

WORKING TOGETHER: FAMILY EDUCATION AND SUPPORT FOR YOUNG ADULTS WITH ASD

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Why Provide Support During Emerging Adulthood?

- Loss of services following high school exit
- High levels of stress for individuals with ASD and their parents
- However, few research-based programs available for families during this period—we aimed to address this gap



Development of *Working Together*

- Comprehensive review of literature, including findings from our 15 year longitudinal study of over 400 families of adolescents and adults with ASD
- Focus groups with adults with ASD, their family members, and service providers
- Feasibility pilot with 4 families
- Refined model based on focus group and feasibility pilot results and input from our stakeholder advisory board



Working Together: Program Goals

- Provide education on topics related to ASD during adulthood
- Provide opportunities for social networking and support
- Emphasize positivity and problem solving
- Key Outcomes: engagement in meaningful activities, behavioral functioning



Working Together: Program Components

- 2 individual family “joining sessions”
- 8 weekly multi-family group sessions for parents
- 8 group sessions for emerging adults
- 3 monthly booster sessions
- Ongoing resources and referrals



Session Topics

Session	Topic	Goals
Session 1	Introduction	<ul style="list-style-type: none">• Meet other families• Learn about developmental course of ASD
Session 2	Goal Setting and Problem Solving	<ul style="list-style-type: none">• Learn and practice problem solving and goal setting
Session 3	Coping Strategies	<ul style="list-style-type: none">• Learn about supportive family climates and coping strategies
Session 4	Planning for Independence	<ul style="list-style-type: none">• Learn about training services and supports for independence
Session 5	Employment	<ul style="list-style-type: none">• Learn about employment services and supports
Session 6	Community and Relationships	<ul style="list-style-type: none">• Finding community activities and social opportunities
Session 7	Personal Safety	<ul style="list-style-type: none">• Receive information on long-term planning (e.g., wills, trusts) and other resources
Session 8	Health and Well-Being	<ul style="list-style-type: none">• Learn about risks to health and well-being and strategies for health



Types of Goals Set by Emerging Adults

- Job-related (70.8%)
 - ▶ Find “steady” job
- Social (45.8%)
 - ▶ Make friends
- Independence (45.8%)
 - ▶ Move out; get a drivers' license
- Health (25%)
 - ▶ Manage health issues; lose weight
- Other/personal (29.2%)
 - ▶ Complete writing project; get a pet



Efficacy Study of *Working Together*

- Randomized waitlist control design with families of emerging adults aged 18-30 years in WI and MN
- 47 families (n=23 intervention; n=24 control)
 - ▶ 89% non-Hispanic White
 - ▶ 33% female
 - ▶ Mean age at diagnosis = 10.85 years
 - ▶ No intellectual disability (Mean IQ = 106.4)
 - ▶ Median family income = \$65,000
 - ▶ 80% at least 1 mental health diagnosis

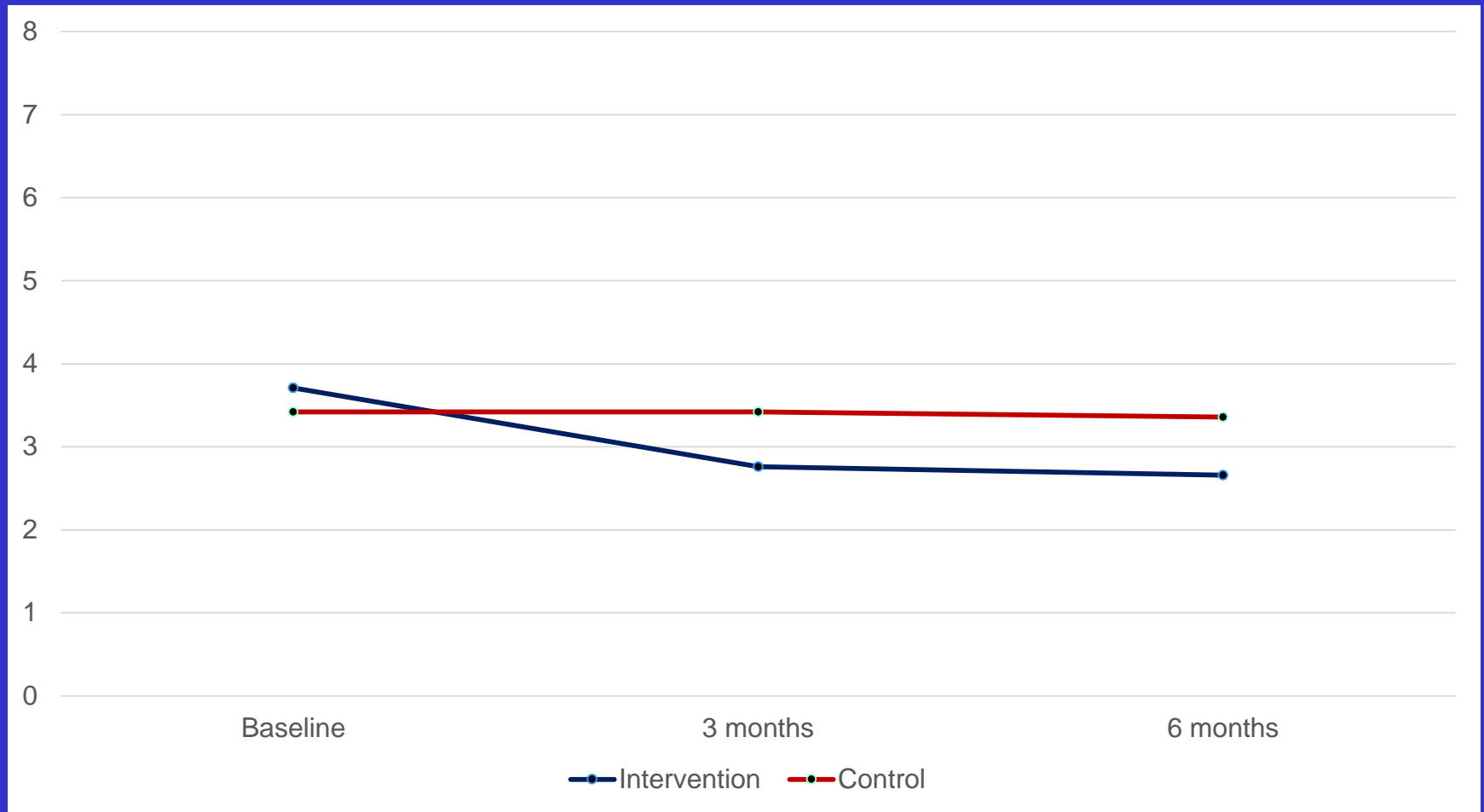


Efficacy Study of *Working Together*

- Data collected from emerging adult and parents at baseline, 3 months and 6 months
- No significant differences between groups at baseline in terms of IQ, age, sex, autism symptoms, adaptive behavior, behavior problems, or frequency of work.



Behavior Challenges (SIB-R)



Social Validity Data

- Families were consistently satisfied or very satisfied with the program
- Areas of Learning Reported by Adults with ASD:
 - ▶ Getting to know others in the group
 - ▶ Personal insights
 - ▶ Coping strategies
 - ▶ Daily living skills
 - ▶ Problem solving
 - ▶ Jobs



Reflections from Emerging Adults

- *I've learned a lot about other people's experiences, other young people my age with autism, and about how they cope with it and about like daily life and getting jobs and keeping jobs. . . . I've made a couple friends through it and it really has helped me a lot, and taught a lot about other people with my condition.*
- *The reason I got along with them is because we have a lot of the same issues and we can work together to fix them. I was the oldest one in the group and I have had a lot of experiences throughout my time. So being able to share my experiences with them made me feel better about myself, it truly did.*



Reflections from Parents

- *I've learned how to help her better by understanding how her brain works . . . really having it broken down and explained has made us view her in a little different way. I'm learning to be more patient. And I realized that other kids have the exact same things going on as our daughter and we thought it was just us.*
- *It was great to meet with other people going through similar kinds of issues . . . Having the bigger group for problem solving was good, since they had different experiences and it would generate a lot of different ideas that you would never think of.*



Summary

- Findings suggest potential benefits of multi-family group psychoeducation for emerging adults with ASD
- Next steps
 - ▶ Test program with larger, more diverse sample
 - ▶ Adapt model for individuals with intellectual disability who are minimally verbal



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