Stigma and Distrust: Engaging Marginalized Populations in Research and Prevention

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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 from 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

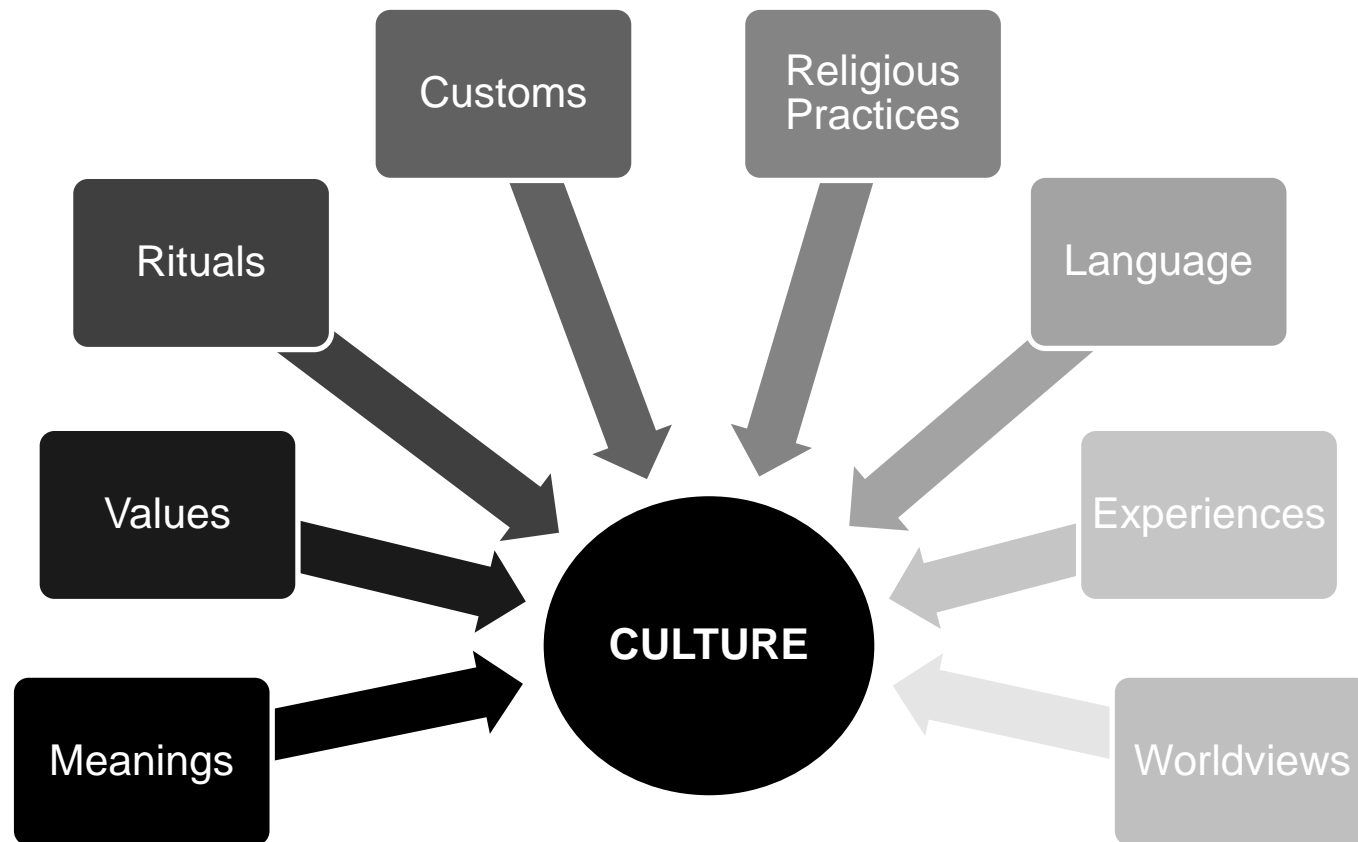Recruiting and Retaining Rural African American Families in Research Projects through Community Partnerships

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

Customs

Religious Practices

Rituals

Language

Values

Experiences

Meanings

CULTURE

Worldviews

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

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 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

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Thank You
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