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

<table>
<thead>
<tr>
<th>Session</th>
<th>Topic</th>
<th>Goals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Session 1</td>
<td>Introduction</td>
<td>• Meet other families • Learn about developmental course of ASD</td>
</tr>
<tr>
<td>Session 2</td>
<td>Goal Setting and Problem Solving</td>
<td>• Learn and practice problem solving and goal setting</td>
</tr>
<tr>
<td>Session 3</td>
<td>Coping Strategies</td>
<td>• Learn about supportive family climates and coping strategies</td>
</tr>
<tr>
<td>Session 4</td>
<td>Planning for Independence</td>
<td>• Learn about training services and supports for independence</td>
</tr>
<tr>
<td>Session 5</td>
<td>Employment</td>
<td>• Learn about employment services and supports</td>
</tr>
<tr>
<td>Session 6</td>
<td>Community and Relationships</td>
<td>• Finding community activities and social opportunities</td>
</tr>
<tr>
<td>Session 7</td>
<td>Personal Safety</td>
<td>• Receive information on long-term planning (e.g., wills, trusts) and other resources</td>
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<tr>
<td>Session 8</td>
<td>Health and Well-Being</td>
<td>• Learn about risks to health and well-being and strategies for health</td>
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</tbody>
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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)

- Baseline
- 3 months
- 6 months

- Intervention
- Control
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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