

# Building a Research-Community Collaborative to Improve Community Care for Infants and Toddlers At-Risk for Autism



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# Setting and Needs

## Community

- Increasing numbers of children with risk for ASD identified at younger ages (12-20 mos)
- Limited community capacity to serve these children and families



## Research

- Limited evidence-based for this age-group
- Translation of research to practice traditionally limited

# Who are the Partners

Community  
Providers

Research  
Team

Funding  
Agency

Families

Occupational  
Therapy

Medical

Autism

Public  
(Part C)

ASD Early  
Start  
Experience

Speech &  
Language

Behavior

CBPR

Private  
Insurance

Multi-  
Cultural

Education

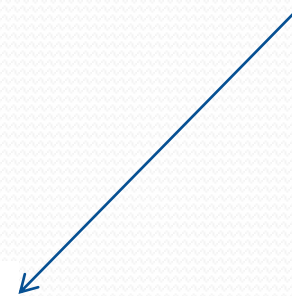
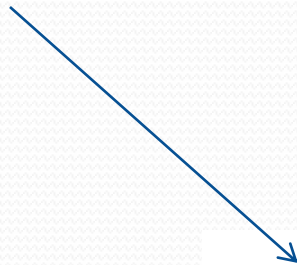
Infant  
Mental  
Health

Community  
Providers

Research  
Team

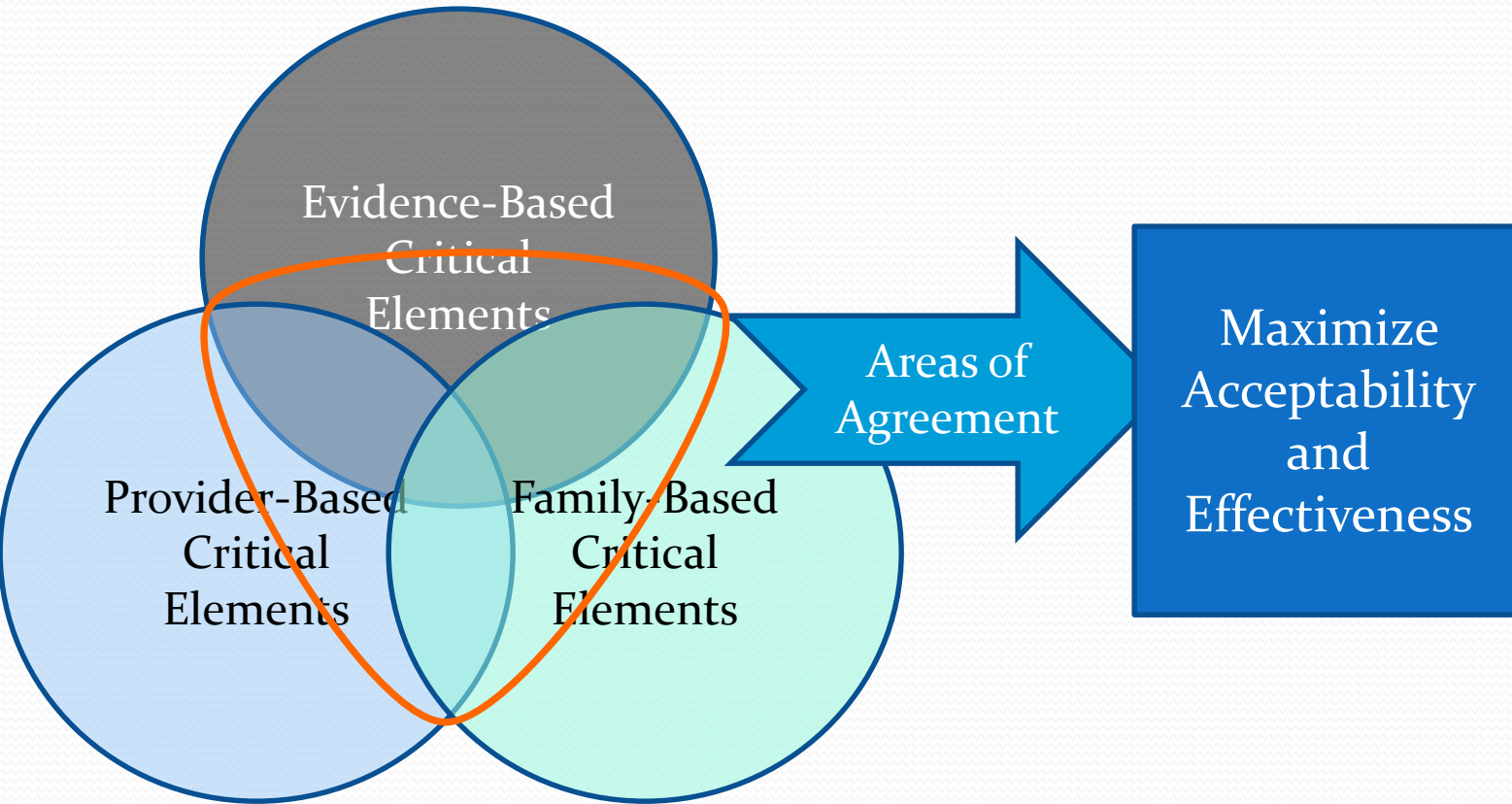
Funding  
Agency

Families



**Bond \* Regulate \* Interact \* Develop \* Guide \* Engage**

# Collaborating



# Roles of the Partners

Operations

Workgroups

Collaborative Process

Coordinating Committee

Community  
Needs

# Funding & Resources

- **Year 1: UNFUNDED**
  - Partner organizations supported time
  - Volunteer
- **Years 2-4: NIH R21**
  - Honorarium for members
  - Materials; Staff; OG salary support
- **Year 5: UNFUNDED**
- **Year s 6-9: Autism Speaks; IES**
  - Training materials & Manual adaptation

# Project Process & Roles



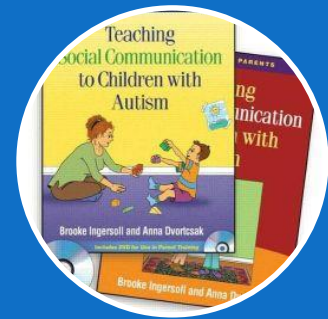
Choosing  
Method of  
Capacity  
Building



Literature and  
Practice Review  
of Potential  
Interventions



Community  
Input and  
Intervention  
Choice



Adaptation /  
Pilot Study &  
Training  
Methods





# Project Process & Roles



Choosing Method  
of Capacity Building



- Early intervention
- Parent Implemented
- Brief
- Evidence-based
- Broad appeal
  - Relationship-based
  - Behavioral

# Project Process & Roles



Literature and Practice  
Review of Potential  
Interventions



- Review of early intervention literature
  - ASD
  - Developmental Delay
  - Attachment
- Introduction to a variety of practices
- Chose top 3

# Project Process & Roles

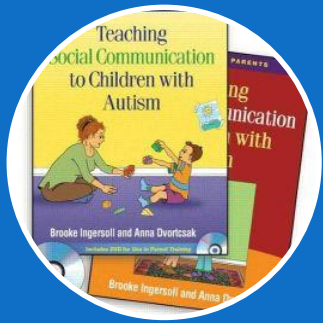


Community Input  
and Intervention  
Choice



- Three ½ day conferences
- Conference Evaluations
- Focus Group meetings after each conference
  - 10 parents
  - 10 providers
- Meetings with intervention developers
- Final intervention choice

# Project Process & Roles

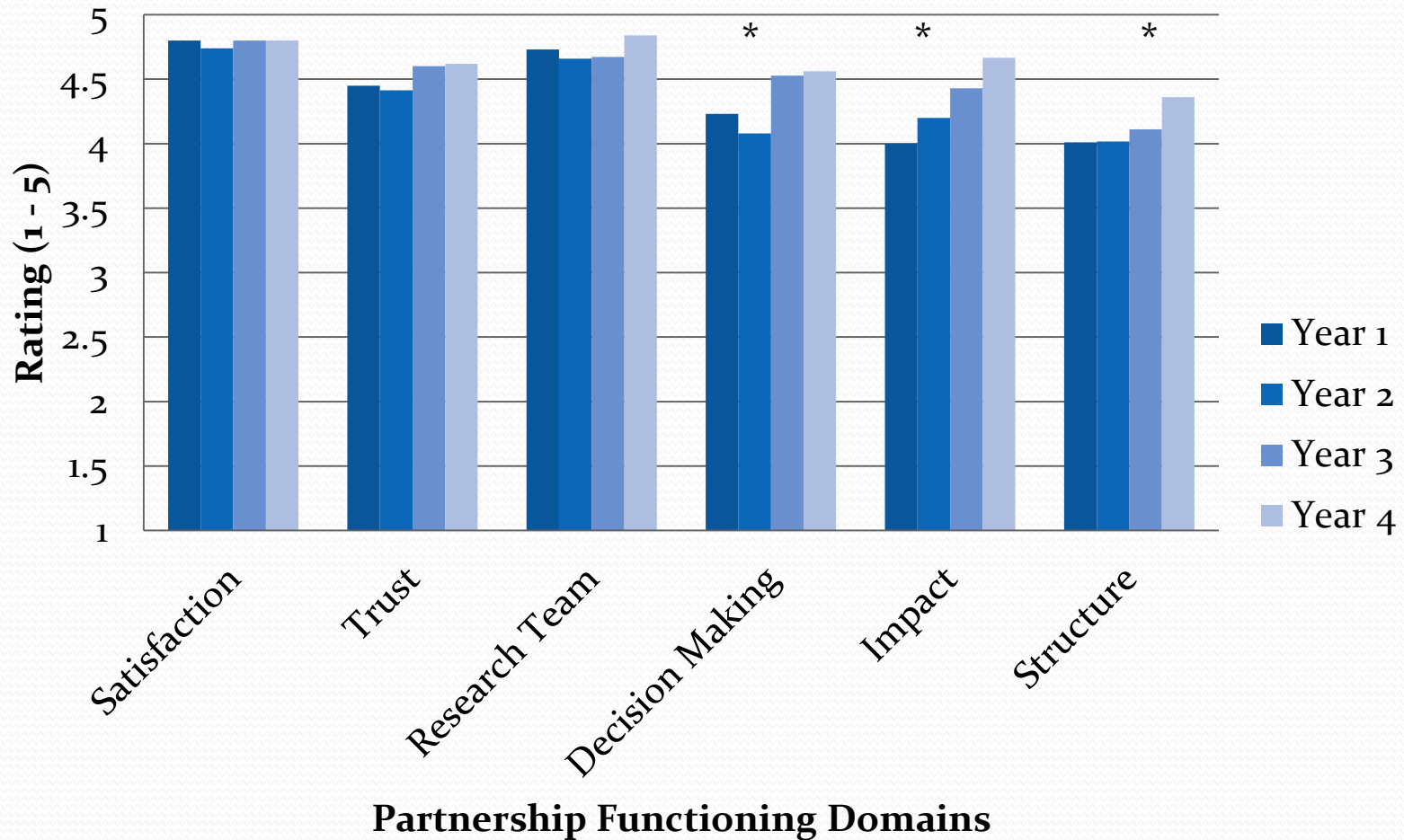


Adaptation / Pilot  
Study & Training  
Methods



- Trained 10 local therapists
- Followed 13 families
- Feasible intervention
- High satisfaction
- Improved child Outcomes

# Partnership Synergy



# Sustainability

- Participation in monthly meetings
  - Year 1 -2 = 70%
  - Year 3-4 = 85%
- 86% of initial members are still active participants
- 90% of agencies committed to ongoing participation
- Intervention publicly funded
- Successful with external funding

# Products

- 4 peer reviewed articles; 1 book chapter
- 27 community and academic presentations
- Invited to participate in 2 county / statewide panels
- 2 federal and 1 foundation grant
- Part C and commercial insurance funding
- Adapted toddler manual
- Community training program and materials
- Web-based training program

# Current Projects

BRIDGE Collaborative - Adapted manual and training materials in collaboration with original model developers



Agency Trainers – One supervisor per agency; Receive training from BRIDGE Collaborative Mentors



Clinicians – Three therapists per agency; Receive training from Agency Trainer with BRIDGE Mentor support



Child & Family Outcomes:



# Important Lessons

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



# Issues in collaboration

## Challenges

- Funding the collaborative work
  - Grant funding
  - Equitable funding
  - Community agency buy-in
- Research designs that fit community need
- Keeping the momentum
- Consensus building

## Benefits

- Community buy-in
- Funding for the service
- Improved quality of care
- Increases sustainability of the EBP
- Research infrastructure
- Community collaboration

# Thank you!

- Research Team
- Community Providers
- Parents
- Children
- Funders:

NIMH, IES &  
Autism Speaks

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- Tom Montgomery
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- Karyn Searcy
- Aubyn Stahmer