Lessons Learned from an Addressing Disparities Trial of School-Based Executive Function Treatments for ASD and ADHD

PCORI AD-1304-7379

OBJECTIVES	The participant will be able to:
Lauren Kenworthy, PhD	describe strategies to identify and engage students who experience disparities in access to treatments
Allison Ratto, PhD	discuss how to address language and cultural disparities in order to engage more families in school-based treatments
Laura Anthony, PhD	summarize the research results examining the effectiveness of two Executive Functioning interventions, including effects in academic classrooms
Bruno Anthony, PhD	Discussant

School Mental Health 2017

Reaching the other half: Moving towards symptom-based referral methods to engage more students and families in school-based treatments

Lauren Kenworthy & Laura Anthony
Kristi Hardy
Jonathan Safer-Lichtenstein
Alyssa Verbalis
Matthew Biel
Sydney Seese
John Strang
Allison Ratto
Cara Pugliese
Bruno Anthony

Funder: PCORI AD-1304-7379
Conflicts of Interest: Royalties on *Unstuck* manuals & BRIEF forms.
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Why do we need creative, community-based strategies for ASD/ADHD treatments?

- Few EBPs available, especially few Tier 2
  - Many typically effective techniques do not work as well in ASD
- Poor generalization despite real world needs
- Vast disparities in diagnosis, access to treatment and participation in research
  - Lacking methods to assess community acceptance
- Disenfranchised population
  - importance of stakeholder input with a focus on appreciation of neurodiversity, empowerment and building on strengths
- Our work represents a shift from a goal of normalization to helping people with ASD/ADHD with the things that they have asked for help with

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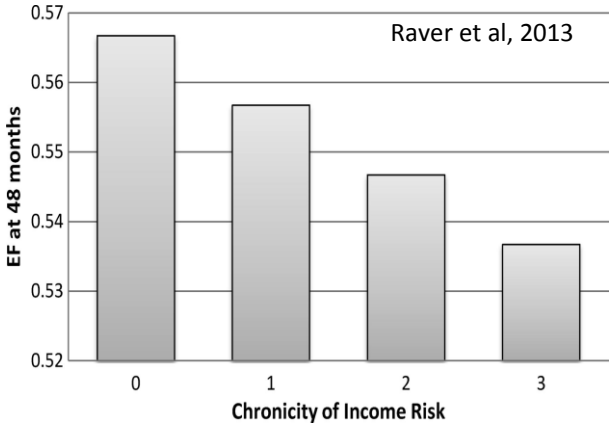
Disparities in *access* to diagnosis & treatment

Disparities in *outcome* = executive dysfunction

- CDC: Under ascertainment of ASD related to under-identification of low-income/minority children with ASD
- AHRQ: Poor/minority children with ADHD undertreated
- Poverty is bad for executive function
- Executive function (EF) is important to outcomes:

  - Flexibility linked to math skills, language comp, disruptive behavior, depression in ADHD (Roberts, 2014, Sjowall 2014)
  - Flexibility predicts anxiety, aggression, adaptive deficits in ASD (Lawson, 2014; Pugliese, 2015)



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Can we improve Flexibility with School Based Tier 2 Interventions: Disparities Comparative Effectiveness Trial

- 3rd – 5th graders (48 with ASD and 98 with ADHD) from three school systems in 21 Title 1 schools.
- Random assignment to revised Unstuck and On Target or adapted Contingency Behavior Management
  - Both target EF/Flexibility
  - Both must be effective
- Adapted interventions for use with (all at once!!):
  - Title 1 schools
  - Either ADHD or ASD
  - Spanish or English speaking families
  - Greater family involvement
  - Strength based, student centered
- School personnel administer tx in school, + parent and teacher training

PCORI AD-1304-7379

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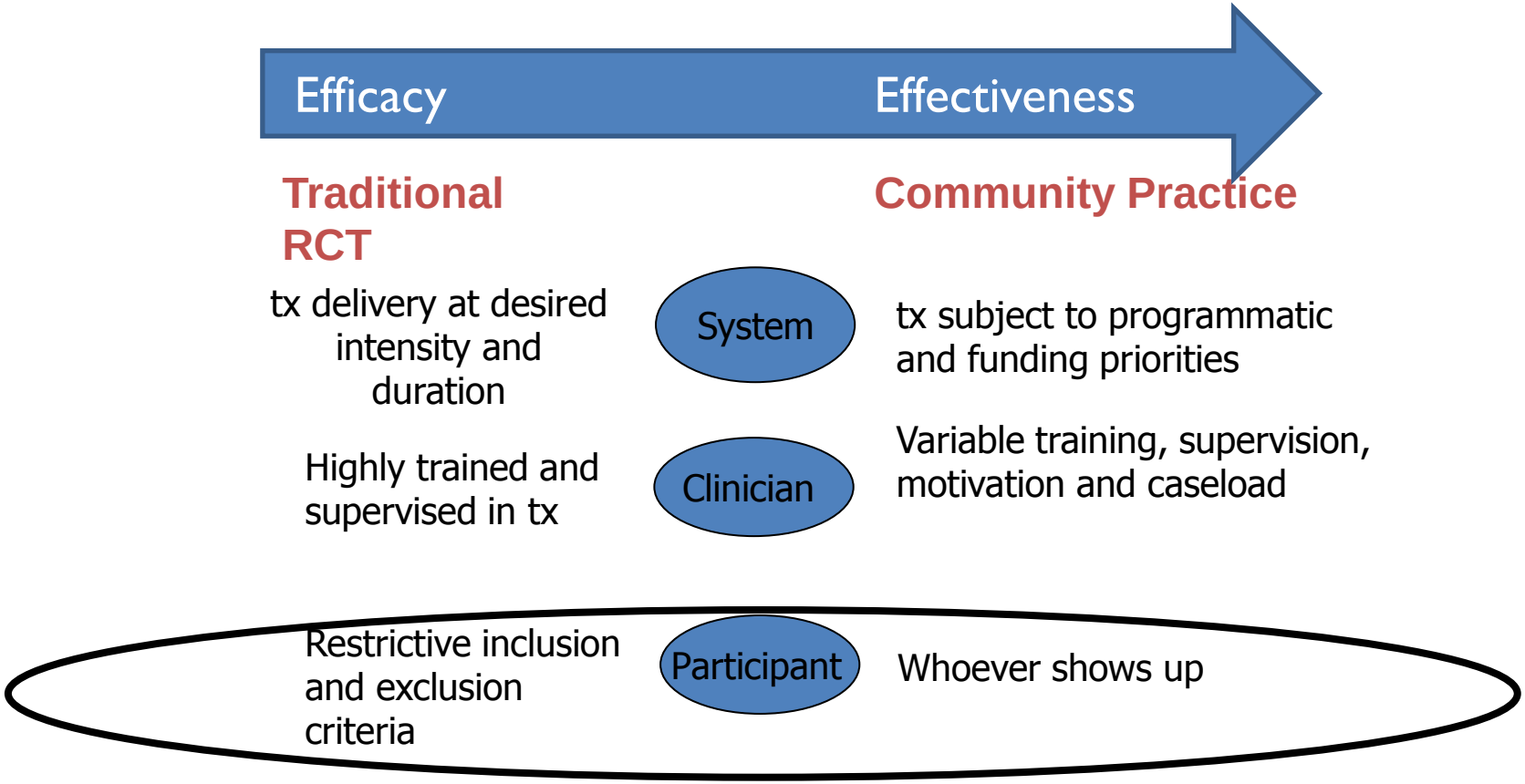
The test of any intervention is the test of that intervention in a context.



Slide Courtesy of David Mandell

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Recruitment Year 1: What didn't work

- Unknown research assistant calls family and asks: "Does your child have autism or ADHD"
- Recruited 41 participants -41% of the target
- Everyone is worried

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Recruitment Year 2: What Worked

- School staff identified students with flexibility problems like:
  - Problems accepting feedback and criticism
  - Problems handling frustration
  - Problems starting something they don't want to do
  - Frequent meltdowns
  - Not stopping doing something even after they have been told to stop
  - Problems with shutting down when something is challenging
- And "characteristics of" either ADHD or an Autism Spectrum Disorder

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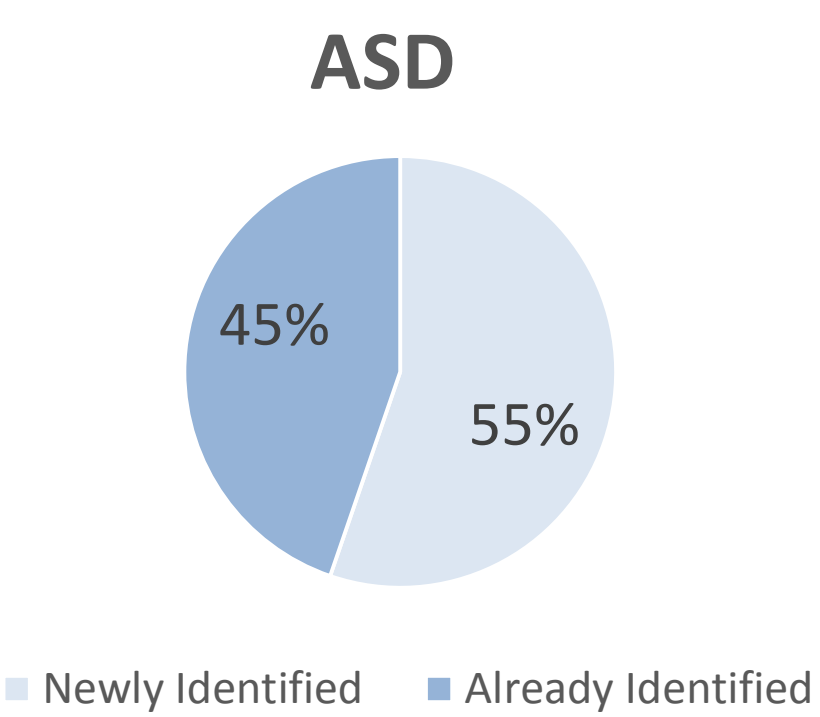
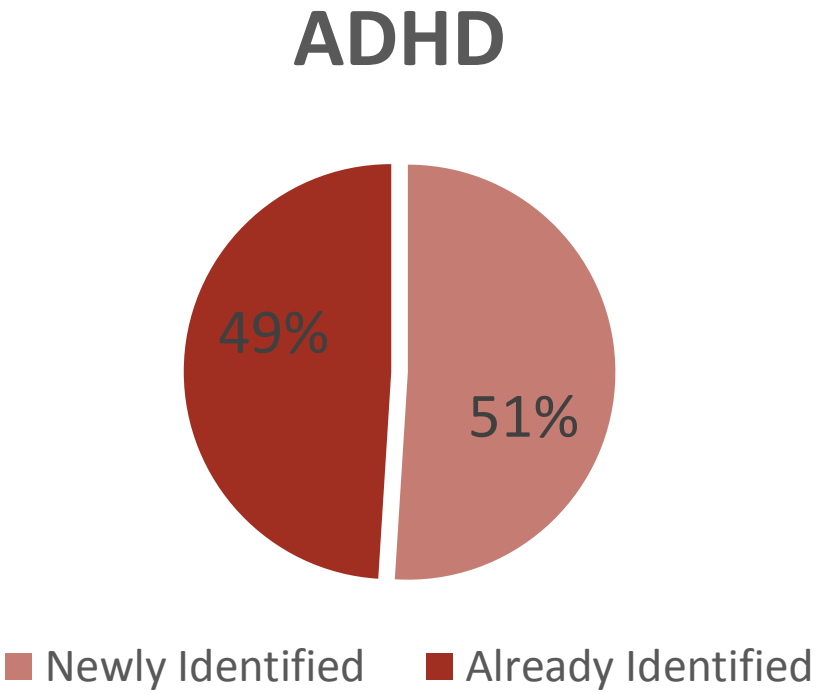
What We Gain When We Don't Require Previous Diagnosis: Reach twice as many children





October 23, 2017

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Demographics mean (range)

	ASD		ADHD	
	Newly identified (n=21)	Already identified (n= 17)	Newly identified (n=36)	Already Identified (n=35)
Child age	9.8 (8.4-11.2)	10.0 (8.8-10.9)	9.4 (8.0-10.8)	9.6 (8.1-11.0)
% male	95.2	94.1	77.8	80.0
IQ	100 (79-138)	99 (79-129)	97.3 (74-133)	96.3 (71-124)
Parent Ed. (yrs.)	16.0 (12-23)	16.7 (12-25)	13.4 (3-21)	14.5 (3-23)
Income/yr ($1000)	112 (14-400)	114 (15-350)	70 (9.6-225)	83 (8.7-210)
%English = 2nd lang	9.5	5.9	36.1	17.1

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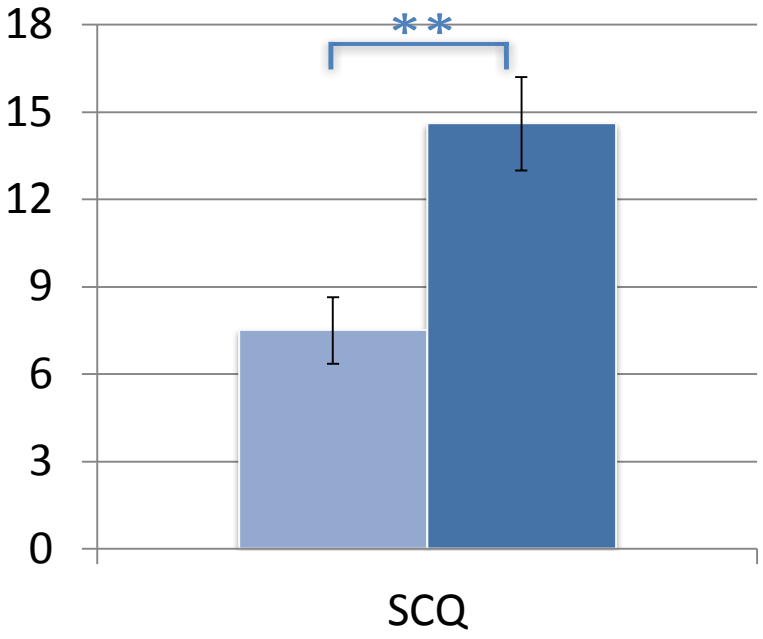
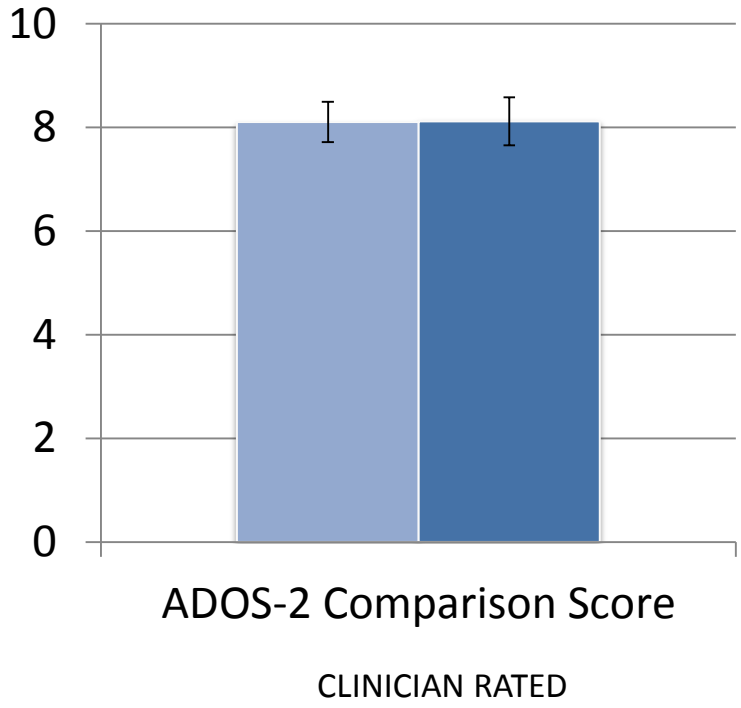
ASD Symptoms Already vs Newly Identified: Parent and Clinician Ratings





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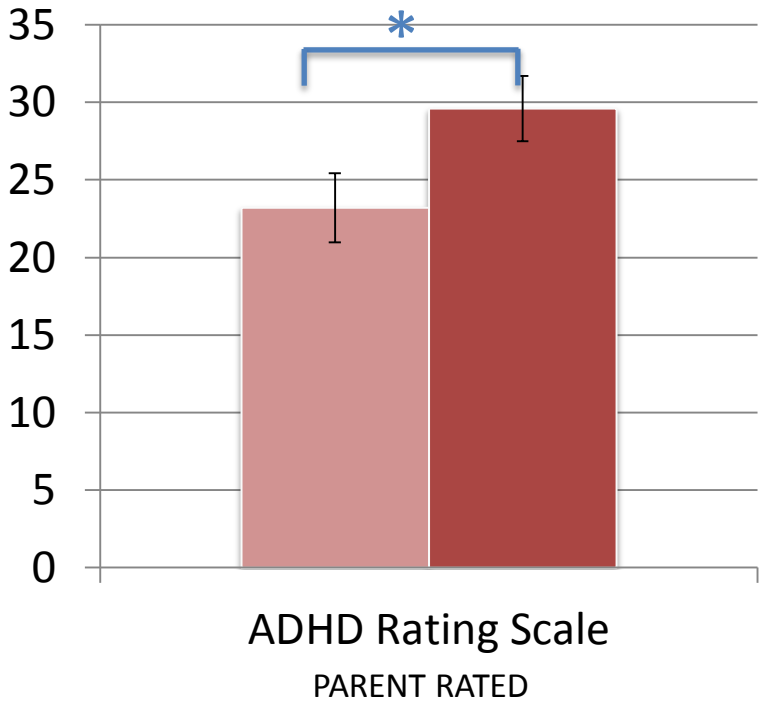
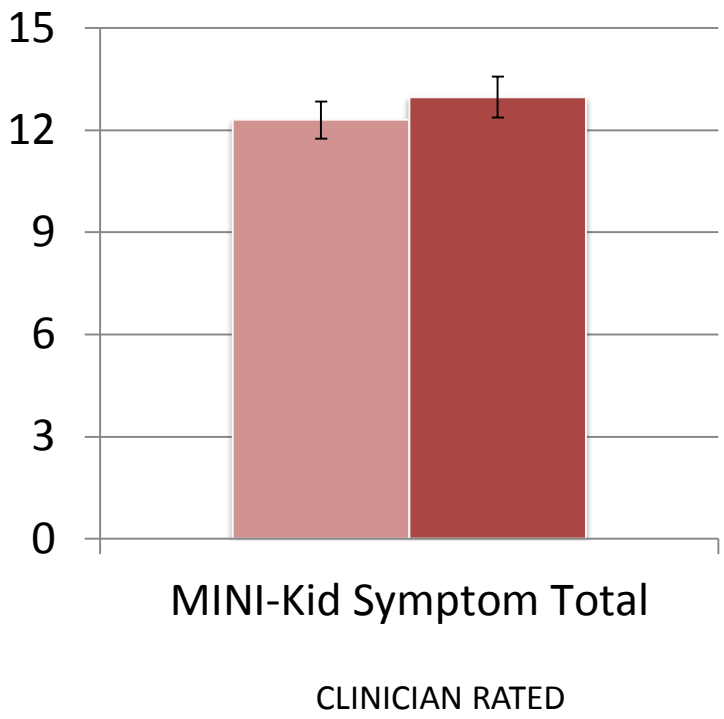
ADHD Symptoms Already vs Newly Identified: Parent and Clinician Ratings





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What We Gain: Intervention Theory

Phenotype vs Diagnostic Specific Intervention

- Targets treatment to those who need it: Individualized Medicine
- Aligns treatment groups with neurobiology
- Reduces false “won’t” attributions
- Expands pool of who you can help
- Clarifies target of treatment for interventionist, parent and participant

Causal Model of Neurodevelopmental Disabilities

Brain

Cognition

Behavior

(Frith, 2001 & Pennington, 2002)

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What We Gain: Demographics

Ethnicity/Race	Evaluated (N=170) N (%)	Included in Study (N=148) N (%)
Caucasian/White Non-Hispanic	N=45 (26.5%)	N=44 (29.7%)
African-American/Black Non-Hisp	N=36 (21.2%)	N=29 (19.6%)
Asian-American/Arab-American	N=10 (5.9%)	N=9 (6.1%)
Hispanic/Latino	N=53 (31.2%)	N=47 (31.8%)
Biracial	N=9 (5.3%)	N=8 (5.4%)
Other/Unreported	N=17 (10%)	N=11 (7.4%)

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What We Gain: Address Disparities and *Reach the other half*

Reach Children and Families who:

- Not getting services in a clinic
- Have the wrong/no IEP
- Speak the wrong language
- Live in the wrong place
- Have the wrong/no insurance
- Don't understand or feel comfortable with a diagnostic label

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ENGAGING LATINO IMMIGRANT FAMILIES IN SCHOOL-BASED BEHAVIORAL TREATMENTS

Allison B. Ratto, Bruno J. Anthony, Cara Pugliese, Rocio Mendez, Jonathan Safer-Lichtenstein, Katerina Dudley, Nicole F. Kahn, Lauren Kenworthy, Matthew Biel, Jillian Martucci, and Laura G. Anthony

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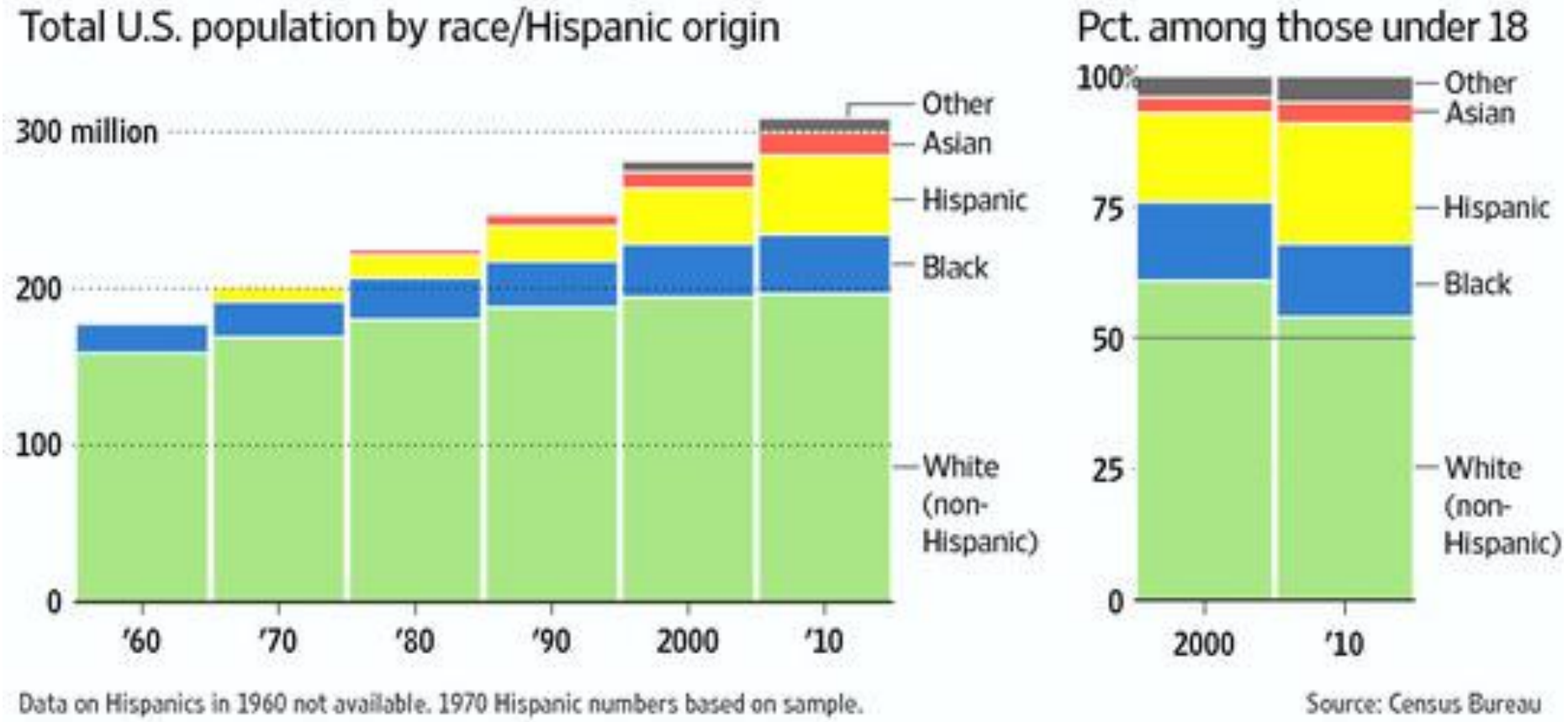
The Changing Face of America

How the demographic breakdown of the U.S. has changed



Data on Hispanics in 1960 not available. 1970 Hispanic numbers based on sample.

Source: Census Bureau

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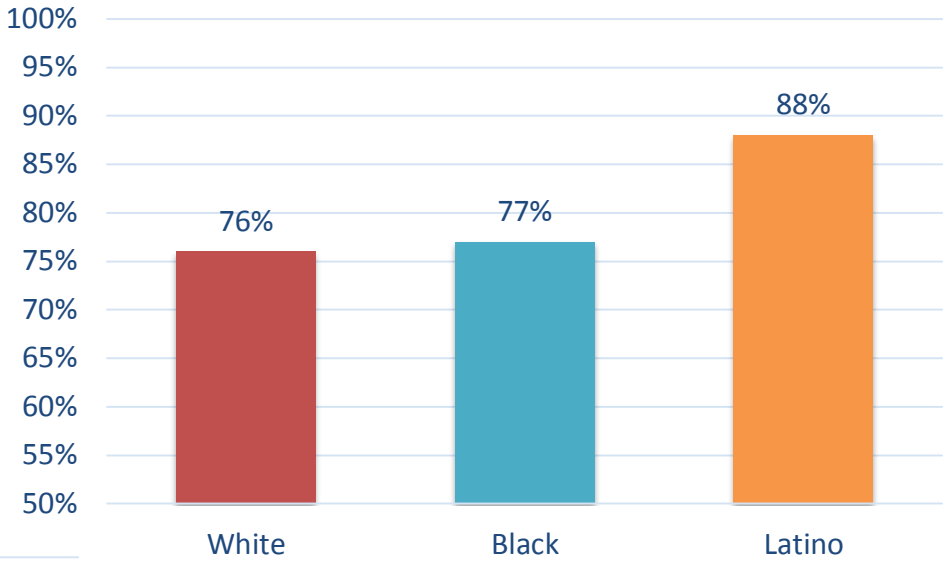
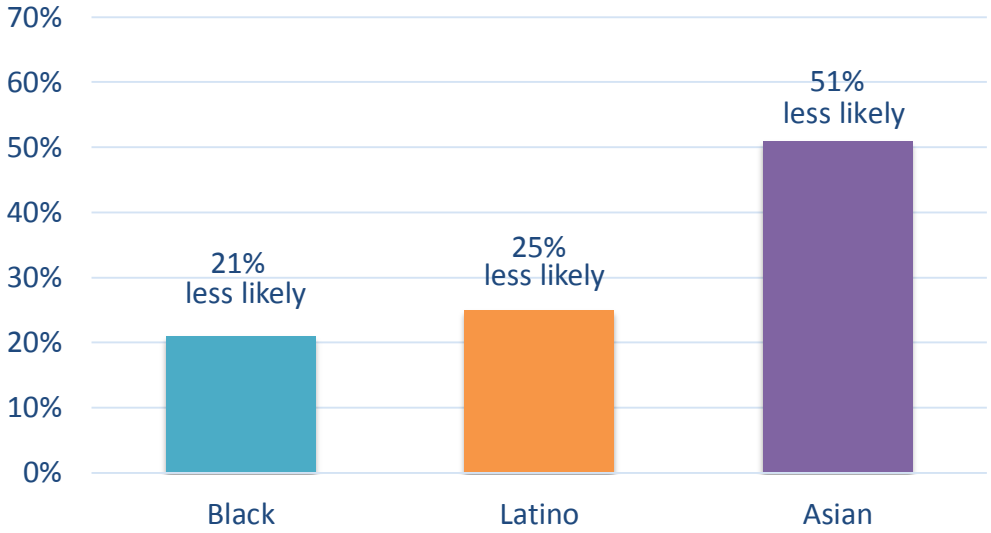
Latino Youth and Mental Health Care

Rates of Unmet Mental Health Needs



Kataoka, S.; Zhang, L.; & Wells, K. (2002). Unmet need for mental health care among U.S. children: Variation by ethnicity and insurance status. American Journal of Psychiatry, 159(9), 1548-1555.

Openness to Mental Health Service Use



Smith, T.B. & Trimble, J.E. (2015). *Foundations of Multicultural Psychology: Research to Inform Effective Practice.* Washington, DC: American Psychological Association.

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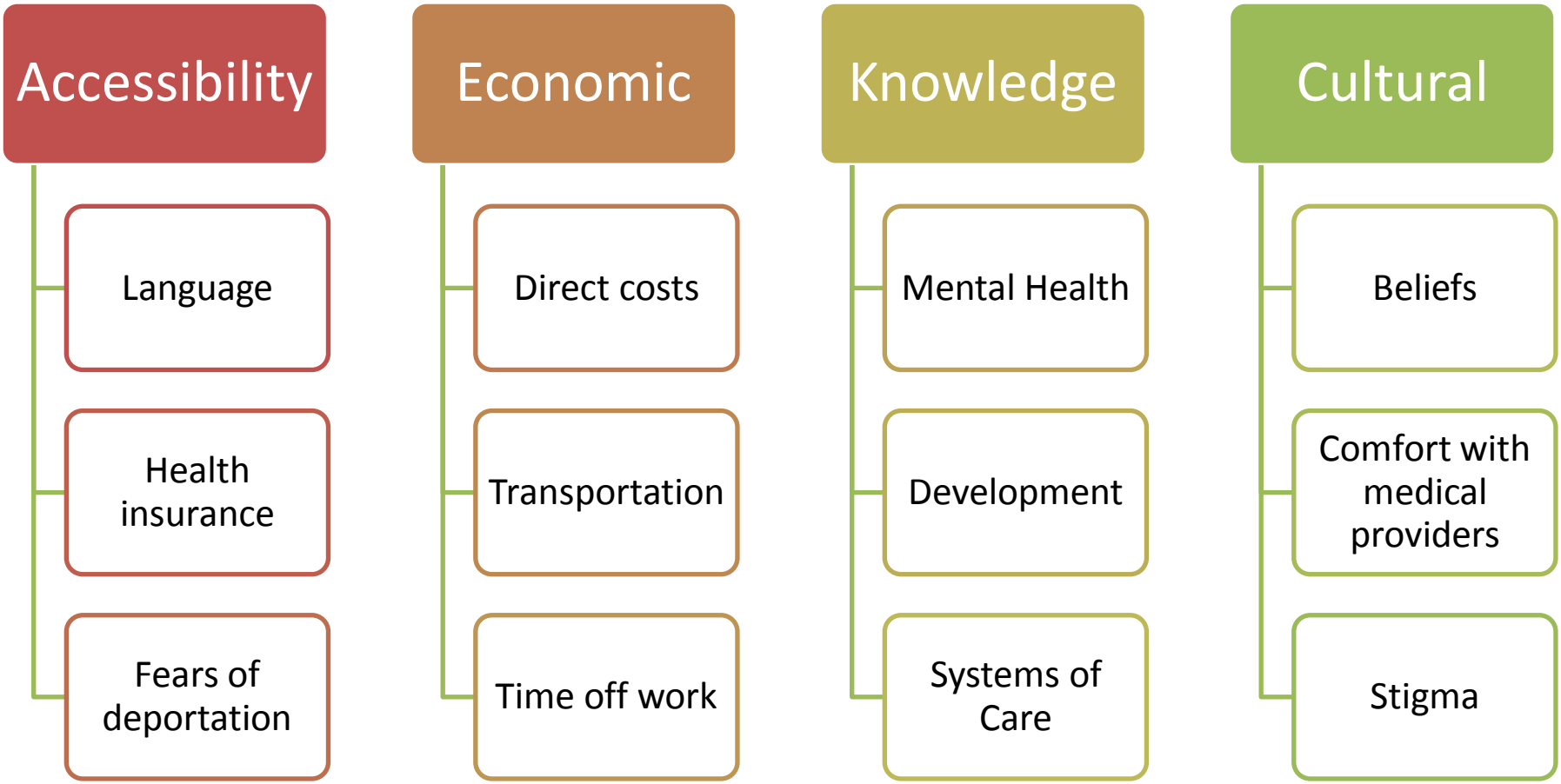
Barriers to Mental Health Care for Latino Immigrant Families



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Additional Barriers to Clinical Research Participation

English proficiency required

Lack of measures

Less comfort

Systemic racism

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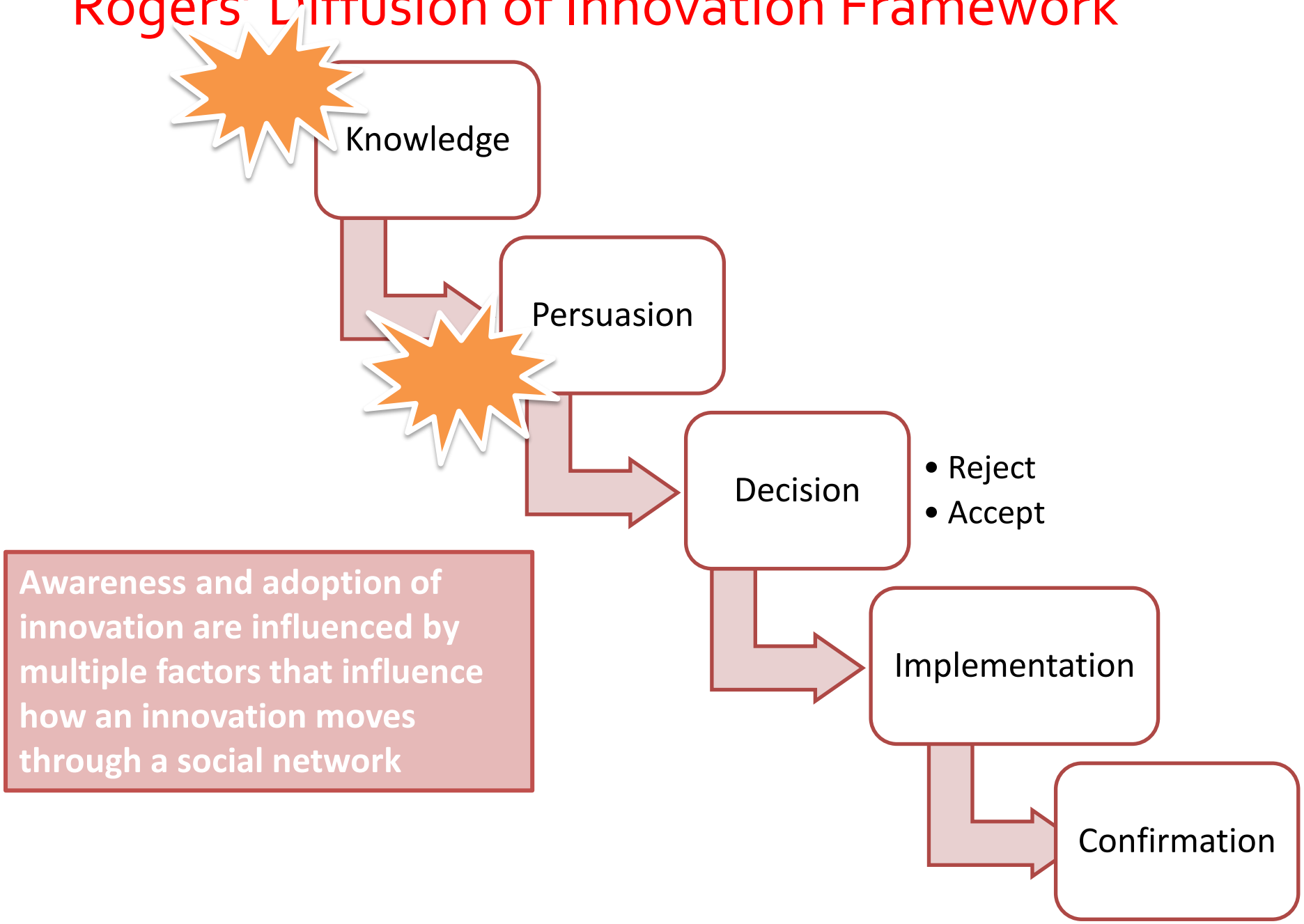
Rogers' Diffusion of Innovation Framework



Innovation Factors Affecting Acceptance

Compatibility	• Does it fit with my values and needs?
Complexity	• How easy is it to use?
Relative Advantage	• What's the return on investment?
Trial-Ability	• How easy is it to try out?
Observability	• Can you see the results?

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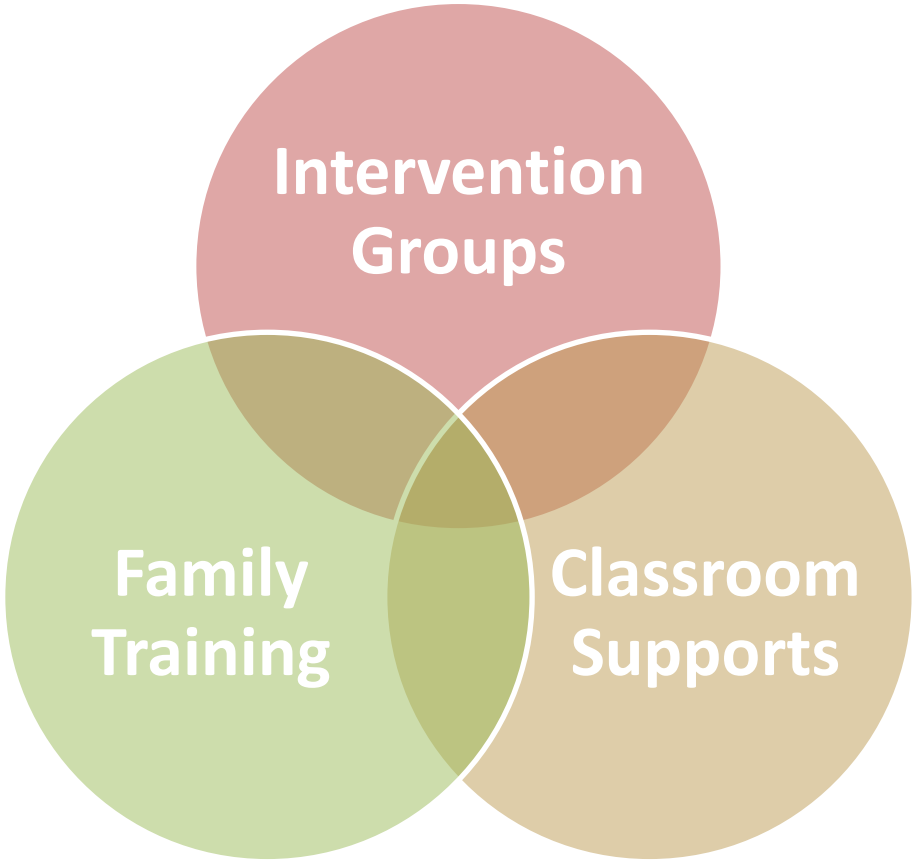
Project Overview

- 3rd – 5th graders (with ASD or ADHD) from 22 Title 1 schools in Washington, DC Metropolitan Area
- Comparative effectiveness trial of two executive function interventions (Unstuck and On Target or Contingency Behavior Management)



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	Latino (N=47)	Non-Latino (N=101)	Test statistic
Yearly Net Income	$41,058 (32,304)	$110,664 (79, 806)	F(1, 125) = 28.84***
Parent Education	10.71 (4.36)	15.76 (2.75)	F(1, 137)= 69.00***
Adults in the Home	2.70 (1.00)	2.06 (.91)	F(1, 137)= 14.03 **
Children in the Home	2.36 (.99)	2.09 (1.17)	F(1, 137)= 1.75 (ns)
Prior Clinical Diagnosis			X^2= 1.94 (ns)
ASD	3	10	
ADHD	21	46	
Other diagnosis	3	10	
No prior diagnosis	20	32	
Research Diagnosis			X^2= 3.32†
ASD	11	39	
ADHD	36	62	
Prior Treatment	38 (80.85%)	80 (79.21%)	X^2= .26 (ns)
Prior Special Education Supports	24 (51.06%)	62 (61.39%)	X^2= 3.79*

†p<.10 *p<.05 **p<.001 ***p<.0001

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Key Strategies Used From the Beginning

Stakeholder Advisory Board

- All factors!

Adaptation and translation of materials

- Compatibility
- Complexity

Collaboration with schools

- Trial-Ability
- Observability

Minimize logistical barriers

- Relative Advantage
- Trial-Ability

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Stakeholder Team Members

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Translation and Adaptation of Materials

- Reduced treatment length and cost for associated materials
- Introduced parent workbook (English, Spanish)
- Used *charlas* rather than leader-driven sessions

- Spanish translation and adaptation of parent workbook (and measures, as needed)
  - Team of 3 bilingual translators (2 native English-speakers, 1 native Spanish-speaker)
  - Review by bilingual psychiatrist (native English-speaker) and bilingual parent advocates (native Spanish-speakers)
  - Consider reading level, approachability
  - Culturally-responsive vignettes

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Collaboration with Schools

- Referral by school staff to treatment
- Using school staff to "sell" the intervention
- Primary intervention provided in school
- Ongoing consultation to school personnel throughout the trial
- School-specific adaptations and control of logistical details

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Easing Logistical Barriers

- Scheduled parent trainings at:
  - Convenient times (weekends, evenings)
  - Convenient locations (in the community, accessible by public transit)
  - With free, on-site childcare

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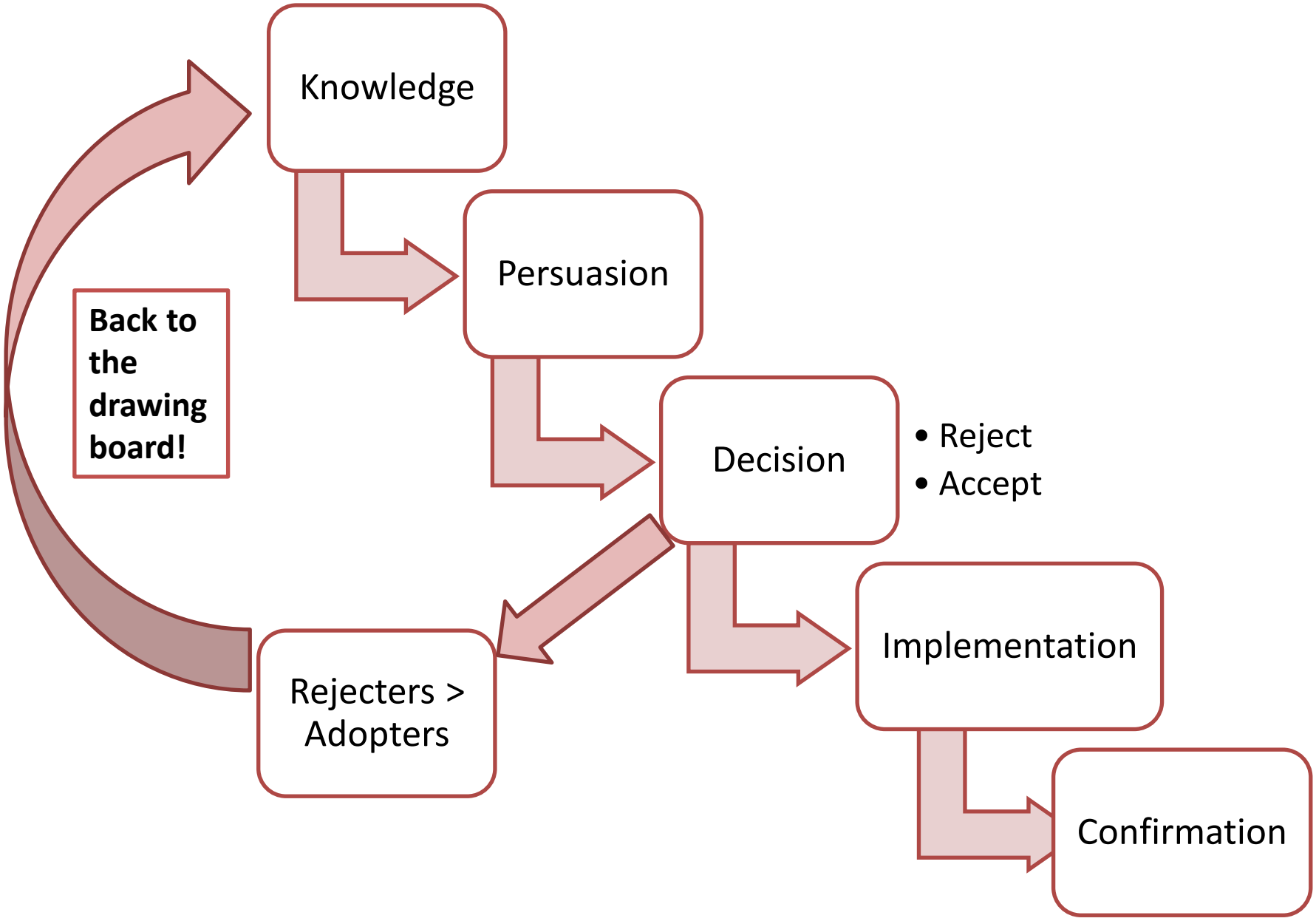
Rogers' DOI Framework Applied Adaptively



Lessons Learned: Knowledge

- Challenges
  - Children lacked prior diagnoses of ASD or ADHD
  - Parents lacked knowledge of ASD/ADHD and community resources

- Response
  - Dropped requirement for prior diagnosis and asked the question later in recruitment
  - Additional psychoeducation incorporated into parent sessions
  - Provided time for parents to share knowledge and experiences

Compatibility

Relative Advantage

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Lessons Learned: Persuasic

Compatibility

- Challenges
  - Parents were not always ready to make immediate decisions about involvement
  - Perceived stigma among family and broader community for seeking diagnosis and/or external support
  - Research process was unfamiliar and frightening

- Responses
  - Recognized *familismo* and adapted research procedures to be open to including extended family members, extending the length of the consent process
  - Extended invitations to additional family and community members
  - Prior participants acted as "intervention ambassadors" through word of mouth
  - Additional information and transparency about the research process

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Lessons Learned: Persuasion

Complexity

- Challenges
  - Family schedules were often in flux
  - Forms and questionnaires were confusing, even when translated

- Responses
  - Stayed in continual contact with families through texting, flexible scheduling, and phone check-ins
  - Provided families with more support, including read-aloud, for completing forms

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Lessons Learned: Persuasion

Relative Advantage

- Challenges
  - Parents lacked knowledge of and access to school supports and staff
  - Families had many competing priorities for their time

- Responses
  - Referrals to bilingual community resources for support with school advocacy
  - Provided time for parents to share knowledge and experiences
  - Value of *personalismo* (personal connections) with study staff in building parent engagement
  - Compensation for parent training attendance

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Lessons Learned: Persuasion

Observability

- Challenge
  - Parents had no prior experience of children participating in behavioral interventions and improving
- Response
  - Allowed time for parents to share their ongoing experiences with the intervention
  - Family navigator and parent trainers disclosed own experiences of success

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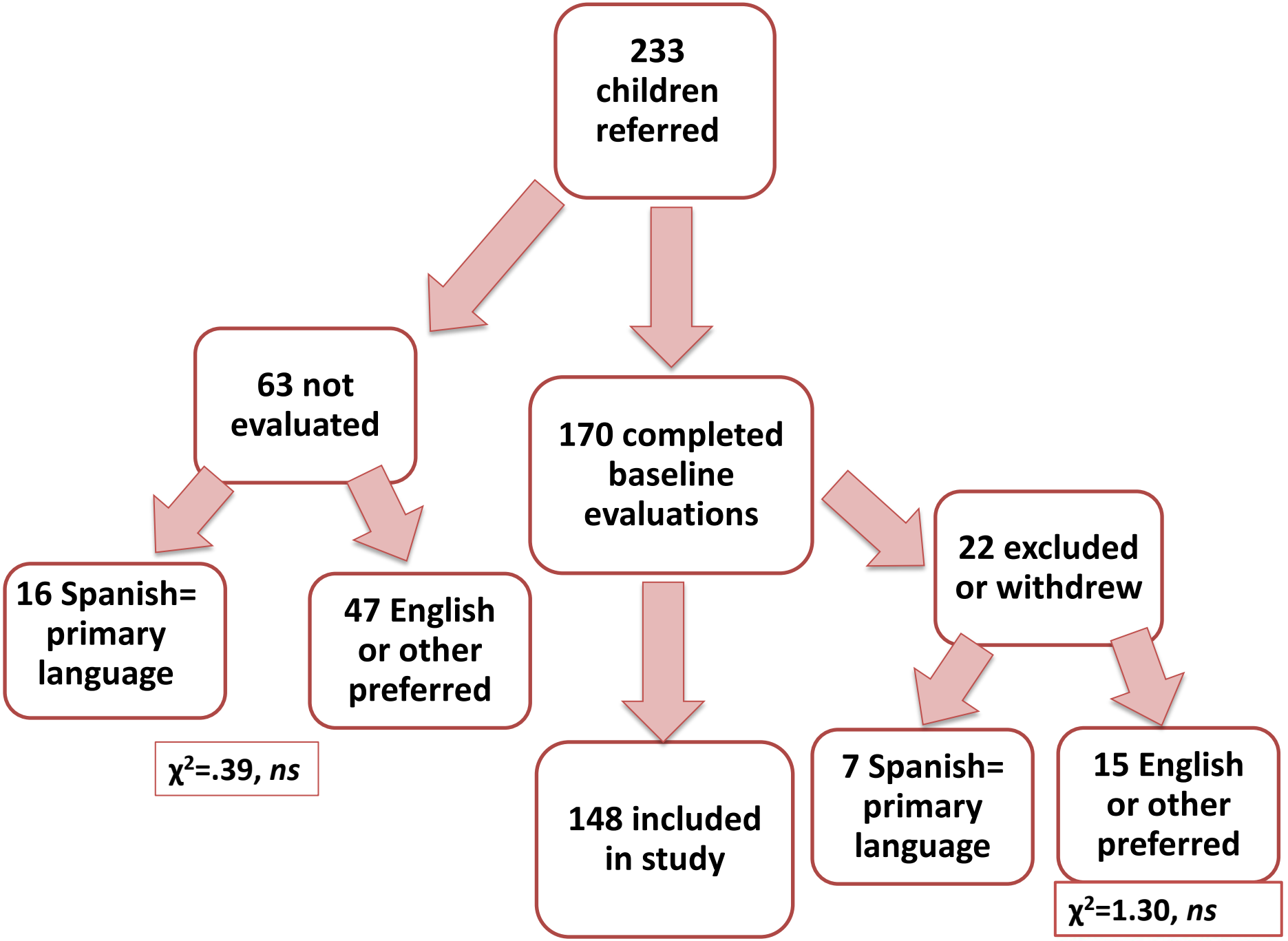
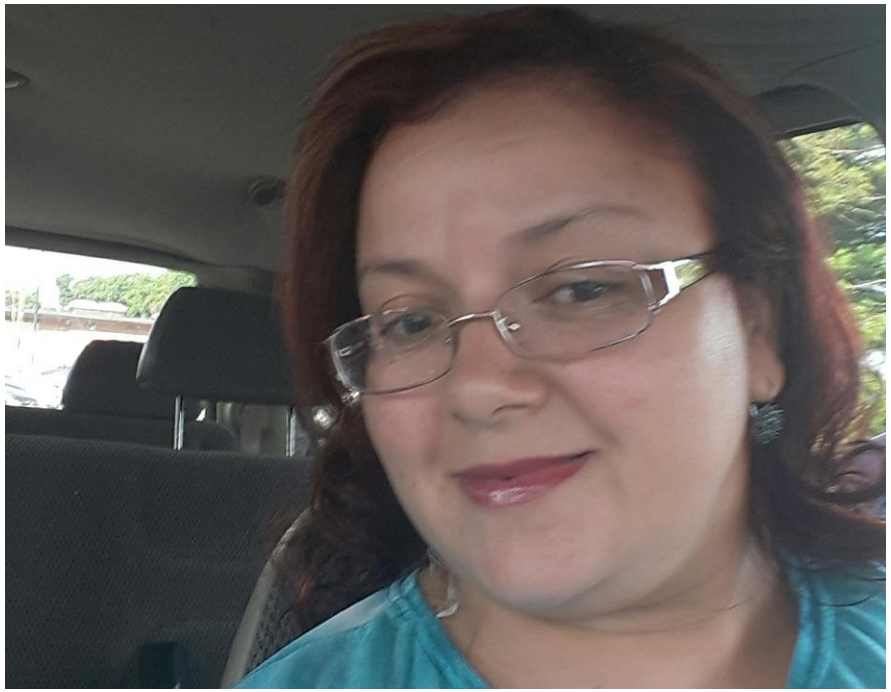

233 children referred
63 not evaluated
16 Spanish= primary language
47 English or other preferred
χ^2=.39, *ns*
170 completed baseline evaluations
148 included in study
22 excluded or withdrew
7 Spanish= primary language
15 English or other preferred
χ^2=1.30, *ns*

Parent Engagement

	Latino Mean (SD)	Non-Latino Mean (SD)	Test Statistic
Trainings Attended (Range: 0-4)	1.74 (1.44)	2.00 (1.60)	F (1, 146)=.870 (ns)



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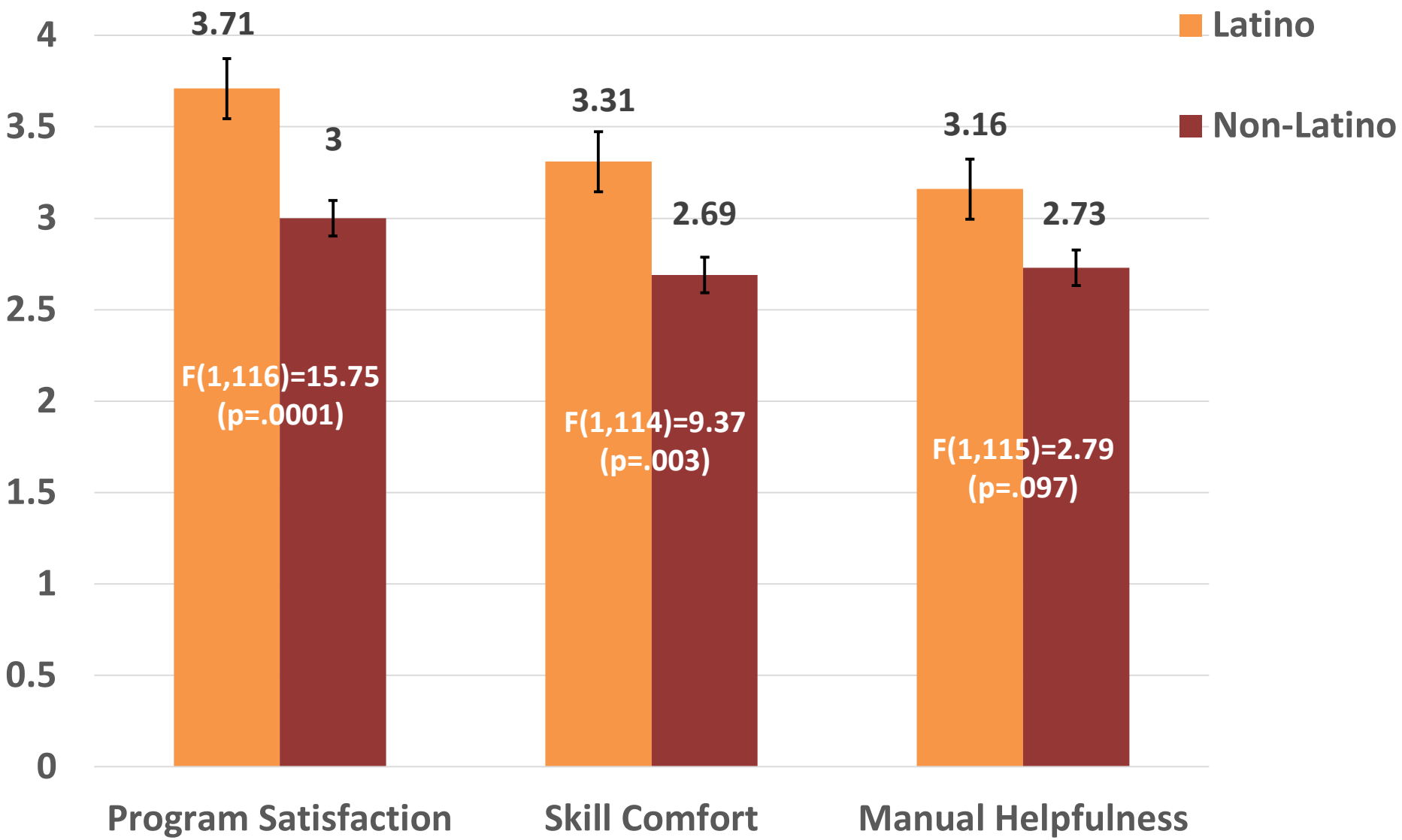
Treatment Acceptability



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Thoughts for the Future

- Focus on treatment dissemination
- Maintain the Stakeholder Advisory Board for continued consultation and future research
- This takes a long time! Long-term community partnerships are needed

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Thank You!

- Alyssa Verbalis, Ph.D.
- Sydney Seese
- Meredith Powers
- Danica Limon
- Volunteers

- Children, families, and school staff who participated!

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Which Works Better for Which Students?: Results from the Comparative Effectiveness Trial

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Children's Hospital Colorado

School Mental Health Conference, 10/20/17

Conflicts of Interest: Royalties on *Unstuck* manuals

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Community-Based Participatory Research

Stakeholder Advisory Board

Yetta Myrick, Chair
Vivian Jackson
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Megan Berkowitz
Rosario Paredes
Sara Cooner
Bettrys Huffman
Michael Bloom
Katherine Price
Nancy Van Doren
Molly Whalen
Caroline Butler
Laura Njanga
Daniel Shapiro

Faculty and Staff

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Lauren Kenworthy, PI
Kristina Hardy
Bruno Anthony
Matt Biel
Alyssa Verbalis
Allison Ratto
Cara Pugliese
John Strang
Catherine Kraper
Lynn Cannon

Kaitlyn Tiplady
Meredith Powers
Jillian Martucci
Katerina Dudley
Chelsea Armour
Sydney Seese
Jonathan Safer
Nicole Kahn
Rocio Mendez
Leah Rothschild
Mary Skapek

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Pre-RCT Development Process

CBPR; Needs assessment with experts and stakeholders

Classroom observations of experts in action

Focus groups with school staff, parents, and children to define key elements

Feasibility and acceptability trial with direct feedback from students with ASD

Skip efficacy altogether

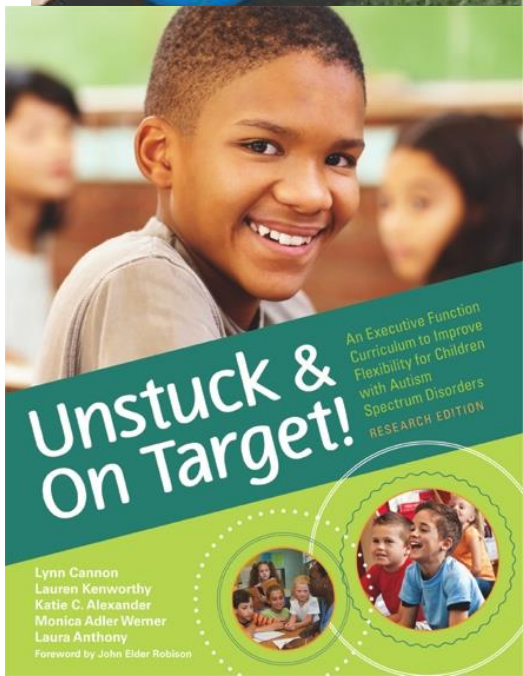
Result: Two Published Manuals

Ivymount Model Asperger Program/Take2 Summer Camp

- Katie Alexander
- Lynn Cannon
- Monica Werner

Children's National Center for Autism Spectrum Disorders

- Laura Anthony (now UCD)
- Lauren Kenworthy



THE JOURNAL OF CHILD PSYCHOLOGY AND PSYCHIATRY
ACAMH THE ASSOCIATION FOR CHILD AND ADOLESCENT MENTAL HEALTH
Journal of Child Psychology and Psychiatry 55:4 (2014), pp 374–383
doi:10.1111/jcpp.12161

Trial #1:

(NIMH 1 R34 MH083053-01A2)

Randomized controlled effectiveness trial of executive function intervention for children on the autism spectrum

Lauren Kenworthy,[1,2,*] Laura Gutermuth Anthony,[1,2,*] Daniel Q. Naiman,[3] Lynn Cannon,[4] Meagan C. Wills,[1] Caroline Luong-Tran,[1] Monica Adler Werner,[4] Katie C. Alexander,[4] John Strang,[1,2] Elgiz Bal,[1] Jennifer L. Sokoloff,[1] and Gregory L. Wallace[5]

[1]Children's National Medical Center, Center for Autism Spectrum Disorders, Rockville, MD, USA; [2]The George Washington University School of Medicine, Washington, DC, USA; [3]Department of Applied Mathematics and Statistics, Johns Hopkins University, Baltimore, MD, USA; [4]The Ivymount School, Rockville, MD, USA; [5]Laboratory of Brain and Cognition, National Institute of Mental Health, National Institutes of Health, Bethesda, MD, USA

- Unstuck (n=47)
- Social Skills (n=20; Baker, 2009)
- Interventions delivered at school by school staff with fidelity
- Parent training, teacher training, pull out groups, fidelity monitoring, interventionist supervision

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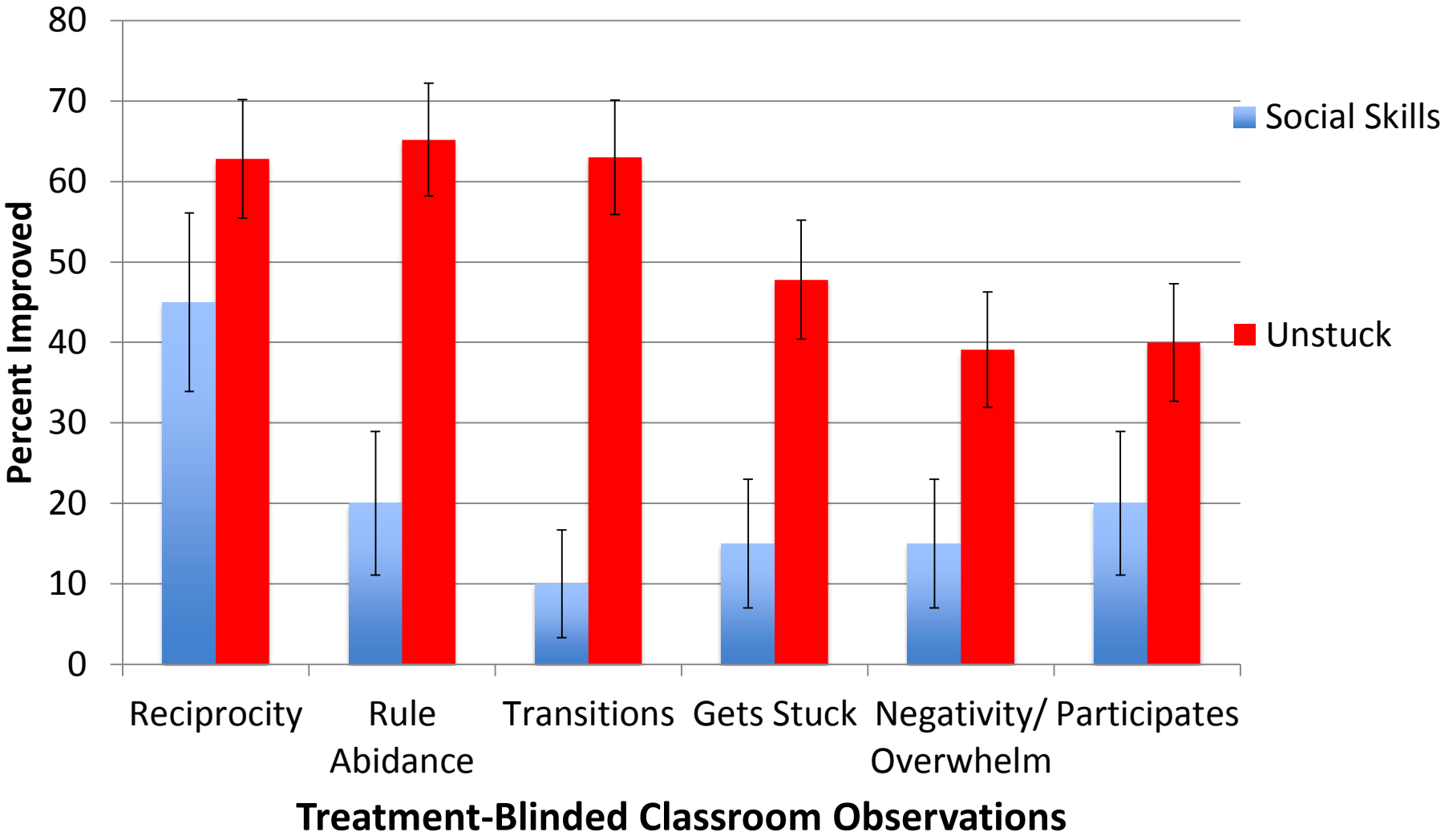
Effects in the Classroom



Kenworthy/Anthony et al., 2014

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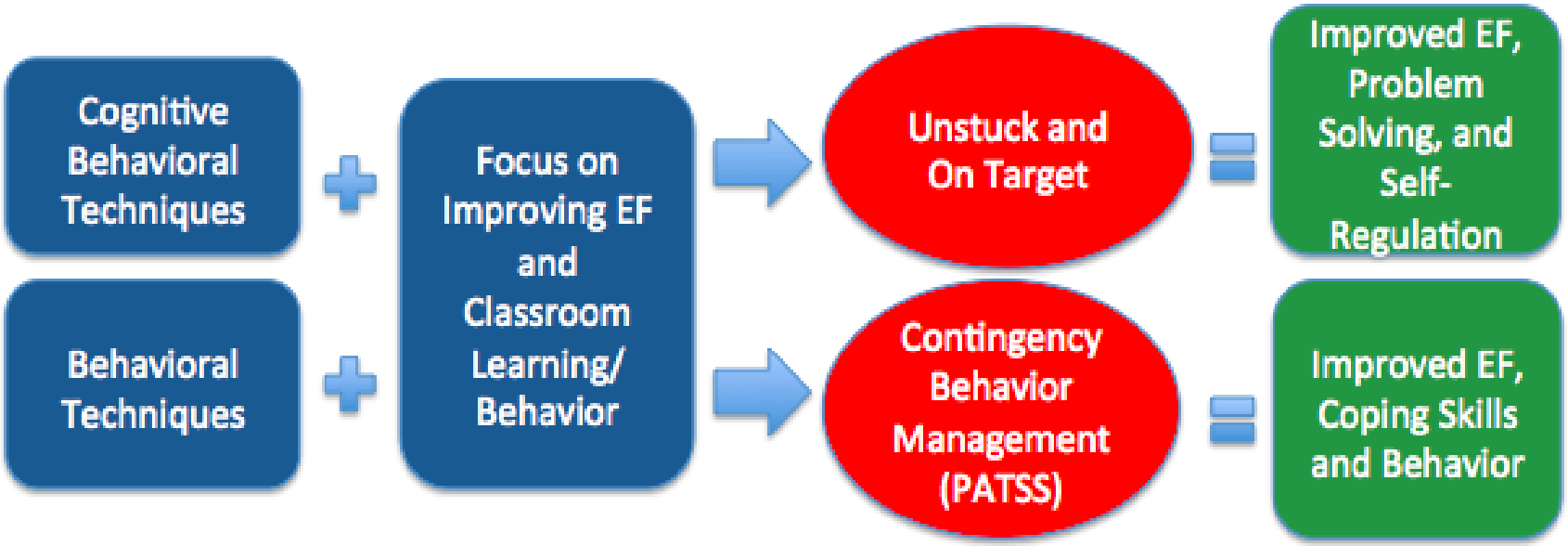
Study #2: Addressing Disparities Comparative Effectiveness Trial

A *randomized, clustered, parallel comparative effectiveness design:*

- **Randomized –** Schools will be randomly assigned (not kids)
- **Clustered –** Treatments will be delivered by school staff and will be matched for "dose" of intervention and training. **(Also pragmatic).**
- **Parallel** – Follow-up 9 months after they complete treatment to evaluate the maintenance of any gains, thus preventing a cross-over design.
- **Adaptive** – To meet the needs of our community (not parallel after all)



Demographics at Baseline

	PATSS	UOT	t/X^2	P-value
ASD	N=26	N=22		
Age: mean years	9.8 (0.9)	10.0 (0.8)	-0.7	.51
Sex: % male	100	92	1.7	.18
FSIQ: mean standard score	97 (12)	100 (15)	-0.8	.40
Income: mean $1000	123 (105)	80 (58)	-1.8	.09
Ethno-racial group: % Hispanic/White/Black/Other	11/61/11/15	36/32/14/18	6.6	.16
ADHD	N=43	N=55		
Age: mean years	9.6 (0.9)	9.5 (0.8)	-0.26	.79
Sex: % male	74	74	0	.99
FSIQ: mean standard score	100 (16)	94 (12)	-0.8	.40
Income: mean $1,000	89 (66)	64 (61)	-1.9	.06
Ethno-racial group: % Hispanic/White/Black/Other	**37/35/19/9**	**37/13/31/18**	**9.9**	**.04**

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Project Overview: Intervention Components (matched)

Student Groups

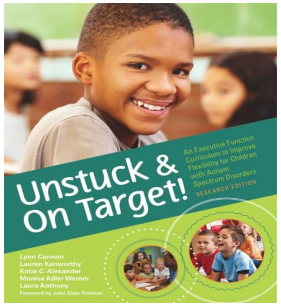
- ~20 Sessions of intervention
- 6 Interventionist Coaching
- 2 observations of intervention

Classroom

- Visuals
- 1 Teacher Training
- 4 Teacher Check-ins

Parents

- 4 Parent Training Sessions
- Homework +Parent Workbook
- Visuals



Your Guide to Executive Functioning:

A Workbook to Make* Unstuck and On Target *a Way of Life!

#1 Foundational Skills

#2 What is Flexibility

#3 How to be Flexible

#4 Why be Flexible

#5 Your Goals: Getting what you want

#6 Flexible, Goal-Directed Futures

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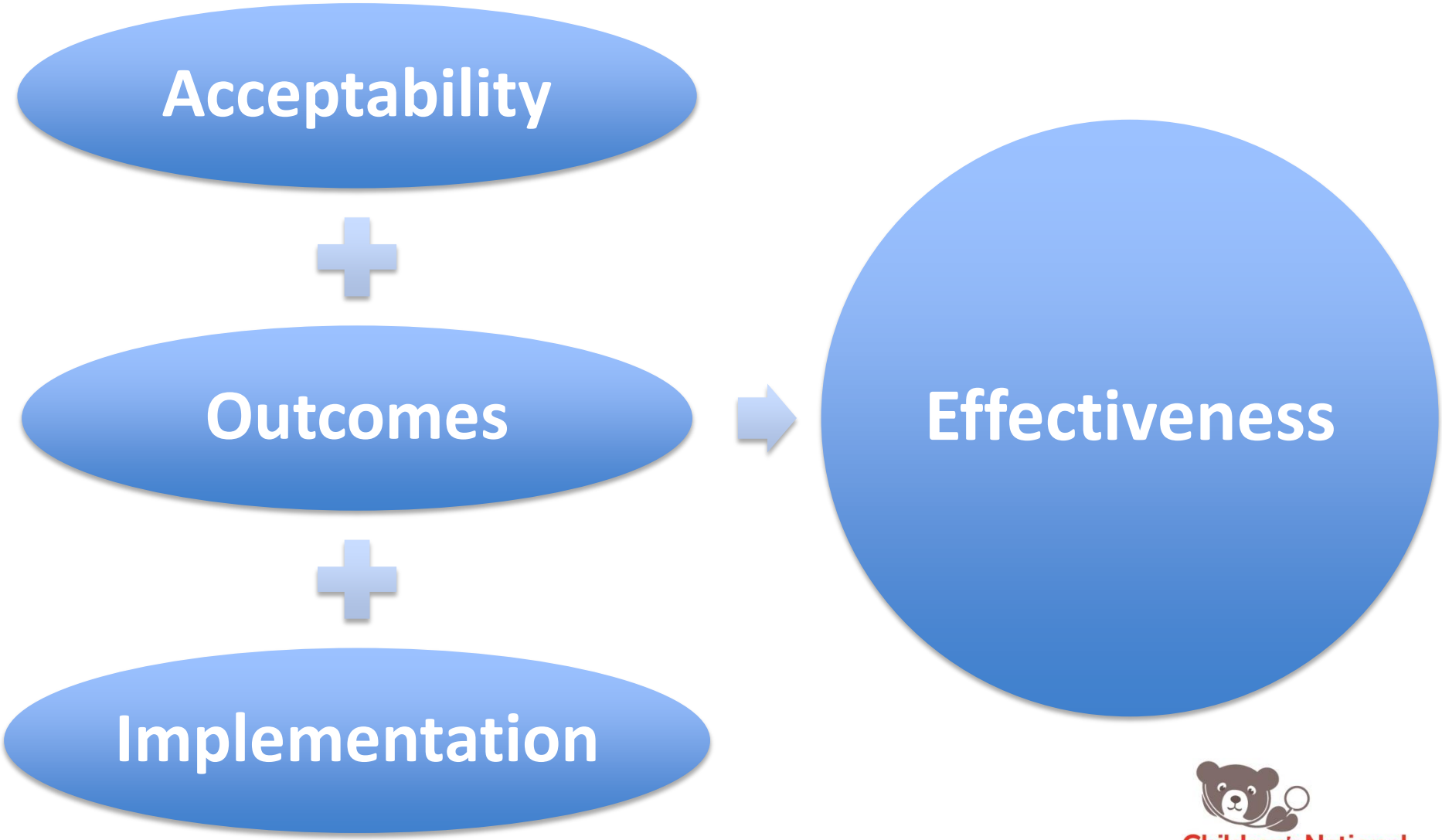
Unstuck & CBM are feasible and can be delivered with fidelity in low-income schools and with Spanish or English speaking families



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Student Feedback

How much did you enjoy the group?

"Not at all" "A little bit" "A lot"

85.1%	69.8%	*
Rated UOT "A lot"	Rated CBM "A lot"	t=2.018, df=128, p=.046

Parent Feedback

How much did your child's school group help your child?

0-4 Scale

44.1%	25.0%	**
Rated UOT "Really Helpful"	Rated CBM "Really Helpful"	t=2.767, df=117, p=.007

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Parent Feedback

Overall satisfaction?

0-4 Scale

56.7%

Rated UOT "Very Satisfied" Range 2-4

44.8%

Rated CBM "Very Satisfied" Range 0-4

**

t=3.015, df=116, p=.003

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Parent Feedback

How likely are you to use these techniques in the future?

0-4 Scale

64.6%	34.1%	*
Rated UOT "Very Likely"	Rated CBM "Very Likely"	t=2.055, df=90, p=.043

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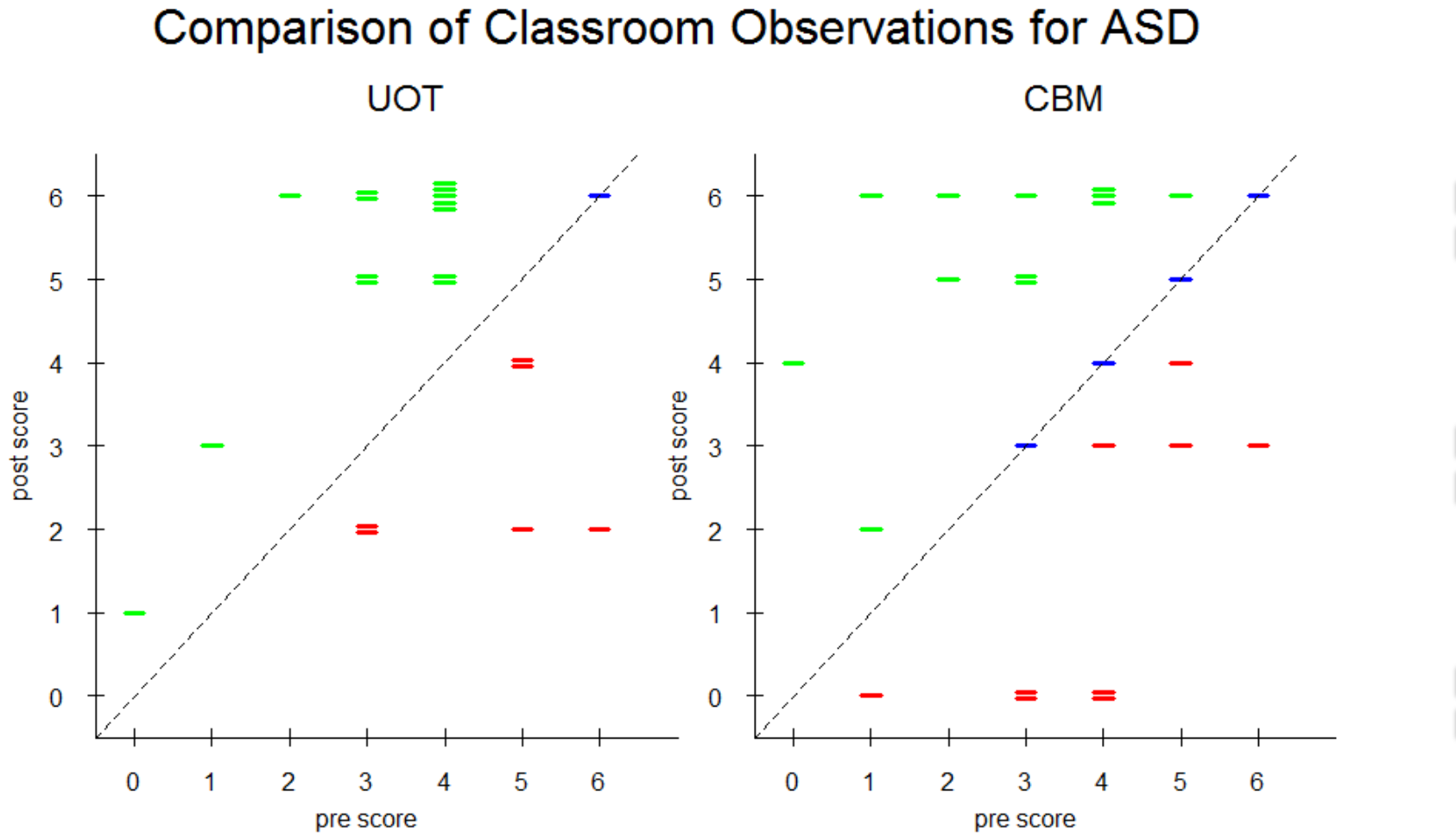
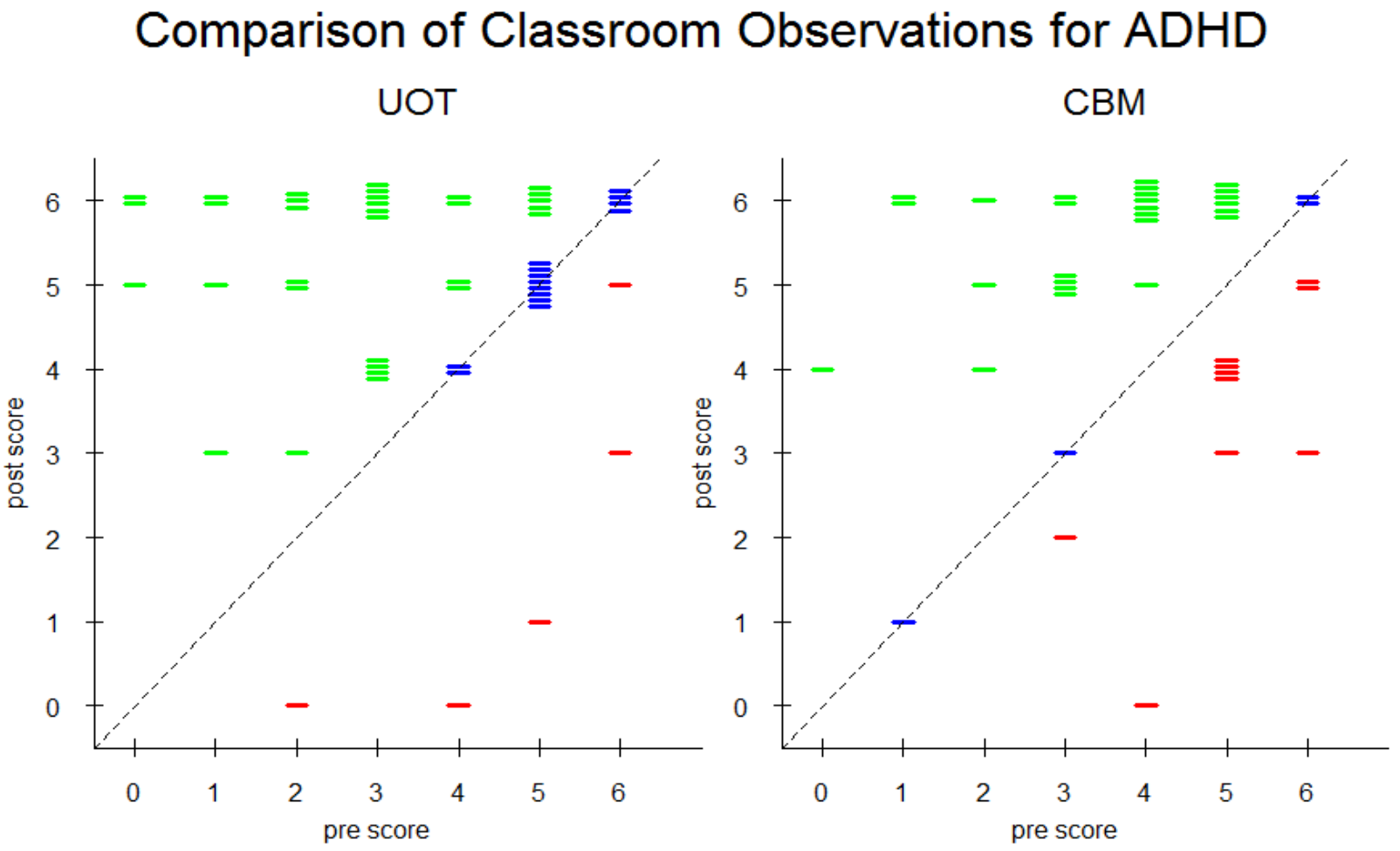
Which Works Better for ASD?



Proportion of kids who improved to kids who got worse: Fisher=.000**

Proportion of kids who improved to kids who got worse: Fisher=.648

Which Works Better for ADHD?



Fisher=.000**

Fisher=.008**

Better

Same

Worse

Blinded Outcomes Pre-Post Paired Sample t-tests

ASD

	CBM			Unstuck		
	N	*t*	Cohen's *d*	N	*t*	Cohen's *d*
Block Design	25	**2.67****	**.53 (Med)**	19	**2.77****	**.60 (Med)**
CT Flexibility	24	1.24	.25 (Small)	18	**1.82***	**.43 (Med)**
CT Plan	24	1.67	.34 (Small)	19	**1.88***	**.43 (Med)**
Class Obs	24	0.78	.16 (Small)	21	**1.93***	**.42 (Med)**

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Blinded Outcomes Pre-Post Paired Sample t-tests

ADHD

	CBM			Unstuck		
	N	*t*	Cohen's *d*	N	*t*	Cohen's *d*
Block Design	39	1.68	.27 (Small)	49	**3.18****	**.45 (Med)**
CT Flexibility	34	**4.00****	**.69 (Med)**	40	**4.43****	**.70 (Med-Lg)**
CT Plan	34	**3.53****	**.60 (Med)**	48	**3.55****	**.51 (Med)**
Class Obs	40	**3.32****	**.52 (Med)**	51	**4.41****	**.62 (Med)**

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Effect sizes for Fever in Children

	2 hours	4 hours	6 hours
Acetaminophen			
Ibuprofen			

Perrott DA[1], Piira T, Goodenough B, Champion GD (2004) **Efficacy and safety of acetaminophen vs ibuprofen for treating children's pain or fever: a meta-analysis.** Arch Pediatr Adolesc Med. 158(6):521-6.

Effect sizes for Fever in Children

	2 hours	4 hours	6 hours
Acetaminophen	.19 (Sm)	.31 (Med)	.33 (Med)
Ibuprofen	.34 (Med)	.81 (Lg)	.66 (Med)

Perrott DA[1], Piira T, Goodenough B, Champion GD (2004) **Efficacy and safety of acetaminophen vs ibuprofen for treating children's pain or fever: a meta-analysis.** Arch Pediatr Adolesc Med. 158(6):521-6.

These student or family factors do not relate to classroom outcome:

1	2	3	4	5
IQ	**Age**	**Income**	**Race**	**Language spoken in the home**
r=.165 p=.055	r=-.033 p=.69	r=.062 p=.495	White non-Latino (30%) change the least	English only (51%) changes the least on CBM

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These implementation factors do not relate to classroom outcome:

1. Treatment fidelity
2. # of sessions
3. Role of school-based group leader
4. Parent knowledge gains

Which should you choose?

Target:	ASD		ADHD	
	UOT	CBM	UOT	CBM
Classroom behavior	✓	x	✓	✓
Student acceptability	✓	x	✓	x
Parent acceptability	✓	x	✓	x
Problem-solving	✓	✓	✓	x
Social Flexibility	✓	x	✓	✓
Planning	✓	x	✓	✓

Effectiveness Summary

- Medium to large effects
- Stakeholder input protects us from mistakes, increased acceptability
- Diversity of sample=increased power
- Committed participants (90% Post testing rate; 70% of parents attended a live training)
- Good real-world generalization
- Easier dissemination and implementation?

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THANK YOU

to PCORI and the dedicated school staff, children and families who made this project possible

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