A Family-Centered Transition Intervention for High School Students with Autism Spectrum Disorders

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Council for Exceptional Children
Boston, MA
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Agenda for Today

• Family Engagement through *Transitioning Together* as part of the larger CSESA study

• Development of *Transitioning Together* Program

• Preliminary findings from the CSESA study

• Lessons learned from implementation in 3 states
Students with ASD

“Our kids are alone . . . They don’t go to dances, they don’t go bowling, and it is not because they do not want to.”
-Parent from CSESA focus group

- Complex Environment
- Transitions
- Social interactions

Poor post-secondary outcomes overall
What About Families?

• Parents play a key role in supporting youth with ASD during transition to adulthood

• High levels of stress for parents of youth with ASD

• Stress has long-term effects on parental health and well-being
  – Depression and anxiety (Barker et al., 2010)
  – Cortisol (Mailick Seltzer et al., 2010)
  – Health problems and symptoms (Smith, Mailick Seltzer, & Greenberg, 2012)
Center on Secondary Education for Students with Autism Spectrum Disorders
About CSESA

• Research & Development Center
• Funded by the Department of Education (IES)
• Purpose: To develop and study a comprehensive high school program for students on the autism spectrum
The Big Picture

2012-2013
Year 1
Development & piloting of individual model components (6 sites)

2013-2014
Year 2
Piloting of several components in combination (6 sites)

2014-2015
Year 3
Randomized control trial (RCT) of full model at 30 sites across the country (Cohort 1)

2015-2016
Year 4
Continue implementation at 30 Cohort 1 sites; enroll 30 more sites (Cohort 2)

2016-2017
Year 5
Continue implementation at 30 Cohort 2 sites, follow-up data at Cohort 1 sites
CSESA RCT: Where We Are Now

- 1,800 consented participants
- 546 adolescents with ASD
- 30 school districts across 3 states (CA, NC, WI)
- 60 schools
- 2,000 hours of professional development (this year)
- Families included as key partners in process
Measures & Data Collection

• Direct and indirect measures at 3 time points (Fall year 1, Spring year 1, Spring year 2)
• Direct student assessments and parent and teacher reports
  • Academic performance, autism symptoms, adaptive behavior, self-determination, parental burden, family empowerment
• Goal Attainment Scaling
• Treatment fidelity data at 3 time points for each intervention
Sample Characteristics (n=547)

- 15 years of age on average (range = 13-20 yrs)
- 86.5% male
- 54.6% Non-Hispanic White
- $60,000-79,000 average household income
  - Approximately 1/3 below $40,000
- Leiter Non-verbal IQ
  - M=85.50, SD=27.25
- Vineland Adaptive Behavior Composite
  - M=75.73, SD=16.69
- 42% with co-occurring mental health condition(s)
Family Burden

% of parents stressed balancing child and other responsibilities

% of parents worried what will happen when can’t care for child

CSESa
The Center on Secondary Education for Students with Autism Spectrum Disorders
CSESA Interventions

- SD-IEPs
- WBLE
- TT

- SCI-H
- Peer supports
- Peer networks

- AAL
- CSR-HS

- Evidence-Based Practices (EBPs)

Academic & Behavior

Peer & Social Competence

Transition and Families
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Support for Families during the Transition to Adulthood

• Few supports for families during adolescence, despite it being a stressful period

• The *Transitioning Together* Program for adolescents with ASD seeks to address this gap

• Based on results from longitudinal research
TT Timeline

Comprehensive Review of Research
Focus Groups with Key Stakeholders
Pilot Study with 10 Families
RCT with 45 Families
Effectiveness Study in Clinic Setting

Focus Groups for School-Based Version
5 Pilot Studies in High Schools

RCT in 60 High Schools Nationwide

Review of Literature on Cultural Adaptation
Pilot Study with Latino Families

Focus Groups with Key Stakeholders
Transitioning Together: Program Goals

- Provide education and support for parents
- Provide opportunities for social interaction and learning for adolescents
- Emphasize positivity and problem solving
Transitioning Together: Four Program Components

- 2 individual family “joining sessions”
- 8 weekly multi-family group sessions for parents
- 8 social group sessions for teens
- Ongoing resources and referrals
Transitioning Together: Topics for Parent Group Sessions

- Autism in adulthood
- Transition planning
- Family dynamics
- Therapeutic problem-solving strategies
- Risks to adult independence
- Community involvement
- Risks to parental health and well-being
- Legal issues
Transitioning Together: Topics for Teen Group Sessions

- Sharing interests
- Goal setting
- Problem-solving
- Social planning
Team Teens

☐ Check In Activity
☐ Stone Activity
☐ Student Snapshot Worksheet
☐ Snack
☐ Draw and Color About Yourself: Group Puzzle
☐ Survey Worksheet
☐ Game All Finished

Name: Ryan
Adapted activities

Draw and Color About Yourself Directions
1) Pick a section of puzzle you want to use
2) Write your name
3) Draw yourself
4) Draw what you like to do
5) Draw what you are good at
6) Decorate using markers
Problem Solving Process

STEP 1: DEFINE PROBLEM

STEP 2: LIST ALL POSSIBLE SOLUTIONS

STEP 3: DISCUSS PROS AND CONS

STEP 4: CHOOSE THE BEST SOLUTION
Common Problems Parents Ask to Solve

- Perseveration
- Coping with stress
- Independent living skills
- Filling unstructured time
- Following through on tasks
- Homework
- Lying
- Social isolation
- Getting stuck on media
- Motivation
- Hygiene
- Sibling concerns
- Getting to sleep and waking up
At The End of Each Session

• Parents and teens complete brief survey on satisfaction with nightly session.

• TT staff complete engagement ratings for both teen and parent participants.

• Session fidelity check completed.
Teen Survey

Teen Group Survey

Session ___ Date __________

Please answer the following questions. Do not write your name.
1. Did you learn anything tonight?
   ___ YES   or   ___ NO
   If YES, what did you learn?

2. How satisfied are you with the session tonight?

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very dissatisfied</td>
<td>Dissatisfied</td>
<td>Neutral</td>
<td>Satisfied</td>
<td>Very satisfied</td>
<td></td>
</tr>
</tbody>
</table>

3. Other comments:
Teen Group Survey

Session Date 4-18-2016

Please answer the following questions. Do not write your name.

1. Did you learn anything tonight?
   - [ ] YES  [ ] NO
   If YES, what did you learn?
   - we just had fun

2. How satisfied are you with the session tonight?

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<tr>
<td>Very satisfied</td>
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3. Other comments:
   - I will miss you guys thank you!
   - It's been fun and awesome
   - Good luck 😊
# Fidelity Checklist

## Before Group Sessions Begin

<table>
<thead>
<tr>
<th>DATE</th>
<th>ACTIVITY</th>
<th>SCORE**</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>Joining sessions completed</td>
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<tr>
<td></td>
<td>List of preferred activities for teens created based on joining session teen interview</td>
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</table>

### Session 1

<table>
<thead>
<tr>
<th>DATE</th>
<th>ACTIVITY</th>
<th>SCORE**</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>Welcome and introductions</td>
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<tr>
<td></td>
<td><em>Stones Activity</em></td>
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<tr>
<td></td>
<td>Handout and review agenda for session</td>
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</tr>
<tr>
<td></td>
<td>Exchange contact information between contact people</td>
<td></td>
</tr>
<tr>
<td></td>
<td>“Get to know you” activities completed</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Play a game or complete a fun activity</td>
<td></td>
</tr>
<tr>
<td></td>
<td>All engagement ratings completed</td>
<td></td>
</tr>
<tr>
<td></td>
<td>All surveys completed</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Summaries of teen activities for each teen sent to parents</td>
<td></td>
</tr>
</tbody>
</table>

### Session 2

<table>
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<tbody>
<tr>
<td></td>
<td><em>Stones Activity</em></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Handout and review agenda for session</td>
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<tr>
<td></td>
<td>Discuss goal setting</td>
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<tr>
<td></td>
<td>Work on goal planning sheet one-on-one with teens</td>
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<tr>
<td></td>
<td>Play a game or complete a fun activity</td>
<td></td>
</tr>
<tr>
<td></td>
<td>All engagement ratings completed</td>
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<tbody>
<tr>
<td></td>
<td><em>Stones Activity</em></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Handout and review agenda for session</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Discuss social problems solving</td>
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</tbody>
</table>
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CSESA Implementation

• Fidelity data from 18 school sites in Cohort 1

• Over half of groups included students from both standard and modified diplomas

• Across groups, high level of treatment fidelity on average = 91%
Treatment Fidelity

High Fidelity Areas (>95%)
• Dosage offered (frequency, length of sessions, joining sessions)
• Preparation (inviting speakers, organized materials)
• Facilitator strategies (positivity, problem-solving focus)
• Relevant content

Low Fidelity Areas
• Group session process (problem-solving, dialogue among families) \( \rightarrow 78\% \)
• Lesson structure (check in with families, introduce topic, follow up on concerns) \( \rightarrow 73\% \)
• Evaluation/progress monitoring (engagement ratings, surveys) \( \rightarrow 58\% \)
Feedback from Parents

Do we have to quit meeting?
We will be doing things differently based on our experience in the group, especially working on the self help skills we never really gave him the opportunity to develop.

I enjoyed problem solving. Sometimes it’s easy to forget the obvious solutions.

Our attitude changed. We didn’t think our son could do a job and go to school—and he can do both.

Group discussions were extremely helpful.
Areas of Growth and Suggestions

Other sessions on transitioning to adulthood like housing, day programs, etc.

I wish it could have been later. It’s hard to make it right after work.

Time was a little difficult; life got in the way.

There were conflicts of time (especially with my son’s schedule), but this probably couldn’t be avoided.

Condense into a Saturday workshop.
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Implementation by School Teams in Three States

Staffing Strategies

• Co-facilitator model: school personnel paired with marriage-family therapist
• Co-facilitator model: school personnel paired with autism community member
• Partnership with community stakeholders to deliver specialized content (e.g., guardianship)

Structural Strategies

• Combined multiple schools to have the right number/composition of families for groups
• Conducted joining sessions at school or by phone
• Provided course credit for students
• Meals provided by school district or local non-profit
Implementation by School Teams: What Has Worked

• Weekly debriefing with facilitators and coaches about fidelity and problem-solving

• Access to key school and local community resources (e.g., DVR, attorneys, adult service providers)

• Students sharing snapshots, videos, etc., with both parents and school team members

• Capitalizing on teen interests
Juntos en la Transición (JET)

- Cultural and linguistic adaptation of TT for Spanish-speaking families
  - Important to truly adapt model and curriculum, not just translate

- Interdisciplinary partnership with CSESA team, U of I Chicago, and Grupo Salto

- Successful pilot in Chicago and now included with CSESA materials
For Additional Information and Resources

CSESA website: [http://csesa.fpg.unc.edu/](http://csesa.fpg.unc.edu/)
Acknowledgements

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• Renee Makuch
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• Laura Hall, PhD, San Diego State
• Sandra Magana, PhD, University of Illinois-Chicago

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• Autism Speaks (AS Grant #7523; Smith, PI)

THANK YOU!!
Deep thanks to the many families who have partnered with us in this work. We have learned so much from your willingness to share your lives with us!
# Teens Can Brainstorm Too!

<table>
<thead>
<tr>
<th>THINGS THAT CAUSE STRESS</th>
<th>THINGS WE CAN DO THAT HELP</th>
</tr>
</thead>
<tbody>
<tr>
<td>Asking for help</td>
<td>Ask for help</td>
</tr>
<tr>
<td>Meeting new people</td>
<td>Find a competent consultant</td>
</tr>
<tr>
<td>Talking in front of people</td>
<td>Sense of humor</td>
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<tr>
<td>School/getting things done</td>
<td>Watch what others are doing</td>
</tr>
<tr>
<td>Being on time</td>
<td>Be vulnerable</td>
</tr>
<tr>
<td>Parents</td>
<td>Ask what expectations are</td>
</tr>
<tr>
<td>Mean people</td>
<td>Apologize</td>
</tr>
<tr>
<td>Doing things that make me nervous</td>
<td></td>
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</tbody>
</table>