

Protecting Sexual Minority Youth from Research Risks: Conflicting Perspectives

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Abstract We describe the dilemmas we encountered in the informed consent process for an HIV prevention project targeting Black gay, bisexual, and non-gay identified young men. We highlight the complexities of applying informed parental consent procedures to sexual minority youth and identify some of the challenges that researchers who work with sexual minority youth face when they must balance the needs and rights of this population against the needs and rights accorded to parents by federal guidelines for protecting minor participants in research.

Keywords Gay and bisexual populations · Minors · Informed consent · Research ethics

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Introduction

In this story, we describe the events leading up to our request for a waiver of parental consent for Black¹ gay, bisexual, and non gay-identified youth to participate in one part of an HIV prevention intervention study administered through our university.² We outline our actions when our waiver request was denied by our institution's human subjects Institutional Review Board, hereinafter referred to as the IRB, and describe the dilemma the denial of our waiver request created for us in managing our project's mission to serve Black gay and non gay-identified young men who had little access to HIV prevention resources. We also describe an adverse event that occurred because we elected to exclude minors from this component of the intervention rather than require parental consent. The case we present illustrates the complexities of applying informed parental consent to sexual minority youth. It also highlights some of the challenges that researchers who work with sexual minority youth face when they must balance the needs and rights of sexual minority youth against the needs and rights accorded to parents by federal guidelines for protecting minor participants in research.

Throughout this case, we take the voice of advocates for young Black sexual minority men. Although we provide our understanding of the reasoning of other parties involved in this story to the best of our ability, we have chosen to

¹ We use the term Black rather than African American throughout this document because our staff, partners, and research participants included Africans, African Americans, and Blacks of Caribbean descent.

² The work described in this article was conducted while the authors were in the Department of Psychology at the University of Illinois at Chicago. All references to our university and institution in the article refer to the University of Illinois at Chicago and not to the institutions with which we are each presently affiliated.

tell this story in a way that represents how we experienced the events we describe, rather than to speculate on what others' thoughts, views, and feelings might have been. Our purpose in so doing is to represent a voice that is seldom heard or recognized in discussions about research, that of researchers who work within and are part of sexual minority communities.

Context

The Community Intervention Trial for Youth (CITY) Project was a multisite, 7-year trial of a community-level intervention to reduce HIV infection among young men who have sex with men (MSM) aged 15 to 25. Thirteen catchment areas were in the trial, each of which enrolled a designated racial or ethnic subgroup of young men. The trial sought to reach young men who identified themselves as gay or bisexual, as well as those young men who had sex with male partners but did not embrace a gay or bisexual identity, hence our use of the acronym "MSM" throughout this paper.

At the Chicago study site, the focus of this story, our intervention efforts targeted Black MSM living in predominately poor, racially segregated areas of the city. In the data we collected from young men in Chicago annually, from 24% to 57% in any given wave of data reported that they did not identify as gay. From 23% to 41% of the young men reported unprotected anal intercourse with a male partner in the prior 3 months, and up to 25% reported trading sex for money or drugs in the prior year.

Chicago's predominately Black communities (in the south and west sides of the city) have not traditionally provided much in the way of HIV prevention services for MSM. When CITY began, the majority of Chicago's HIV prevention infrastructure was on the north side of downtown in areas of the city that had strong ties to the White gay community. Chicago had a handful of longstanding efforts devoted to the HIV-prevention needs of the Black community on the city's south side and modest efforts for Blacks on the west side of the city. In the formative data we collected, young men reported they did not feel Blacks were welcome in Chicago's non-Black communities, so they did not access north side services. They also reported reluctance to have services that would "out" them located within their home communities. Young men described a complex set of strategies for how they managed racial and sexual oppression in their lives (Stokes & Peterson, 1998; Stokes, Miller, & Mundhenk, 1998; Wilson & Miller, 2002); young men reported they were highly selective about when, where, and to whom they would allow their sexual orientation and their sexual identification to become visible. If we could manage to deliver our interventions in ways that were culturally welcoming, sensitive to young

men's concerns about selectively maintaining their privacy, and affirming of their diverse sexual identities, we could fill a void for men in great need.

The CITY Project investigative teams had community collaborators and youth advisors who helped design and implement the interventions and research so that the project would be responsive to local needs and the specific cultural milieu of the targeted young men in the various sites and so that the projects associated with CITY might be sustained after the trial if proven beneficial. The individuals directly involved in the day-to-day workings of the Chicago study site included more than 40 people representing over 20 service-providing organizations, bars, clubs, and other institutions. Our community collaborators included local leaders and activists whose expertise reflects Black gay and lesbian concerns, Black issues in HIV prevention, and issues affecting Black youth. Most of these individuals are gay or lesbian and Black and most are affiliated with a local government entity or not-for-profit organization or are intimately involved in the lives of young Black MSM and the social venues available to them. In addition, we had youth advisors who were involved in specific tasks related to the research and intervention, such as developing social marketing ideas and plans for specific interventions. These youth are Black MSM.

The Chicago site was led by the first author, a heterosexual Black-identified biracial woman who has extensive experience working on HIV prevention programs in gay communities. The Chicago intervention staff members are all Black and included one gay man, one straight woman, and one straight man. Although they were not centrally involved in the events described here, the research staff was quite diverse and included Latinos, Whites, and Blacks, men and women, gays, lesbians, and heterosexuals, and people of diverse socioeconomic backgrounds.

The remaining actors in this story are the members of one of our institution's three IRBs. The identities of the individual members of the various boards are not published. According to our university's website, the various boards comply with federal guidelines for membership and include scientists and non-scientists, university and non-university employees, men and women, and members of varied racial and ethnic backgrounds. The expertise of the board to which our research was assigned for review includes cardiology, digestive and liver diseases, health policy research, early childhood education, internal medicine, medical surgical nursing, obstetrics, oncology, pharmacy practice and services, investigational drug service, pediatric hematology, philosophy, psychiatry, radiology, nuclear medicine, respiratory critical care, and surgery.³

³ Sexual orientation and sexual identification are not among the diversity criteria for IRB composition required by federal guidelines.

The events that compose our diversity challenge surround a single element of the intervention, the Community Health Advisors Network (CHAN). The CHAN was based on the success of the Popular Opinion Leader program (Kelly, St. Lawrence, & Diaz et al., 1991; Kelly, St. Lawrence, & Stevenson et al., 1992) and the Mpowerment Project (Kegeles, Hays, & Coates, 1996). Community health advisors were young MSM or near peers (e.g., older Black MSM, MSM allies). They were expected to advocate for the needs of young Black MSM to service providers and officials who have authority over institutions that affect MSM. CHAN members also referred young MSM to the few available services designed to meet their physical and mental health needs. Following the Popular Opinion Leader model, CHAN members verbally modeled risk reduction strategies to peers and provided social support around AIDS-related issues. Finally, the CHAN members helped us adapt and implement the other elements of the intervention. The CHAN was central to the intervention because all the other elements of the intervention (social marketing, social events, skill-development workshops) were linked to it.

Among the elements of the intervention, our local community collaborators expressed the most excitement about CHAN. In our formative work, we had been told that a critical factor in the success of prevention for young Black MSM in Chicago was youth involvement. The few local organizations that were willing to take on HIV prevention for young Black MSM or to expand their activities to include young Black MSM programs wanted efforts that engaged young men. Many of our local stakeholders saw CHAN as a means to get agencies to respond better to young men by having young men play central roles in the agencies. Another reason why the CHAN was appealing to local stakeholders was that it would provide young Black MSM with the opportunity to gain skills in HIV prevention, allowing them to become the next generation of HIV prevention and Black MSM leaders. This appealed to young men because many saw few career opportunities available to them, especially in settings where they felt free from harassment for being sexual minorities. In a city where not much was happening for Black MSM, agencies and Black MSM were hungry for a program like the CHAN.

Because it is the focal challenge of this story, we present a brief overview of how the recruitment and training for CHAN were structured at the multisite level. The multisite intervention protocol described a multiple step process of recruiting people to become part of the CHAN. Fliers and announcements inviting those who were eligible to become a community health advisor would be distributed widely at social events, through agencies, and via snowballing. Fliers would invite people who might be interested in the program to a 2-hour informational meeting. At the meeting, men and

women would be provided detailed information about the CITY Project, the role of the CHAN, CHAN training, the CHAN supervision meeting schedule, CHAN expectations, and other information related to performing as an advisor. Those who were still interested in the project would complete a brief interview conducted by the CHAN supervisor to determine their understanding of the project. Those who possessed adequate grasp of CITY and of CHAN would be invited to complete a 6-session training, after which their suitability to conduct the work of the project would be assessed (e.g., mature, supportive of Black MSM communities, mastered training material). Training would culminate in a graduation ceremony with certificates of achievement for the graduating CHAN members. Each CHAN cohort would then be based at a local organization. No data would be collected from CHAN members at any point in the research, though they would provide process data enabling us to monitor their activities. The CHAN members would be excluded from participating in the outcome evaluation of the intervention. At the insistence of our community collaborators, Chicago CHAN members were compensated at the rate of \$50 a month for a minimum of 10 hours of work. No other site compensated members of CHAN.

Because the multisite project evolved over several years and in collaboration with local community partners and a multisite study team, IRB applications were filed in stages, with multiple amendments, rather than in a single package at the project's outset. All of the sites in the multisite study submitted their IRB applications in parallel fashion at each stage of the study, though each application was prepared to accommodate local requirements for format and level of detail and each reflected unique tailoring to suit the local culture. The original Chicago site protocol was approved in 1996. However, in August of 1999, all human subjects research at our university was suspended by the Federal Office for the Protection of Research Risks for violations of its administrative and procedural guidelines. Following extensive mandatory retraining of all IRB members and campus researchers and a complete overhaul of all IRB procedures and forms, on the occasion of our university's reinstatement every protocol on the campus was re-reviewed in its entirety. Thus, we were required to resubmit all of the data collection protocols, measures, and consents that had been previously approved, as well as all of the material concerning future activities, including CHAN as a single package. The outcomes of our emergent community-negotiated dialogue, formerly presented to the IRB incrementally, were now a single, 10-inch tall document.

As part of the IRB application for the intervention and outcome components of the study, all sites requested a waiver of parental consent for the outcome data collection – a street intercept sexual behavior interview – and all were granted such a waiver. All sites also argued that the dynamic, community-

level nature of the intervention made it unfeasible to obtain consent from those who accessed the intervention, and so no consents would be obtained from those who interacted with the CHAN members, dropped in on small groups, saw social marketing materials, or attended social events. All of the IRBs agreed that the way in which our interventions were to be implemented made it unfeasible to obtain informed consent and that the lack of informed consent would not be detrimental to the well-being of the participants. Unexpectedly, as part of the 1999 re-review, our IRB required that CHAN members provide written informed consent to participate in the CITY Project, a requirement we initially objected to given the extent to which our recruitment procedures fulfilled the aims of providing informed consent and the fact that we collected only process data from CHAN members. Nonetheless, we designed an informed consent document describing the research, the role of CHAN members, the risks and benefits of the research, the voluntary nature of their participation, and the fact that we collected no personal data from them. Although this form was deemed acceptable, we had not designed a parental consent and youth assent form for CHAN members who might be minors. Our IRB came back to us requesting that we develop a CHAN parental consent/youth assent procedure and forms.

Challenge and response

Should parental consent to be a CHAN member be required of minors? Staff felt strongly that the answer to this question was “no.” These youth should not have to acknowledge to their parents or guardians that they might be MSM in order to participate in the CHAN. It was not possible to write a parental consent document that accurately described our research without it being obvious that this project was focused exclusively on MSM and that CHAN members were, more often than not, MSM. We thought a parental consent process ran the risk of ‘outing’ some youth to their parents or guardians, with potential harmful results.

Through our formative research (Stokes & Peterson, 1998; Wilson & Miller, 2002) and our knowledge of the literature on MSM youth, we knew that many youth had probably not disclosed to their parents that they were having sex with men and feared the consequences of such disclosure. Some might have little if any contact with parents or guardians. Given this, parental consent would create *de facto* exclusion of youth who were not out—a potentially large group of youth and one that we were especially interested in reaching with prevention information—and might put some youth at risk of harm from parents and guardians whose reaction to their child’s disclosure the youth had miscalculated. The process of consent might alter normal parent-child relationships by conferring stigma on the youth or inviting rejection or abuse,

a principal criteria for granting a waiver of parental consent outlined in the federal guidelines governing human subjects protections. Youth might also seek to avoid disclosure to their parents via a consent process, declining to participate in the program on that basis alone. In this sense, running the CHAN for our 15 to 18 year olds was potentially impracticable if parental consent was required to participate.

Two additional factors led us to question the appropriateness and necessity of obtaining parental consent. First, CHAN members were not subjects as much as they were lay staff and partners. CHAN members were delivering the intervention for compensation, as well as for direct and indirect personal benefits (e.g., future employment, knowledge about HIV, learning how to reduce their risk of exposure to HIV). A parental consent/youth assent process seemed incongruous with the lay professional role that we were asking them to assume. Youth could work for us in any other capacity, such as serving as a project advisor or interviewing other young men about their sexual behavior, without a parental consent requirement. And, as noted above, we were not collecting personal data from CHAN members, so although they were integral to the research and potential beneficiaries of it, they were not its object in the traditional sense. Second, we were granted a waiver of informed consent for participation in every element of the intervention and a waiver of parental consent to participate in our outcome data collection. To single out participation in CHAN training from social events, skills-building workshops, being counseled by a CHAN member, and participating in data collection seemed inconsistent with the logic of these waivers. Given the potential direct benefits of participation, the potential harms to youth of requiring parental consent, and the impracticality of carrying out this part of the research with a parental consent requirement, we thought we had an especially strong case to be granted a waiver of parental consent. Further, across 13 sites we were the only site whose IRB insisted we obtain parental consent for the CHAN. These points formed the substance of the argument we made to our IRB. We applied for a waiver, outlining our position that it could be dangerous to put youth in the position of disclosing that they were MSM to their parents or guardians and that seeking parental consent would therefore not necessarily operate to protect the child.

Our IRB disagreed with our position. For the IRB, a parent’s right to determine what activities their children are engaged in, especially when an invasive topic such as sex is involved, trumps a child’s right to privacy. Additionally, the nature of our study, because of its focus on HIV prevention, made the research more than minimal risk (e.g., greater than the risks encountered in daily life) and subject to the most stringent criteria for waiving parent consent. Further, these youth were not anonymous because they had repeated contact with us, so a waiver of parental consent was considered inappropriate. Through multiple written exchanges, we argued

our position. To each letter, we received a non-negotiable response. Thus, we were unable to make our case effectively, were denied permission to recruit minors as CHAN members without the consent of a parent or guardian, and had to decide how the work would go forward. As all of the sites in the study that focused on Black MSM were on hold pending our IRB approval, resolution of this issue was of the utmost urgency for the multisite work to move ahead.⁴

Because the protocol allowed youth to participate in any other intervention activity, including being counseled by a CHAN member, without parental consent, our research team decided with regret and a great deal of anger to exclude those under 18 from CHAN. We were the only site in the multisite study to disallow youth participation in CHAN. Our deliberations on this point were nothing short of agonizing. Here we were in a state in which 12-year olds could access reproductive and sexually transmitted disease services without parental consent or knowledge, yet a 16- or 17-year-old Black MSM could not decide to work for our project as a peer leader without a parent's consent! The goal of CHAN was to connect youth to one another and to agencies, to develop their skills in advocacy and risk-reduction, and to build a supportive, healthy, affirming community of young Black MSM. The trial was purposefully designed to include those young men who were not yet old enough to access bars, those who were close in age to their initial experience of sexual intercourse, and those who had little access to a supportive community. How could we keep this commitment and at the same time allow only those youth who maintained good and open relationships with a parent or guardian to participate? We reasoned that it was better to exclude all minors from participating in CHAN than to include only those who were out to their parents or who might be willing to out themselves in order to participate. The risk that one youth would experience adverse consequences through the parental consent process was deemed too great.

Although our morale was low at other points in the 7 years we worked on this study, this event marked one of our lowest moments. For many of the members of our study site, the IRB's decision mirrored the day-to-day oppression we experienced in our personal lives, exacerbating our frustration. No matter what we decided to do, any decision we made would in one way or another betray our commitment to those with whom we had worked to create an accessible intervention for marginalized young Black MSM. Little did we know that our morale was about to further slip.

Not long after our second cohort of CHAN members had completed training, our CHAN coordinator received a telephone call from a social worker. She was calling because a young Black gay man in her guardianship had told her that

he was part of the program. She wanted to learn more about it and seek guidance from us about how she could better help the youth. The youth had stopped going to school and other activities. CHAN was the only pro-social activity in which he participated. She wanted to know what we were "doing right."

The quick-thinking staff person who received the call realized that the CHAN member was a minor ward of the state and that the youth had misstated his age when he signed the informed consent. The staff person did not acknowledge that he knew of the youth's participation, which would violate the youth's confidence and our interpretation of the protections we were obligated to provide him once he had signed our informed consent document. The CHAN coordinator instead referred the caseworker to the PI. The CHAN coordinator and the PI agreed not to disclose information to the caseworker without the express written permission of the youth; they also agreed that the youth would have to be withdrawn from the program unless there was a way to obtain the guardians' consent and permission from the IRB to handle the situation in this manner.

In speaking with the caseworker, the PI did not acknowledge whether or not the youth was a program participant. She explained that the project was a research project and that youth under the age of 18 were ineligible to participate in the CHAN component of the study without the consent of a guardian. The caseworker told the PI that the youth had reported to her how positively he felt about his participation in the program. The caseworker expressed dismay that the youth was ineligible and was eager to allow his continued participation.

The PI contacted the IRB and proposed a special consent process to allow the youth's continued participation. The IRB agreed that withdrawing him might do more harm than good, so would allow his continued participation with the signature of his guardian, as the PI proposed. However, negotiating the institutional bureaucracy of the Illinois Department of Children and Family Services (DCFS) was too daunting and lengthy to make obtaining his guardian's consent feasible before the intervention would end. We withdrew his participation, while also making it clear to him and to his guardian that he could come to events or other project activities. The young man's caseworker maintained contact with us in order to keep abreast of what youth-focused activities might be going on for Black MSM in which he might participate, which he occasionally did.⁵

⁴ All of the Black-focused sites were subcontracted through our site, so beholden to our IRB's ruling, as well as their own.

⁵ We would have had to file an IRB application with the DCFS and go through multiple internal DCFS review processes to obtain his guardian's signature.

Reflections

We have many more thoughts and reflections on our experience than can be reasonably discussed here, so we focus on the decision-making rubric articulated in the code of research ethics promulgated by the U.S. Department of Health and Human Services in light of our work with Black sexual minority youth.

The Code of Federal Regulations for the Protection of Research Subjects, 45 C.F.R. 46, outlines two circumstances under which parental consent may be waived. The first circumstance is when research of minimal risk (i.e., not greater than what a youth experiences in daily life) is impracticable to conduct with parental consent and a waiver, if granted, would not adversely affect the child or compromise his or her rights. When research is judged as more than minimal risk, as ours was because of its sexual content, stricter standards apply. The second condition is when the consent process will not protect the child, as might be the case with youth whose parents have demonstrated abusive or neglectful behavior. An essential question raised by our case concerns why, among a sexually active population of young men in one of the highest risk groups in the nation—economically-disadvantaged Black MSM under age 25—would learning how to be a peer leader and talk to others about HIV prevention be considered more than minimal risk?

In assessing the risk of our research to these young men, we took the perspective that risk of harm varies as a function of context and social position. As such, factors such as race, class, gender, sexual orientation, sexual identity, and social power should inform an assessment of risk. In thinking about these youth, therefore, our standard for judging the risk of our research to them was the risk of participating in our study relative to the risk typically experienced by similar youth engaging in similar risk behavior and with similar access to information and services and at similar risk of exposure to HIV and *not* the background of heterosexual youth living in advantaged communities in which information is more readily available and the background prevalence of HIV is markedly lower. As Macklin (1992) notes, the ordinary daily life experiences of youth such as ours are imbued with many risks that other groups of youth seldom encounter.

The everyday life experiences of Black MSM youth can routinely place them at harm if only simply the harm to mental health associated with living in a homophobic society and society in which Black access to power and resources is low. Our formative data describe youth who are disenfranchised from mainstream institutions and struggling to cope with their sexual identity in the face of heterosexism, poverty, and racism (Stokes & Peterson, 1998; Wilson & Miller, 2002). Our data are also consistent with multisite data indicating that these youth are at high risk of exposure to HIV. Our research was designed to reduce some of those

everyday harms using interventions that enjoy scientific support among youth who lived in an environment that offered few HIV-related and gay-sensitive resources—a point we did not emphasize to the IRB because the overall purpose of the study was to establish the benefits of the interventions with these youth. Although there was always the possibility that our interventions could actually harm youth, scientific evidence for interventions such as ours suggested that this was a reasonably unlikely occurrence. Viewed in this context, our research was not terribly risky and held out the possibility of direct benefit to youth.

That this was a low risk intervention seemed so plain to us that we failed to see how unobvious this is to others. Why did our IRB view our research, and CHAN in particular, as more than minimal risk? Most obviously, HIV prevention research may cause psychological discomfort for participants, including embarrassment, shame, and fear (risks of which we are well aware and do not consider greater than those encountered in the day-to-day lives of most of the youth with whom we worked). Viewed against the daily life background of youth who are enfranchised because they are heterosexual, white, or economically better off, our interventions could readily be judged as more than minimal risk because they expose youth to information, ideas, and material that is likely to be atypical of their daily experience. We were not privy to the IRB member's discussions on this point and the correspondence we received provide no insight regarding whether these or other issues informed their judgment of the risk of our research. It is certainly plausible that IRB members may have felt that it was especially prudent to be cautious in granting waivers of parental consent, as our institution was functioning under the close scrutiny of federal overseers as a result of our federal sanction.

A parent's right to know what their child is involved in and determine whether those activities are permissible outweighs a child's right to privacy and autonomy in federal law and in day-to-day social practice. It is the parent who has the authority to determine what is and is not harmful to his or her child and it is the parent who has ultimate responsibility to keep his or her child out of harm's way. It is assumed that parents will fulfill this responsibility and act with the child's benefit in mind, protecting the child from harmful experiences. No parent ought to be viewed as abrogating his or her parental responsibility without compelling evidence that he or she is derelict in fulfilling this social responsibility. Hence, waivers of parental consent require clear evidence that parents do not have the best interest of youth in mind or that the research cannot be carried out without such a waiver. Given a conservative interpretation of these guidelines, our research did not provide a strong case for a waiver.

There are many kinds of behavioral research in which knowing that someone might participate provides little or no private information about the individual and has little if

any material impact on the beneficence of the relationship between those who know of a subject's participation (e.g., parents) and the subject (e.g., children). However, for some research, the consent process itself may change the parent-child relationship—if it exists at all—from beneficent to non-beneficent (Grisso, 1992). Research on sexual minorities and on topics such as AIDS can create situations in which knowing of someone's participation (or prospective participation) may cause direct harm in the form of rejection, stigma, and physical and emotional abuse, among other potential harms (Rotheram-Borus & Koopman, 1992). For this reason, it is the practice of many agencies specializing in the needs of sexual minority youth to advise youth not to disclose their sexual identity or orientation to others, including parents, unless they are absolutely certain of their safety. Some professionals further advise youth to line up some place safe to stay and arrange for someone to check to make sure that they are okay after a disclosure.

Although not all sexual minority youth are rejected, there is ample evidence to suggest that these youth are more vulnerable to non-beneficent behavior on the part of their parents than are heterosexual youth (Rivers & D'Augelli, 2001; Rosario, Rotheram-Borus, & Reid, 1996). As a result, assumptions regarding "normative" parent-child relationships may not apply equally to sexual minority youth. Further, some cultural groups are perceived as especially intolerant of sexual minorities, which may serve to alter the character of the relationship between a sexual minority youth and his or her parent and a youth's perception of his or her safety within his or her cultural community (see, for example, discussions of homophobia in the Black community in Brown, MacIntyre, & Trujillo, 2003; Cohen, 1999; Dalton, 1989; Quimby, 1993; Roberts & Miller, 2004; Stevenson, 1994). Male youth, in particular, may be subject to abuse and rejection given the widespread tendency in U.S. society to feminize and emasculate sexual minority men. Even parents who tolerate their sexual minority youth may be sufficiently removed from the interests of these youth as a result of ignorance of or antipathy toward sexual minorities to compromise their ability to make sound judgments about what might harm or benefit their youth. Should we extend parents the benefit of the doubt or assume the worst of them, given entrenched homophobia in our culture? Given their status as vulnerable minors, should we usurp parental authority as a precaution against the non-beneficent parent?

The case of sexual minority young men and women highlights the ethical tensions between youths' rights to autonomy, privacy, and freedom and parents' right to protect their children from harmful experiences. Perhaps we were wrong to refuse to require youth to obtain parental consent and to exclude them from the CHAN. A case can be made that we – not the IRB – were overly paternalistic and that we – not the IRB – failed to have the best interest of vulnerable minors

in mind. The cost of not doing the research was reasonably high, given the dearth of published HIV-prevention interventions for young Black MSM and the practical value of delivering a program based on well-documented strategies to youth in great need. Arguably, we should have made sure that any youth who assented to be in the program and could also obtain parental consent was entitled to participate. But sexual minority youth face unique circumstances that may warrant alternative approaches to consent procedures. In the absence of such procedures, we thought that adverse events resulting from disclosure and de facto exclusion of youth who were unwilling to disclose was the greater harm.

Our experience highlights the central role diversity plays when considering difficult questions about harm and safety in research. Stories such as ours serve to illustrate the assumptions underlying federal standards governing research and also help us to crystallize and examine the worldview that guides our own ethical decision making process. Our IRB members acted to protect our youth from research-related harms, as is their charge. On a personal level, we saw this issue much the way the young Black MSM with whom we worked saw it: an act of insensitivity to the alternative life circumstances of young MSM and an obstacle to our taking care of young members of our community. This difference in worldview remains emblematic of the challenges we will continue to face working in the context of diversity.

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