

[Roundtable Discussion Symposium; Word count = 1,106; Rating = 5.0]

Title: Overcoming Obstacles to Research with Gay, Lesbian, Bisexual, and Transgender Youth

Chair: [name]: Recruitment of GLBT youth- overcoming sample and sampling limitations

Panelist 1: [name]: Why we have an ethical obligation to do this research

Panelist 2: [name]: Waivers of parental consent and other IRB issues

Panelist 3: [name]: Defining the GLBT youth target population

Panelist 4: [name]: Collaborating with GLBT community agencies

Although scholarship on gay, lesbian, and bisexual (GLBT) youth has been conducted for over three decades, only recently have rigorous behavioral science methodologies been applied to the study of their psychology and health. Early studies focused on GLBT youth in difficult circumstances—in support groups, psychiatric offices, and homeless shelters—because these youth were most readily identifiable by behavioral scientists (Savin-Williams, 2001a). In the last decade several cultural shifts have produced a sea of change in the lives of GLBT youth who are now coming out earlier, organizing, and becoming agents in both the gay community and youth culture (Savin-Williams, 2005). The heightened accessibility of GLBT youth and dramatic changes in their social status requires new research to identify both health disparities and areas of resilience among this sub-population of youth.

One area where this research has already begun to grow is in HIV risk. The shifting demographics of the HIV pandemic towards youth (CDC, 2006) has led to a surge in research on young men who have sex with men (MSM). According to a seven-city CDC study of >3,000 young MSM ages 15-22 years old, 7.2% were HIV positive, with dramatic disparities by race (3.3% White, 6.9% Hispanic; 14.1% Black) (Valleroy et al., 2000). These rates are 36 times those found in the most comparable general sample of young men—applicants to the Federal Job Corps program (Valleroy, MacKellar, Karon, Janssen, & Hayman, 1998). In addition to elevated HIV risk among young MSM, research has also found sexual orientation disparities among youth in other aspects of health and health behaviors. For example, there is evidence that GLBT youth report higher rates of alcohol consumption and problem drinking that do not drop off with age as quickly as their heterosexual peers, although findings have been inconsistent. Use of other serious drugs, such as crystal methamphetamine, have also been documented in the literature at alarming rates (Garofalo, Mustanski, McKirnan, Herrick, & Donenberg, 2007). Finally, although no research has found GLBT youth to be over-represented in completed suicides, at least 16 studies have reported high rates of suicide attempts, ranging from 20% to 53% (McDaniel, Purcell, & D'Augelli, 2001;

Savin-Williams, 2001b). Unfortunately, the public health response to the health needs of GLBT youth has not been commensurate with the magnitude of these health disparities (Mustanski, Garofalo, Donenberg, & Herrick, 2007).

Clearly the prevalence and disparities in these health domains warrant further understanding of the unique risk and protective factors for these youth. Unfortunately, a number of logistical and scientific barriers stand in the way of this important research. These issues include attaining IRB approval and the role of parental permission, recruitment and sample representativeness, successful collaboration with community-based GLBT agencies, obtaining funding, and defining the target sample (GLBT, sexual minority, same sex attracted?).

The issues around IRB approval are significant. Recently Miller and colleagues (2006) described a situation where a particular IRB would not grant approval for young gay men to act as community organizers/educators in the context of a CDC funded community-based HIV prevention program. Miller et al. discuss how the ethical principals of beneficence and justice come become unbalanced by overly paternalistic efforts to protect participants. Similarly, many investigators have put extensive resources into arguing for waivers of parental permission for GLBT youth participation based on the concept that requiring parental permission could increase risks to participants (i.e. potentially requiring them to out themselves and be at risk for parental retribution). Dr. [panelist name] will provide an overview of these issues.

Issues with recruitment and representativeness of GLBT youth have plagued this area of work since the start. Convenience sampling approaches lead to questions about generalizability, while questions about sexual orientation are rarely included in major epidemiological studies of youth. Novel approaches for allowing generalization of data to “hidden populations,” such as Respondent Driven Sampling (Heckarthon, 1997), have been successfully used with adult gay men, but their feasibility with GLBT youth is still unresolved. Drs. [panelists’ names] will describe their experiences using these approaches.

Collaboration with community-based GLBT agencies can be a critical step in successfully conducting research with GLBT youth, but these relationships can be difficult to negotiate. Some agencies are weary and distrustful of researchers as they can be viewed as exploiting the agencies’ client-base and their presence can be seen as a breach of confidentiality in the services being sought being sought by GLBT

youth. Recruiting participants for research out of these community agencies can create problems of its own. It is often difficult to find members of hard to reach populations by canvassing the community so it can be necessary to use agencies as bases for recruitment. However, individuals who access services at such agencies may represent a significantly biased subgroup. For example, GLBT youth who access services at community agencies may be further along in the process of “coming out” as GLBT and more comfortable with their own sexual identities than the population as a whole. On the other hand, youth may access these agencies to receive help with psychosocial or health problems. Dr. [panelist name] will lead the panel discussion in this area.

Funding is critical for large-scale research, but substantial difficulties arise in obtaining grants for GLBT youth research. The limited representative data on this population make it difficult to argue decisively for the significance of the research question, while at the same time limited background and preliminary research can make applications appear unfeasible. Panelists will discuss their approaches to successfully receiving federal research grants to study GLBT youth.

A final complexity in conducting GLBT research is defining the community being studied. Some have argued that recruiting participants who identify as GLBT excludes many other youth who may have same-sex attractions or have engaged in same-sex behavior, but do not use the GLBT label (R.C. Savin-Williams, 2005). But attempting to recruit youth based solely on stigmatized attractions or behaviors can be difficult if not impossible. Mr. [panelist name] will lead the panel discussion on this topic.

The goal of this innovative roundtable discussion is to discuss these issues and offer illustrative examples of how they have been addressed in successful research with GLBT youth. The panel is comprised of four principal investigators of federally-funded (NIH and CDC) studies of GLBT youth, the deputy director of the Midwest’s largest GLBT health center, a graduate student focusing on GLBT youth, and is multidisciplinary (including Adolescent Medicine, Clinical, Community, and Developmental Psychology). Each panelist will describe a particular obstacle to successfully conducting this research and how it was overcome and then lead a panelist discussion on this topic. At least 45 minutes will be left for audience questions and discussion.