



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

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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



- 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



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





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:

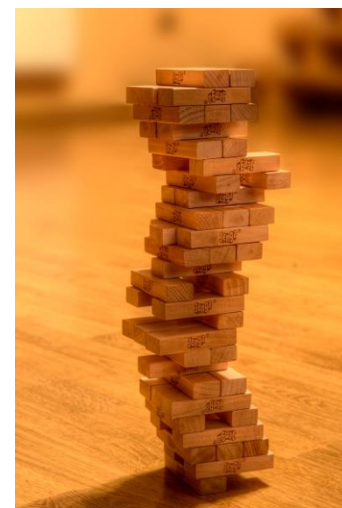
Topics for Parent Group Sessions

- 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!

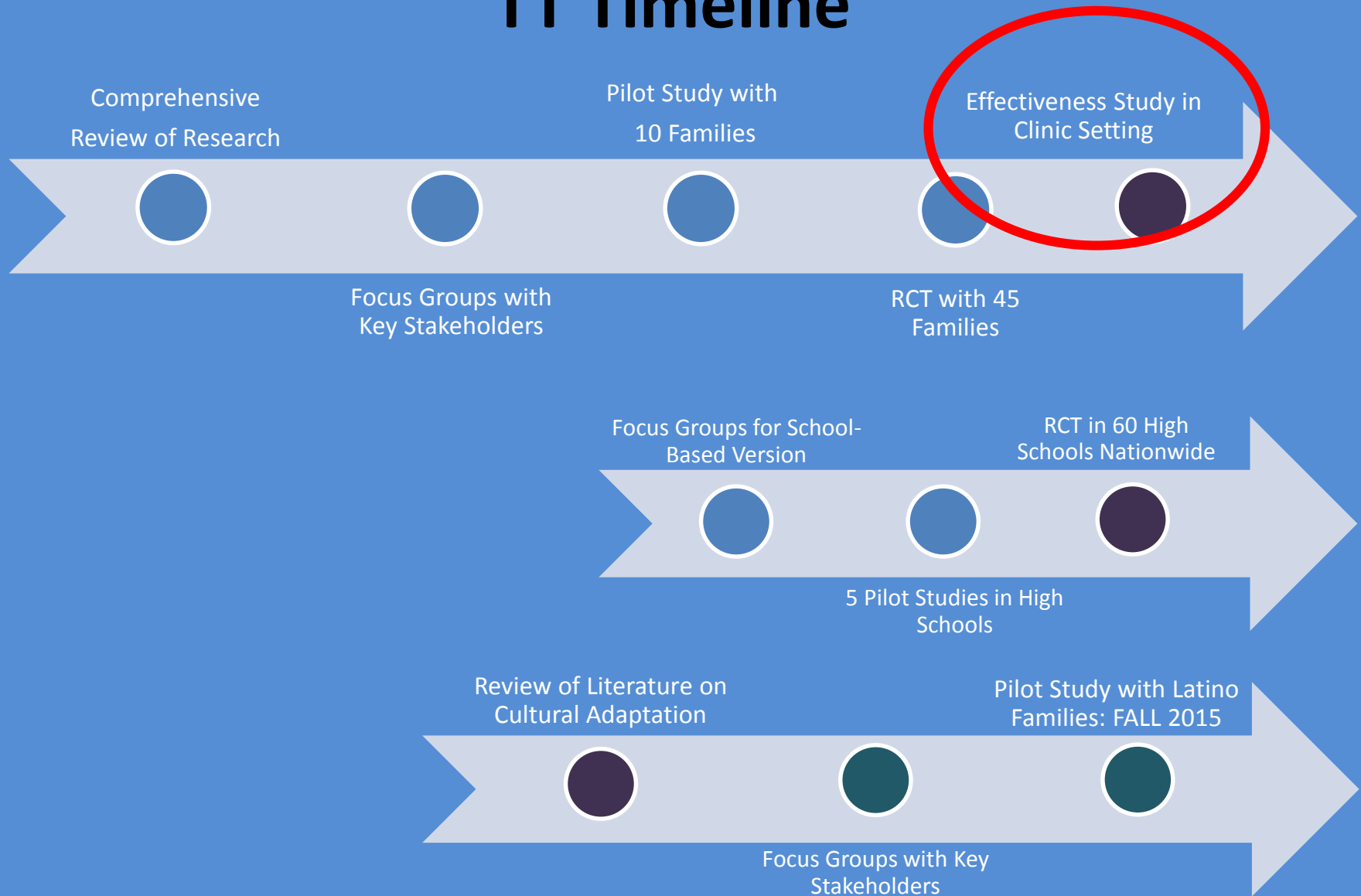
THINGS THAT CAUSE STRESS

- 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





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

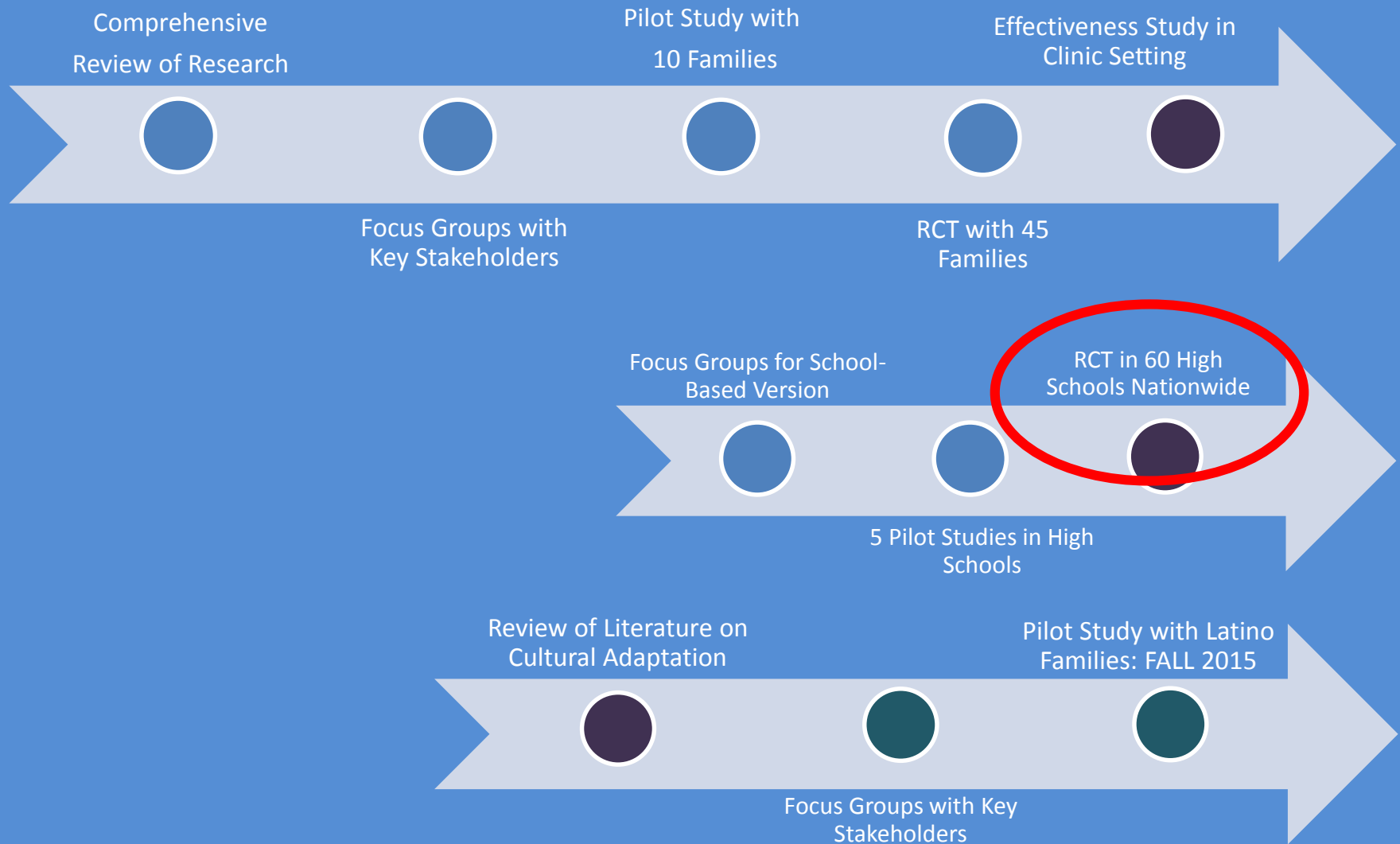
From Parents:

- *“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





CSESA

The Center on Secondary Education for
Students with Autism Spectrum Disorders

Center on Secondary
Education for Students with
Autism Spectrum Disorders

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



UNCCHARLOTTE



UNC

FRANK PORTER GRAHAM
CHILD DEVELOPMENT INSTITUTE

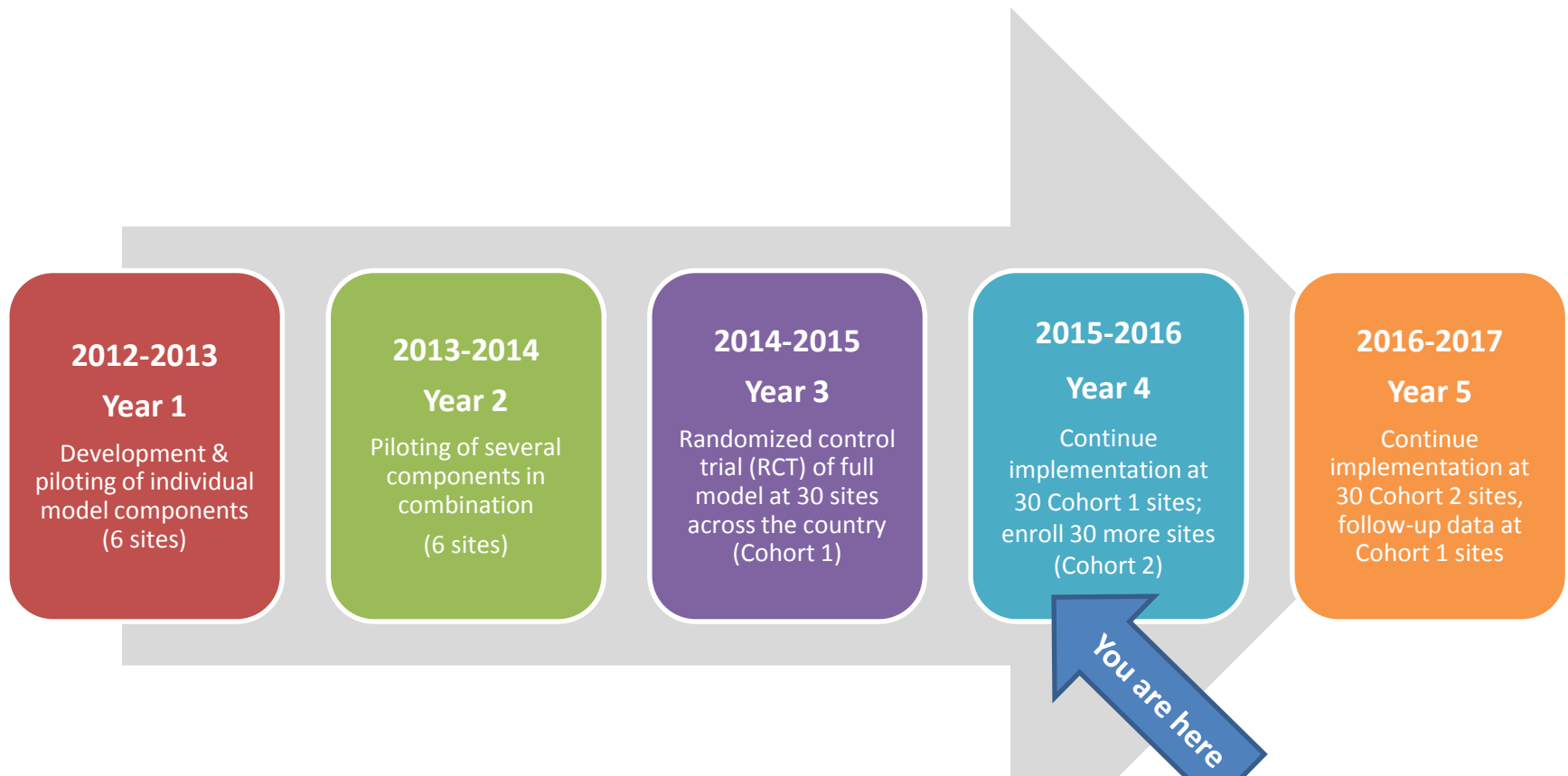
UCDAVIS
MIND INSTITUTE

THE UNIVERSITY OF
TEXAS
AT AUSTIN



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

The Big Picture



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

				Frequency					Participant						
				Year 1 Fall	Year 1 Spring	Year 2 Spring	Year 3 Spring	Other	Student	Parent	School A-team	Familiar School Staff (1 per stud.)	Other School Staff	CSESA staff	Student Body
Assessment	Abbr.	Format	Amt of Time												
American Institute of Research Self-Determination Scale	AIR-SDS	Questionnaire	10-15 min	X	X	X	X		X	X		X			
Autism Program Environment Scale – Middle/High School	APERS-MHS	Observation	6-8 hrs	X		X		*NOTE: Subset of parents/staff		I	I/O			X	
		Interview	30-60 min per												
Child-Family Demographic Forms	C/F Demo	Questionnaire	5-10 min	X						X					
Cost Study Forms	CSF	Questionnaire	5-10 min					1x over 2 years			X		X		
Evidence-Based Practices Attitude Scale	EBPAS	Questionnaire	5-10 min	X							X				
Evidence-Based Practices Inventory	EBP-I	Questionnaire	10-15 min	X	X	X					X				
Family Empowerment Scale	FES	Rating scale	10 min	X	X	X	X			X					
Goal Attainment Scaling	GAS	Rating scale	30-45 min					3x per goal, varies by year			I			X	
Implementation Index	II	Interview	30-60 min					Cont.-CSESA 1x-Control	O		I/O		O	X	
		Observation	8-15 hours												
Leiter International Performance Scale-Third Ed.	L-3	Standardized test	20-45 min	X					T					X	
School Staff Demographic Forms	S/S Demo	Questionnaire	5-10 min	X							X				
Secondary School Success Checklist	SSS-C	Online scale	30-45 min	X		X	X		X	X		X			
Social Communication Questionnaire-Lifetime	SCQ	Rating scale	10-15 min	X						X					
Social Responsiveness Scale-Teacher	SRS	Rating scale	10-20 min	X	X	X	X					X			
Student Information Form	StudInfo	Questionnaire	10-20 min	X	X	X	X							X	
Student Proximal Measure	Prox	Online scale	10-15 min					Y1:2x, Y2:3x		X		X			
Supports Intensity Scale-Children Short form	SIS	Rating scale	5 min	X	X	X	X			X		X			
Technology Survey	Tech	Questionnaire	15 min					1x over 2 years	X	X	X				
Usage Rating Profile – Intervention		Rating scale	10-15 min		X	X		Component-level measures	X	X	X				
Vineland Adaptive Behavior Scale-II (Teacher r.f.)	VABS	Rating scale	20-30 min	X	X	X	X					X			
Woodcock Johnson Test of Achievement-III	WJ-III	Standardized test	20-40 min	X	X	X	X		T					X	
Zarit Burden Inventory	ZBI	Rating scale	10-15 min	X	X	X	X			X					

Key: X = completed by, O = observed, I = interviewed, T = tested

Note: gray items are administered/completed by CSESA research staff

Time 1 Data

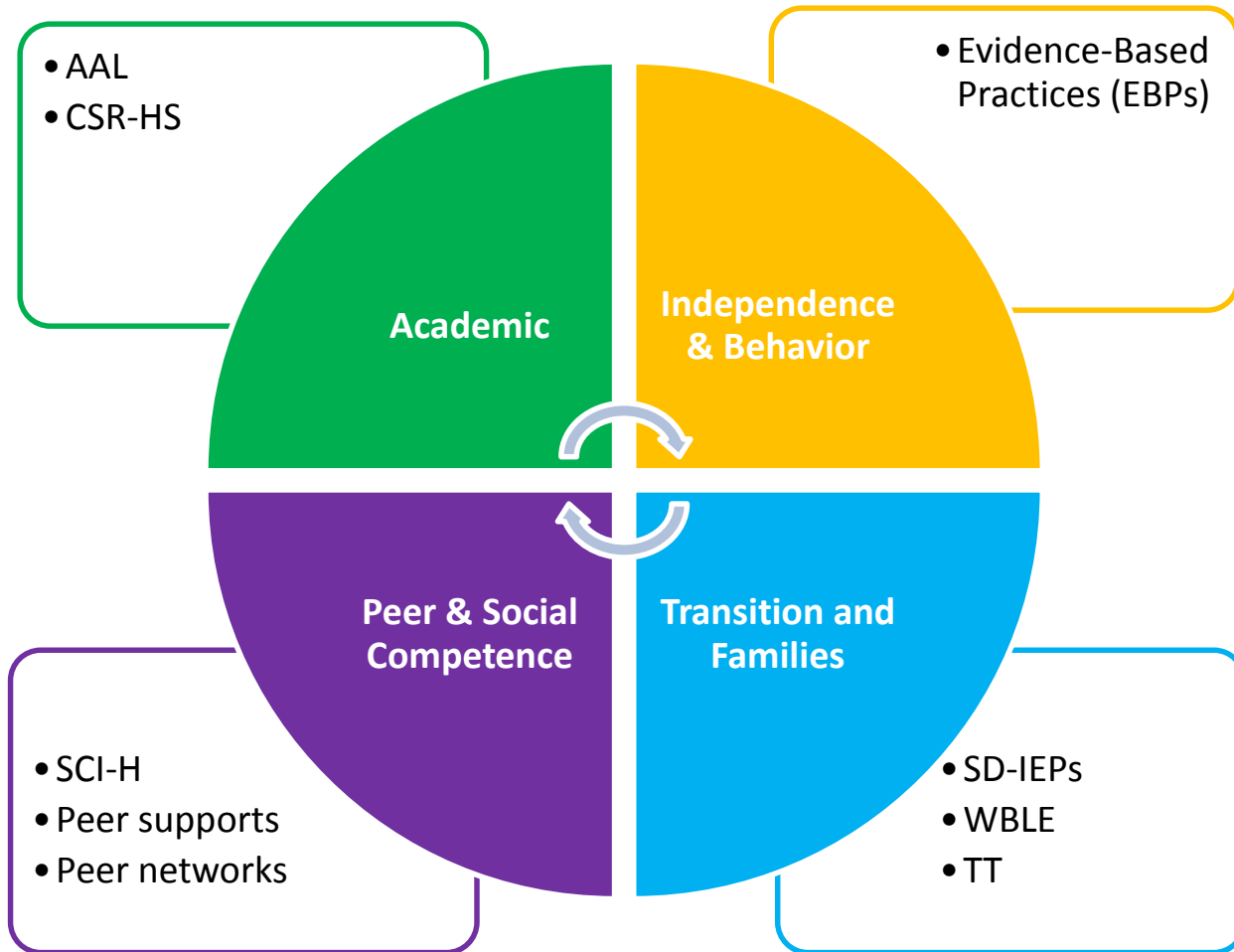
Cohort 1 Demographics

Variable	Categories	All (n=281)	SAU (n=126)	CSESA (n=155)
Age		M=16.3 SD=1.5 13.8-20.9	M=16.6 SD=1.6 13.9-20.9	M=16.0 SD=1.3 13.8-20.2
Diploma Type	Standard Diploma	n=163 %=58.2	n=72 %=57.6	n=91 %=58.7
	Modified Diploma	n=117 %=41.8	n=53 %=42.4	n=64 %=41.3
Gender	Male	n=235 %=83.6	n=106 %=84.1	n=129 %=83.2
Ethnicity	Hispanic/ Latino	n=32 %=15.8	n=16 %=18.0	n=16 %=14.2
	Non-Hispanic/ Non-Latino	n=170 %=84.2	n=73 %=82.0	n=97 %=85.8
Household Income	<\$20K	%=9.0	%=9.1	%=9.0
	\$20-39K	%=12.6	%=10.2	%=14.4
	\$40-59K	%=10.6	%=10.2	%=10.8
	\$60-79K	%=15.6	%=17.1	%=14.4
	\$80-99K	%=10.6	%=14.8	%=7.2
	>\$99K	%=41.7	%=38.6	%=44.1

Time I (Cohort 1) Student Data

Assessment	Description	All (n=281)	SAU (n=126)	CSEA (n=155)
Leiter-3	Nonverbal IQ Composite score	M=85.8	M=86.3	M=85.4
SCQ	Total SCQ Score 0-39	M=20.5	M=20.9	M=20.1
	0 (No ASD)	n=51 %=22.8	n=18 %=18.6	n=33 %=26.0
	1 (ASD)	n=173 %=77.2	n=79 %=81.4	n=94 %=74.0
SIS Parent	Response to Single Item at bottom Range of 1-5	M=3.5	M=3.5	M=3.6
SIS Teacher	Response to Single Item at bottom Range of 1-5	M=3.4	M=3.4	M=3.4
SRS	Total T-score	M=71.8	M=71.3	M=72.2
	No ASD	n=38 %=14.4	n=17 %=15.0	n=21 %=14.0
	Mild	n=46 %=17.5	n=20 %=17.7	n=26 %=17.3
	Moderate	n=80 %=30.4	n=35 %=31.0	n=45 %=30.0
	Severe	n=99 %=37.6	n=41 %=36.3	n=58 %=38.7
Vineland Teacher	Adaptive Behavior Composite T-S	M=75.0	M=75.9	M=74.5
	Communication T-S	M=77.6	M=78.5	M=77.0
	Daily Living T-S	M=80.4	M=81.1	M=79.9
	Socialization T-S	M=72.4	M=73.3	M=71.7
WJ-III	Standard Score on Passage Comp.	M=70.2	M=71.1	M=69.5
	Age-equivalent on Passage Comp.	M=10.1	M=10.4	M=9.9
	Standard Score on Academic Knowledge	M=71.1	M=71.7	M=70.6
	Age-equivalent on Academic Knowledge	M=10.7	M=11.0	M=10.5

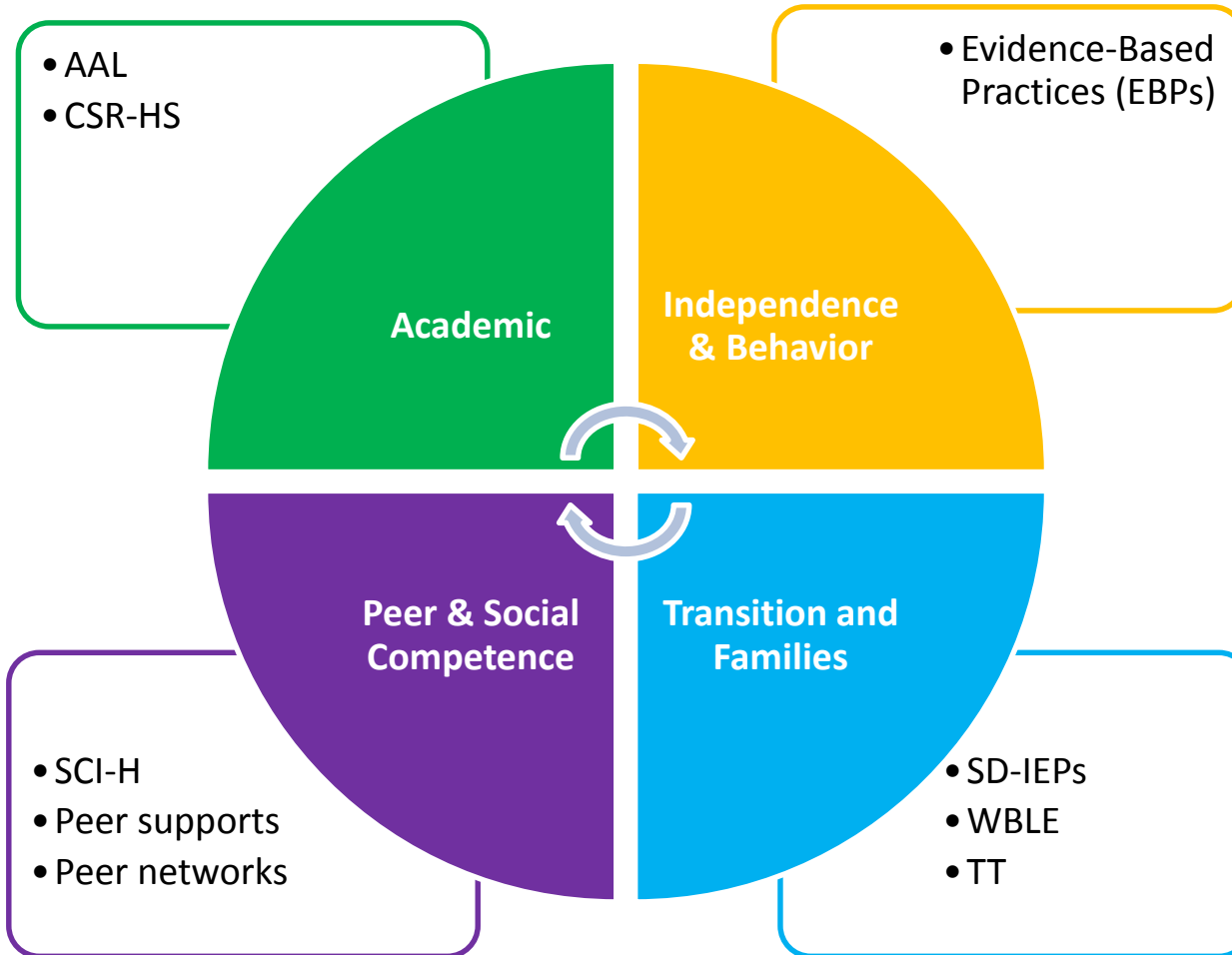
CSESA Domains



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

2. Overall, how useful was this session?

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

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

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

4. Any additional thoughts or concerns?

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:

Engagement Ratings

TEEN GROUP ENGAGEMENT RATINGS

SESSION ____ DATE _____

PARTICIPANT NAME	VERY LITTLE ENGAGEMENT	SOMEWHAT ENGAGED	CLEARLY ENGAGED
1.			
2.			
3.			
4.			
5.			

Ratings Completed By: _____

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

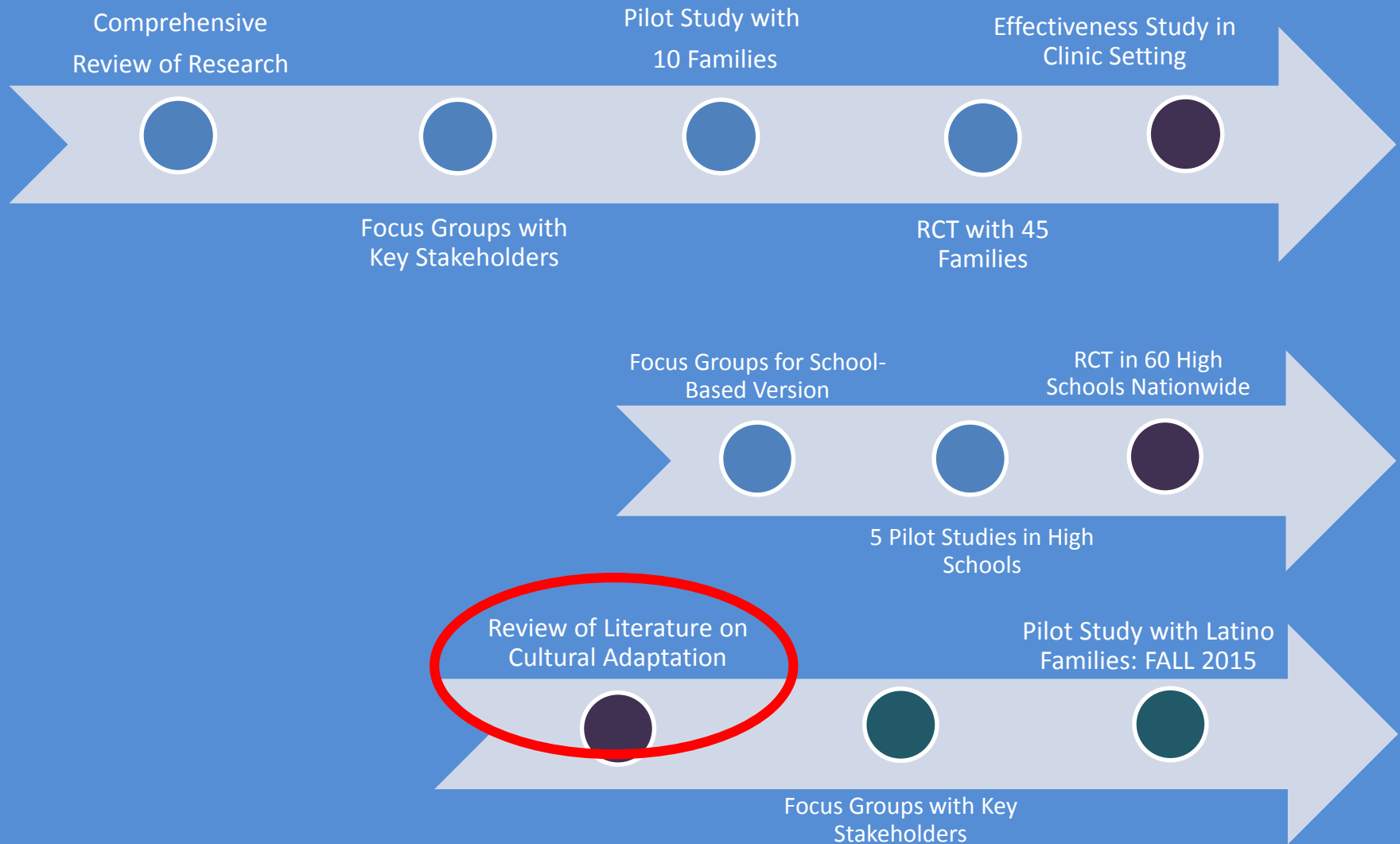
DATE	ACTIVITY	SCORE**
	<i>Stones Activity</i>	
	Handout and review agenda for session	
	Discuss social problems solving	

For Additional Information and Resources

CSESA website:

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

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 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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