

Improving Access to Evidence-Based Care in Autism

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Drexel Public Health Lecture

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Who is here?



Today's Plan

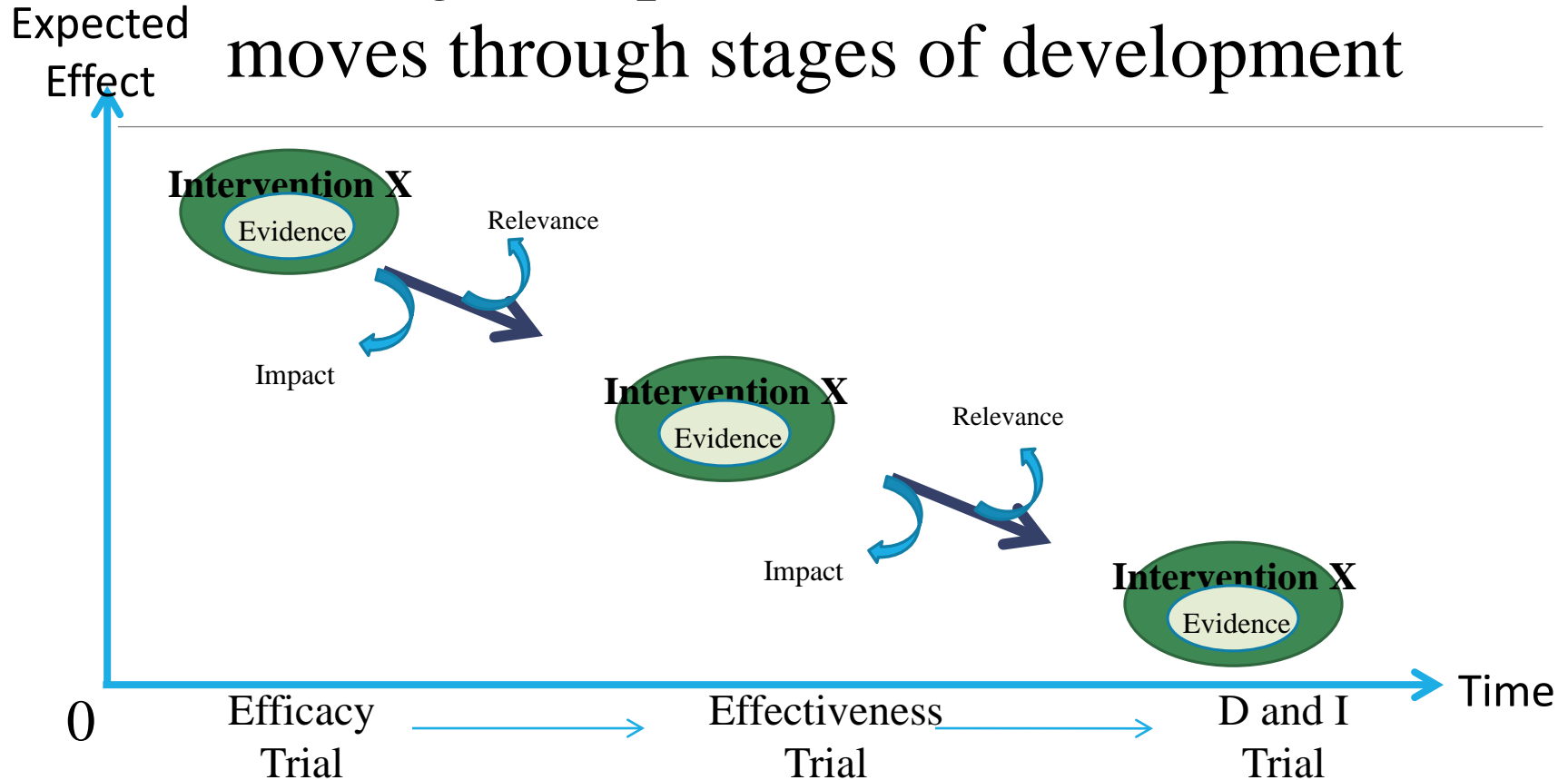


- ❖ Implementation Science
- ❖ Academic-Community Partnership
- ❖ Partnership Examples
 - Education
 - Early Intervention

Traditional Research Pathway



“Voltage Drop” of an intervention as it moves through stages of development

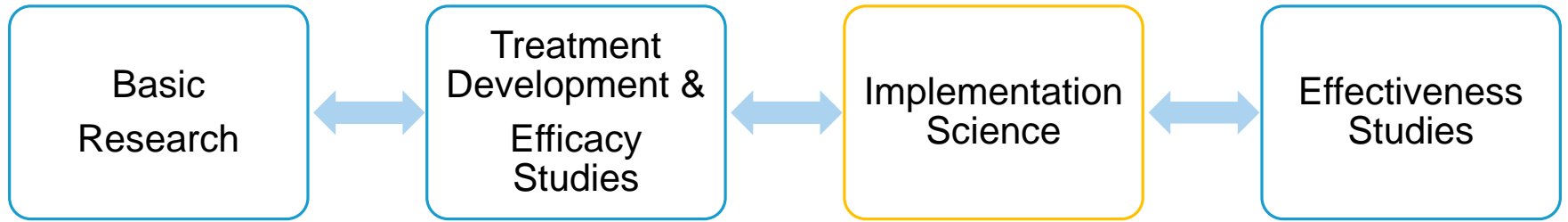


Research Data



Effective
Community
Care

Translational Research Context



Strategic Objective 4:
Strengthen the Public Health
Impact of NIMH-Supported
Research

Factors Affecting Implementation

Outer Context

Service System

Policies, Regulations &
Funding

Consumer Support/
Advocacy

Intervention

System fit

Organization fit

Complexity

Developers

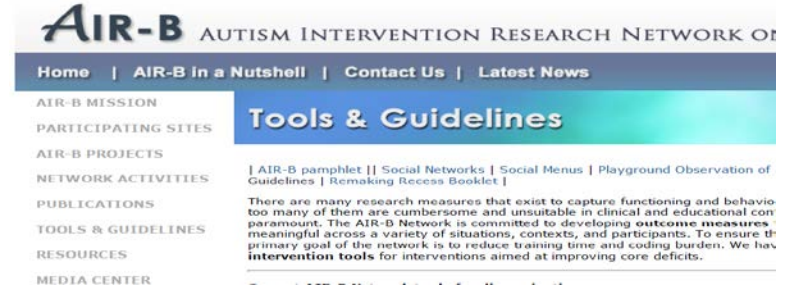
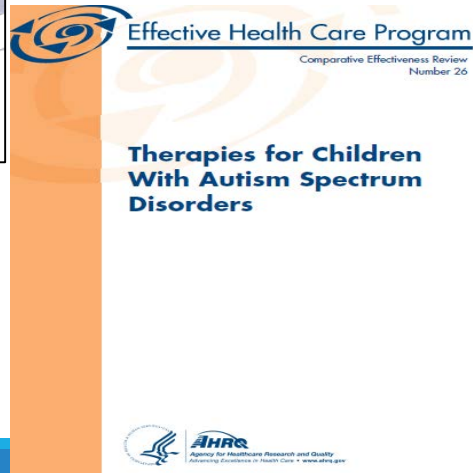
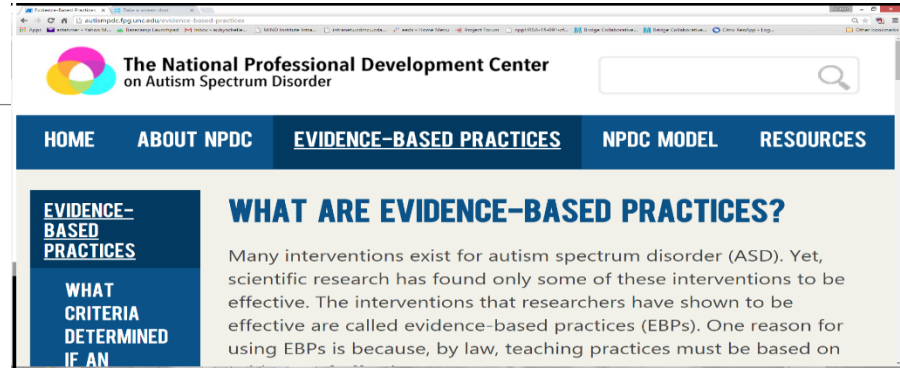
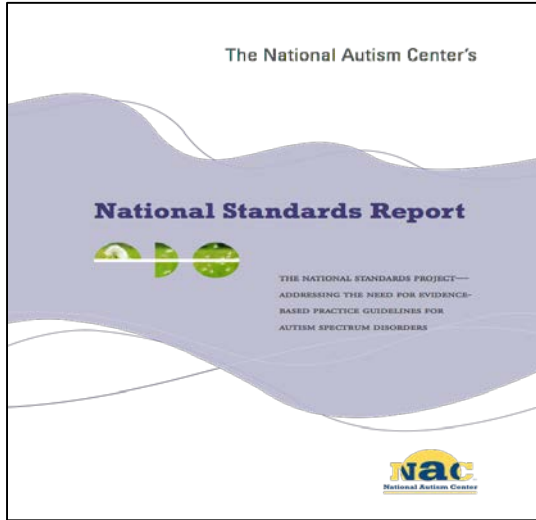
Inner Context

Organization
characteristics

Individual provider
characteristics

Child & Family
Characteristics

EBP are Available for Autism



Do we have the same issues in the treatment of autism?

**Voltage
Drop**



Developing partnerships to solve the Problem

RESEARCH GAIN

- Real world knowledge & insight
- Increased relevance & feasibility
- Understanding context
- Increase cooperation and trust

COMMUNITY GAIN

- Access to evidence-based intervention
- Measuring effectiveness
- Professional development
- Increase quality of care



Community-Academic Partnerships: What do we know?

(Drahota et al., 2016)

Limited research: 50 articles (1993-2015)



19%



26%

Finding a good
match



Strong partnership

Trust & respect

Mutual benefit for all partners

Frequent and effective communication

Shared vision and good quality leadership

Clear roles/functions

Effective conflict resolution

Positive community impact

(Drahota et al., 2016)

10 NECESSARY TIPS
for a
SUCCESSFUL FIRST DATE



What gets in the way?

Unclear role/function

Poor communication

Inconsistent participation or expectations

High burden of activities or tasks

Lack of shared vision

Lack of common language/shared terms

Mistrust/poor relationships

(Drahota et al., 2016)



Community Partnered Participatory Research

Partnership



Collaborate among:

- Families / Consumers
- Funders
- Researchers
- Community Agencies
- Leaders

Learn



Identify community strengths & needs:

- Focus Groups, Interviews
- Ongoing partnership

Develop



Pilot Test & Adapt:

- Gather feedback
- Feasibility
- Adaptations
- Acceptability
- Materials

Evaluate



Effectiveness:

- Test in community
- Scale up

Levels of Involvement

INFORM

- Researchers conduct, analyze, disseminate, design
- Study plans communicated to community

CONSULT

- Researchers conduct, analyze, disseminate, design
- Partners give opinions, advice and feedback

COLLABORATE

- Joint identification of research questions
- Joint decisions & actions
- Researchers handle data based on suggestions

STAKEHOLDER DIRECTED

- Community generates research question
- Full collaboration and involvement at all stages



Pivotal Response Training Adaptation

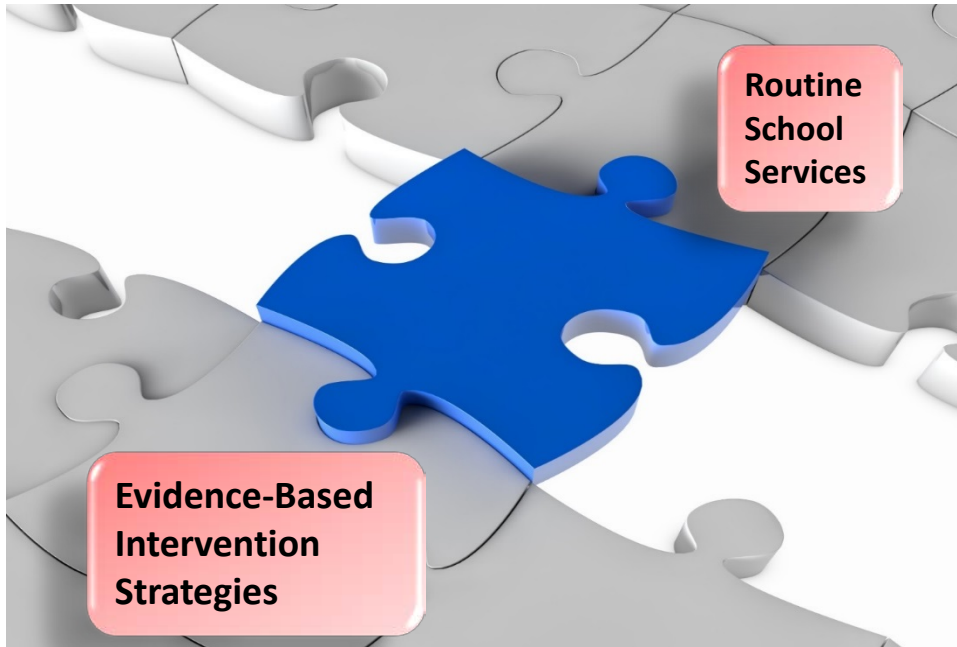


PI & Co-Investigators: Aubyn Stahmer, Jessica Suhrheinrich, Laura Schreibman, Cynthia Bolduc

Teacher Advisory Board: Pat Belden, Thesa Jolly, Linda Reeve, Catherine Pope & Lauren Ungar

This research supported by U.S. Department of Education Grants: R324B070027 and R324A130349

Responding to Research-Practice Gap in School Services for ASD: Classroom Pivotal Response Training (CPRT)

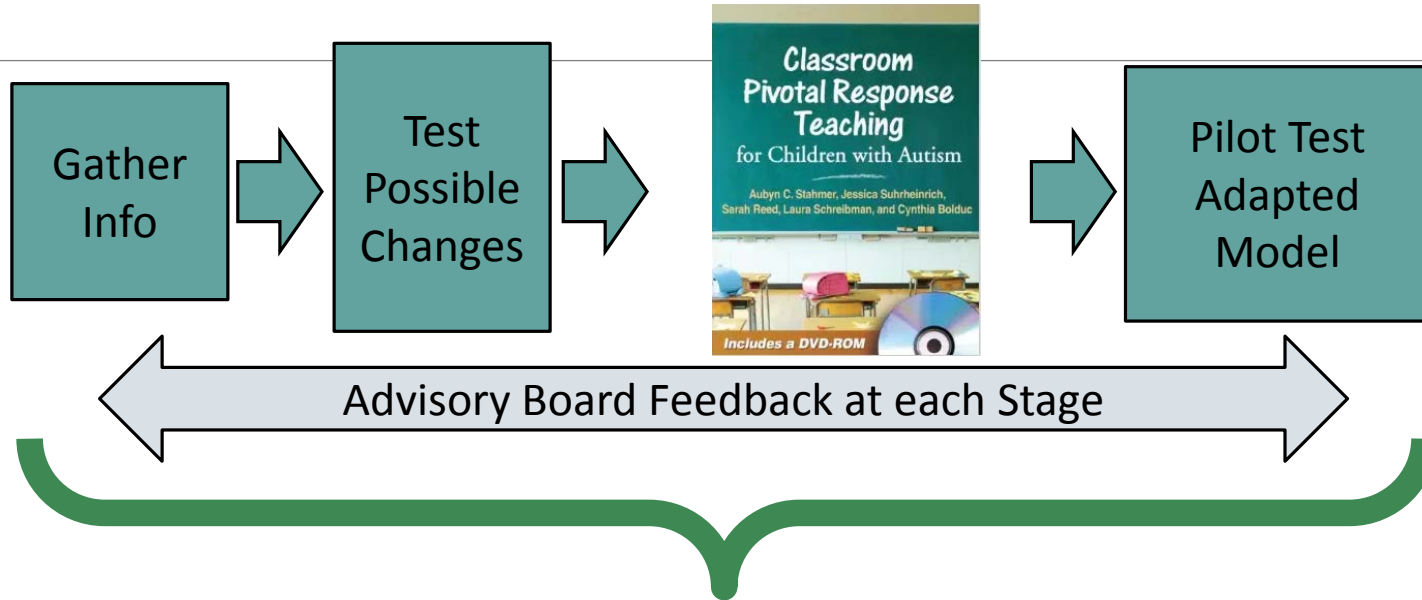


Naturalistic, behavioral, evidence-based intervention for autism

Developed and validated in one-on-one, highly controlled settings

70% of local teachers report PRT use, but modified

Systematic Adaptation of PRT for the Classroom



Randomized Controlled Efficacy Trial

Systematic Adaptation of PRT for the Classroom

- Working directly with children with ASD
- Mix of familiar with PRT and not
- Range of ages/programs
- Collaborative

End users –
teachers;
beh spec

Advisory Board Feedback at each Stage

- Gather information
- Interpret data
- Develop & try resources
- Recruitment



Gathering Information



Gathering information

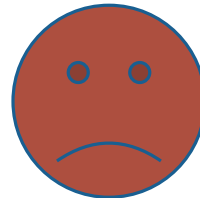
Components teachers supported and did well in classroom



Components supported but did not use well in classrooms



PRT Components teachers didn't support or use



Test Possible Changes

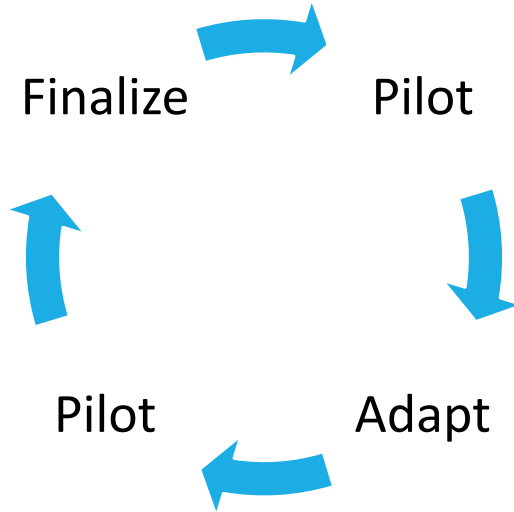


CPRT Training Materials

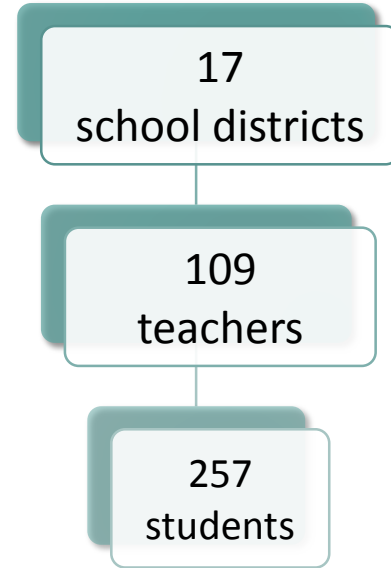


Test Adapted Model

PILOT TEST



EFFECTIVENESS TRIAL



Teacher Outcomes

73% successfully
meet CPRT fidelity
criteria

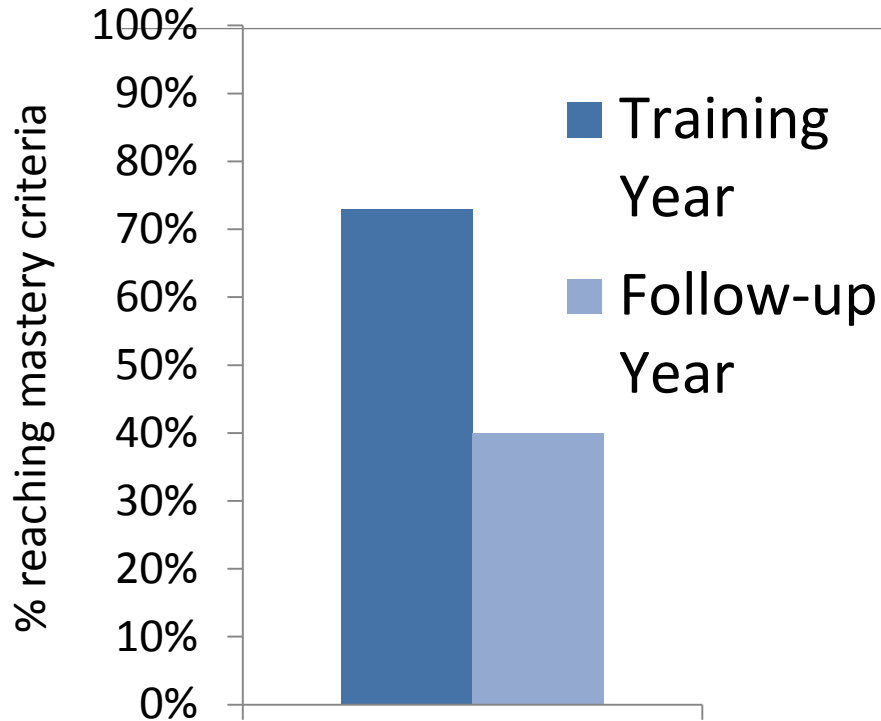
Significantly higher
fidelity after
training than
control

High confidence,
satisfaction &
perceived student
outcomes

Generalization of
strategies to new
students and
activities



Teacher Fidelity at Follow-up



Survey Questions	Agree or Strongly Agree
I continue to use CPRT	93%
I am motivated to use CPRT.	86%
I use the full CPRT protocol with new students.	53%
I use parts of the CPRT protocol or certain CPRT strategies with new students.	90%

Understanding Variability in Teacher Outcomes



Lessons Learned

Practice-based evidence informs science

- We can test this!

Presentation is important

Teachers like:

- To be heard
- Understanding of their situation
- Seeing change in their own students
- Feedback

- More work is needed to provide ongoing support for sustainment of EBP
- Need to involve leadership to support use of EBP
- What level of fidelity is “good enough”?

Levels of Involvement

INFORM

- Researchers conduct, analyze, disseminate, design
- Study plans communicated to community

CONSULT

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COLLABORATE

- Joint identification of research questions
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BRIDGE Collaborative

This research supported by NIMH Education Grant: 1R21MH083893-01A1, Autism Speaks 8136; IES R324A140004

Co-Investigators:

Lauren Brookman-Fraze

Sarah Rieth

Karyn Searcy

Rachel Haine-Schlagel

Collaborative:

Providers

Marilee Burgeson* Beth Calarco* Sherry Casper*

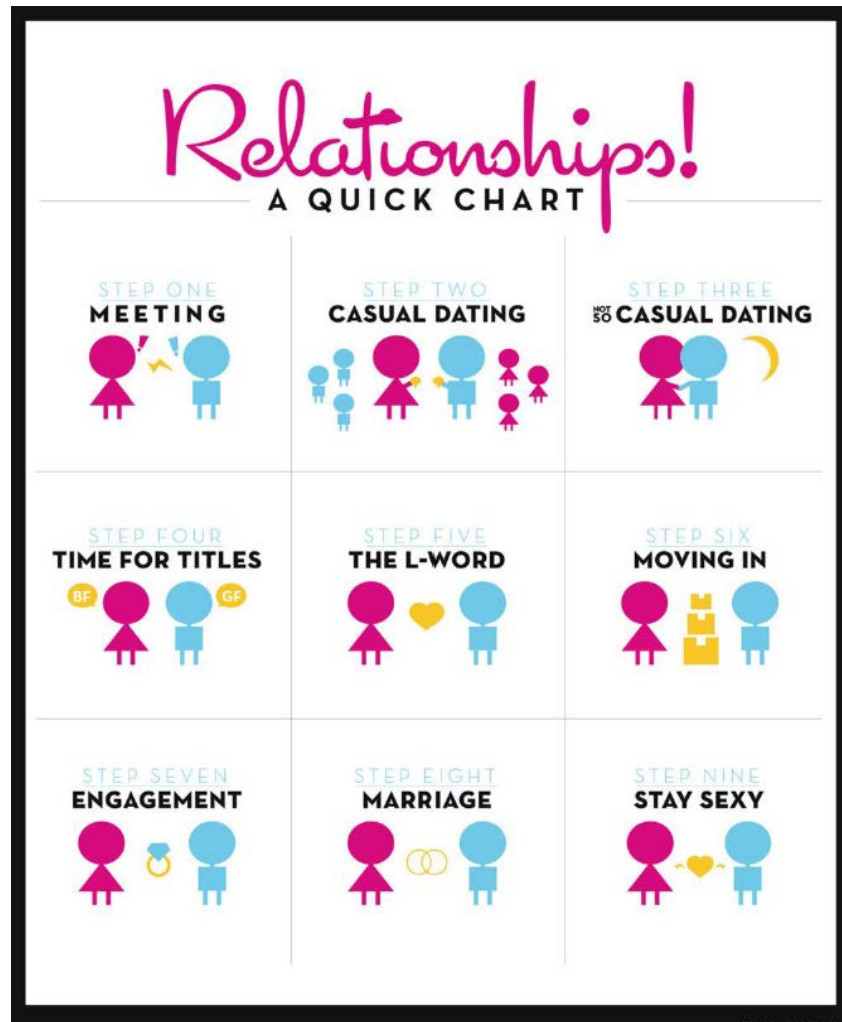
Josh Feder* Erica* Mary Pat Culligan

Parents: Cherri Cary* Laura Cervantes* Rie Ozawa

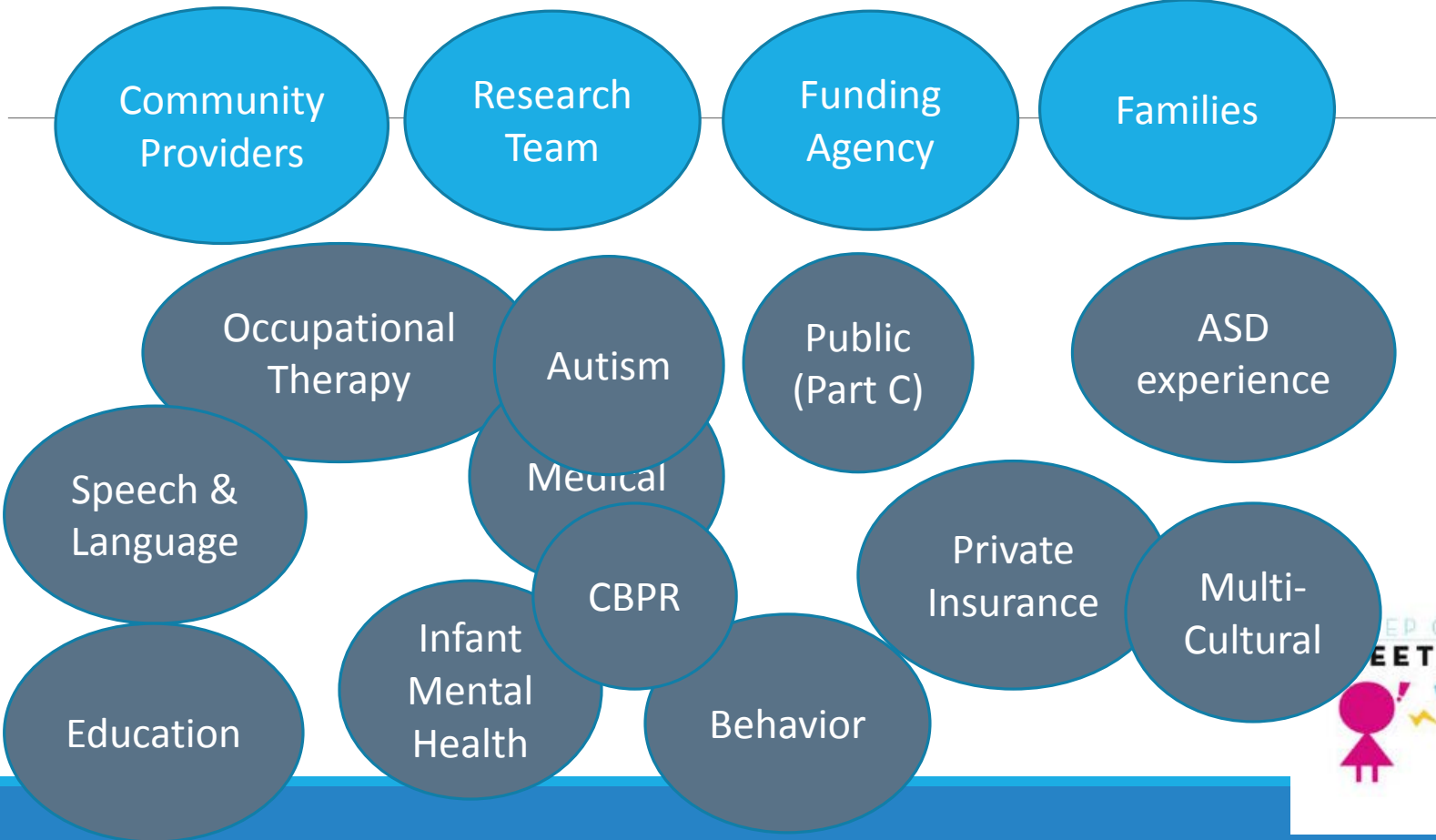
Funders: Terri Cook-Clark* Tanya Dansky



Building the Partnership



Intervention with Toddlers with ASD?



Opinion leaders

**Developmental /
Relationship-Based**



**Naturalistic
Behavioral**



Community
Providers

Research
Team

Funding
Agency

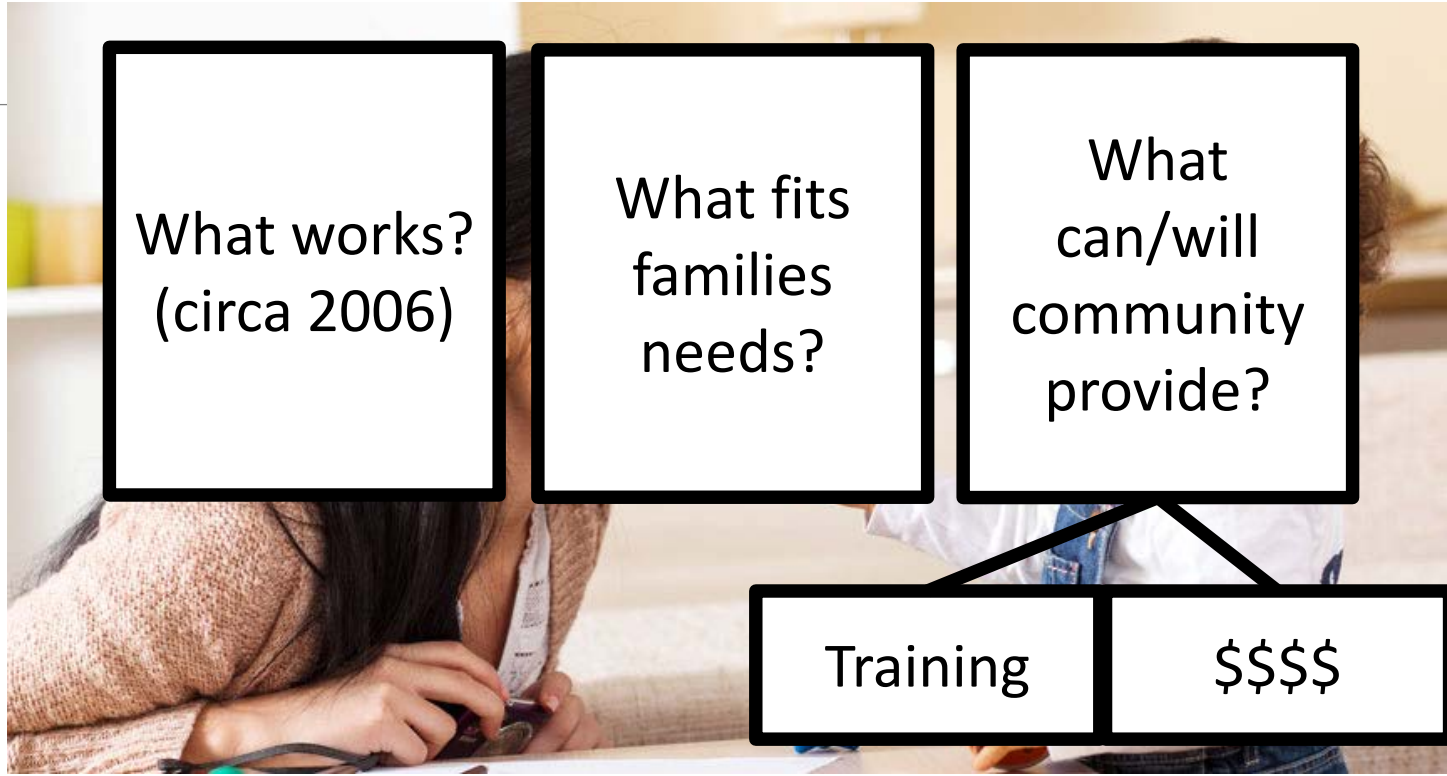
Families

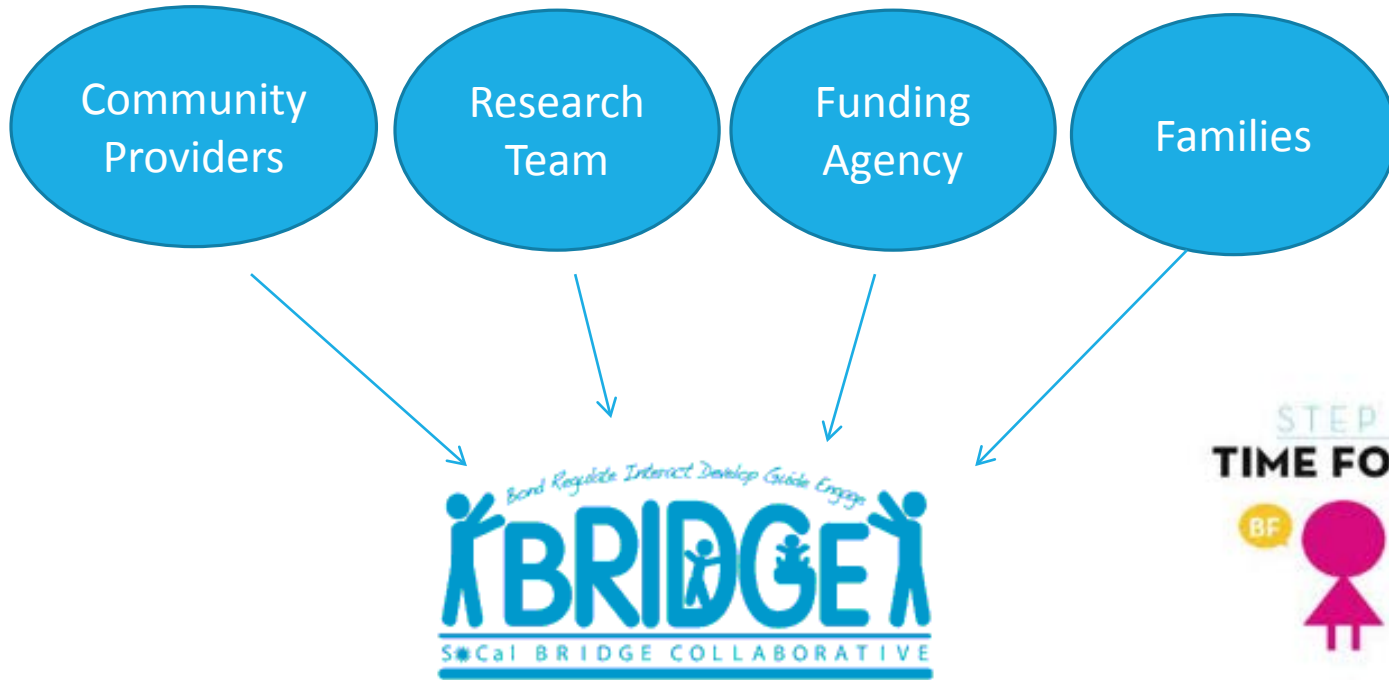


STEP TWO
CASUAL DATING



Intervention with Toddlers with ASD?





Bond * Regulate * Interact * Develop * Guide * Engage

Project Process & Roles



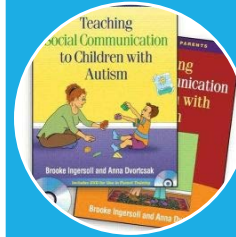
Choosing
Method of
Capacity
Building



Literature
and Practice
Review of
Potential
Interventions



Community
Input and
Intervention
Choice



Adaptation
& Training
Methods

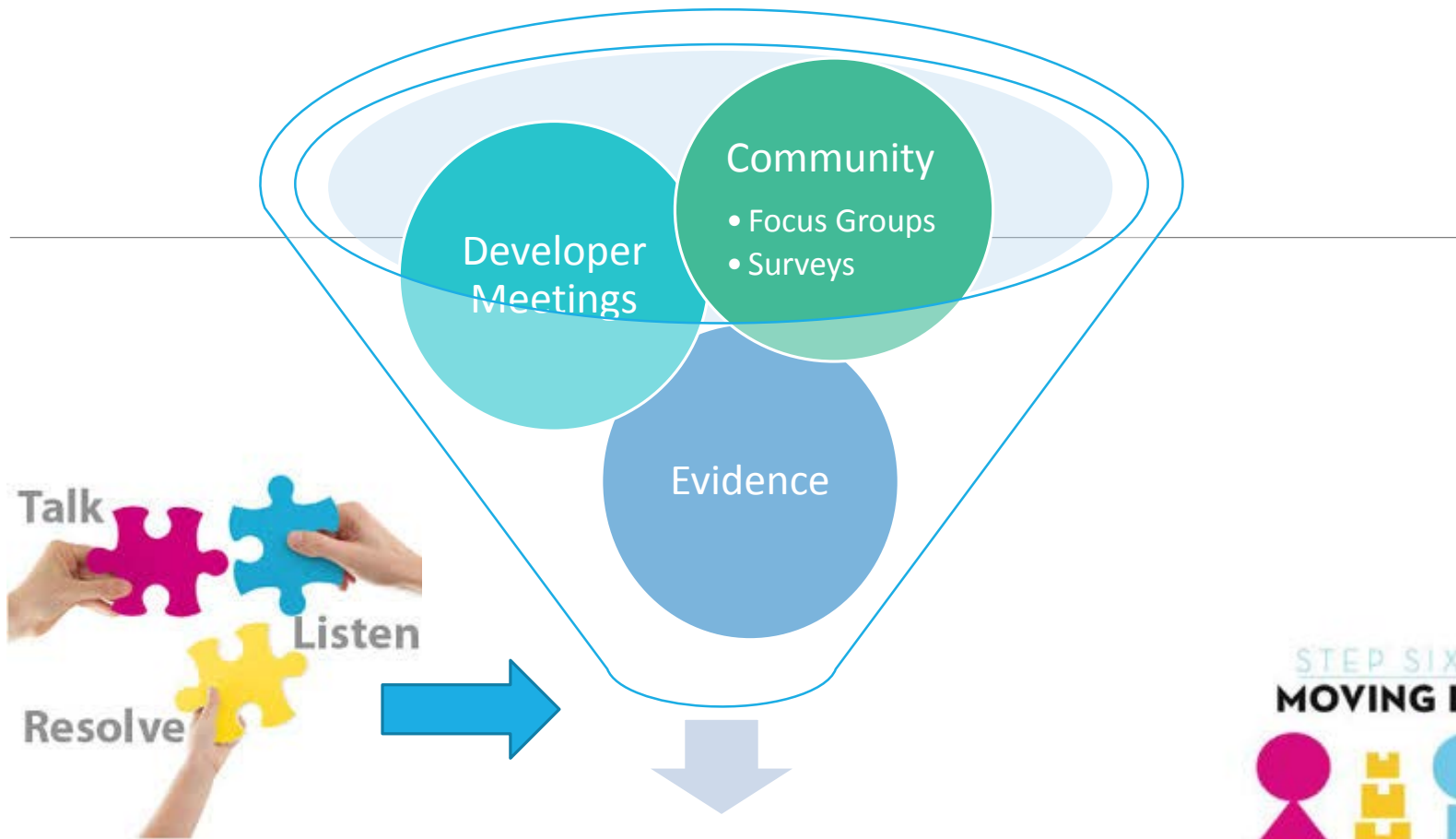


Pilot Study



STEP FIVE
THE L-WORD





STEP SIX
MOVING IN



Responding to Community Needs



Two Recent Studies



Train The
Trainer –
Community
Capacity

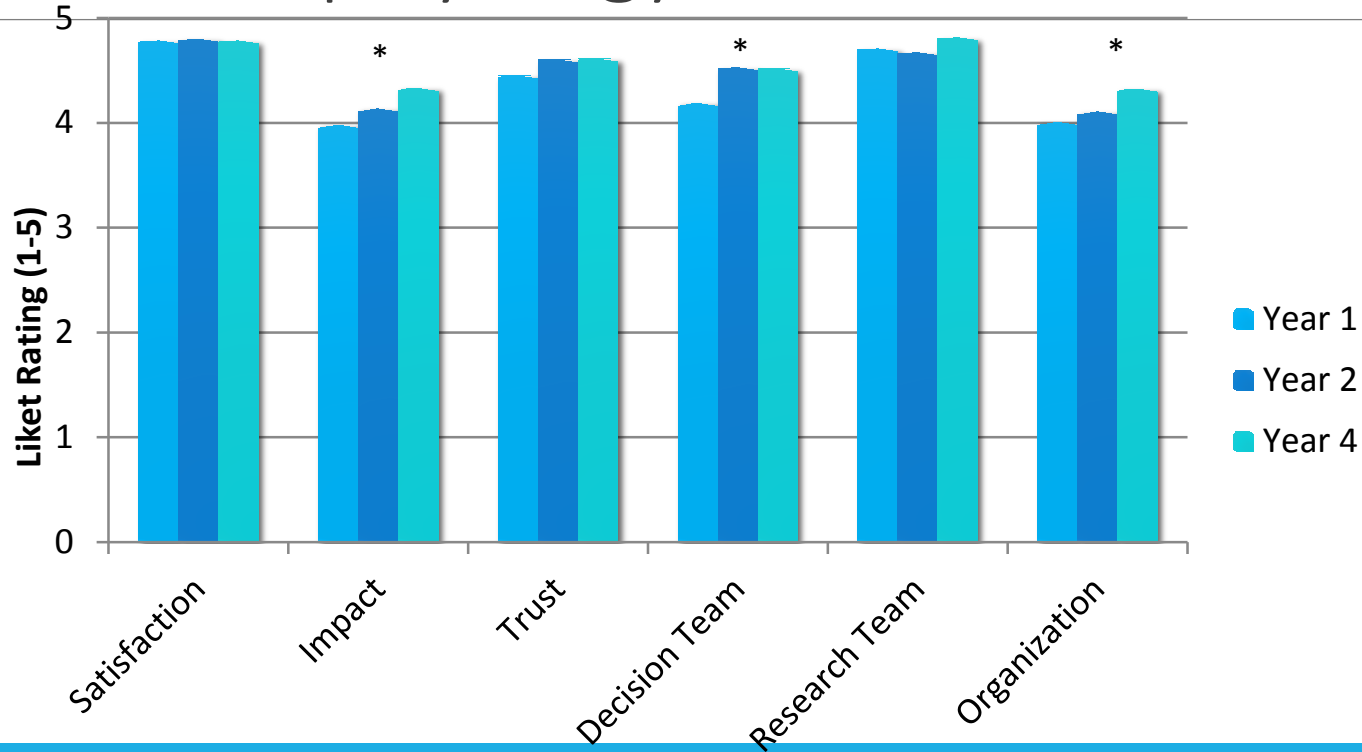


Pilot Study –
Child
Outcomes

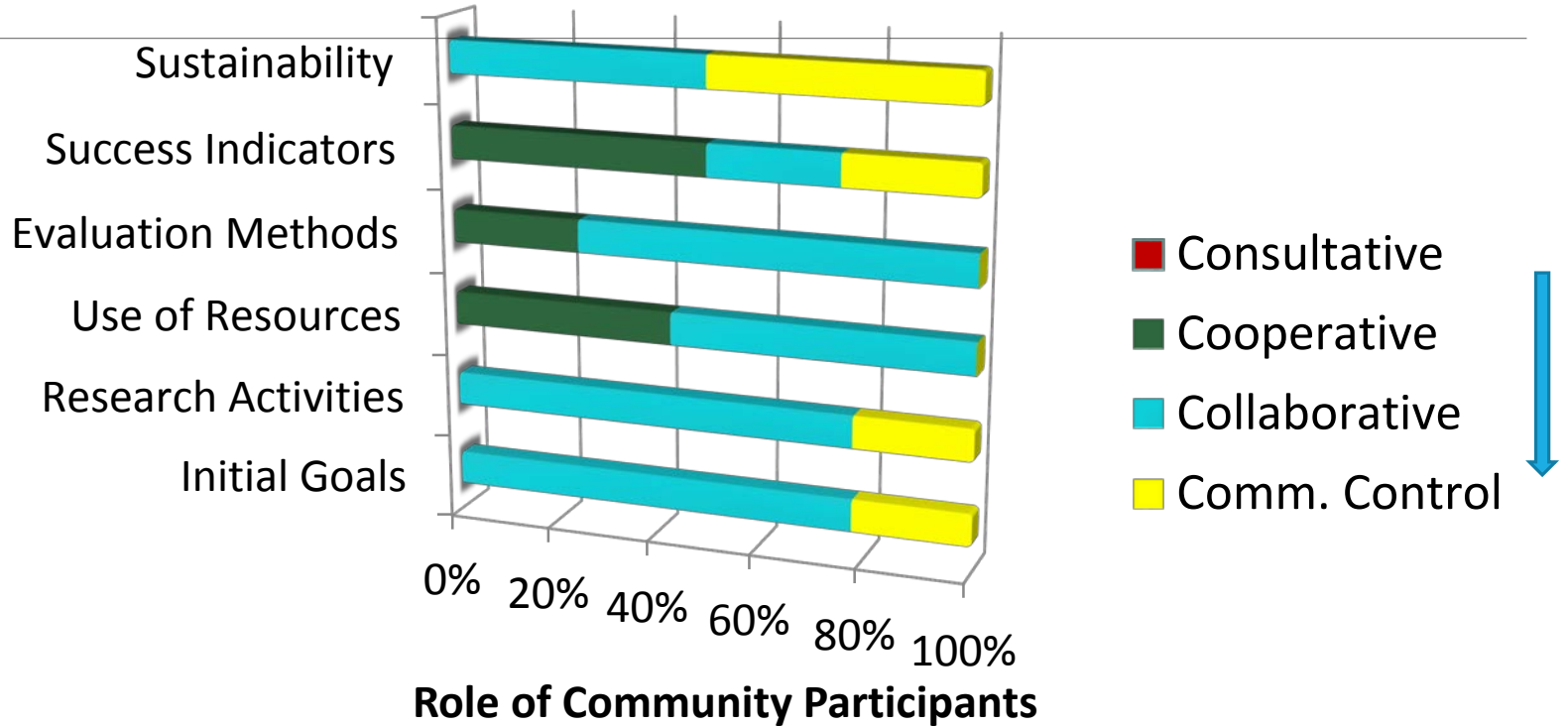
STEP SEVEN
ENGAGEMENT



Partnership Synergy



Participatory Research Elements



Sustainment

86% of initial members are still active participants

90% of agencies committed to ongoing participation even during times of limited funding

2 federal & 1 foundation grant, training contract

Part C and commercial insurance funding

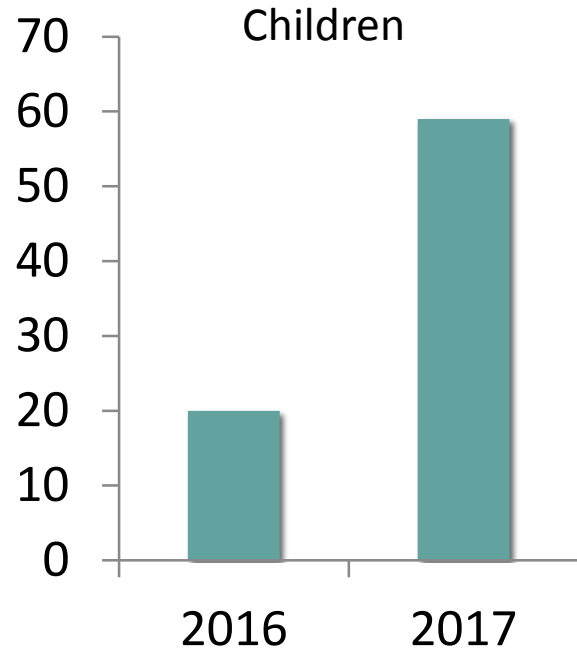
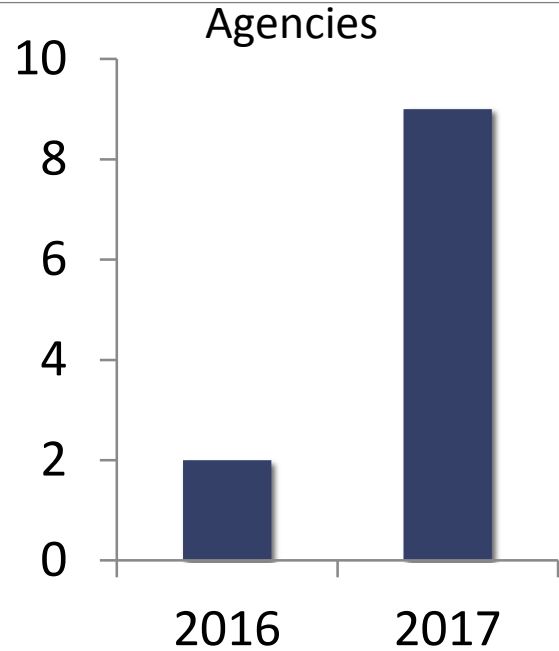
7 peer reviewed articles; 2 book chapters

Community training program and materials

>60 community and academic presentations



Building Community Capacity

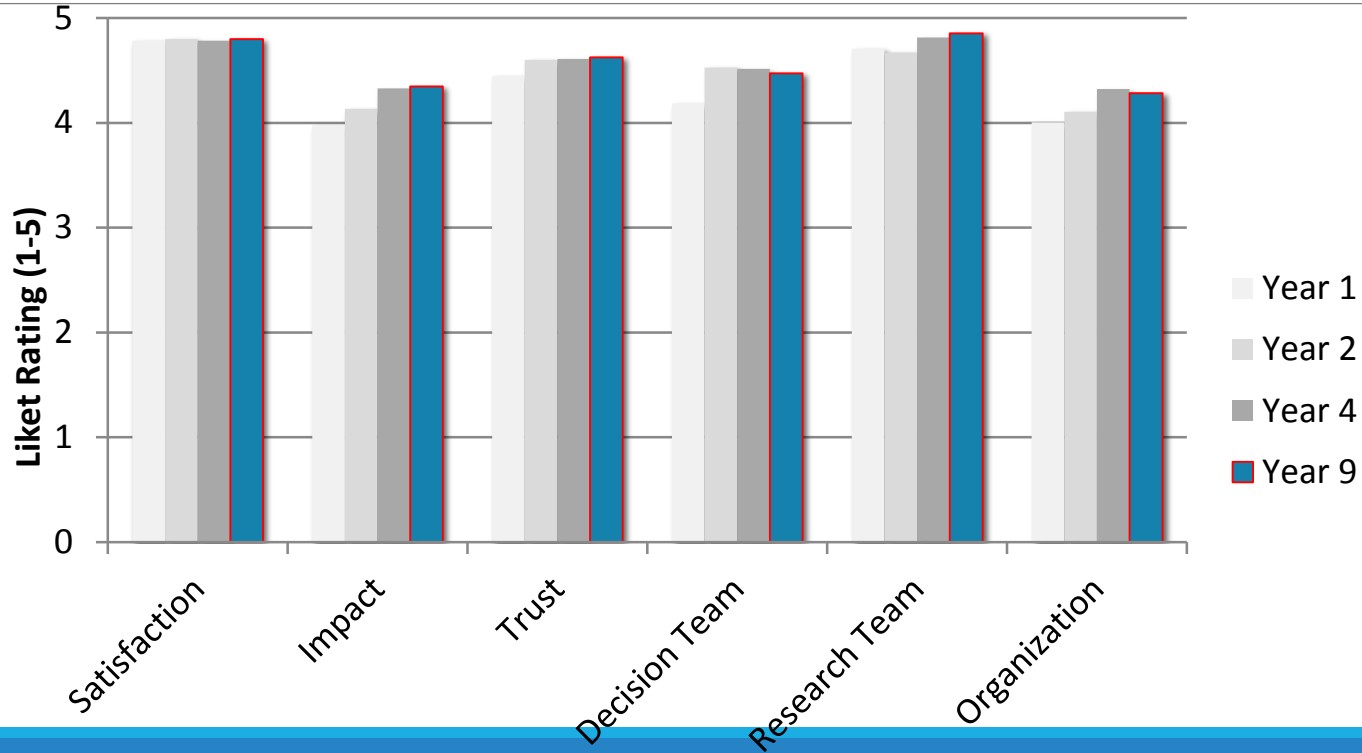


Moving Forward

- Increasing access to care for traditionally underserved families
- Scale up of the intervention
- Scale up of the collaborative process
- Consultation on other research projects



Partnership Synergy



Important Lessons

- Collaborative models can be highly productive
- Collaborative models take time, commitment and humility from both research and community members/organizations
- Necessary components
 - Joint learning to build trust
 - Specific tasks
 - Clear expectations
 - Leadership structure
 - Flexibility



Should you participate in an academic community partnership?

- ✓ Good listener
- ✓ Knowledge to share
- ✓ Things to learn
- ✓ Time to commit
- ✓ Flexible
- ✓ Snacks to share



What to look for

RESEARCH

- Willing to work with partners
- Research interests aligned with community need
- Structure and processes that support collaboration
- Accept input from all partners
- Provide research updates
- Sharing of funding beyond the funder

Kind
Fighter

Out



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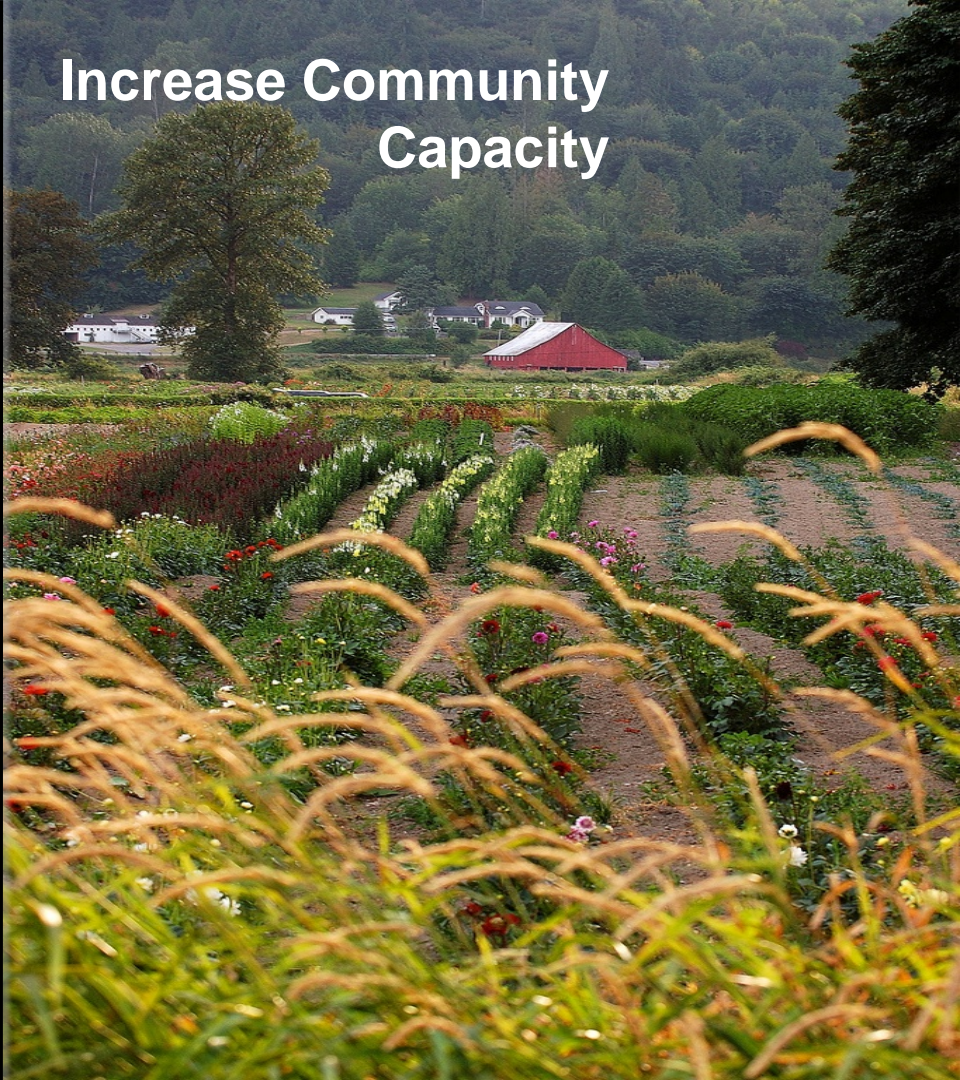
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se to partners

mitment



**Increase Research
Impact**



**Increase Community
Capacity**

Thank you!

astahmer@ucdavis.edu



Today's "Worth Sharing" Thought

**The awkward moment
when you don't have
any friends in your class
and your teacher says,
"find a partner!"**

[FACEBOOK.COM/SHUTUPIMTALKING.NET](https://www.facebook.com/shutupimtalking.net)