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

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Portland, Oregon
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Agenda for Today

• Development of Transitioning Together Program

• Transitioning Together as part of the larger study

• Lessons learned from implementing as part of a high school intervention model
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
Why Provide Support During Adolescence?

• Adolescence is an important time

  – Multiple transitions

  – Loss of services following high school exit

  – Increased risk for difficulties in symptoms and behavior problems
Why Do Families Need Supports?

• High levels of stress for parents of children with ASD

• Stress has long-term effects on parental health and well-being
  – Depression and anxiety (Barker et al., 2010)
  – Daily positive and negative affect (Smith et al., 2010)
  – Cortisol (Mailick Seltzer et al., 2010)
  – Health problems and symptoms (Smith, Mailick Seltzer, & Greenberg, 2012)
Diversity of Family Experiences

• “He is all-consuming of our time, energy, patience. It can be emotionally and physically draining to be constantly vigilant of his emotional arousal levels. I cannot work outside the home. It is a full-time job caring for our son.”

• “I’ve tried things and done things I never would have without him, such as running for school board and serving for 15 years. Having him has been a chance to grow in unexpected ways.”
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

RCT in 60 High Schools Nationwide

5 Pilot Studies in High Schools

Review of Literature on Cultural Adaptation

Pilot Study with Latino Families: FALL 2015

Focus Groups with Key Stakeholders
Research-Based Strategies for Families

- Stay connected within and outside of your family
- Keep your environment positive
- Make a plan
- Recognize growth
- Utilize respite and take time for leisure
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 14-17 years of age seeks to address this gap

• Based on results from longitudinal research
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: 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
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
# Teens Can Brainstorm Too!

## Things That Cause Stress
- Asking for help
- Meeting new people
- Talking in front of people
- School/getting things done
- Being on time
- Parents
- Mean people
- Doing things that make me nervous

## Things We Can Do That Help
- Ask for help
- Find a competent consultant
- Sense of humor
- Watch what others are doing
- Be vulnerable
- Ask what expectations are
- Apologize
TT Timeline

1. Comprehensive Review of Research
2. Focus Groups with Key Stakeholders
3. Pilot Study with 10 Families
4. Effectiveness Study in Clinic Setting
5. RCT with 45 Families
6. Focus Groups for School-Based Version
7. RCT in 60 High Schools Nationwide
8. 5 Pilot Studies in High Schools
9. Review of Literature on Cultural Adaptation
11. Focus Groups with Key Stakeholders
Program Outcomes

- Recently completed randomized waitlist control study

- 45 families of teens (aged 14-17 years; M=15.44; SD=1.03)

- For families in the intervention group:
  - Improvements in adolescent social engagement
  - Improvements in parental positivity about child
  - Improvements in parental problem solving
  - Reductions in parental depressive symptoms
Reflections from Families

From Parents:
• “At times with my son I’ve felt very isolated and alone. Hearing other families talk about having the same types of experiences was really validating.”

• “It gave me a wealth of information about what should have been going on at school as far as transitioning.”

• “I wish Transitioning Together was required for every student.”

From Teens:
• “Pretty much all of us had some sort of interest that people usually don’t. It was really cool. We could share our ideas on these like weird topics.”

• “When I’m riding home [after group], it feels like, I’m tired but I’m happy. And it’s almost like you get this warm fuzzy feeling.”
TT Timeline

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Focus Groups with Key Stakeholders
Ongoing National Study

• Center on Secondary Education for Students with ASD (CSESA)
  – Research and development center funded by the Department of Education
  – Partnering with 6 other universities: UNC-Chapel Hill, UC-Davis, UNC-Charlotte, UT-Austin, Vanderbilt University, San Diego State University
  – Goal to develop and study a comprehensive school-based program to improve transition outcomes for students with ASD
  – *Transitioning Together* is included within the comprehensive model
  – 60 high schools in US (20 schools in WI, 20 in NC, 20 in CA)
  – 600 students
CSESA Sites

VANDERBILT KENNEDY CENTER for Research on Human Development

SAN DIEGO STATE UNIVERSITY

UNC FRANK PORTER GRAHAM CHILD DEVELOPMENT INSTITUTE

UC DAVIS MIND INSTITUTE

WAISMAN CENTER UNIVERSITY OF WISCONSIN-MADISON University Center for Excellence in Developmental Disabilities

THE UNIVERSITY OF TEXAS AT AUSTIN
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

You are here
Where We Are Now: Beginning of Yr 4 (Second Year of RCT)

• Working in 60 comprehensive high schools. 20 in San Diego, 20 in Wisconsin, and 20 in North Carolina.
• 8 to 12 students with ASD identified at each school
• Participants must be at the HS for 2 years. Includes 18-22 programs if housed on the comprehensive HS campus.
• 30 schools are CSESA schools and receive the comprehensive intervention over a 2 year period. 30 schools are Services as Usual (SAU). Receive intervention manuals following 2 years.
• Autism teams at each intervention school receive extensive training on the interventions along with weekly coaching and feedback by CSESA staff.
• CSESA coaches at each CSESA school 6 hrs a week.
• Parents active participants.
Measures & Data Collection

• Both direct and indirect methods of assessment are implemented at 3 time points across the 2 year intervention period for each cohort (Fall year 1, Spring year 1, Spring year 2)
• Indirect measures are completed by parents, teachers, and the students themselves.
• Direct measures completed by CSESA staff
• All participating students have goals developed in each intervention domain area. Goal Attainment Scaling process used. Data collected at 3 time points for each GAS goal.
• Students at SAU schools have goals pulled from their IEP that align with CSESA components as much as possible.
• Treatment fidelity data collected at 3 time points per intervention component.
## Measures at a Glance

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<th>Year 1 Spring</th>
<th>Year 2 Spring</th>
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<th>Parent</th>
<th>School A-team</th>
<th>School Staff (1 per stud.)</th>
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Key: X = completed by, O = observed, I = interviewed, T = tested
Note: gray items are administered/completed by CSESA research staff
### Time 1 Data

#### Cohort 1 Demographics

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<th>Categories</th>
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<th>SAU (n=126)</th>
<th>CSESA (n=155)</th>
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# Time I (Cohort 1) Student Data

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<th>Assessment</th>
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<td>M=74.5</td>
</tr>
<tr>
<td></td>
<td>Communication – SS</td>
<td>M=77.6</td>
<td>M=78.5</td>
<td>M=77.0</td>
</tr>
<tr>
<td></td>
<td>Daily Living – SS</td>
<td>M=80.4</td>
<td>M=81.1</td>
<td>M=79.9</td>
</tr>
<tr>
<td></td>
<td>Socialization – SS</td>
<td>M=72.4</td>
<td>M=73.3</td>
<td>M=71.7</td>
</tr>
<tr>
<td>WJ-III</td>
<td>Standard score on Passage Comp.</td>
<td>M=70.2</td>
<td>M=71.1</td>
<td>M=69.5</td>
</tr>
<tr>
<td></td>
<td>Age-equivalent on Passage Comp.</td>
<td>M=10.1</td>
<td>M=10.4</td>
<td>M=9.9</td>
</tr>
<tr>
<td></td>
<td>Standard score on Academic Knowledge</td>
<td>M=71.1</td>
<td>M=71.7</td>
<td>M=70.6</td>
</tr>
<tr>
<td></td>
<td>Age-equivalent on Academic Knowledge</td>
<td>M=10.7</td>
<td>M=11.0</td>
<td>M=10.5</td>
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</tbody>
</table>
CSESA Domains

- **Academic**
  - AAL
  - CSR-HS

- **Independence & Behavior**
  - Evidence-Based Practices (EBPs)

- **Peer & Social Competence**
  - SCI-H
  - Peer supports
  - Peer networks

- **Transition and Families**
  - SD-IEPs
  - WBLE
  - TT
CSESA Domains

- **Academic**
  - AAL
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  - SD-IEPs
  - WBLE
  - TT

CSESA: The Center on Secondary Education for Students with Autism Spectrum Disorders
Implementation by School Teams

What has worked

• Weekly debriefing with facilitators and coaches about fidelity and problem-solving
• Course credit for students
• Meals provided by school district
• Access to key school and community resources (e.g., DVR, local attorneys, adult service providers)
• Students sharing snapshots, videos, etc., with both parents and school team members
• Capitalizing on teen interests
Implementation by School Teams

• Co-facilitator model with school personnel paired with MFT in running parent groups.
• Multiple CSESA schools combining to make parent and teen groups.
• Partnering with community stake holders to deliver specialized content
• Joining sessions that take place at the school
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.
Parent Survey

Please answer the following questions:

1. How much did you learn from this session?

   1  Not at all   2  A little   3  Moderately   4  Quite a bit   5  Extremely

2. Overall, how *useful* was this session?

   1  Not at all   2  A little   3  Moderately   4  Quite a bit   5  Extremely

3. Overall, how *satisfied* are you with this session?

   1  Very dissatisfied   2  Dissatisfied   3  Neither satisfied or dissatisfied   4  Satisfied   5  Very satisfied

4. Any additional thoughts or concerns?
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?

   |   |   |   |   |   |
   | 1 | 2 | 3 | 4 | 5 |
   | Very dissatisfied | Dissatisfied | Neutral | Satisfied | Very satisfied |

3. Other comments:

   [Emoji] [Emoji] [Emoji] [Emoji] [Emoji]
# Engagement Ratings

## Teen Group Engagement Ratings

<table>
<thead>
<tr>
<th>Session __</th>
<th>Date ______</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Participant Name</th>
<th>Very Little Engagement</th>
<th>Somewhat Engaged</th>
<th>Clearly Engaged</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Ratings Completed By: ____________________________
## Fidelity Checklist

### Before Group Sessions Begin

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

### Session 1

<table>
<thead>
<tr>
<th>DATE</th>
<th>ACTIVITY</th>
<th>SCORE**</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Welcome and introductions</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Stones Activity</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Handout and review agenda for session</td>
<td></td>
</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>
<thead>
<tr>
<th>DATE</th>
<th>ACTIVITY</th>
<th>SCORE**</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Stones Activity</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Handout and review agenda for session</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Discuss goal setting</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Work on goal planning sheet one-on-one with teens</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>
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</tbody>
</table>

### Session 3

<table>
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<tr>
<th>DATE</th>
<th>ACTIVITY</th>
<th>SCORE**</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Stones Activity</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>
<td></td>
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</tbody>
</table>
For Additional Information and Resources

CSESA website:

http://csesa.fpg.unc.edu/
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

RCT in 60 High Schools Nationwide

5 Pilot Studies in High Schools

Review of Literature on Cultural Adaptation

Pilot Study with Latino Families: FALL 2015

Focus Groups with Key Stakeholders
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 UW Madison, U of I Chicago, and Grupo Salto

• Implemented by trainees in the Leadership and Education in Neurodevelopmental Disabilities program (LEND)
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• Bonnie Kraemer & Laura Hall PhD, San Diego State
• Sandra Magana PhD, UIC

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• IES (R324C12006, Odom, PI)
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• Autism Speaks (AS Grant #7523; Smith, PI)
• Autism Society of Southeastern Wisconsin

THANK YOU!!
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