Improving Access to Evidence-Based Care in Autism

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Drexel Public Health Lecture
March 27, 2018
Who is here?
Today’s Plan

- Implementation Science
- Academic-Community Partnership

- Partnership Examples
  - Education
  - Early Intervention
Traditional Research Pathway

Basic Research → Treatment Development & Efficacy Studies → Effectiveness Studies

Adapted from Landsverk, 2005 and Westfall et al. 2007
“Voltage Drop” of an intervention as it moves through stages of development

Slide from David Chambers, IRI, 2013
Research Data

Effective Community Care
Translational Research Context

Basic Research

Treatment Development & Efficacy Studies

Implementation Science

Effectiveness Studies

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

Adapted from Landsverk, 2005 and Westfall et al. 2007
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

Adapted from Aarons, Hurlburt & Horwitz, 2011
EBP are Available for Autism
Do we have the same issues in the treatment of autism?
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)
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)
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

Gather Info → Test Possible Changes → Pilot Test Adapted Model

Advisory Board Feedback at each Stage

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

Advisory Board Feedback at each Stage

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

End users – teachers; beh spec
Gathering Information
### Gathering information

<table>
<thead>
<tr>
<th>Components teachers supported and did well in classroom</th>
<th>![Smiley face]</th>
</tr>
</thead>
<tbody>
<tr>
<td>Components supported but did not use well in classrooms</td>
<td>![Neutral face]</td>
</tr>
<tr>
<td>PRT Components teachers didn’t support or use</td>
<td>![Sad face]</td>
</tr>
</tbody>
</table>
Test Possible Changes
CPRT Training Materials
Test Adapted Model

PILOT TEST

Finalize → Pilot

Pilot → Adapt

EFFECTIVENESS TRIAL

17 school districts

109 teachers

257 students
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

<table>
<thead>
<tr>
<th>Survey Questions</th>
<th>Agree or Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I continue to use CPRT</td>
<td>93%</td>
</tr>
<tr>
<td>I am motivated to use CPRT.</td>
<td>86%</td>
</tr>
<tr>
<td>I use the full CPRT protocol with new students.</td>
<td>53%</td>
</tr>
<tr>
<td>I use parts of the CPRT protocol or certain CPRT strategies with new students.</td>
<td>90%</td>
</tr>
</tbody>
</table>
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
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This research supported by NIMH Education Grant: 1R21MH083893-01A1, Autism Speaks 8136; IES R324A140004

Co-Investigators:
Lauren Brookman-Frazee
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Karyn Searcy
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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
Intervention with Toddlers with ASD?

What works? (circa 2006)

What fits families needs?

What can/will community provide?

Training  $$$$
Community Providers
Research Team
Funding Agency
Families

Bond * Regulate * Interact * Develop * Guide * Engage
Choosing Method of Capacity Building

Literature and Practice Review of Potential Interventions

Community Input and Intervention Choice

Adaptation & Training Methods

Pilot Study
Responding to Community Needs
Two Recent Studies

Train The Trainer – Community Capacity

Pilot Study – Child Outcomes
Partnership Synergy

Likert Rating (1-5)

- Year 1
- Year 2
- Year 4

- Satisfaction
- Impact
- Trust
- Decision Team
- Research Team
- Organization
Participatory Research Elements

- Sustainability
- Success Indicators
- Evaluation Methods
- Use of Resources
- Research Activities
- Initial Goals

Role of Community Participants:
- Consultative
- Cooperative
- Collaborative
- Comm. Control
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

**Agencies**

<table>
<thead>
<tr>
<th>Year</th>
<th>Count</th>
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</thead>
<tbody>
<tr>
<td>2016</td>
<td>2</td>
</tr>
<tr>
<td>2017</td>
<td>10</td>
</tr>
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</table>

**Children**

<table>
<thead>
<tr>
<th>Year</th>
<th>Count</th>
</tr>
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<tbody>
<tr>
<td>2016</td>
<td>5</td>
</tr>
<tr>
<td>2017</td>
<td>60</td>
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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

Likert Rating (1-5)

Year 1  Year 2  Year 4  Year 9

Satisfaction  Impact  Trust  Decision Team  Research Team  Organization
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

Am I a good partner?
What to look for in a partner

**RESEARCH**

- Willing to work with community timelines
- Research interests that fit community need and goals
- Structure and organization
- Accept input at all levels
- Provide research expertise to partners
- Sharing of funding and commitment beyond the funding period

**COMMUNITY**

- Willing to work with research timelines
- Community need compatible with research goals
- Consistent attendance
- Provide input at all levels
- Provide contextual expertise to partners
- Sharing of funding and commitment beyond the funding period
Increase Research Impact

Increase Community Capacity
Thank you!

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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!”

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