

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

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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



- Complex Environment
- Transitions
- Social interactions

“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



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



Original CSESA Collaborators



VANDERBILT
KENNEDY CENTER
for Research on Human Development



SAN DIEGO STATE
UNIVERSITY



UNC CHARLOTTE



UNC

FRANK PORTER GRAHAM
CHILD DEVELOPMENT INSTITUTE

UCDAVIS
MIND INSTITUTE

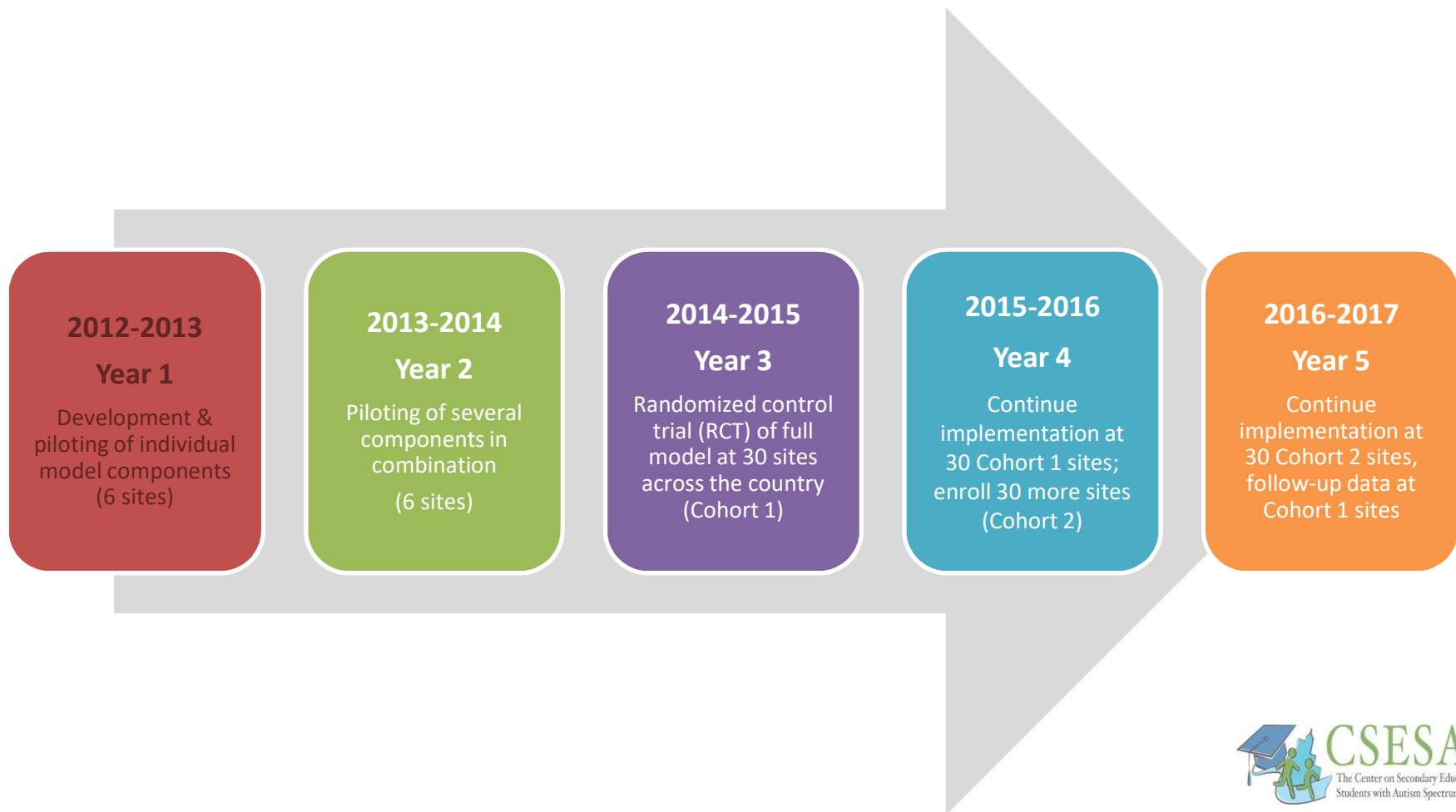
THE UNIVERSITY OF
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WAISMAN CENTER
UNIVERSITY OF WISCONSIN-MADISON
University Center for Excellence in Developmental Disabilities



The Big Picture



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

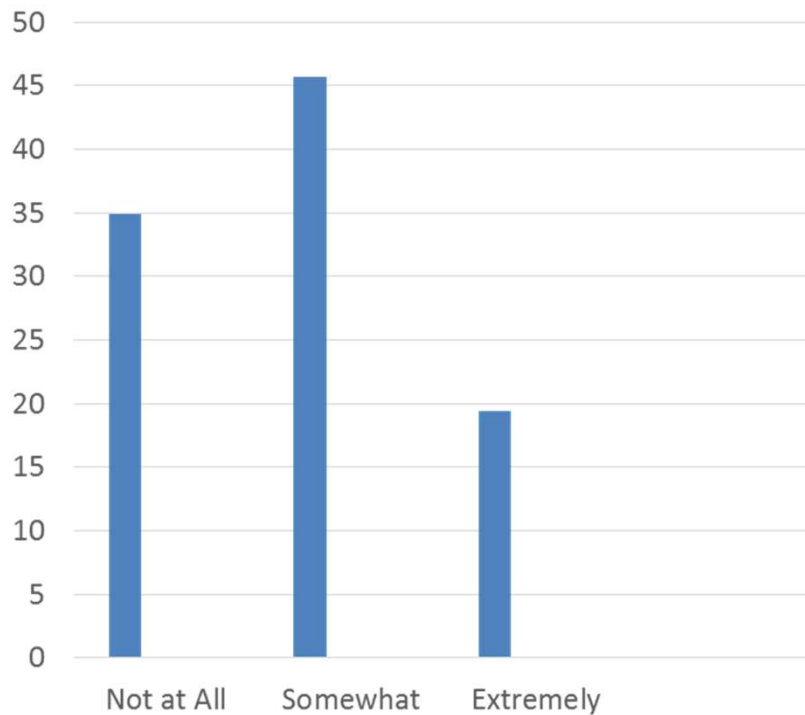
- Direct and indirect measures at 3 time points (Fall year 1, Spring year 1, Spring year 2)
- Direct student assessments and parent and teacher reports
 - Academic performance, autism symptoms, adaptive behavior, self-determination, parental burden, family empowerment
- Goal Attainment Scaling
- Treatment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

Sample Characteristics (n=547)

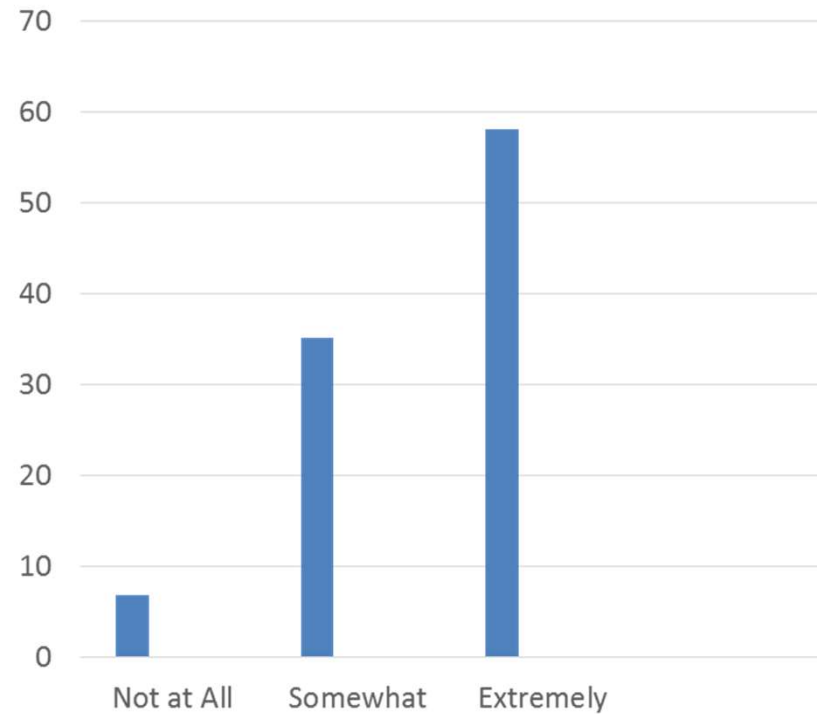
- 15 years of age on average (range = 13-20 yrs)
- 86.5% male
- 54.6% Non-Hispanic White
- \$60,000-79,000 average household income
 - Approximately 1/3 below \$40,000
- Leiter Non-verbal IQ
 - M=85.50, SD=27.25
- Vineland Adaptive Behavior Composite
 - M=75.73, SD=16.69
- 42% with co-occurring mental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

Family Burden

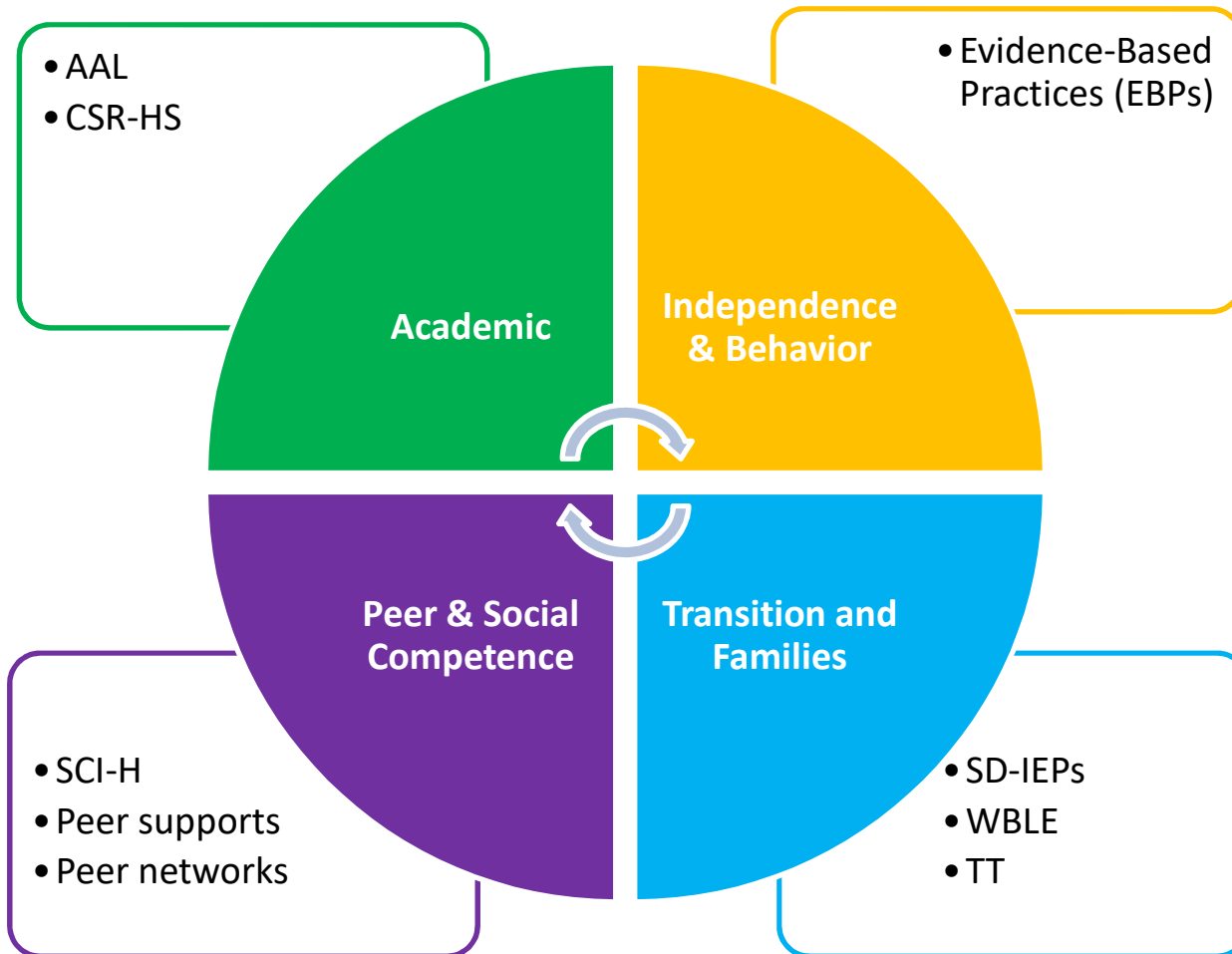
**% of parents stressed
balancing child and other
responsibilities**



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



CSESA Interventions





Agenda for Today

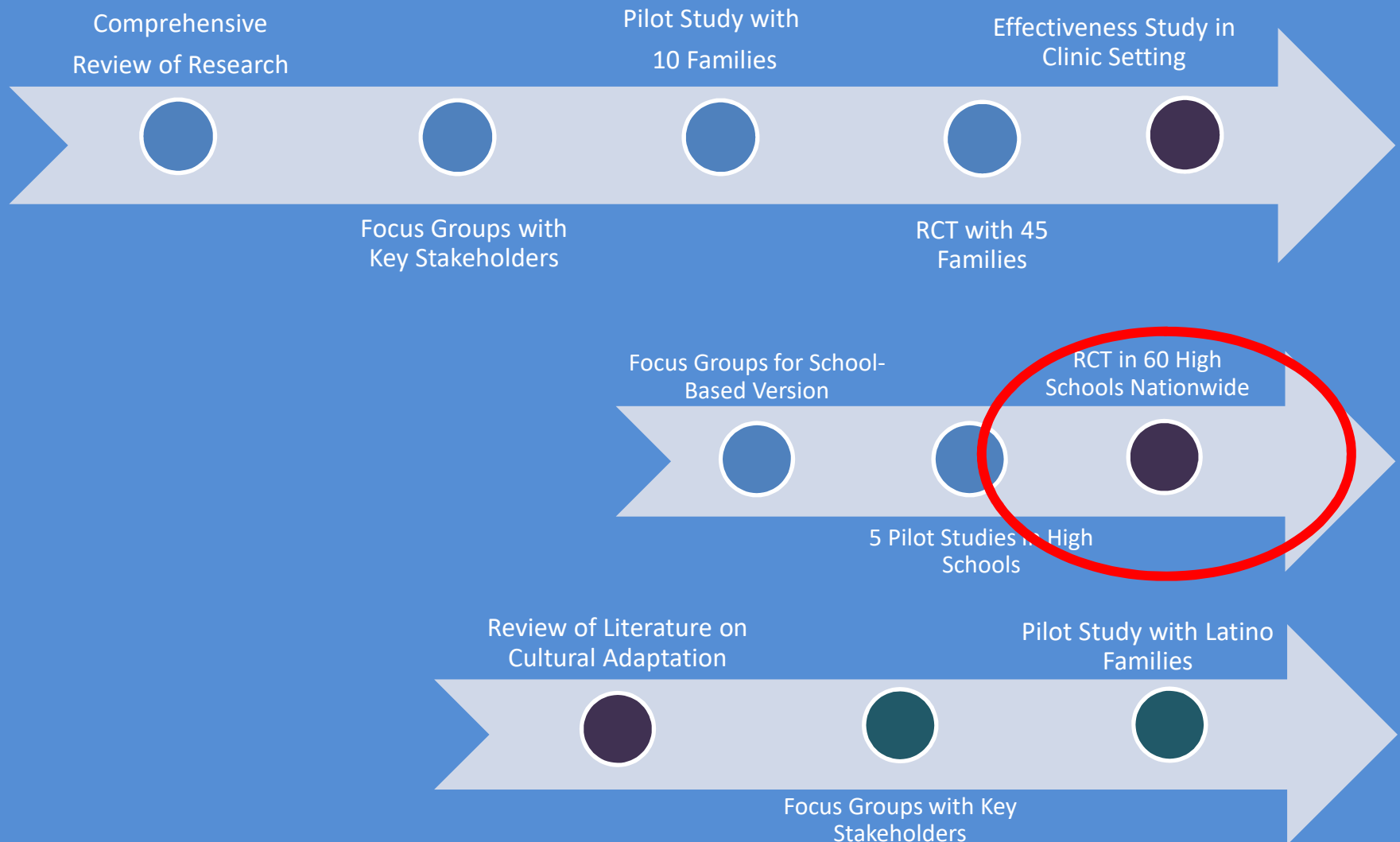
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Support for Families during the Transition to Adulthood

- 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





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

Name:

RYAN

☒ Check In Activity

☒ Stones Activity

☒ Student Snapshot Worksheet

☒ Snack

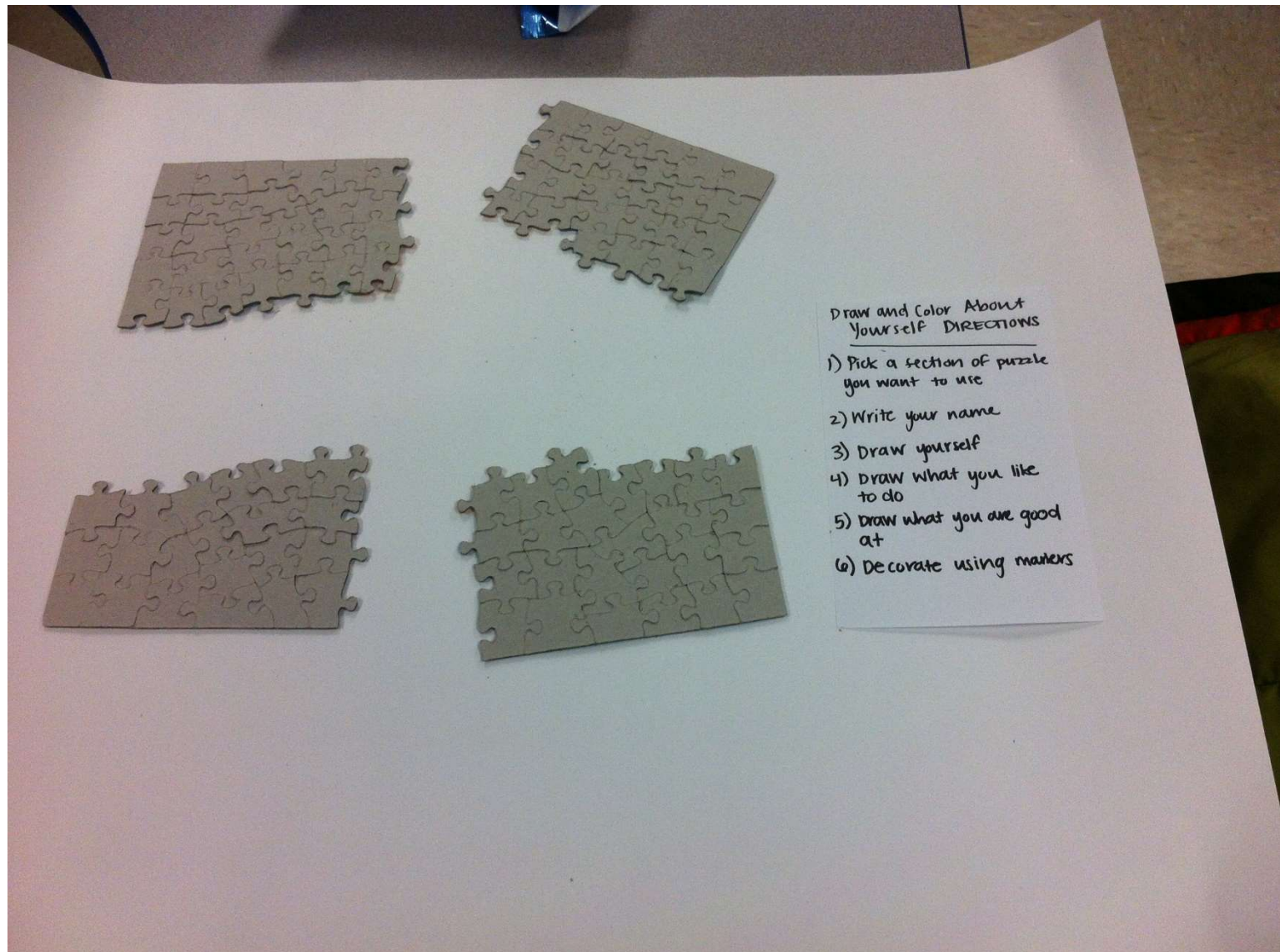
☒ Draw and Color About Yourself: Group Puzzle

☒ Survey Worksheet

☒ Game All Finished!



Adapted activities



Team Tasks
Made in Activity
Stomach Activity
Shin and Ankle
Wrist
Back
Dye and color About
Horse, Group Note
Survival
Game
All Finished

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Bou +
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o

RYAN
PREMO



olor About
DIRECTIONS

1) Pick a

Team Teens



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?

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

3. Other comments:

Daniel Akoch

Translating Together: Templates

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?

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

3. Other comments:

I will miss you guys thank
Its been Fun and awesome
GOOD LUCK !!

Fidelity Checklist

TREATMENT FIDELITY CHECKLIST

Before Group Sessions Begin

DATE	ACTIVITY	SCORE**
	Joining sessions completed	
	List of preferred activities for teens created based on joining session teen interview	

Session 1

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

Session 2

DATE	ACTIVITY	SCORE**
	<i>Stones Activity</i>	
	Handout and review agenda for session	
	Discuss goal setting	
	Work on goal planning sheet one-on-one with teens	
	Play a game or complete a fun activity	
	All engagement ratings completed	
	All surveys completed	
	Summaries of teen activities for each teen sent to parents	

Session 3

DATE	ACTIVITY	SCORE**
	<i>Stones Activity</i>	
	Handout and review agenda for session	
	Discuss social problems solving	



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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) → 78%
- Lesson structure (check in with families, introduce topic, follow up on concerns) → 73%
- Evaluation/progress monitoring (engagement ratings, surveys) → 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.

Group discussions were extremely helpful.

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.

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)

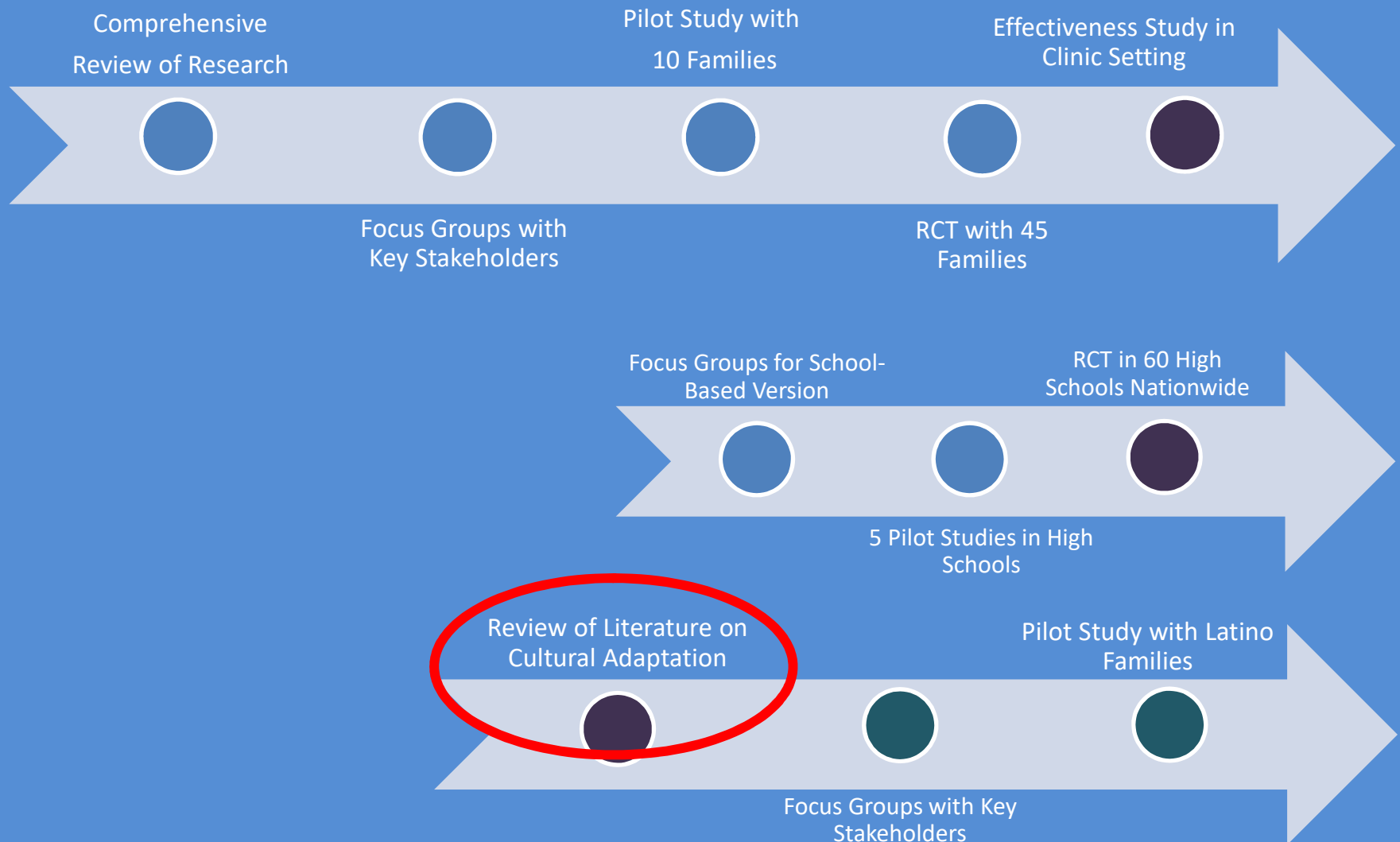
Structural Strategies

- 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

TT Timeline





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/>



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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!

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