Community-Partnered Participatory Research & Implementation Science

Loretta Jones, MA, ThD
Founder & CEO Healthy African American Families
Kenneth Wells MD MPH UCLA/RAND and Colleagues
(Aziza Lucas Wright, Med; Keith Norris, MD PhD; The CPIC Council)
A Short Course for Presentation by Implementation Science Researchers and Community Partners
Challenges of engaging minority communities in services and research

- Tragic historical legacy of research abuses of minority populations
- Distrust of government programs and health services
- Community-based participatory research approaches are recommended to build trust in research and services
Disparities in care persist

• Minorities are less likely to get any or appropriate mental health care when needed.
• Disparities in care remain or are worsening over time.
• Disparities in healthcare workforce exist.
• Community-based participatory research is recommended to address disparities and develop programs, research and evaluation for under-resourced or vulnerable populations.
Equality and Equity in Health

**EQUALITY = SAMENESS**
Giving everyone the same thing
It only works if everyone starts from the same place

**EQUITY = FAIRNESS**
Access to the same opportunities
We must first ensure equity before we can enjoy equality
Source: This model was developed by L. Jones, M.A., D.S. Martins, M.D., Y. Pardo, R. Baker & K. C. Norris, M.D.
Community Partnered Participatory Research (CPPR)

CPPR Principles:

• Transparency
• Respect
• Power sharing
• Co-leadership
• Two-way knowledge exchange
Principles & Structure of CPPR

• Core Principles
  – Transparency
  – Respect
  – Power sharing
  – Co-leadership
  – Two-way knowledge exchange
  – Strength-based

• Structure
  – Partnered Council (frames and guides initiative)
  – Community Forum (broad input)
  – Partnered Work Groups
    • Develop action plans for community approval
    • Implement and evaluate plans
    • Disseminate programs and findings

• Stages: Vision, Valley and Victory—equally important

• Jones and Wells, 2007; Wells and Jones 2009; www.communitytrials.org; Jones et al., 2009
## Building the Partnership: Find the Win-Win:

<table>
<thead>
<tr>
<th>Sector</th>
<th>Wins</th>
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<tbody>
<tr>
<td>Veterans</td>
<td>Better daily lives</td>
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<td></td>
<td>Indirect benefits to whole community</td>
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<tr>
<td>Community Organizations</td>
<td>Community, political, financial support,</td>
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<td></td>
<td>recognition, networking, resources</td>
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<tr>
<td>Healthcare Agencies</td>
<td>More efficient or effective care,</td>
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<td>Increased market share,</td>
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<td>Positive image, tax write-off</td>
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<td>Government</td>
<td>Improved implementation of programs,</td>
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<td></td>
<td>services; public trust in programs or research</td>
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<tr>
<td>Universities</td>
<td>Greater impact, partnerships for research and training with 2-way</td>
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<td>knowledge transfer</td>
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Shifting the Paradigm from Involvement…

- One step removed from partnership
- Builds consensus on predetermined actions
- Report back to funders
- “For” not “with” partners
- Provides resources during the initiative
- Timeline for success regardless of community reality
- Predetermined agenda, plan, and method
…to Engagement

- Builds sustainable capacity
- Builds trust and co-ownership
- Honors shared agendas, plans, and methods
- Partners own the initiative, mind its collaborative nature
- Report back to partners and funders
- Work is done “with” not “for” the partnership
The Model of Partnership
Hand-off or Engagement?
How To Build Partnerships

• Identify trusted agencies that work with community
• Develop a common understanding of mission
• Identify strategies to engage systems and communities; what works and what has not; who is engaged, who is not
• Develop messages and partnership strategies to engage stakeholders in the mission
• Formalize new networks for change
• Have an engagement model (Jones and Wells, 2007)
Vision: Community Design Input: Sampling

• Community Definition:
  – Geographic boundaries or other definition of community (where people live, work, play)

• Agencies
  – Traditional/”usual suspects”
  – Nontraditional: “community-trusted”, e.g., community centers; faith-based agencies, local businesses)

• Providers
  • Traditional service providers
  • Nontraditional: Key community leaders, case workers and agency staff with front-line contact

• Patients/Clients: Community will often prioritize the most vulnerable for a more inclusive approach
Community Design Input: Intervention

- Community may be more concerned about equity in access/capacity building
- Can lead to somewhat greater intensity than expected for intervention and control
- Plan for flexibility in resources use
- Leverage with other existing community capacities
- Be realistic about resource limits
Community Randomization Approach

- Two-way exchange on science and experience
  - Randomization, validity
  - Community trust/Tuskegee
- Council votes on overall strategy and co-presents to community and science stakeholders
- Community leaders participate in implementation of randomization (e.g., matching agencies for randomization or selecting seed numbers to initiate randomization)
- (Belin et al., 2012, CPIC)
Community Design Input: Conceptual Framework and Outcomes

• Two-way exchange on goals, logic model
  – Evidence-basis and Community-defined evidence
  – Review and translate key theories
  – View measures, language, length

• Workgroup recommends strategy to Council

• Broader Community approval is helpful

• Examples: Wellness, social risk factors (e.g., employment housing) may be as important as disease outcomes for some
The Road(s) Ahead: Outcomes that Matter

Courtesy of Sergio Aguilar-Gaxiola, M.D., Ph.D
Victory: The Win-Win

- Community Benefit of Study Implementation:
  - Resources Guides for agencies and clients
  - Safety protocols for agencies and study
- Products: partnered research papers, presentations
- Reputation/Visibility: locally and nationally
- Basis for new proposals and community funding, matching dollars for community grants and letters of support
- Partnership can represent a paradigm shift for community & academic partners
Other Potential Community Benefits

- Trainings for intervention and research
- Leader development in intervention and research
- CME, CEUs, certificates of appreciation
- Contributed resources for $-matching requirements
- Research opportunities
- Data for community programs and policy makers
- Sustainable resources: Website, toolkits
- Hope for improved programs, community assets built, needs addressed
- Plan for and develop opportunities for benefit
Challenges to Partnered Research

• Partners Need Resources: (CPIC formula: 1/3 academic, 1/3 community, 1/3 shared data and programs over diverse grants)

• Infrastructure for Two-Way Capacity Building –
  – Training for academic investigators in Community Engagement—CSP curriculum
  – Training community members in Research Concepts & Approaches—seminars and play
  – Common growth—workshops, retreats

• Partnered Presentations and Products
  – Mechanisms to facilitate input of community members and attention to community venues
Words to Remember:

- Improvisation
- Resiliency
- Connectedness to others
- Spirituality
- Emotional Vitality
- Gallows Humor
- Healthy Suspicion of the Message and the Messenger

Joe White, Ph.D  February 23, 2006 African American Mental Conference, Los Angeles, CA
Icebreakers
Building Communication and Trust

- Effective approach to team-building
- Establish common purpose and understanding
- Fun approach to beginning a meeting
- Building on a topic
- Functions from principles of communication and trust
Who has keys?: Building Commitment

Purpose
Each key represents a privilege and an asset we hold. It’s important to recognize that in the work we do, many do not have these keys or the opportunities to voice their concerns.
Ethics of CPPR: Respect

- For potential and enrolled participants
- For community
- For research partners
- Trust and trustworthiness
- Joint development of guiding principles, agreements, and conflict resolution
- Community and Research dissemination
- Recognition of both community and research biases, stereotypes, and politics
Scientific Validity

- Research must be scientifically valid to be ethical
- Research must have community validity to be scientifically valid
- Community should have a role in developing the design
- Community input can increase validity of interpretations
Summary: How To Build Capacity

- Build relationships and trust, invite people to the table, & stay involved over time
- Knowledge-exchange activities: conferences, webinars, websites, discussion groups, newsletters, radio
  - *Develop and use a common, simple language*
- Support working groups of many stakeholder levels, to work as equals on key issues
- Develop action plans & programs to support understanding and implementation
- Disseminate information & products to community
- Social activities – before and after meetings, and separate from meetings
- Food and fun at meetings and outside of work
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Questions?