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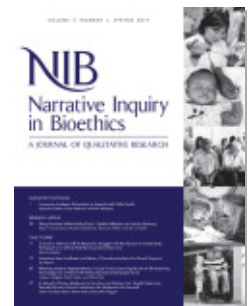
## Youth Giving Voice in Research Ethics

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### Youth Giving Voice in Research Ethics

Armida Ayala

About fourteen years ago, I began a partnership as an evaluator with a community outreach project aimed at encouraging young girls in elementary school to seek a higher education because they were underrepresented in attaining college degrees. This experience turned out to be one of the most transformative in my life. Through this longitudinal study, I began to mentor a bright, energetic, young girl when she was ten years old. At the time I met her, I was in transition from being a researcher in public health to leading an Institutional Review Board (IRB) at a large research program. Mentoring her over the years and transitioning into the field of research ethics, significantly shaped how we both view research from a position of power, privilege and trust, between researchers/institutions and participants. This experience later draped and bent how we approached the participation of culturally diverse youth in research.

During the course of our mentor/mentee relationship, I started my job at the IRB and continued to do research. I began growing into a deeper consciousness into the field of human subject protections. My view of research shifted. More than ever, I felt that conducting research was a privilege and not a right. This was evident in my new role as an advocate for human subjects, and in the often meaningful but difficult conversations with my mentee about the power imbalances between researchers and participants. As she grew older, we

discussed her first experience in research with me as the researcher. She shared that her perception of the power I represented as an authority figure, during our first encounter, led her to feel pressured to participate. When I asked her why she decided to participate, she responded that it was because she trusted me when I reassured her that she didn't have to and it was entirely her decision even if her mother consented. I reflected about the communication gap still present in the researcher-participant interaction.

I was consistently present in her life, guiding her through her successes and challenges. Admirably, she successfully continued her education and completed a master's degree from a prominent university much earlier than expected. As the time passed, our trust grew stronger and there was a gradual shift in our roles from mentor-mentee to peers; she eventually became a colleague. We met regularly for the years to come. I was often stimulated during our sessions because she constantly challenged me about the dominance of researchers in the field of research ethics. I never knew what controversial topics she was going to come up with next. Some of our interactions were to guide her with her school projects, but in some others, I felt she was shaking the very foundation of how I engaged communities. Our relationship had some setbacks, many times I failed to understand her point of view. Sometimes she didn't understand mine, but somehow we became efficient and trusted partners.

What began to bother me, was how blind I had been about the lack of participation of youth in research ethics. I started to notice that both at

conferences and our IRB meetings the voice of young people like her was missing, in spite of the multiple studies targeting them. Most IRBs I knew, had no young patients or former research participants as members. Having never had young people in our IRB, I didn't know where to start to include them. Working with them was challenging, time consuming and costly. I trusted that our IRB had the expertise to make decisions for youth, so I was slow at making changes in our membership to include them.

Then, there was a study in particular that caused me to consider including the voice of youth. The study was a diabetes intervention targeting children and adolescents. I consulted with my mentee and other youth for community input. They gave me an earful! They talked about issues that concerned them like trust, power, privilege, and equal treatment and respect for their culturally diverse communities from researchers and institutions. They were frustrated that there were no youth in IRBs, especially youth of color. Most of the articles they read about research ethics were about the lack of community trust in research, and from researchers complaining about the burden of the regulations. "What about the burden from research in our communities?" they asked. They felt that when researchers included them in research planning, it was only on an advisory capacity, but not as equal partners in all stages of the research, especially in the dissemination of findings and regulation of research.

Within the next few years, from that public comment, the young woman I had been mentoring for many years, and other youth, began the foundation for what was to become our partnership in developing a mentoring program, including a specific research ethics training, to increase the voice of culturally diverse youth in research ethics. We assembled a group of youth and a project that later actively involved youth in research ethics. I will call this "The Project". We discussed implementing an engaged ethics model, however, I had budget and time constraints that posed a challenge to launch it. I also had concerns that there would be additional pressures because the youth may be reluctant to speak up in an environment

dominated by much more seasoned and older IRB professionals. Many times I felt that being in an IRB requires both a higher education and the ability to win a bar fight. The combination of unanticipated budget/time constraints and dynamics increased challenges to implement The Project, for which I was not prepared.

As I spoke to other youth about joining The Project, it was sad to hear how little trust they had in institutions and how much they felt there were abuses of power in research. The youth were not interested in discussing their own personal stories. They wanted to focus on the larger reasons why racial and ethnic communities didn't trust research. Even more disturbing to them, were stories in the media about retraction of journals, conflicts of interest, fraud, and misconduct about research that eroded public trust in science. I was dealing with a well-informed group of young people who gave specific examples. Some of the youth mentioned that racial/ethnic groups lost trust when hearing recent news stories about the inclusion of Latino and Black orphans in research that normally required parental consent. I painfully acknowledged that the cultural distance between these diverse groups and institutions still persisted. I often felt that the field of research ethics faces a critical moment; overall trust in research is low given the conversations I had with these youth; especially youth of color. There seems to be a break-down in understanding how to build relationships with diverse communities who believe that we can all courageously work on often-difficult research issues of public concern. These issues can be resolved without falling into the mistakes of needless harms, research rights violations and contentious relationships between researchers and regulators.

Given these experiences with youth, my practice towards engaged ethics could not have looked more differently about how information is shared among researchers, research participants and institutions. I had known for a long time that we needed to involve youth but didn't fully appreciate their voice. Having this long-term experience with a former research participant, and others like her, showed that we needed to involve diverse

populations at all stages including organizational components of the research, in meaningful ways. I have come to appreciate the views of youth. For example, the youth raised concerns that communities are experiencing a huge growth in cultural diversity. I reflected that our future challenges are not going to be how we implement better information systems, but how well we work with people in multicultural and multigenerational settings. I relearned that the strength of a collaboration is based on forming strong relationships, which can be a slow, long-term, uncomfortable, confusing, and unpredictable process. Also, an engaged ethics is not just about telling people what we do; it's about linking people to the inside of what we do. Giving young people the best opportunities to get ahead and learn means there is a need for patience in continuing the professional development of youth workers. Research ethics professionals like me can do this by mentoring youth in these fields that require specialization.

This appreciation changed the way I practice research ethics. In collaboration with the youth and other community partners, I included the voice of youth in this field. It has not been easy. Since we started The Project, many youth dropped out and some failed the training program. Others preferred to pursue careers in other settings like technology companies where they could work with more of their own peers. Fortunately, as we built trust, the youth who remained showed their strength, courage and confidence by speaking up on issues such as recruitment, the informed consent process and conflicts of interest; important issues of concern to them. The practice of an engaged ethics model is in how a culturally diverse group of youth can change an IRB towards a more engaged ethics. Together, we succeeded in placing four youth, as IRB members and staff, in the field of research ethics. I know this is not a large sample. But engaged ethics is not about numbers, it is about building long, lasting and trusting relationships. Of this, one of the youth commented to me that “one cannot measure trust in a spread sheet”. During their participation in IRB meetings, we engaged in exceedingly controverted discussions that highlighted issues of

power, privilege and trust. My eyes were opened by how the youth challenged some traditional assumptions and questioned the value of previous institutional decision-making. I learned important insights to respond to the lack of trust in research from diverse communities. This joint involvement led to an increased focus on participation disparities of underserved groups. As a result, the youth helped improve the recruitment, informed consent guidelines and conflict of interest policies of an IRB.

This experience converted me into an organizational innovator, which significantly transformed the work I do in collaboration with youth. Since our partnership began, I, along with colleagues, have experienced better connections with youth. The lessons learned by all of us about an engaged ethics are the most prevalent and common in our field. We learned that youth have great cultural capital to offer in terms of understanding the local context, a requirement of the federal regulations for human research. When working with culturally diverse groups, it's important to invest significant time and funds to involve them in all stages of a project, including mentoring, partnering on regulatory guidelines and publications; and not just on an advisory capacity. It is equally important to take action on issues of trust and power that affect the ways ethical standards are developed to do research, with these groups, while considering age, other demographics, and inclusion disparities. Build trust with communities with limited control over decisions made on their behalf, by engaging in discussions about power imbalances and their impact on trust and ask: “are we repeating the same plots or are we organizational innovators?” Then, take action on these perspectives with the partner communities so that they feel like their voices count.

Successful partnerships are built on trust and equal treatment. No researcher–community partnership can exist without both parties participating side by side. Involving youth in all stages of The Project was unusual, but proved powerful to achieve ethics engagement. Trust builds stronger systems of protections and the shift to a collaborative culture is a long-term process. Hopefully, others can join me and the youth with whom I

partnered, to advance their development and increase their voice in research ethics.

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### **Engaging the Disengaged Community: Opportunities, Strategies and Lessons Learned Working with African American Males**

Keon L. Gilbert

#### **A Need for Focusing on Black Males' Social and Health Issues**

Recently, national organizations such as the American Public Health Association have initiated a National Campaign Against Racism to address racism as a underlying force of the social determinants of health and barriers to achieving health equity. The campaign calls for a clear shift in focus, a re-imagining of our traditional research methods, and identification of new and strengthening of existing community relationships and partnerships. More authentic and culturally embedded interventions must be developed that aim to change not just behaviors but systems. The field of public health has made some headway in addressing the root causes of health disparities; however, research on the prolific and constitutive lower health trajectories of black males lags behind this progress. One strategy to do this is to find unique ways to build relationships and partnerships within black communities and with organizations and programs that provide support and assistance to black males.

I, like many other researchers and practitioners, am being called to better understand the social statuses of black males as well as their access and use of health care services and health behaviors

across the life course. The field of public health lacks the contextual evidence that provides us with meaningful processes of engagement and points us towards effective interventions. My work with black males aims to understand the healthy transitions to adulthood that will lead to better negotiations of gender identities and identify key resilience and support factors that lead to engagement in positive coping behaviors. I have used methods such as photovoice (described below) to engage middle school and high school black males in discussions about their health risks and threats to completing high school. These conversations helped me to understand that at these ages and developmental stages there are constant negotiations of their racial and gender identities, which are being shaped by interactions and relationships within their homes, neighborhoods, schools, churches, and in mentoring programs. These are the interactions and contexts public health professionals like myself need to be locate our work and interventions.

To advance research and practice to improve the health of black males, we have to be able to identify not only the barriers to healthy transitions across all life stages, but identify sources of resilience and support. Identifying a way to understand these influences within these various contexts could become part of the key to healthy identity development for black males and become an opportunity to re-structure how these contexts shape what some call hypermasculine behaviors that can be damaging and help community based organizations incorporate this evidence into their programs.

This central focus of my work began with my entrée into the study of black men's health as a W.K. Kellogg Health Scholar (postdoctoral fellow) at the University of North Carolina at Chapel Hill. During this time I worked with a project focusing on cardiovascular disease (CVD) risk for black men in rural black churches in Orange County, North Carolina. This project included a partnership with a community-based organization and the local health department. Also, during my time in North Carolina I began working with middle school and high school boys around issues related to dropping out of high school and health risks. Currently, I am