

Use of Community Advisory Boards to Enhance Recruitment

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Why use a Board

- African Americans and other minority and underserved groups are under-represented in research
- Many reasons
 - Distrust of medical establishments
 - Distrust of research
 - Lack of relevance
 - Lack of community gatekeepers and ambassadors

Creating a Board

- Recognition of lack of diversity in research sample by an African American participant, Mr. Norman R Seay, a prominent civil activist
- After discussion with center leadership an **African American Advisory Board (AAAB)** is created, chaired by Mr. Seay.
- The Education Core coordinates the AAAB, which meets on a bi-monthly basis since Fall 2000.

Defining a role

- The AAAB role is to review our clinical and research programs, suggest new programming and target audiences, and refer individuals from their organizations for research participation.
- The AAAB advises the Center on issues of cultural competence and sensitivity, recruitment, building trust in the community, and event planning.

AAAB Composition

- Each member was chosen for their strength of leadership and ties to key civic, religious, education and health organizations
- 21 current members
 - Clergy, civil activists, health professionals, community leaders, administrators, and media representatives
- Supplemented by liaisons from ADRC
 - Minority Outreach Coordinator
 - Education, Clinical and Administrative Cores
 - African American Outreach Satellite

Characteristics of Board Members

- An appreciation for the value and importance of clinical research;
- A basic understanding of Alzheimer's disease and related disorders and their under-recognition in the African American community;
- A willingness to serve as an ambassador and liaison for the ADRC-MAP in the local African American community;
- A willingness and ability to attend quarterly AAAB meetings;
- A willingness to serve as a member of the AAAB for a term of 3 years.

Tasks of Board Members

- Actively represent the research mission and participation interests of the ADRC-MAP in the African American community;
- Serve as an ambassador and liaison for the ADRC-MAP in building strong individual and local partnerships to enhance research participation;
- Advise Washington University Investigators in the development of culturally appropriate and sensitive education, outreach, recruitment, and retention strategies, products and programs;
- Review print, video and other materials of the ADRC-MAP to ensure the communication of consistent, appropriate, and effective messages.

Nuts and Bolts

- The Education Core hosts meetings with the AAAB at least six times per year.
 - Four meetings are held at the St. Louis chapter of the Urban League
 - Two meetings are held at the ADRC.
 - One meeting per year is dedicated to a training session giving an updated overview of our research programs, recruitment needs and planned programming.
- We occasionally hold additional meetings on an ad-hoc basis for strategic planning, video screenings, or any other special causes that might arise throughout the course of the year.

Board Development Activities

- During the last funding period, we reviewed our mission and vision statements, and new member application process
- Board development activities with goals and objectives and a SWOT (strength, weakness, opportunity, threat) analysis.
- This process led to an overhaul of AAAB leadership with a new Chair/Vice Chair structure, reorganization of our subcommittees and continued board development activities.

Mission Statement

- Counsel the research team concerning cultural sensitivity and appropriate outreach strategies to encourage active, long-term participation of African Americans in memory and aging studies at Washington University School of Medicine.
- Our commitment to inclusiveness, diversity and justice (fairness) for research participants is integral to our mission.

Example of Board Activities

- The Board reviewed our current lumbar puncture fact sheet and made significant recommendations to enhance accessibility and cultural sensitivity.
- The Board reviews survey tools and questionnaires
- A number of AAAB members are active research participants, and several have had lumbar puncture.
- The former chair of the AAAB, Norman R. Seay, appeared in a video about lumbar puncture.

Listening to the AAAB

- At the suggestion of the AAAB, we sought to enhance our ability to interact with underrepresented populations.
- We arranged Cultural Sensitivity training in December 2007 under the direction of Brenda Battle, Director of the Center for Diversity and Cultural Competence, Barnes-Jewish Hospital. Ms. Battle is also an active member of our AAAB.
- This training session included didactic and interactive role-playing sessions and was attended by 44 faculty and staff of the ADRC.
- The outcome was a measurable gain of cultural competence by pre- and post-testing measurements .
- To extend this discussion of cultural sensitivity and the importance of diversity in research studies, Ms. Battle presented on this topic at our Participants Meeting in June 2009.

Committees

- Clergy Outreach
- Cultural Competence
- Health Professional Outreach
- Public Relations
- Ad-Hoc

Example of Ad Hoc Committee

- July 2009, discussion of how to make new connections in the African American Community
 - Creation of 6 member ad-hoc committee to address issues
- August 2009, committee meets and sets agenda for breakfast meeting to engage representatives from community-based organizations without previous engagement
 - Minority Outreach Coordinator given ~50 names
 - Several follow-up conference calls
- September 2009, Breakfast meeting set for Nov 18th at Missouri History Museum with 24 confirmed attendees
 - Invited speakers include Orien Reid and Marie Bernard

Building visibility and trust in the community takes time, effort and patience

- To build visibility, find partners in the community to serve as liaisons and goodwill ambassadors
- To build trust, make efforts at understanding and cultural competency
- The Education Core has as its focus a top-down approach to education and recruitment, which involves making in-roads with the executive committees of key local organizations, often with introductions by way of the AAAB.
- The Ed Core and the AAAB engages actively with the African American Outreach Satellite (to the Clinical Core)
- Success is a team approach; the year in which the Minority Outreach Coordinator was hired, 2007, saw the highest number of new African Americans enrolled in the Clinical Core (24% of total enrollees in 2007 were African American)