

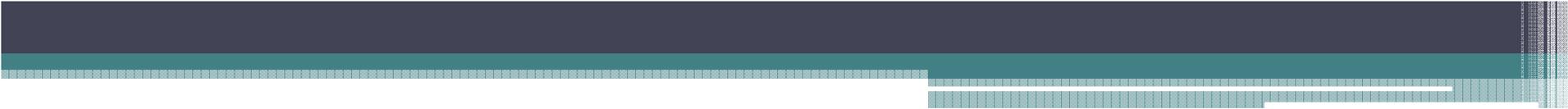
AIR-B

Community-Partnered Participatory Research Practices in Autism Intervention Research



June 10, 2017
Bethesda, MD



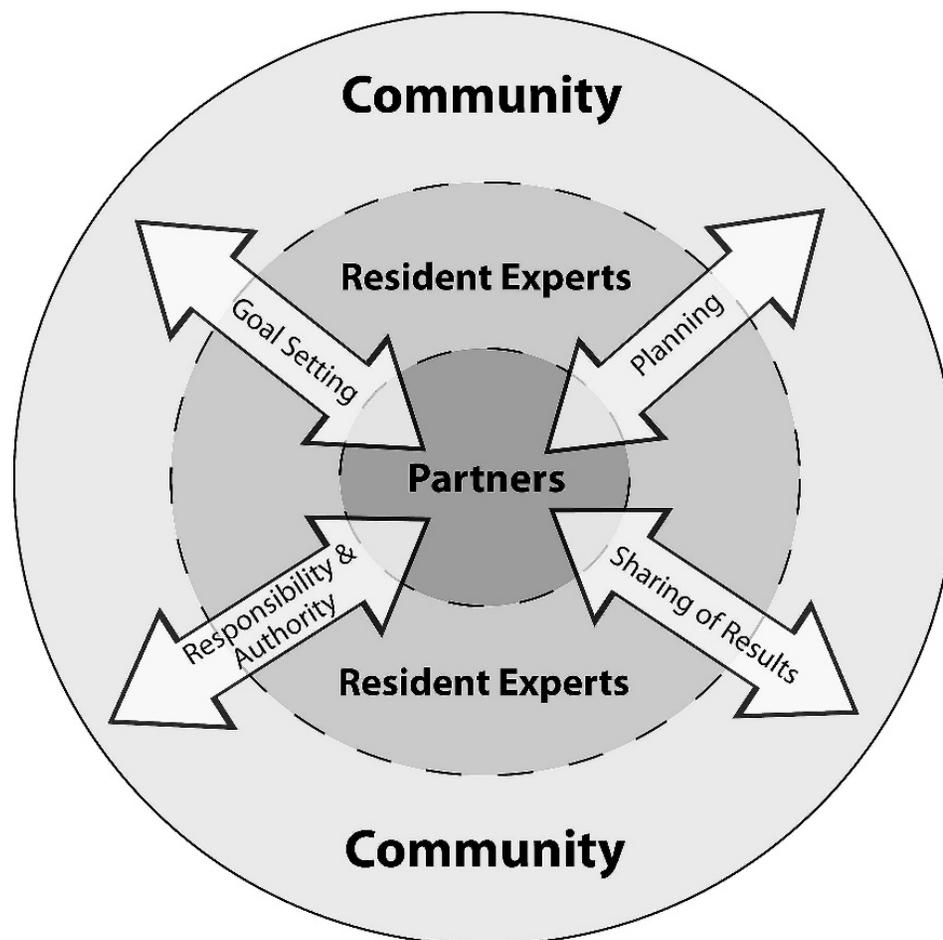


Community-Partnered Participatory Research (CPPR)

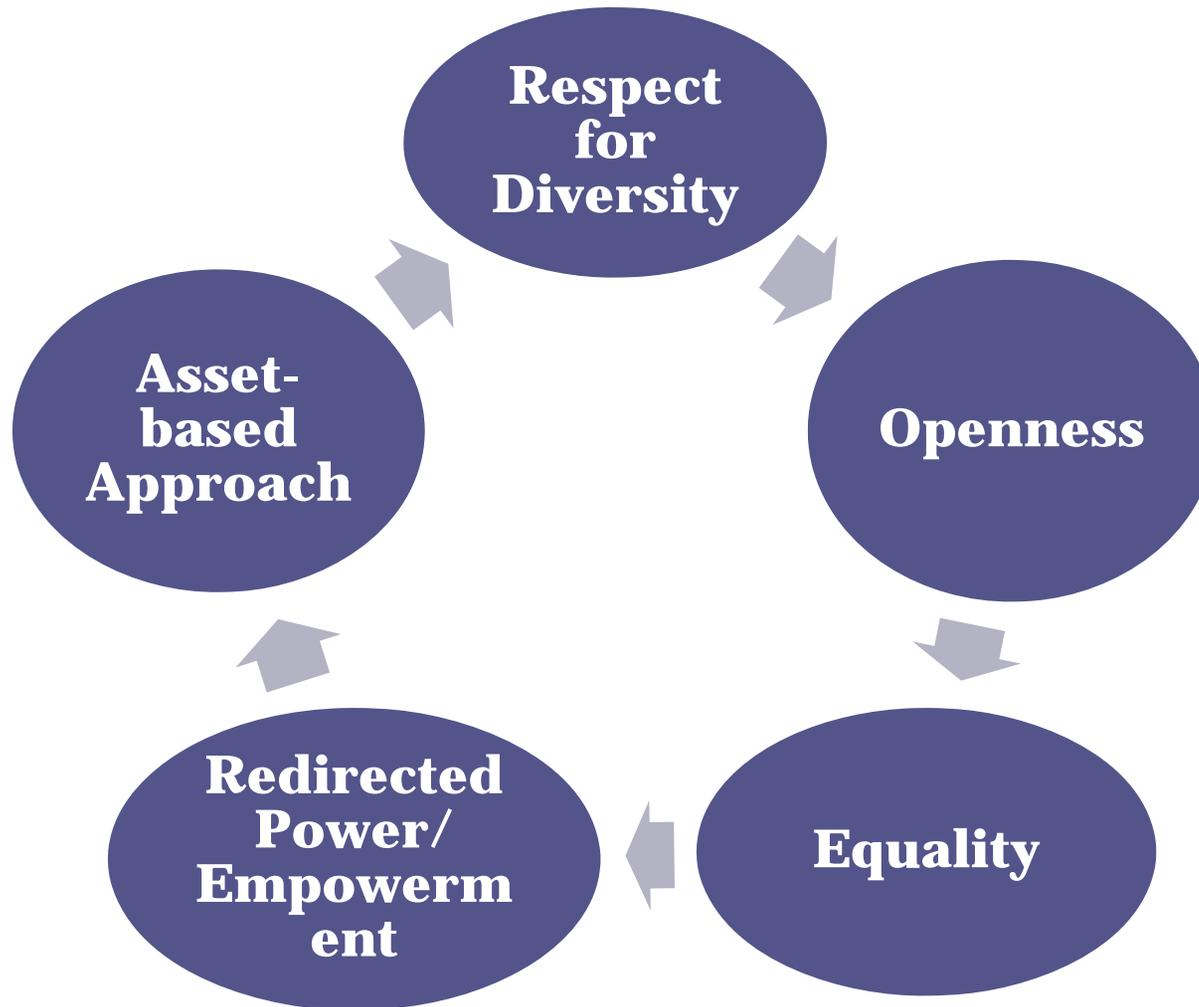
- Methodological approach in community health to reduce health disparities
- Community-academic partnership in all phases of research
- Emphasizes **community engagement** over *involvement*
- Core group of partners working with resident experts and community members

Circles of Influence

Jones, L., Martins, D.S., Pardo, Y., Baker, R., Norris, K.C.

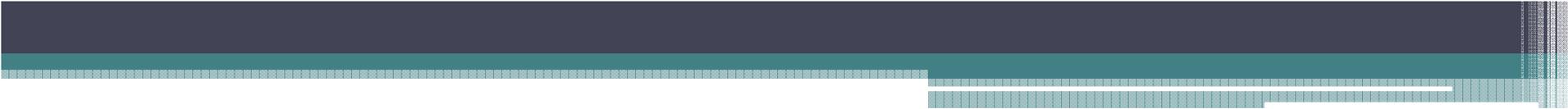


CPPR Core Values



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

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- ❑ 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



FY	Project Activities	Additional Community Outcomes
2015-2016	<ul style="list-style-type: none"> •Formation of local partnerships •Conduct <i>dialogue groups</i> with target population •AIR-B3 Community Conference (UCLA) 	<ul style="list-style-type: none"> •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	<ul style="list-style-type: none"> •Analyze data and develop intervention •Conduct MTG Pilot •AIR-B3 Community Conference (UPenn) 	<ul style="list-style-type: none"> •Growing community-academic partnerships for additional projects (early screening tool) •Expanded community reach and engagement
2017-2018	<ul style="list-style-type: none"> •Analyze MTG pilot data •Begin RCT •AIR-B3 Community Conference (Rochester) 	
2018-2019	<ul style="list-style-type: none"> •Continue RCT •AIR-B3 Community Conference (UC Davis) 	
2019-2020	<ul style="list-style-type: none"> •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



Healthy
African
American
Families, II

Protecting the Legacy



AIR-B

UA3MC11055



UCLA

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.



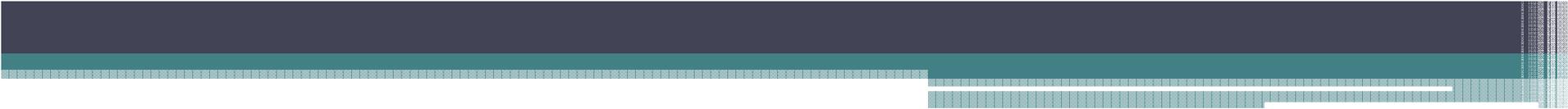
Lessons Learned from Vision Stage

- 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

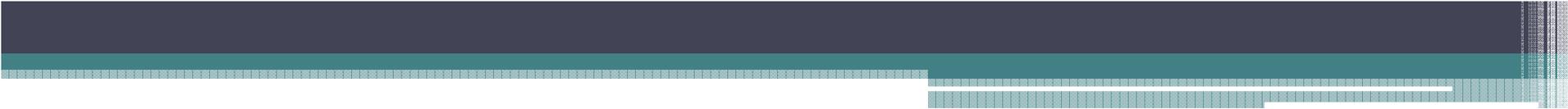
- HAAF Parent Support Group
 - Began in March 2016 to address an identified need
 - Founded and operated by community member
- GROW-Rochester's Early Screening Tools
 - Added ASD screening for 3-year olds

*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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2020+	Continued Community-Academic Partnerships	



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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Treatment