parents' depressive symptoms, general life stress, and positive feelings toward their teen. We also anticipated that teens in the intervention group would have greater increases in the frequency of social interactions and improvements in autism symptoms compared to the teens in the waitlist group.

Our secondary research questions related to the “social validity” of the intervention and included:

- How satisfied were parents with the intervention?
- What did parents report learning from the intervention?
- What did parents report doing differently as a result of the intervention?

To answer our research questions, we recruited 45 parent-adolescent pairs through local Wisconsin autism groups, clinics, and the university research registries to participate in the intervention study. We included adolescents with a diagnosis of ASD who:

- were between the ages of 14 and 17 years.
- spent at least 50% of their school day in general education classrooms.
- were able to participate in a social group by having back and forth conversations with facilitators and peers.
- lived at home with their parents or legal guardian.

After families completed a pre-intervention interview, families were randomly assigned into one of two groups: those who received the *Transitioning Together* intervention right away (intervention condition) vs. those who received the intervention after a three-month waiting period (waitlist control). Families in both

groups participated in a post-intervention interview about 3 months after the pre-intervention interview took place.

During the pre- and post-intervention interviews, we collected information on the following outcomes for all parents in the intervention group and in the control group:

- Problem solving skills
- Depressive symptoms
- General life stress
- Parents' feelings of burden in interactions with their teen
- How often parents felt happy or proud of their teen

We also collected information on the following outcomes for teens:

- Frequency of social interactions
- ASD symptoms

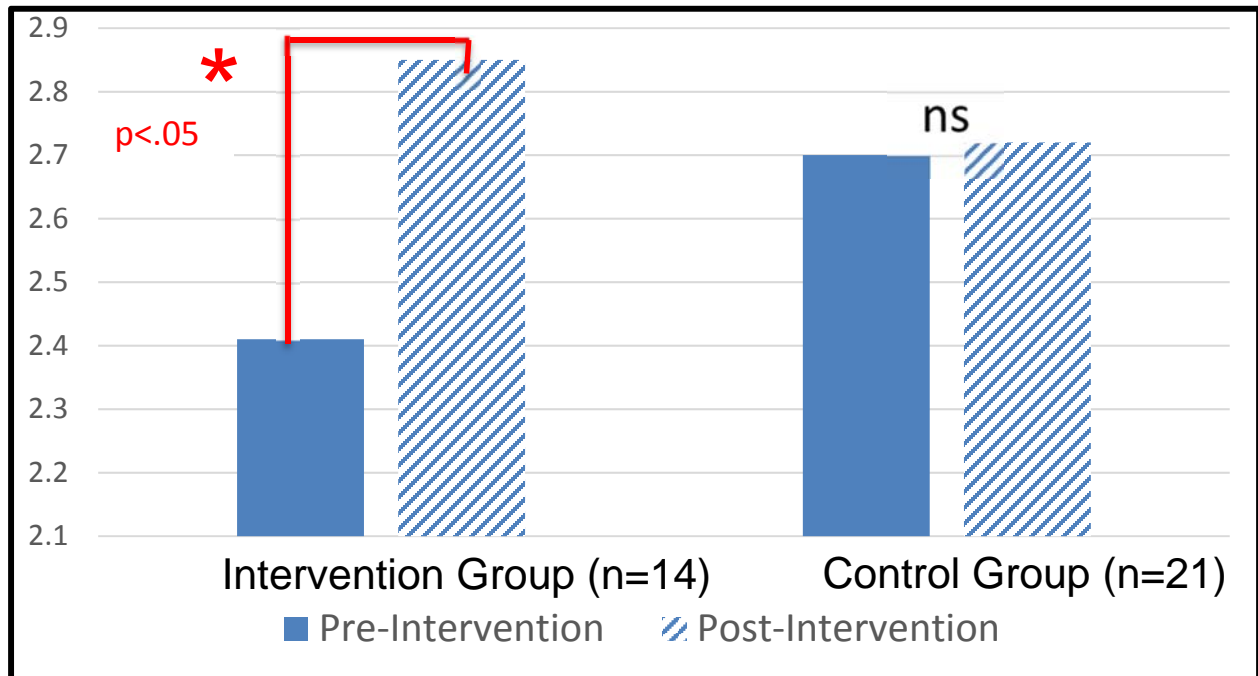
During the post-intervention interview, parents in the intervention group additionally answered open-ended questions about what they learned from the intervention and what they will do differently as a result of the intervention. Parents also completed a short satisfaction survey, indicating how valuable they felt the information presented during group sessions was on a 4-point scale (from 1 = not at all valuable to 4 = very valuable) and how satisfied they were overall with the program on a 7-point scale (from 1 = very dissatisfied to 7 = very satisfied).

Outcomes for Parents

There were several areas of improvements for parents in the intervention group compared to parents in the waitlist control group.

- As shown in Figure 1 on the next page, parents who received the intervention increased their problem-solving skills from pre- to post-intervention compared to the control group, suggesting that parents learned new strategies and gained confidence as a result of training and practice in finding solutions for problems related to their children.

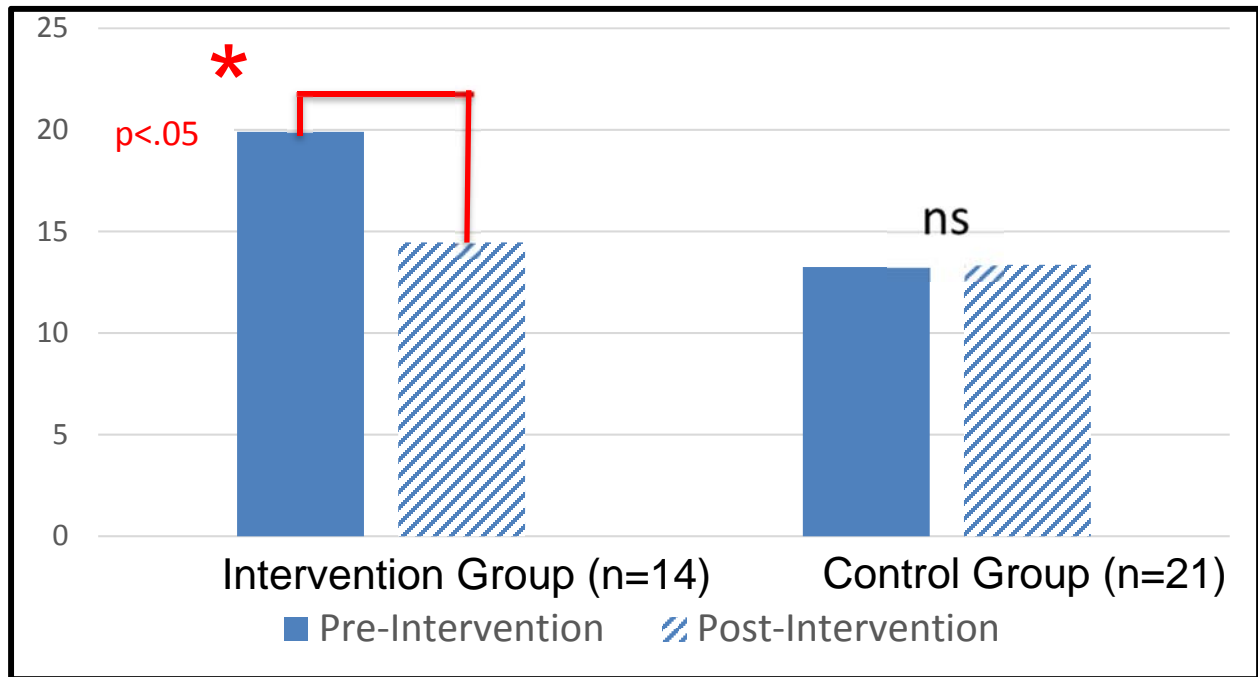
Figure 1: Increased Problem-Solving Skills for Parents Who Received the *Transitioning Together* Intervention



*** indicates statistical significance; ns indicates no statistical significance**

- As shown in Figure 2 on the next page, parental depressive symptoms also decreased from pre- to post-intervention for families in the intervention group, but not for parents in the control group.
- We also found that parents in the intervention had significant increases in being happy or proud of their adolescent with ASD; there was no change in these feelings for parents in the control group.
- There was a trend for parents in the intervention group to have lower levels of burden in their interactions with their teens compared to parents in the control group.
- There were no significant differences in change from pre- to post-intervention between the two groups regarding general life stress.

Figure 2: Decreased Parental Depression Symptoms for Parents Who Received the *Transitioning Together* Intervention

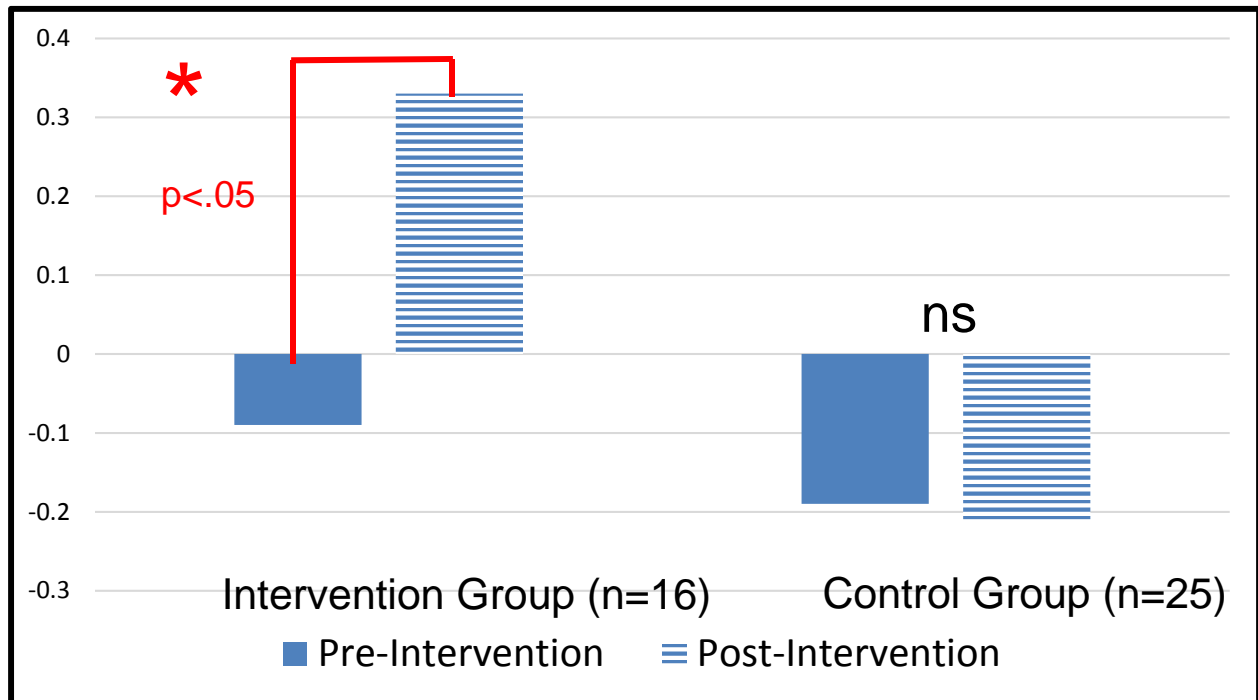


*** indicates statistical significance; ns indicates no statistical significance**

Outcomes for Adolescents

We also found significant benefits of the intervention for the adolescents with ASD. Consistent with findings of family psychoeducation interventions with adolescents with other conditions, there was a significant improvement in the frequency of social interactions for adolescents with ASD in the intervention group but not for the adolescents in the control group. Differences are shown in Figure 3 on the next page.

Figure 3: Improved Frequency of Social Interactions for Adolescents with ASD Who Received the *Transitioning Together* Intervention



*** indicates statistical significance; ns indicates no statistical significance**

We also note that there were no statistically significant improvements in autism symptoms for either group from pre- to post-intervention.

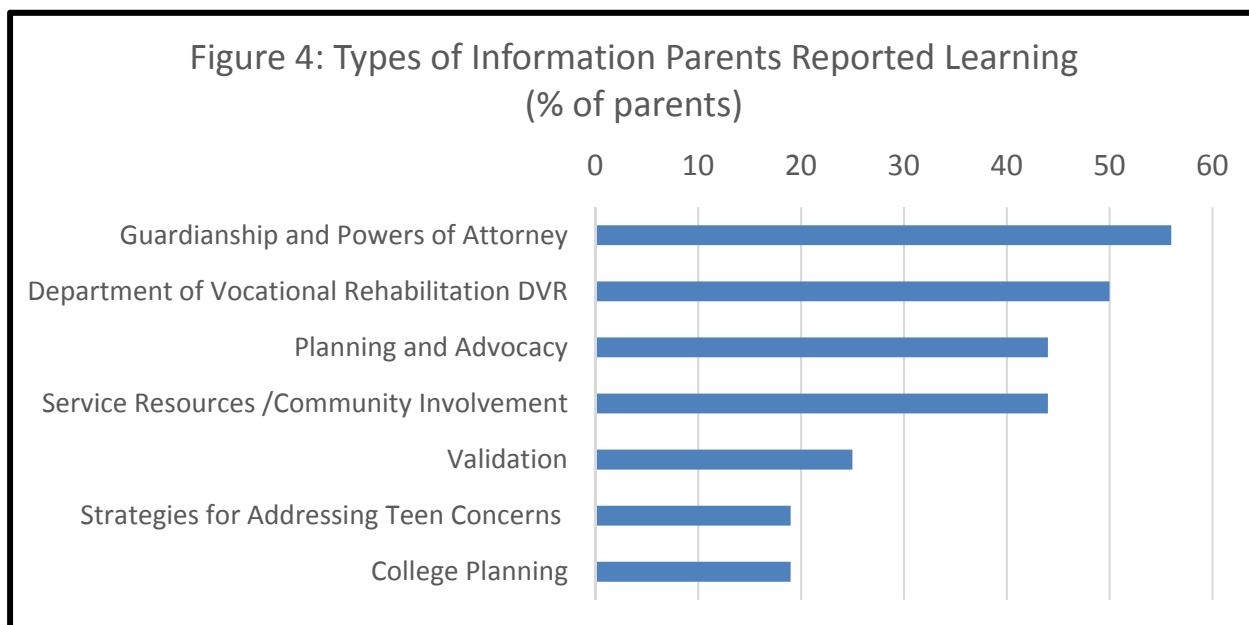
Social Validity

Data from the satisfaction survey and open-ended questions during the post-intervention interviews suggested that the parents who participated in the *Transitioning Together* program were very happy with the experience. Parents reported that the information was valuable and they were very satisfied with the program.

We also coded parents' responses to the open-ended question, "Did you learn any new information during the course of the program?" Figure 4 shows the type of information parents reported learning during the 8-week program followed on the next page by representative quotes.

More than half of the parents reported that they learned about guardianship and types of powers of attorney. Further, half of parents indicated that they learned about vocational rehabilitation services and how to connect with them. Almost half of parents reported learning about transition planning and advocacy as well as specific services and resources in their local communities. These key themes were consistent with what we hoped parents would learn from participating in the program.

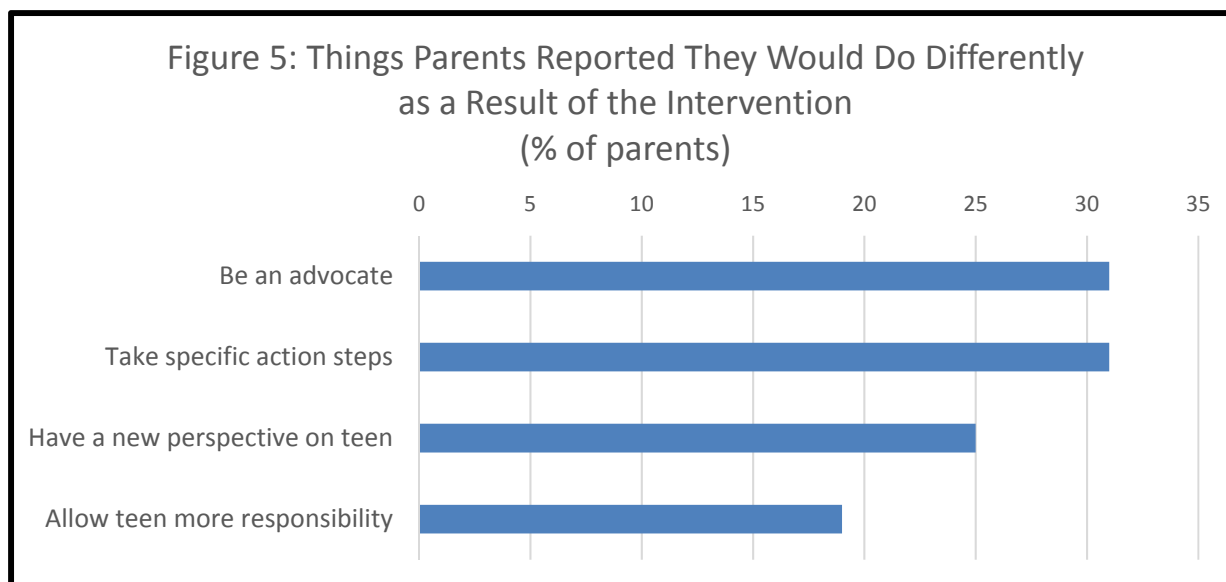
Several parents had responses related to feelings of validation (25%). These families found that hearing about the common experiences of other participating families validated their own experience in raising a teen with ASD.



Parent responses to the open-ended question, “Did you learn any new information during the course of the program?”

- “All the information was geared towards kids like mine. It was so very helpful, the resources, the things that we knew nothing about or didn’t know.”
- “We didn’t know that DVR existed so we went from having no idea that he would qualify for something like that to going through the whole process.”
- “The legal pieces were very helpful to our family, like learning about guardianship.”
- “Knowing what questions to ask when considering postsecondary education was really useful.”
- “We got the validation that his struggles are very much similar to other families who have kids with autism...That validation was really huge.”
- “It gave me a wealth of information as far as what should have been going on in the school as far as transition planning.”
- “I got ideas for handling issues and also for looking at issues in a different way.”

We coded parents’ responses to the open-ended question, “What will you do differently as a result of the intervention?” Figure 5 and the representative quotes on the next page show things that parents reported doing differently after participating in *Transitioning Together*. Over 60% of the parents reported that they would take specific action steps or advocate to help their teen. We also note that many families gained a better perspective on their teen and were ready to allow their teens more responsibility. These findings suggest that parents increased in their understanding that the teen years are a time to encourage their child to try things for themselves, even if they are challenging.



Parent responses to the open-ended question, “What will you do differently as a result of the intervention?”

- “We let go and have given that responsibility to him. We have more things we need to think about letting go of.”
- “It’s not that we forgot that he has autism, but this group brought that back. You know, it’s hard for him, too, and we don’t want to forget that...We want to step back and think about how autism affects him and respond with that in mind and plan with that in mind.”
- “We are in better position to advocate for the services (child) should be receiving...it empowered us to do that.”
- “I’ve been working with him at home going through his likes and dislikes about careers, using what we got at the program.”

In summary, findings from our RCT study of *Transitioning Together* show positive benefits for families in terms of increased frequency of social participation for teens and improved problem-solving skills and depressive symptoms for parents. Qualitative data also suggested that parents gained new knowledge and engaged in advocacy efforts as a result of the intervention.

Section V: Expanding the Reach of *Transitioning Together*

Following the exciting results of our randomized controlled trial of *Transitioning Together*, we have been engaging in several activities to expand the reach of the program, including modifying the program for implementation in school settings, training providers to use the curriculum in clinical settings, and adapting the program for different cultural and linguistic groups.

Transitioning Together in High Schools

As part of the Institute of Education Science (IES)-funded Center on Secondary Education for Students with Autism (CSESA), our team has recently developed a school-based version of *Transitioning Together* implemented by educators who are working with transition-aged youth on the autism spectrum. We tailored the intervention to include additional student activities that support the development of self-determination and executive functioning skills. The revised version was included in a larger package of research-based interventions that were designed to improve outcomes for adolescents with ASD. The CSESA study examined the school-based implementation of the intervention package. 547 adolescents participated from 60 high schools in Wisconsin, North Carolina, and California. The study included *Transitioning Together* as one of the components in their comprehensive intervention model. Our study team was proud to help facilitate including family supports in school transition planning as part of this national effort.

Transitioning Together in Clinical Settings

Our team is also working to disseminate *Transitioning Together* in clinical settings. Through the University of Wisconsin Institute for Clinical and Translational Research (ICTR) Dissemination Supplement Award, we have provided training and coaching in the implementation of *Transitioning Together* to several teams. We note that when we provide this training not only do we share the specifics of how to implement *Transitioning Together*, but we also report on the findings from the AAA study that we learned from your study participation. In this way, we hope to raise awareness on the part of clinicians and professionals about the unique concerns, needs, and strengths of families of adolescents and adults with ASD. In addition to our own Waisman Center and UW Hospital and Clinics, we have trained teams in the following states: California, Connecticut, Florida, Kansas, Louisiana, Michigan, Minnesota, New York, Ohio, Pennsylvania, and Alberta, Canada.



Transitioning Together for Spanish-Speaking Families

Through our work implementing *Transitioning Together* in high schools nationally, we learned of the need for more accessible programming for Spanish-speaking families. As such, in collaboration with Dr. Sandra Magaña from University of Illinois at Chicago, we worked to culturally adapt the program for Spanish-speaking families of adolescents with ASD. To do this, we reviewed the literature on cultural adaptations for Latinos, met with community stakeholders on an ongoing basis, and piloted a revised version of the model, *Juntos en la Transición (JET)*. In addition to the change in language, key adaptations included changes in content (e.g., more information on U.S. educational and vocational rights; cultural considerations of autonomy) and delivery (e.g., Saturday workshops rather than weekly evening sessions; activities for siblings). The groups were recently implemented in the Chicago area. Parents reported high levels of satisfaction and there was perfect attendance at the culturally-adapted program.

Section VI: Summary and Conclusions

This report has presented a summary of our activities, to date, related to the *Transitioning Together* intervention. The knowledge we have gained from your contributions to the AAA study has served as a call for better services and interventions during adolescence and adulthood, and 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:

- Based on findings from more than 14 years of the AAA study, we developed, pilot-tested, and researched 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. Teens showed an increase in social interactions. Parents also reported improved problem-solving skills and depression symptoms after completing the program.
- The team has expanded the use of the *Transitioning Together* program in a number of ways. Clinical teams across the US and in Canada have been trained to offer *Transitioning Together* to local families. The program also has been adapted and researched for use in school settings. Finally, we piloted a cultural adaptation of *Transitioning Together* to address the needs of Spanish-speaking families.

We also want to share we are currently developing *Working Together*, a program for young adults with ASD who are not involved in work or post-secondary education, and their families. Our preliminary results indicated significant reductions in challenging behavior and increases in engagement in vocational activities.

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 families. 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. Specifically, we are hoping to develop evidence-based programming for women who are diagnosed with ASD, who may have different needs than men with ASD.

In addition to our intervention work with the *Transitioning Together* curriculum, we are excited to continue conducting research to understand factors that promote healthy aging and 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!