Using Asset-Based Community Involvement to Address Health Disparities and Increase African American Participation in AD Research: Experiences from the Wisconsin Alzheimer's Institute

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Learning Objectives:

• Learn about the Wisconsin Registry for Alzheimer’s Prevention (WRAP) – a longitudinal study of preclinical AD.
• Learn about the key components of the Wisconsin Alzheimer’s Institute (WAI) Milwaukee Regional Office’s Asset-based Community Development (ABCD) partnership model- Using a culturally inclusive lens to address barriers to research.
• Learn how implementing ABCD improved community engagement, patient care, improved knowledge of AD, and established social support for AA elders and caregivers.
• Learn how this comprehensive model has been effective to increase the representation of African Americans WRAP.
African Americans are at Greater Risk for Alzheimer’s disease

The prevalence of Alzheimer’s disease or other dementias among older African Americans is roughly double that among non-Hispanic Whites, and is significantly higher than that among Hispanics.

Impact of AD on Communities of Color

• AD and other dementias are a public health crisis in communities of color in the US
• AD and other dementias are less likely to be diagnosed or treated
• Undiagnosed AD complicates the management of other comorbid conditions
• Majority of care provided by unpaid informal caregivers
• Structural, social and attitudinal barriers unique to minority elders and their families
• Non Hispanic blacks had significantly higher costs of care (CMS)
Despite these Health Disparities, AAs are Underrepresented in Research

- African-Americans have been under-included in many prominent U.S. AD biomarker and clinical trials. Shin & Doraiswamy (2016) (Brickman et al., 2008; Alzheimer's Association, 2010)

- The recruitment and retention of African Americans in research studies has been challenging, because of cultural and historical barriers, particularly for neurobiologic studies (Barnes and Bennett, 2014)

- One study not included in Shin & Doraiswamy (2016) is the Wisconsin Registry for Alzheimer’s Prevention (WRAP).

Barriers to Research Participation

- Recruitment methods
- Mistrust
- Implicit Bias
- Strict investigator participation criteria
- Protocol developed w/o including target population
- “Superman” syndrome
Overview of WRAP

  - N=1551, Mean baseline age=54 years, 70% women, 72% family history of AD, 10 years average follow-up
- Initial recruitment strategies
  - Diagnostic Memory Clinics, Newspaper Ads
  - In ~2004, control group recruitment for WRAP was targeted to those with UW e-mail addresses
- Recruitment methods inadvertently focused primarily on Caucasians. By late 2005, only 6(0.8%) of the 711 participants were AA
- To address the disparity, Milwaukee was added as a recruitment site (5/2006).

WAI-Milwaukee Recruitment Strategy I

- Hired Research Program Manager - located inside local hospital
- Hired Outreach Research Coordinator - no office space or office support
- Lacked strategic recruitment plan that included the community
- Nearly $450,000 spent over 2 years
- AA enrollment still <2% of 1163 at end of 2007

AA Enrollment, by Site

Cumulative AA enrollment over time for Madison, LaCrosse, and Milwaukee.
WAI-Milwaukee Recruitment Strategy II

An asset-based community-involvement approach was developed and implemented by new WAI-Milwaukee leadership in 2008.

- Strengthen ties between UW and community to build trust
- Identifying key stakeholders – grassroots, non-traditional leaders...
- Address barriers through service

- Provide counsel to UW PI and researchers
- Guide the process of introducing research to potential participants

- Recognize the community as experts
- Validate the community

- 8 years committed service (WRAP participants)
- CAB recognized across UW and other as resource
- Increased access to and participation in research
- Instrumental in developing more successful programs
- CAB has given UW more visibility and credibility within communities of color

McKnight & Kretzmann (1993). Building Communities From the Inside Out: A Path Toward Finding and Mobilizing a Community’s Assets

Asset Based Community Development Model
Community Advisory Board
Addressing the Community’s Concerns
MHSI Memory Clinic Model

Milwaukee WRAP Research Participation Highlights

- 189 people are enrolled in WRAP in the Milwaukee area:
  - African-American/ black (110)
  - Caucasian/white (41), Hispanic/Latino (35)
- Currently in 4th wave of return for participants
- Primary focus in the Milwaukee area is within the African-American community.

By 2012, AA’s comprised ~8% of WRAP sample
Conclusions

• African Americans bear a disproportionate burden of AD and other dementias
• Structural and social barriers affect access to diagnosis, treatment and family support
• Culturally tailored community based services are needed to reduce inequities and improve access to education, diagnosis, treatment and prevention programs
• Asset Based Community Engagement programs have the potential to improve quality of care, reduce costs, decrease burden and improve quality of life
• Use of this model has resulted in increased participation in research of African Americans.

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