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Commentary

Lessons Learned with an HIV Youth Advisory Board- Conversations Eight Years Later

Judith B Cornelius*

School of Nursing, University of North Carolina, Charlotte, USA

Introduction

Advisory boards have been used to make participants equal partners in the process to address a societal problem [1]. Each partner is able to contribute in the decision-making process and share his or her specific expertise on a topic [2]. How you recruit participants for an advisory board depends on the purpose of the project. Advisory board participants can be recruited from an organization or from the general population and should represent the targeted population directly impacted by the societal problem. Rules of engagement should involve using language that the advisory board audience can understand, be an active listener, and remain culturally sensitive at all times [3]. Involving community partners can create more visibility for the research effort and help move the community to create positive change around a societal health issue [3]. For our project, the societal health issue was HIV prevention.

A community leader involved with adolescent teen health recruited youth to work with a research team at a local university. We established a youth advisory board consisting of 12 African American youth, 13 to 18 years of age. The youth advisory board was comprised equally of African American males (n=6) and females (n=6), 13 to 18 years of age. The youth represented community organizations and local schools. Consent and assent were provided. The youth were compensated \$20 for their participation with each of the advisory board meetings.

The purpose of the project was to adapt an HIV risk reduction curriculum, *Becoming a Responsible Teen*, for enhanced text messaging delivery to African American youth [4-7]. Guided by the ADAPT-ITT model, we began the pre-testing methodology. The project consultants and advisory committee members examined a

*Corresponding author: Judith B. Cornelius, School of Nursing, University of North Carolina, Charlotte, USA, Email: jbcornel@uncc.edu

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draft protocol of the adapted curriculum. The adapted curriculum was piloted tested for feasibility and acceptability of the text messaging process. We also examined if there was any evidence of change that would provide justification for proceeding to a larger application in a randomized controlled trial. For 3 months, the youth advisory board was involved with developing and pre-testing the text messaging enhanced intervention.

We learned lessons working with youth 13 to 18 years of age, which has guided our program of research decades later. While we learned lessons, we began to wonder if the project had a long-term effect on the lives of the youth advisory board participants. As a result, we had conversations with them eight years later.

Lessons Learned

One of the major lessons that we learned is that youth do not speak the same language that we do. We had to listen carefully to what they said and how they said it. Non-verbal cues were important in assessing the product that we developed and tested. Second, we learned that it was important to keep the youth engaged. If we did not keep them engaged with the adaptation process, they became disinterested and non-productive. We provided incentives for creative text messages, awards and recognition for special occasions, and snacks. The text messages had to be understandable by the general population so we critiqued each message and established inter-rater reliability among the youth advisory board members. The third lesson was that youth advisory board training had to occur in multiple sessions so that we could introduce concepts of the project and allow time for questions and answers. Fourth, we also had to acknowledge parents' commitment to bring their child to each meeting. We began to recognize their contribution to this process. We also identified that bus passes would allow some youth to attend when their parents could not bring them for a scheduled meeting. Fifth, we had to vary in the ways in which we presented information, since some people learn differently. Therefore, we began to provide visual, auditory, and kinetic methods for developing the text messages. For example, the youth developed videos were created with closed caption and music. Last, team building was important so we established team building exercises. The youth began to develop relationships among their peers beyond the advisory board meetings.

The project was a success and the youth received certificates for their participation. They were featured on the project web site, with a picture and a written narrative describing why they were involved with an HIV youth advisory board that enhanced HIV risk reduction information with text messages. They were also featured in press releases about the project.

Eight Years Later- Follow-up with Youth Advisory Board Participants

Eight years after the project ended, we began to wonder how being an advisory board member influenced them today? And how working with researchers at a university benefited them today?

A graduate assistant attempted to reach each of the 12 youth advisory board participants to ask the following questions:

1. What are you currently doing? If you are in college, what year are you and what is your major? If you are working, what type of job are you doing? Is there any other information you would like to share?
2. How has being a part of the youth advisory board prepared you for what you are doing today? Do you pass on safer sex messages/information to your friends?
3. Have you volunteered for other advisory board, research or civic projects?

We were able to reach 8 of the 12 participants. Four were currently enrolled in college, two were seniors in high school and the other two were working full time. One worked in a health care setting and the other worked with a local business. The advisory board participants indicated that they were more knowledgeable about peer pressure and making responsible choices about life. Two of the participants shared that they were able to educate younger family members about safer sex practices. They worked with community agencies such as Big sis Lil sis, participated in freshman health promotion programs, and volunteered to teach classes on HIV/AIDS. One youth also shared HIV prevention information with a global program called Generation Rwanda. Each one indicated that their self-esteem improved and those who attended college felt comfortable working with university professors.

Conclusion

Relationships are developed when you establish advisory boards with community participants. As a research team, we were able to supply accurate and appropriate information to guide a community initiative and evaluate a community-based intervention. The lessons that we learned remain priceless. Eight years later, we found that being a youth advisory board member empowered the youth most affected by conditions or issues in their community to analyze and change them. We were able to obtain community buy-in and support for an initiative designed by youth for youth. For the advisory board participants who we were able to reach, they found additional opportunities to become peer educators. Last and, perhaps most important, being a youth advisory board member led to long-term social change that improved the quality of life for the youth, their family, and closest peers.

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