Community-Partnered Participatory Research Practices in Autism Intervention Research

June 10, 2017
Bethesda, MD
Community-Partnered Participatory Research (CPPR)

- Methodological approach in community health to reduce health disparities
- Community-academic partnership in all phases of research
- Emphasizes **community engagement** over involvement
- Core group of partners working with resident experts and community members
Circles of Influence
Jones, L., Martins, D.S., Pardo, Y., Baker, R., Norris, K.C.
CPPR Core Values

- Respect for Diversity
- Openness
- Redirected Power/Empowerment
- Asset-based Approach
- Equality
12 Operational Values for CPPR

- Each activity is co-planned; equal decision-making power
- An MOU should outline the goals of the project
- Project leaders communicate regularly and recognize that conflict and disputes are required for growth
- TRANSPARENCY to build trust
- Financial resources and in-kind support
- Respect and follow community values and time frames
- High standards of productivity, impact, and accountability
- Seek help from community leaders to resolve conflict
- Understand community priorities and histories
- Community input is formally recognized
- Institutional leadership understands and values academic-community partnering process
- Leaders agree on standards and tools for evaluating progress and impact
3 Stages of CPPR

**Vision:** Consensus on goals and strategy of the project

**Valley:** Conducting the activities to achieve the vision

**Victory:** Sharing the story, plan for sustainability and policy changes

Plan → Do → Evaluate
CPPR: an Effective Approach

- Well documented in community health and medical literature
  - Underrepresented communities
- Incorporates mixed methods, logic models, etc.
- Quasi-experimental, descriptive, exploratory
- Derived, but different from community-based participatory research (CBPR)
CPPR in AIR-B3

• Choosing a Partner ...
  ▫ *Healthy African American Families*
    (Loretta Jones, M.A., Founder)

• Goals of the Collaboration
  ▫ Applying CPPR methods to autism-specific research with children
  ▫ Addressing disparities in autism for ethnic minority and low-resourced communities
  ▫ Build partnerships with local community and others in the field
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<tr>
<th>FY</th>
<th>Project Activities</th>
<th>Additional Community Outcomes</th>
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| 2015-2016 | • Formation of local partnerships  
• Conduct *dialogue groups* with target population  
• AIR-B3 Community Conference (UCLA) | • Formation of ASD-specific community groups  
• Community capacity-building for research; **creation of local ASD parent support group**  
• Engage local community for strong partnerships |
| 2016-2017 | • Analyze data and develop intervention  
• Conduct MTG Pilot  
• AIR-B3 Community Conference (UPenn) | • Growing community-academic partnerships for additional projects (**early screening tool**)  
• Expanded community reach and engagement |
| 2017-2018 | • Analyze MTG pilot data  
• Begin RCT  
• AIR-B3 Community Conference (Rochester) |                                                                                               |
| 2018-2019 | • Continue RCT  
• AIR-B3 Community Conference (UC Davis) |                                                                                               |
| 2019-2020 | • Follow-Up Assessment of Sustainability  
• AIR-B3 Community Conference (UCLA) |                                                                                               |
CPPR Stage: Setting the Vision

- Build local partnerships
  - FQHCs
  - School district(s)
  - CBOs
- Formation of recurring partner group meetings
  - *Resident experts* come from local partners, and are committed throughout the process
  - Diversity of stakeholders is vital for partnership
Setting the Vision - Los Angeles

HAAF Autism Community Group
HAAF Autism Community Group

- **Mission**
  - provide information and awareness of autism
  - connect people to services in the community
  - develop a research plan to reduce disparities in service of people on the autism spectrum

- **Vision**
  - everyone gets the services they need regardless of race/color
  - join community and academia in one voice to inform and change policy
  - reduce stigma and misconceptions
  - develop a community driven workforce of self advocates, PARENTS, educators, family members, and researchers partnering to establish autism resources that will STAY in the community

- **Core Values**
  - EDUCATION, COLLABORATION, ACCOUNTABILITY, EMPOWERMENT, COMMITMENT, RESPECT
Setting the Vision - Rochester

• ROC the Future
  ▫ Collaborative action networks
  ▫ Goal is academic achievement
    • School Readiness CAN
    • GROW comprehensive screening for 3 year olds

• Parent Engagement CAN
  • Increase parent engagement and understanding in early development

Comprehensive, broad scope, but parent engagement and education missions align.
Lessons Learned from Vision Stage

• Revisit Mission/Vision/Values frequently!
• People get on and off the bus, but the bus still rolls to its destination!

• Relationship-building is vital and on-going = trust in others’ intentions and capabilities!
• Permanent fixtures are key from your partners (i.e., resident experts)!
Moving to the Valley

- Implementing the work to achieve the vision
- Engagement through all stages of research:
  - Planning
  - Collecting Data
  - Interpreting Results
  - Sharing Results
- Achieved through regular communication and collaboration with partners
- Shared success across stakeholders
In the Valley

• **Vision:** Develop a research plan to reduce disparities in service of people on the autism spectrum

• **Plan:** Work with partners to
  - Identify and locate target population
  - Conduct focus dialogue groups to determine barriers and gaps

• **Do:** Dialogue groups conducted in March 2016-June 2016 across network

• **Evaluate:** Activities expand beyond intended outcomes!
Outcomes from the Valley Lead to Early Victories

- HAAF Parent Support Group
  - Began in March 2016 to address an identified need
  - Founded and operated by community member
- GROW-Rochester’s Early Screening Tools
  - Added ASD screening for 3-year olds

Although we have some victories, we are still in the Valley!
Lessons from the Valley

- Language matters ... a lot!
- It’s a s-l-o-w process, requiring checks and balances to ensure shared decision-making!
- Dissemination is key! You never know what unintended (positive) outcomes will develop.
- Requires constant reminders of goals and objectives – which should be greater than simply conducting research!
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Recommendations for Employing CPPR Methodology

• When done right, it’s more than a methodology! It becomes a way of life.
• Conflict and disputes are natural occurrences within the process. Reflect on others’ positions and approach from a common place of understanding.
• Know yourself, your positionality, your interaction style, and your thoughts about engaging with others different from you.
• Reflect on the bi-directional learning inherent in CPPR. How are you changing community, and how is the community changing you?
Thank You!

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