Stigma and Distrust: Engaging Marginalized Populations in Research and Prevention

Velma McBride Murry, PhD
Betts Chair, Education and Human Development Professor, Human & Organizational Development
Vanderbilt University, Peabody College
Presented at NIH Health Outcomes among Rural Children and Families Conference

December 1, 2011
Acknowledgements

• Georgia and Tennessee Rural African American Families
• Colleagues at The University of Georgia, Center for Family Research:
  – Gene H. Brody, PhD
  – Olive S. Conyers, MA
• Center for Research on Rural Families and Communities Staff, Vanderbilt University:
  – Sonya S. Myers, PhD
  – LaTrina M. Slater, PhD
Funding Support

• National Institute of Child and Human Development
• National Institute of Mental Health
• National Institute on Alcohol Abuse and Alcoholism
• National Institute on Drug Abuse
Presentation Outline

• Overview of Program of Research on Rural African American Families

• Why focus on Rural African American Families?
  – Context and Challenges

• Implication of Context and Challenges for Recruitment
  – Relevance and Consequences of Stigma and Distrust

• Fostering Program of Research through Community Partnerships
Research History in Rural Communities

- 1995 - ongoing
  - Longitudinal, developmental research with rural African American families, includes 900 families was launched (NIMH)

- 2000 - ongoing
  - The Strong African American Families Program, consisting of 700 families (NIMH)
  - Adults in the Making, includes 400 families (NIDA)

- 2007 - ongoing
  - Pathways for African American Success, involves 420 families (NIMH)
Why focus on rural African American families?
Overview of African Americans in the Rural South

• Several million families living in small towns and rural communities

• Poverty rates among the highest in the nation
  – 50% live below federal poverty standard
  – another 25% live close to the standard
Unique Challenges Confronting Rural Families

- Lack of access to resources
- Lack of public transportation, impeding travel to places where educational and mental health services are available
- Low revenues due to a lack of non-agrarian businesses
- Low population density
- Reluctant to advocate for the establishment of services
- Greater reliance on family members for help and support during times of need
- Are skeptical about mental health services
Rural African Americans’ Responses to Research and Service Delivery Opportunities

• Concerns about ethics of clinical science
• Belief that researchers will experiment on them without their consent
• Suspicion about how the information will be used.
  – Who will benefit from their participation and involvement?
  • Researchers and educational institutions
  • African American communities
Mistrust

• Mistrust toward research
  – Reliance on folk beliefs that create skepticism about Western medicine and mainstream values about health
  – Oral history has been passed down regarding research studies conducted on African Americans:
    • Cadavers of enslaved African Americans used to train medical students
    • Tuskegee Syphilis Experiment – 1930s-1970s
Mistrust

- Lack of understanding of the benefits of research and consequences for their daily lives
- Exposure to chronic and acute episodes of discrimination in the daily lives of African Americans
Mistrust

• Mistrust toward researchers
  – Fear of breach in confidentiality
  – Previous history of exploitative relations with researchers
  – Belief in several conspiracy theories linked to health disparities, such as origin of HIV and devastating effect on their community
Stigma

• Stigma associated with enrollment
  – Being labeled “at risk”
  – Labeling their place of residence as “a problem community”

• Stigma associated with participation
  – Perceived engagement in risky behaviors
  – Perceived engagement in behaviors disapproved by family/community

(Murry, Helflinger, Suiter, & Brody, 2011)
Implications For Engagement

• Reluctance to participate in research studies and preventive interventions

• Reluctance to seek mental health treatment

• Suspicion and negative attitudes toward researchers, program implementers, and health care providers (Nickerson, Helms, & Terrell, 1984, Whaley, 2001)
CASE STUDY EXAMPLE

Recruiting and Retaining Rural African American Families in Research Projects through Community Partnerships
Philosophical Views Guiding Our Program of Research

• Community involvement
  – Understanding what, how, when, and where to do our work in rural counties

• Strength-based and competence-focused service delivery models
  – Based on designs that support and enhance families and communities
Culturally Sensitive Approaches

CULTURE

- Customs
- Religious Practices
- Language
- Experiences
- Worldviews
- Rituals
- Values
- Meanings
Implication of Community Context and Culture for Recruitment

• Determines
  – Relevance of projects and worthiness to the community
  – Legitimacy of the presenting problem for families residing in the community
Partnering with Community Stakeholders to Reach and Recruit Rural African American Families

• Community Liaisons
  – Networking system to assist with
    • Entry into rural African American communities
    • Recruitment and retention of families

(Murry & Brody 2004)
Community Liaisons

• Reside in the counties where the study families live
• Selected for their positive reputations and extensive social contacts
• Act as contacts between our research group and the communities
• Do invaluable work in establishing the Research Team’s credibility with the study participants
Role of Community Partners

• Provide feedback and evaluation in focus groups
  – Data collection procedures
  – Prevention/intervention programs
  – Curriculum and other program materials and Procedures
  – Establish ecology validity
    • Provide guidance on ways to effectively market the program to help reduce stigma and elicit trust
    • Inform us on ways to ensure that the program is worth the participants’ time and effort –
Cultural Sensitivity

- Selection of project names and logos
- Inclusion in program materials (e.g., videotapes) content and images representing the targeted population
- Sensitivity to effects of staff race/ethnicity on families’ receptivity to programs
- Collection of data in families’ homes rather than clinical or academic settings
- Deliver preventive interventions in the rural communities in which families reside
Other Community Stakeholders

- Schools
- Faith-based organizations
- Cooperative Extension Service
Community Partnership Models for Recruiting and Retaining Rural African American families in research studies and preventive interventions
Community Participatory Approach

PHASE 1 – ATTRACTING ATTENTION BY ESTABLISH PRESENCE AND DEVELOP RAPPORT IN THE COMMUNITY
- Identify local community hangouts
- Establish rapport with community residents
- Create list of contacts by providing characteristics of community leaders

PHASE 2 – BUILDING A PERSONAL RELATIONSHIP WITH POTENTIAL COMMUNITY PARTNERS
- Contact community leaders to schedule a face-to-face meeting
- Vet the potential Community Liaison through other community contacts
- Facilitate program buy-in by introducing program, strengths that they can bring to the program, and benefits to community

PHASE 3 – SOLIDIFY RELATIONSHIP - FORMALIZE COMMUNITY LIAISON NETWORK
- Establish & nurture working relationship
- Formally train community leaders on program and associated protocols
- Maintain contact with Community Liaisons over time to sustain the relationship and partnership
Effective Recruitment Strategies

• Use recruiters that participants are comfortable with
• Culturally matched site coordinators
• Recruitment at community events
• Referrals from community agencies and organizations
• Media
• Use internet social network approaches, particularly when youth are targeted
Results

- Multi-informant, multi-method, longitudinal studies
- Approximately 1,200 African-American families in 16 rural counties in southeastern United States

83 to 90% Retention Rate
Conclusions

• Reciprocal relationships between researchers and community partners lead to success.

• Our work:
  – Challenges the notion of whether we should consider to characterize rural African American families as “difficult or hard-to reach”
  – Shows that the recruitment and retention of rural African American families is a journey that involves researchers, families, and partners within the community.
References


Thank You
Contact information:

Email: velma.m.murry@vanderbilt.edu
Website: http://www.vanderbilt.edu/crrfc/