

Community Perspectives on Developing a Sexual Health Agenda for Gay and Bisexual Men

Stewart Landers · Jim Pickett · Leo Rennie ·
Steve Wakefield

Published online: 19 February 2011
© Springer Science+Business Media, LLC 2011

Abstract Community mobilization around gay rights in the late 1960s and 1970s led to the first efforts to improve the health of gay and bisexual men. In the 1980s the deadly AIDS epidemic was responded to with fierce organizing and community activism, primarily led by gay men. Today, community involvement is crucial to many advocacy and organizing efforts for the health of gay and bisexual men. This article begins with the roots of this history and then describes how they are reflected in a number of key health initiatives for this community including the National Black Gay Men's Advocacy Coalition, the Legacy Project, International Rectal Microbicide Advocates and the Gay Men's Health Agenda. A path forward is described in terms of next steps for advocacy for gay men's health and the health of gay and bisexual men of color emphasizing cultural viability, development of new leaders, and strategic alliances.

Keywords Activism · Community organizing · Gay men's health movement · Rectal microbicides · Vaccine preparedness · HIV/AIDS

Introduction

A gay men's health movement has emerged in the past decade that has changed the notion of how we think about the health of gay, bisexual and transgender men as well other men who have sex with men (MSM) [referred to throughout as "gay and bisexual men"]. Prior to the twenty-first century, research and programs to improve gay and bisexual men's health focused almost exclusively on HIV/AIDS. Today, however, there is increasing recognition that gay and bisexual men's health involves much more than the prevention and treatment of HIV/AIDS. In fact, gay and bisexual men experience significant disparities in physical, behavioral, and mental health, and must contend with widespread stigma and structural homophobia. For gay and bisexual men of color, these problems are compounded by institutionalized racism.

Given the magnitude of these issues, a growing number of advocates, researchers, public health officials, and clinicians believe that the best strategy for improving gay and bisexual men's health should be one that is assets-based, holistic, and sex positive. Community advocates have driven this shift in perspective, much as they drove the response to the HIV/AIDS epidemic. Those who promote this approach are a loose collective of individuals who make up the revitalized gay men's health movement.

The purpose of this article is to demonstrate some of the ways that community mobilization has worked to improve gay men's health, to propose a national advocacy plan to promote gay men's health in the near future, and to discuss the challenges and opportunities that lie ahead for implementing the policy and programmatic changes in the advocacy plan. To that end, this article presents highlights from gay and bisexual men's historic community involvement in HIV/AIDS advocacy, including efforts to

S. Landers (✉)
John Snow Inc., 44 Farnsworth Street, Boston, MA 02210, USA
e-mail: landers@jsi.com

J. Pickett
AIDS Foundation of Chicago, Chicago, IL, USA

L. Rennie
American Psychological Association, Washington, DC, USA

S. Wakefield
HIV Vaccine Trials Network, Seattle, WA, USA

include and address issues of gay and bisexual men of color. It then highlights some key community initiatives that take an assets-based approach to HIV/AIDS prevention and other gay men's health issues. Finally, the article finishes with a look at the current action plans of the gay men's health movement, and discusses ways in which advocates, policymakers, and public health officials can partner to improve the health and well-being of gay and bisexual men in the U.S. and internationally. We believe that the passion and organizing strengths of the gay community can be directed toward developing and implementing an assets-based and culturally adaptable framework for improving the health of gay/bisexual men and other MSM.

Early Community Activism

Community involvement has been an essential part of the history of gay and bisexual men's struggle for civil and human rights, and has been a hallmark of the response to the HIV/AIDS epidemic from the beginning. AIDS was first reported to the public by the Centers for Disease Control and Prevention (CDC) on June 5, 1981 [1]. Soon thereafter, people living with AIDS and other AIDS activists came together at a conference in Denver, CO to voice their commitment to take action. There they drafted and presented a document, called the Denver principles, which boldly listed demands for rights, support, and equity for people with AIDS. The opening line of the Denver principles reads: "We condemn attempts to label us as 'victims,' a term which implies defeat, and we are only occasionally 'patients,' a term which implies passivity, helplessness, and dependence upon the care of others. We are 'People With AIDS' [2]."

Around the same time as the Denver conference, chapters of the AIDS Coalition to Unleash Power (ACT-UP) formed in New York, Chicago, San Francisco and other cities across the country. ACT-UP members performed non-violent direct action activities such as "die-ins," chaining themselves to the Food and Drug Administration building in Washington, and hurling condoms at parishioners. Their civil protests were designed to bring attention to the great need for improved and accelerated AIDS research, education, and treatment.

A common misconception of the gay men's health movement, especially in its earlier years, has been that it is primarily a movement for and by white men. In fact, men of color have been involved in ACT-UP and other advocacy work since the beginning of the epidemic. For example, in 1985, the National Association of Black and White Men Together (NABWMT), an organization of gay men dedicated to overcoming racism, sexism, homophobia,

and HIV/AIDS discrimination, noted a lack of HIV education and service programs by and for gay and bisexual men of color. That same year, the National Task Force on AIDS Prevention (NTFAP) called for the development of racially and culturally-specific prevention models, including services and education for African Americans, Latinos, Asian-Pacific islanders and native Americans. NTFAP quickly became a resource for collective and community action across racial, ethnic, and cultural lines to foster creative responses, train trainers, and develop culturally-appropriate materials to address gaps in prevention services. NTFAP also worked vigorously to ensure that gay and bisexual men of color are explicitly targeted for HIV/STD prevention and mobilized to ensure prevention services. Despite these efforts, the goals of deeper involvement of men of color in the gay men's health movement, as well as greater consideration for the epidemic's disproportionate burden among these men have not yet been realized.

Current Community-Based HIV Prevention Programs

National Black Gay Men's Advocacy Coalition (NBGMAC)

In 2005, the CDC released data that a startling 46 percent of black gay and bisexual men sampled in a five-city behavioral surveillance study tested positive for HIV [3]. After the report's release, black gay and bisexual leaders noticed that no one seemed surprised by the data; moreover, they sensed an absence of real urgency from the public health community, governmental officials, and the community itself to respond. Advocates began pushing for a response equal to the enormity of the problem, eventually leading the CDC to convene, in August 2005, its first consultation ever to focus on the HIV prevention needs of black gay and bisexual men.

In January, 2006, black gay and bisexual men working in community-based organizations, national HIV/AIDS policy organizations, and health departments held a retreat in Miami, FL to develop organizing principles for the group that would become the NBGMAC. The NBGMAC was officially formalized in April 2006 with an executive committee put in place for governance.

Today, NBGMAC is recognized as an important advocacy force on black gay and bisexual men's health and wellness issues. In 2007, the coalition hired a national policy advisor to guide its work, which focuses on research, policy, education, and training.

NBGMAC pursues its national policy priorities by building and maintaining strong relationships with federal agencies, members of congress, and national organizations.

The coalition is an important model of how a community can mobilize in response to data and the urgent need to effect change in gay men's health.

The Legacy Project

A critical component of the response to the HIV/AIDS epidemic is prevention research, both behavioral and biomedical. Historically, men of color have been mistreated and abused by medical research, leading to a deep distrust of the field and a reluctance to participate in trials. To help stem the HIV/AIDS epidemic among gay and bisexual men of color, however, it is necessary to engage these men in HIV prevention research studies so that the interventions developed will be effective for them within the specific circumstances and context of their lives. Agencies charged with conducting HIV vaccine research (namely the HIV vaccine trials network [HVTN], which is supported by the Division of AIDS [DAIDS] of the National Institute of Allergy and Infectious Diseases [NIAID]) discovered that this was not happening. Among vaccine studies, it was found that 30.6 percent of all volunteers were black and only 5.3 percent were Hispanic. These numbers are not adequate to accurately assess the effectiveness of any vaccine candidate within these communities. To respond to this problem, in 2006, the HVTN in conjunction with DAIDS and the NIH Office of AIDS Research examined its global efforts to ensure capacity to create an effective vaccine for all people. It determined that the types and numbers of HIV vaccine research participants be based on a formula that reflects each group's level of risk and HIV infection rates.

Research sites and academic and civic leaders worked together to develop HVTN's Legacy Project with the main goal of increasing the participation of African Americans and Hispanics in HIV vaccine studies. Pilot projects were mounted that went beyond historic efforts to be client-centered but began to build cultural viability. Legacy is committed to building bridges of trust to overcome historic perceptions and misinformation about research in a manner that includes education and skills building for clinical staff while educating potential trial participants. The project seeks to increase participation of black and Hispanic people of all genders, but has found particular success with black gay and bisexual men, many of whom have identified Legacy as an ally in addressing research challenges.

In 2009, building on the success of the HVTN Legacy Project and broadening the focus to all the DAIDS-funded HIV clinical trials networks, a new set of clinical trials is underway in which enrollment of representative numbers of people of color is critical. These trials reflect the perspective of community advisors and advocates that future prevention trials should incorporate multiple biomedical

interventions including microbicides, pre-exposure prophylaxis (PREP), vaccines, and/or behavioral interventions. The Legacy Project is leveraging relationships and working hard to broaden the focus to all the DAIDS-funded HIV clinical trials networks. Another new effort is the NIAID HIV Vaccine Education Initiative (NHVREI) which helps educate gay and bisexual men of color about HIV vaccine research and creates an environment that encourages them to develop more positive attitudes towards clinical trial volunteerism.

International Rectal Microbicide Advocates (IRMA)

Along with HIV vaccine research, scientists are currently attempting to develop safe and effective microbicides—compounds that can be applied to the vaginal or rectal mucosa to prevent HIV infection during sexual intercourse without a condom. Until recently, however, the research was focused on vaginal microbicides, and there was little to no discussion or activity around development of a rectal microbicide due to homophobia and a myopic focus on condoms.

Men working in HIV prevention, many of whom are part of the gay men's health movement, joined in the advocacy and education efforts around the need for vaginal microbicides without hesitation, and understood that putting a safe and effective vaginal microbicide into the hands of women is critically important, especially in countries where women bear the brunt of the epidemic. But as more and more gay and bisexual men became aware of the quest for a vaginal microbicide, many asked, "what about rectal microbicides?" High rates of infection in gay and bisexual men had not abated, and the "wear a condom every time" message no longer resonated as it did prior to the advent of effective anti-retroviral therapies. A new tool in HIV prevention was clearly needed for gay and bisexual men. The energy around their desire for a rectal microbicide, coupled with the growing evidence that women also engage in anal sexual behaviors, pointed to the need for a movement dedicated to rectal microbicide research specifically. Anna Forbes of the Global Campaign for Microbicides (GCM), a leading advocacy organization dedicated to the pursuit of vaginal microbicides, understood that gay and bisexual men, in alliance with women, should take the lead on such an endeavor.

At Forbes' urging, representatives from GCM, the Community HIV/AIDS Mobilization Project, Canadian AIDS Society, and the AIDS Foundation of Chicago came together in 2005 to form IRMA. IRMA has since grown into a global network of advocates, scientists, policy makers and funders from six continents working together to advance a robust rectal microbicide research and development agenda with the goal of creating safe, effective,

acceptable and accessible rectal microbicides for the women, men, and transgender individuals around the world who engage in anal intercourse. Key to the mission is confronting the institutional, socio-cultural and political stigma around the public health need for rectal microbicide research. Gender dynamics, human rights, lesbian, gay, bisexual, and transgender (LGBT) rights, and criminalization are also addressed in IRMA's work. Anal health, including HPV and anal cancer, is also an important part of the agenda, as is lubricant safety and the promotion of female condoms.

Community building and organizing activities spearheaded by IRMA include the maintenance of a vigorous, highly utilized, moderated listserv in which information is regularly disseminated and members engage in multi-directional dialogue and debate. Regular global teleconferences feature speakers from around the world who are leading rectal microbicide research and advocacy efforts, providing an important opportunity for members who are not able to travel to conferences to learn the latest developments from experts in the field. Additionally, IRMA maintains a resource-rich website, an active blog which is available on Facebook and through a syndication service called FeedBurner among other means of accessibility, and a dynamic presence on Facebook and Twitter. In addition to information dissemination, these tools personalize the movement by providing a platform to highlight the faces behind the work. Biennial reports, the third of which was published in May 2010, analyze the state of research and advocacy efforts and track global resources devoted to the rectal microbicide field.

IRMA launched a global web-based survey for 29 weeks in 2007. (An overview of the results from this survey can be found in IRMA's report: *Less Silence, More Science: Advocacy to Make Rectal Microbicides a Reality*.) The survey provided extensive information on lube use, preferences, and acceptability among nearly 9,000 men, women and transgender people from over 100 countries, and established a prioritized list of the most widely-used lubes to test for rectal safety. This data was subsequently used to inform a laboratory study, and was published in *Sexual Health* in 2010 [4].

The Gay Men's Health Agenda (GMHA)

In the midst of advocating for a broader and more inclusive response to the HIV/AIDS epidemic, community activists began to recognize the need for expanding the gay and bisexual men's health movement beyond just HIV/AIDS. This realization was part of a larger, re-energized LGBT health movement that began in the late 1990s, and that developed as a way to bring more research and clinical attention to the many health inequities found among LGBT

people. In 1999, Eric Rofes and other community leaders organized the first Gay Men's Health Summit, a convening of gay, bisexual, trans men, other MSM, and their allies to discuss a diverse array of health topics relevant to their lives [5]. The summit movement has flourished over the past decade with literally scores of national, regional and local summits held across the United States and internationally.

The Gay Men's Health Summits helped spur the development of a gay men's health advocacy plan, labeled the GMHA. To develop the agenda, Project CRYSP—a Chicago Department of public health gay men's health collaboration—solicited input on priorities, asking “what is your vision of a GMHA?” Throughout most of 2008, stakeholders from across the United States submitted their ideas and suggestions in the form of blogs posted to LifeLube—a gay and bisexual men's health and wellness portal—with comments and discussion encouraged.

These comments were gathered together and presented at the closing plenary of the 2008 Gay Men's Health Summit in Seattle in October of that year. Top priorities were suggested by gay and bisexual men attending the meeting. A core group of individuals were tasked with creating a draft that was reviewed by a similar number of activists through online and teleconference communications. The resulting 2009 GMHA highlighted eight key areas:

1. Fund and expand social, behavioral and biomedical research;
2. Develop and fund data collection efforts on sexual orientation and gender identity in all federally funded research;
3. Fund campaigns to combat homophobia, biphobia, and transphobia;
4. Eliminate “No Promo Homo” (Section 2500 of the federal Public Health Service Act (42 U.S.C. Section 300ee (b), (c), and (d)) that bans “promotion” of any type of sexual behavior);
5. Create an office for LGBT health at the U.S. Department of Health and Human Services (HHS);
6. Develop and implement a strategy to reduce health disparities among gay, bisexual and transgender men through direct programmatic funding;
7. Implement and fund sexual health and wellness campaigns directed toward the gay, bisexual and transgender men's communities utilizing an array of public and private resources; and
8. Develop and implement a strategy to remove barriers to health care among transgender people through legal changes and education of medical and health insurance professionals [6].

The agenda was presented at additional meetings in 2009 including the annual meetings of the Gay and Lesbian

Medical Association and the American Public Health Association. Toward the end of 2009, with assistance from the National Coalition for LGBT Health, a monthly eblast was initiated to over 200 individuals and 100 organizations who had endorsed the GMHA or signed on to receive these emails. At the 2010 Gay Men's Health Summit, gay men's health movement leaders established a national steering committee to carry forward the goals of the agenda.

The Path Forward: Successes, Challenges, and Opportunities

The task of implementing the priorities set forth by the GMHA and other community-based LGBT health organizations is challenging, but achievable. After years of concerted organizing efforts nationally, we are beginning to see the adoption of many of the main tenets of the gay men's health movement into mainstream organizations. For example, the CDC recently launched a webpage devoted to gay and bisexual men's health [7], and has unveiled their plans for a new sexual health framework to address sexually transmitted diseases, including HIV [8]. A major departure from previous deficit-based models that alienated many men from the very programs meant to benefit them, the new paradigm frames sex and sexuality within a positive approach bound to physical and mental health, with the goal of increasing healthy, responsible and respectful sexual behaviors and attitudes.

The Department of HHS is also making efforts to address LGBT health issues in a more holistic fashion. For example, HHS has an internal work group on LGBT issues, and different HHS agencies have created their own LGBT-focused task forces or work groups. This past December, Healthy People 2020, the blueprint for the nation's health, included a topic area on LGBT Health for the first time [9].

While we must celebrate the successes, much work remains. National legislative change around LGBT health is not likely to occur in the very near future, but there are provisions of the GMHA that can be realized now without requiring the passage of legislation in Congress. For example, supporters of the GMHA can work towards integrating questions on sexual orientation and gender identity into the National Health Interview Survey and other key national health and behavioral surveys. Advocates can also focus on ensuring that the HHS internal work group on LGBT issues is functional and effective, and can advocate for the HHS to immediately create an office for LGBT Health. This office would be responsible for identifying key gay and bisexual men's health priorities, developing a plan to significantly improve health outcomes for gay and bisexual men's nationally, and coordinating agency wide efforts.

Moving forward, the GMHA cannot remain static, but must evolve with the changing political and research environments, and must take advantage of the ever growing grassroots mobilization effort. Potential additions to the GMHA include: 1) establishing national standards of care for gay and bisexual men to be implemented and enforced by the Centers for Medicare and Medicaid Services; 2) improving coordination with community health centers to strengthen their ability to offer culturally competent medical care to gay and bisexual men; 3) expanding funding for existing and for the development of new LGBT federally qualified health centers; and 4) monitoring the NIH's National Institute for Minority Health and Health Disparities to ensure sufficient and relevant research focus on gay and bisexual men's health.

Furthermore, advocacy efforts to promote gay and bisexual men's health should:

- Be less disease specific with more focus on the whole individual across the lifespan with explicit support for healthy relationships and healthy sexuality;
- Embrace the syndemic framework in all aspects of program and policy development to promote gay and bisexual men's health;
- Prioritize addressing mental health disorders and substance abuse in strategies to improve gay and bisexual men's health;
- Ensure that as health policy increasingly employs the social determinants of health construct, that these include those related to trauma, stigma and discrimination based on sexual orientation and gender identity;
- Examine the intersections of health disparities based on sexual orientation and race/ethnicity [10];
- Be informed by, connected to and supportive of the global men's health movement; and
- Cultivate allies to establish meaningful, sustainable and strategic partnerships diseases, disciplines, professions and communities to advance gay and bisexual men's health.

Conclusion

As we move forward, many questions arise: How will this new paradigm be implemented? Who will monitor the progress of these efforts, and offer critical analysis along the way? Who will push, cajole, and demand ongoing change around health disparities and social determinants so that gay and bisexual men as well as lesbians and bisexual women and all transgender people may gain unfettered access to comprehensive, culturally competent healthcare that addresses our diverse needs?

The answer is the gay men's health movement. Efforts to transform promise into policy should be done in

collaboration, consultation, and solidarity with gay men's health movements around the world, sharing information, ideas, and resources. The endeavor should continue to be fed by grassroots activity, and directly engaged with a wide array of stakeholders including community leaders, advocates, policy makers, organizations, institutions, funders, and elected officials. And there must be special emphasis placed on the importance of nurturing young leaders to take this movement beyond the current field of vision. Tapping into the creativity and boundless energy of young gay, bisexual and transgender men in our community will ensure the movement thrives and remains relevant. Partnering with lesbians, bisexual women and transgender women, as well as heterosexual allies, will continue to be critical to success.

Among the lessons learned from the community organizing perspective is that there is a need to form alliances in order to be successful in advocacy. At the same time, you can have all the alliances in the world, but you need passion to keep people committed to fighting for the next set of needed actions. Passion by itself is insufficient; it must be supplemented by people armed with the resources they need to make their voice and positions heard.

References

- Centers for Disease Control and Prevention. Pneumocystis pneumonia—Los Angeles. *MMWR*. 1981;30:250–2.
- The Denver Principles. Available at: <http://www.actupny.org/documents/Denver.html>. Accessed 17 July, 2010.
- Centers for Disease Control and Prevention. HIV prevalence, unrecognized infection, and HIV testing among men who have sex with men—five U.S. Cities, June 2004–April 2005. *MMWR*. 2005; 54(24):597–601.
- Javanbakht M, Murphy R, Gorbach P, LeBlanc MA, Pickett J. Preference and practices relating to lubricant use during anal intercourse: implications for rectal microbicides. *Sex Health*. 2010;7(2):193–8.
- Los Angeles Gay and Lesbian Center. Advancing gay and lesbian health: a report from the Gay and Lesbian Health Roundtable. January 2000. Available at: <http://www.lgbthealth.net/downloads/research/LAGLCRoundTable2000.pdf>. Accessed 16 July, 2010.
- The 2009 Gay Men's Health Agenda. Available at: <http://www.scribd.com/doc/12186690/Gay-Mens-Health-Agenda-2009>. Accessed 10 July, 2010.
- Gay and Bisexual Men's Health. Available at: <http://www.cdc.gov/msmhealth/>. Accessed 30 Sept, 2010.
- Rausch D, Cheever L, Dieffenach C, Fenton K. Toward a more coordinated federal response to improving HIV prevention and sexual health among men who have sex with men. *AIDS Behav*, in press.
- Healthy People: What's New for 2020. Available at: <http://www.healthypeople.gov/2020/about/new2020.aspx>. Accessed 17 Dec, 2010.
- Krehely J. How to close the LGBT health disparities gap: disparities by race and ethnicity. Center for American Progress, December 21, 2009. Available at: http://www.americanprogress.org/issues/2009/12/lgbt_health_disparities.html. Accessed 11 July, 2010.