

The BOBA Youth Advisory Board as a Case Study for the Role of Community Advisory Boards in Human Subjects Research

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Background

- Marginalized groups have been underrepresented in or excluded from psychiatric research.
- Barriers to participation include mistrust, unawareness, and ineffective messaging (Erves et al., 2016).
- Community Advisory Boards (CABs) act as **liaisons** and represent **community perspectives** to increase engagement and provide insight recommendations to researchers (Strauss et al., 2001)

Methods

- The Building Our Bonds Authentically (BOBA) Project is a longitudinal study of identity, discrimination, and mental health in Chinese American families.
- Participation involves a survey and parent-teen conversation, responding to 3 hypothetical race-based vignettes
- BOBA's Youth Advisory Board (YAB) consists of 20 Chinese-American teens from local middle/high schools, meeting on a biweekly basis for 1 year.
- Responsibilities of the YAB include [insert things from Ritika's YAB repsonsiblity document]

References and Acknowledgments

- Erves, J.C., Mayo-Gamble, T.L., Malin-Fair, A. et al. Needs, Priorities, and Recommendations for Engaging Underrepresented Populations in Clinical Research: A Community Perspective. J Community Health 42, 472–480 (2017). https://doi.org/10.1007/s10900-016-0279-2
- 2. Strauss RP, Sengupta S, Quinn SC, Goeppinger J, Spaulding C, Kegeles SM, Millett G. The role of community advisory boards: involving communities in the informed consent process. Am J Public Health. 2001 Dec;91(12):1938-43. doi: 10.2105/ajph.91.12.1938. PMID: 11726369; PMCID: PMC1446908.
- 3. https://grants.nih.gov/grants/guide/rfa-files/RFA-MH-25-205.html
- 4. NIH 1R21 HD115355-01; 1R21 HD107512-01A1; 1R01 MH129360-01 (Pls Liu & Yip)

CABs are chosen to be representatives of community perspectives and advocate for community needs CABs act as liaisons, helping disseminate study information across their broad networks and increasing trust

- Provides community-relevant feedback on research design and outreach messaging -> 524 participants enrolled
- Spurs new research ideas based on direct community experiences



Results

- 1. **Messaging** The YAB provided specific feedback to refine messaging based on their experiences with community outreach and as eligible participants.
- a. Framing: Examples include
 - i. The study is framed as a "project" or "free resource" rather than a research study during teen recruitment
 - ii. Change recruitment demographics from "Asian Americans" to "Asian/Asian American" to improve inclusivity
- b. Marketing: During outreach, the benefit of improving family relationships rather than mental health was emphasized
- c. <u>Design</u>: To make participation easier, the project was adapted to provide a survey-only option for teens
- 2. Community Engagement The YAB introduced researchers to their community network and helped organize 15 community events and presentations.





- 3. **Brainstorming Future Research** The YAB have also provided insights and recommendations to research design
- a. <u>Piloting</u>: BOBA YAB members provide feedback informally (eg. discussion) and formally (eg. form) on new research ideas
- b. Yield: 3 NIH applications on: Asian American (AA) sexual/gender minorities, biracial AAs, and Indian American teens.

Conclusion

The BOBA YAB is a proof of concept of the benefits of CABs:

- Providing crucial research input that informs the research design, recruitment, and future directions of a study on an underrepresented community.
- Bolstering enrollment, community trust, and addresses NIMH's recommendation for a YAB (NIMH), with its structure adaptable depending on a study's specific needs and capacities.

Recommendations

Forming a CAB:

- 1. CAB members are chosen based on specific project needs and audience
- CAB member/researchers
 brainstorm relevant outreach
 strategies based on network and
 perspectives
- 3. CAB members regularly provide feedback on request and connect researchers with community

Future Directions:

- Researchers should balance considering a potential CAB member's connections with how aligned their experiences and perspective are with the community
- Interest and commitment to the specific project is critical