

L.A. Gay & Lesbian Center

**Advancing Gay and Lesbian Health:
A Report from the Gay and Lesbian
Health Roundtable**

January 2000

CO-CONVENERS:

The Gill Foundation

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Emeritus, of the
California Assembly,
The Honorable
Antonio Villaraigosa**



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Table of Contents

INTRODUCTION.....	1
OVERVIEW.....	4
KEY FINDINGS AND RESEARCH ISSUES.....	7
<i>CONCEPTUALIZING LGBT HEALTH & HEALTH RESEARCH</i>	<i>7</i>
<i>HEALTH RISKS.....</i>	<i>8</i>
<i>HEALTH INSURANCE AND ACCESS TO HEALTH CARE AND PREVENTIVE SERVICES.....</i>	<i>9</i>
<i>ISSUES IN ADVANCING LESBIAN AND GAY HEALTH RESEARCH</i>	<i>9</i>
CLINICAL PRACTICE IN THE LGBT COMMUNITY.....	11
<i>HEALTH CARE DELIVERY SYSTEMS.....</i>	<i>11</i>
<i>TRAINING FOR CULTURALLY COMPETENT HEALTH CARE</i>	<i>12</i>
FUNDING AND MOBILIZATION OF RESOURCES.....	14
RECOMMENDATIONS	15
<i>I. RESEARCH.....</i>	<i>15</i>
<i>II. EDUCATION AND TRAINING OF HEALTH PROFESSIONALS.....</i>	<i>17</i>
<i>III. HEALTH CARE SYSTEMS AND DIRECT SERVICES.....</i>	<i>18</i>
<i>IV. OTHER FUNDING AND MOBILIZATION OF EXISTING RESOURCES.....</i>	<i>19</i>
CONCLUSION	21
REFERENCES	22

Introduction

The L.A. Gay & Lesbian Center has provided a wide-range of social, educational, advocacy, and health services since its inception in 1971. The L.A. Gay & Lesbian Center includes the McDonald/Wright Building, The Village at Ed Gould Plaza, the Jeff Griffith Gay & Lesbian Youth Center, the California AIDS Clearinghouse, and the Lambda Medical Group. As a local service provider and national voice on behalf of lesbian, gay, bisexual and transgender (LGBT) communities, the L.A. Gay & Lesbian Center is committed to working in collaboration with a wide range of allies to help advance the health of LGBT communities.

The L.A. Gay & Lesbian Center provides a wide-range of health services through its Lambda Medical Group and several special clinics: the Jeffrey Goodman Special Care Clinic for HIV positive patients, the Audre Lorde Lesbian Health Clinic, and the Pedro Zamora Youth HIV Clinic. Lambda Medical Group participates in most insurance programs, accepts Medicare and Medi-Cal, and provides the same quality services for those without insurance or financial resources. In recent years, the L.A. Gay & Lesbian Center has substantially expanded the provision of health services to LGBT communities. At the end of 1999, there were approximately 1,500 active patients at Lambda Medical's primary health care program. Of these patients, approximately 25 percent of men and 60 percent of women were uninsured. By comparison, uninsured rates are approximately 24 percent in California and 17 percent in the rest of the United States.¹ Uninsured rates in California vary among sub-populations. For example, the odds of being chronically uninsured (without insurance for five or more years) is 3.8 times greater for Latino vs. non-Latinos, 1.7 times greater among people below the poverty line, and 2.1 times greater for employed workers, particularly among those in small firms.² Many patients in the primary care program and other service areas, including those with insurance, report stories of frustration, discrimination, bias, and maltreatment in their efforts to receive services in mainstream clinics and programs.

The emerging stories and data from Lambda Medical Group, combined with concerns expressed by other LGBT health and social service providers, researchers, health advocates and policy-makers have made clear the importance of taking action to advance the health of LGBT communities. Many national organizations, community centers, researchers, and individual advocates have, and continue, to work toward such advances on behalf of LGBT communities in the health, mental health and substance abuse arenas. As a community-based organization with local, state and national linkages, the L.A. Gay & Lesbian Center explored how it might best contribute to this larger movement to address LGBT health issues. Accordingly, the L.A. Gay & Lesbian Center organized a Health Roundtable. The L.A. Gay & Lesbian Center enlisted support and endorsement for the Roundtable from several foundations, research institutions, corporate organizations, and policy makers who share an interest in LGBT health.

The Gay and Lesbian Health Roundtable was held in January 2000. The overall purpose of the Roundtable was to provide a forum for dialogue on advancing lesbian, gay, bisexual and transgender health among lesbian and gay health researchers, providers, and advocates as well as allies from research institutions, government agencies, political representatives, and foundations. Over 50 individuals representing these different sectors gathered for the Roundtable. Although

most of the participants were from California, several presenters and participants brought a national perspective to the proceedings. Specific aims of the Roundtable were to:

- Educate potential allies in varied sectors about the lesbian, gay, and bisexual health disparities and help identify ways in which they, through state, federal or local initiatives can help address these disparities.
- Generate recommendations for advancing appropriate research on lesbian, gay, and bisexual health issues.
- Develop ideas for building the capacity of health systems and practitioners to serve lesbian, gay and bisexual communities.
- Facilitate interest in supporting these efforts among private and government funders and other potential partners.

The Roundtable was structured to facilitate discussion around three key areas: research, practice and funding. Brief presentations were interspersed with discussions in these three areas. Some of the questions explored during participant discussions included:

- What do we know about lesbian, gay and bisexual health through research and what are some of the key gaps in research and methodological issues that need to be addressed?
- What appears to work in addressing lesbian, gay and bisexual health needs and what strategies should be employed to help make health services more accessible and appropriate to diverse lesbian, gay, and bisexual consumers?
- What needs to occur in education and continued training of health care professionals to enhance competency and sensitivity in working with lesbian, gay and bisexual people and how should this be advanced?
- What funding strategies and partnerships would need to be developed to better address research and practice needs of lesbian, gay and bisexual populations?
- What existing resources could be leveraged to advance research and practice and who would need to be on board for these ideas to work?

The Gay and Lesbian Health Roundtable and this document are intended to complement rather than duplicate the many other valuable efforts to improve health systems and care for LGBT communities. Many national LGBT organizations have directed substantial effort to developing gay and lesbian health policies and initiatives, among these: the National Gay and Lesbian Task Force, the National Center for Lesbian Rights and LLEGO, the National Latino/a Lesbian, Gay, Bisexual and Transgender Organization.³⁻⁵ Although the recent dissolution of the National Lesbian and Gay Health Association was a loss to the community, many national and local groups with a dedicated focus on health continue to build momentum to make advances in various health domains. These include convening lesbian researchers and organizing local forums following the 1999 release of the Institute of Medicine Report on Lesbian Health, the formation of the Gay Men's Health Summit, the work of the Gay and Lesbian Medical Association, and local efforts in Boston and San Francisco to develop standards of care for LGBT populations.⁶⁻⁸ All of these efforts, along with a myriad of other national, state and local work on LGBT health issues are critical to building an LGBT health movement and to linking these issues to intersecting concerns related to health disparities associated with socioeconomic status, immigration status, ethnicity and race. The Gay and Lesbian Health Roundtable represents one unique contribution to this overall movement to increase understanding and support of LGBT health.

The reader will note that different terms are used throughout this document. As discussed later in this document, sexual orientation is multi-faceted and encompasses behavioral, affective and cognitive (e.g. identity) dimensions. Many women who have sex with women, and men who have sex with men may not identify with the terms lesbian, gay or bisexual. For example, a study of different dimensions of sexual orientation found that nearly all women who self-identified as lesbian reported same-sex desire and behavior yet many women who reported same-sex behavior and/or desire did not identify as lesbian.⁹ Consequently, many researchers frame their work in terms such as women who have sex with women that are more inclusive and reflective of human sexual behavior. This terminology is used in several parts of the document when referring to the work of specific researchers or clinicians. However, the language lesbian, gay, bisexual, and transgender (LGBT) is predominantly used throughout the document. It is important to note that the body of literature examining health issues among gay men and lesbians is not consistently inclusive of bisexuals and rarely provides information about transsexuals. In spite of the paucity of research with these populations, bisexuals and transgender populations were intentionally included in the ensuing discussion of health issues and recommendations. In sum, the use of LGBT is intended to be inclusive of all men who have sex with men, women who have sex with women, and persons whose gender identity conflicts with his/her anatomy.

Although definitive information about LGBT demographics is not available and estimates are profoundly influenced by how sexuality is measured, LGBT communities represent a diverse and substantial segment of the population whose unique health issues need to be addressed.¹⁰ Estimates of the total number of men reporting same gender sexuality range from 2.8 to 7.7 percent overall and from 9.2 to 16.7 percent in urban areas.⁹ Similarly, estimates of women reporting same gender sexuality range from approximately 2 to 10 percent.⁸ LGBT populations are comparable in number and intersect many other demographic groups. For example, demographic estimates by race and ethnicity for 1997 from the California Department of Finance found that the state population was 53 percent White, 29 percent Hispanic, 11 percent Asian and Pacific Islander, and 1 percent American Indian.¹¹

The information and recommendations from the Gay and Lesbian Health Roundtable are summarized in this document. Highlights from the presentations and common themes from the discussion are outlined followed by a separate summary of recommendations that emerged during facilitated discussions. This document will be disseminated to Roundtable participants and LGBT health advocates, researchers, and practitioners. In addition, the document will be sent to other stakeholders including foundations, researchers, health policy advocates, organizations working to advance the health of communities of color, and government allies on local, state and national levels. The recommendations developed through this process will be used to inform the L.A. Gay & Lesbian Center's efforts to expand advocacy efforts and seek additional funding for health care services and research. It is anticipated that other stakeholders will use this document to identify how they can also work with one another and seek opportunities to advance lesbian, gay and bisexual research and practice in their own spheres of influence.

Overview

Several presenters spoke to overall issues that frame the health issues of concern to diverse gay, lesbian and bisexual communities. Joyce Hunter, DSW, Research Scientist at the HIV Center for Clinical and Behavioral Studies and long time activist provided a social and historical context for viewing the constellation of health issues of concern to LGBT communities. Steve Oxendine, Director, African American Men s Health Institute, provided written information about the August 1999 convening and future plans of the Gay Men s Health Summit. Dr. Marsha Martin, Special Assistant to Secretary of Health & Human Services (HHS), Donna Shalala, described the federal role in LGBT health issues and opportunities for integrating current gay, lesbian and bisexual health concerns into national health initiatives.

Steve Oxendine provided information about the Gay Men s Health Summit that was held in 1999. Over 300 people convened at this gathering to lay the groundwork for an expanded, activist gay men s health movement in the United State. The overall purpose of the summit was to open the discussion and affirm a commitment to a broader gay men s health and wellness agenda without abandoning the continuing important issues specific to HIV/AIDS. The Summit was organized, in large part, to ensure continuation of the work of the National Lesbian and Gay Health Association (NLGHA). Objectives of the Summit included expansion of gay men s health projects throughout the country, expanding the focus of gay men s health, shifting from pathologizing gay men to a focus on resilience and strengths of individuals and communities, and development of leadership among men 35-years-and-younger. In addition to plans to organize another national convening, the Summit generated plans for the organization of regional and local Health Summits in 2001.

Dr. Hunter pointed out that the movement to advance LGBT health and the formation of the National Gay and Lesbian Health Association began before the AIDS crisis. It was fortunate that this movement was formed before the emergence of the AIDS crisis so that the community was in a stronger position to respond in the arenas of research, care and advocacy. During most of the 80s and early 90s health advocacy and health care issues centered primarily on the crisis of HIV/AIDS. In recent years, there has been a concerted effort to broaden the focus of LGBT health care, research and advocacy beyond the single issues of HIV/AIDS among gay men and breast cancer among lesbians. For example, in 1989-1990 the Women s Caucus of the National Lesbian and Gay Health Association met in New Orleans to identify strategies to forward the lesbian health movement and in 1999 gay men convened in Boulder, Colorado, to expand common notions of gay men s health. Dr. Hunter also acknowledged several pioneering researchers who were among the first, and who continue, to increase understanding of LGBT health issues and the specific health issues of communities of color including Dr. Vickie Mays, Dr. Susan Cochran, Dr. Cynthia Gomez.

Dr. Hunter outlined several issues that need to be considered to understand lesbian health. First, it is important to recognize the multiple dimensions of sexual orientation that include sexual behavior, self-identity, and desire/attraction. There is no common agreement about which of these elements define lesbians, and lesbians themselves, and adolescent lesbians in particular, are not always consistent across these dimensions. Second, lesbian health must be discussed in the context of women s health in general. However, a number of factors work together to influence the health risks of lesbians in unique ways such as experiences of heterosexism and homophobia.

For lesbians of color, racism and in the larger society and in the lesbian/gay movement causes enormous stress. Sexism in society as well as cultural and familial gender role expectations can also be stressful. Third, it appears that lesbians may have risk factors that differ from their heterosexual counterparts and may impact health in a number of areas including cancer, cardiovascular disease, hypertension, mental health concerns, substance use, and sexually transmitted diseases. Lesbian adolescents, who are faced with the developmental task for formation of a personal identity, often struggle with sexual development and coming out and may have health risks related to suicide ideation, suicide attempts, and unplanned pregnancy associated with efforts to hide their sexuality. The particular concerns of LGBT adolescents are often ignored in research and clinical contexts.

Dr. Hunter also discussed three types of barriers to health care that are typical for lesbians. First, structural barriers including lack of access to quality health care that is lesbian sensitive and lack of legal recognition of partners are problematic. These issues are often exacerbated in a managed care environment where limits placed on time with a provider may impair the ability to establish trust, and selection of a lesbian-friendly health or mental health provider may be difficult. Financial barriers to health care are often associated with lower socioeconomic status among women, particularly among many women of color and immigrant women. These barriers include lack of insurance and lack of access to insurance through partners. Finally, lesbians may delay care or withhold health information because of homophobic attitudes of providers. Care may be inadequate when providers fail to understand the impact of group membership on health status, behavior, and attitudes.

Marsha Martin, DSW, Special Assistant to Secretary of Health & Human Services (HHS), Donna Shalala, pointed out that health care access will be the truest test of our democracy. She noted that the federal government has been actively addressing lesbian and gay health issues. There are lesbian and gay working groups within the government and many special projects in HHS as well as HHS agencies such as the Substance Abuse and Mental Health Services Administration (SAMHSA). At the same time, she suggests that advocates will need to rethink how we are doing things to become more effective. She also pointed out that gatherings such as the Gay and Lesbian Health Roundtable need to be more representative of the diverse race and ethnic groups in the LGBT communities.

Martin noted that it is the responsibility of HHS to serve America's families and children who are needy — where the government feels the need to address the gap for those people without the resources to access health care. In this context, it is important for health providers and advocates to understand the health care logic of the federal government. Initially, there were plans to cover all Americans with Clinton's presidency. The current plan is to piece together how public and private sectors can get as many people as possible into care. There are government programs for people in need over 65 (Medicare) and for children under the age of 18. There is an effort to expand these efforts and, concurrently, to facilitate coverage of adults 18-65 years by employers. There is a perceived need to mobilize resources and plans to obtain health coverage for everyone.

Martin emphasized the importance of examining government constructs for improving health and identifying ways that gay and lesbian health issues intersect these. One of the most important frameworks is that of Healthy People 2010, a national health promotion and disease

prevention agenda launched by the U.S. Department of Health and Human Services in January 2000. The Healthy People framework evolved out of recognition that health access will not matter if the nation is not healthy. In 1979, the government initiated the healthier people paradigm to obtain the health industry's commitment to attain measurable improvement in specific health outcomes/goals. At that time, five goals and 15 strategic areas were proposed. In 1989, Healthy People 2000 identified three overall goals including the increase of the life span of Americans, reduction in health disparities, and provision of access to preventive health services for all Americans. Twenty-two priority areas were identified to achieve these goals. Healthy People 2010 focuses on two primary goals: the elimination of health disparities (e.g., by race, ethnicity, income, gender, disability and age) and improved years and quality of healthy life. Approximately 20 areas of priority have been identified to measure health status. Some of these areas address physical health, nutrition, tobacco, food safety, environmental health, HIV, substance abuse, sexually transmitted disease and other infectious disease. The criteria for selection of health indicators include whether these indicators are worth measuring, whether they can be measured for diverse populations, whether they can be understood by people who need to act, and whether they will inspire action that will lead to measurable improvement. When looking to HHS for resources, it is important to examine these goals and priority areas and how LGBT people fit into this paradigm.

Thus, it is crucial that LGBT communities look to integrate LGBT concerns into these outcome measures. Goals and disparities specific to LGBT communities are not yet explicitly included in Healthy People 2010. There is progress along these lines. A number of researchers across the country are writing a companion document related to 2010 goals and will articulate measures and goals of 2010 for the LGBT community.⁶ Although many individuals and organizations have been involved in contributing to 2010 objectives, many government representatives were surprised to receive letters from the LGBT community pointing out the absence of LGBT issues. Government representatives need to be educated in order to take the conversation about LGBT health concerns beyond a sole focus on HIV/AIDS and breast cancer. There are opportunities to strengthen federal efforts and to obtain attention for LGBT issues: through participation from more LGBT organizations, greater discussion about how LGBT health concerns fit in the 2010 framework, and about the intersection of LGBT issues and health disparities based on race and ethnicity. Coverage of the progress of 2010 and other federal initiatives and how LGBT communities can have a voice in these processes is rarely, if ever, covered in LGBT media. Our newspapers and other media have a role to play in informing the community about how the government is doing something about these issues and how we can do more as a community.

If the LGBT community is to engage with and access HHS and other government resources, it is important to frame what is specific to the community in the context of larger policy questions. This approach to impacting health extends beyond Healthy People 2010 to other federal policy issues that impact LGBT communities. Many homeless youth are lesbian, gay, bisexual and transgender. How can the LGBT community obtain funds for mainstream resources to serve youth, work with the Administration on Children and Families to strengthen the capacity of children's services to address LGBT youth, and collaborate with agencies like the Substance Abuse and Mental Health Service Administration to define appropriate treatment models? LGBT communities need to be involved in emerging discussions about addressing the issues of the uninsured, and the expansion of Medicare, and the evolution of research such as the allocation of resources by the Centers for Disease Control to investigate risk factors for women who have sex with women.

Key Findings and Research Issues

Several researchers with substantive history in LGBT health research provided an overview of their research and helped to frame Roundtable discussion about gaps and methodological issues in research. Allison Diamant, M.D., MSHS, RAND Corporation/University of California, Los Angeles, presented background information and data from her research on assessing lesbian health care and health. Ron Stall, Ph.D., MPH, Center for AIDS Prevention Studies/University of California, San Francisco, presented on access to health care among men who have sex with men based on data from the Urban Men's Health Study. Kenneth Mayer, M.D., Fenway Community Health Center's Research Department at Brown University in Boston described a model for community-based research based on the Fenway experience in developing a lesbian health research program. Highlights from the panel presentation and themes from Gay and Lesbian Health Roundtable discussions are summarized in three areas: LGBT health risks, access to health care, and issues in LGBT health research.

Conceptualizing LGBT Health & Health Research

Dr. Diamant echoed Dr. Hunter's conceptualization of lesbian, gay, bisexual and transgender health. LGBT health issues take place in a larger societal context (including stigmatization of LGBT populations), involve interaction with the health care system (including issues of access and quality of care) and, in the case of lesbian health, exist within the paradigm of women's health. She forwarded several reasons to study lesbian health that apply to the study of gay, bisexual and transgender health:

- To gain knowledge that is useful for improving the health care and health status of lesbians.
- To confirm beliefs and counter myths about the health risks of lesbians, and
- To identify areas, in which lesbians are at risk or at increased risk, compared to females in general, for health problems.

Dr. Mayer presented a conceptual and practical model for creating a research enterprise that is connected to both the community and direct clinical health care. Specifically, he described Fenway Community Health Center's experience and evolution in developing a lesbian health research program. The Fenway Community Health Center (FCHC) started as part of the free clinic movement in the early 1970s, began care for persons with AIDS in 1980, started a formal research program in 1983 and, subsequently, conducted a number of HIV-related research studies. Having developed an infrastructure for research as well as an organizational commitment to both research and responding to community need, Fenway looked to develop a broader research agenda. An FCHC women's health task force was created that provided leadership in convening community health days, educational series and development of a lesbian health research committee. As a result of this endeavor, the clinic and the community are committed to a specific research agenda that will ultimately inform clinic practice, provide direction for other service and systems changes for meeting the needs of lesbians, and contribute to larger efforts to create and share research information by and about the LGBT community. Specific study areas that were identified as priorities include sexually transmitted disease between women, mental health, domestic violence, parenting and families, and substance abuse. Roundtable participants, in general, discussed the importance of research that is community-based rather than isolated from the concerns and priorities of communities.

Health Risks

Research suggests that there are disparities in health risk and protective factors between LGBT communities and the population as a whole. Dr. Diamant found that lesbians were more likely to have poor health behaviors than heterosexual women were.¹² For example, lesbians were more likely to report heavy drinking, more likely to report current smoking, and less likely to report having never smoked in the past than heterosexual women. Dr. Stall also reported high rates of alcohol and tobacco use among gay men.¹³

Other research affirms that lesbians may engage in behaviors that increase their risk for health problems in comparison to heterosexual women and may be more likely to avoid health screening and to delay care.¹⁴⁻¹⁶ Some of the concerns of lesbian patients that are often not addressed in clinical settings include cancer screening, sexually transmitted disease, HIV status, substance abuse, mental health issues, relationship issues, pregnancy and parenting.¹⁷ Contrary to popular assumption, many adults, and particularly adolescents, who identify as lesbian and gay, have sex with opposite sex partners.^{18, 19}

Dr. Hunter emphasized the importance of sexual identity as an important aspect of adolescent development and of addressing the frequently ignored high-risk behaviors of lesbian, gay, and bisexual and questioning youth.²⁰ Gay, lesbian and bisexual youth are at high risk for a number of health, social, and emotional problems including sexual risk-taking, mental health problems, and poorer health maintenance than heterosexual youth.^{21, 22} It appears that lesbian, gay, bisexual youth may also be at greater risk for suicide attempts, substance abuse, depression, school dropout, and being runaways or rejected from their homes because of homophobia.²³⁻²⁹ Gay male adolescents are often at high risk for HIV/AIDS and remain neglected in both research and prevention efforts.³⁰ Lesbian youth, as well as gay youth, often participate in high-risk sexual behaviors with both genders.³¹

Panelists and Roundtable participants discussed the important connection between mental health issues, particularly stress related to homophobia and other experiences of discrimination, and health. Many discussants stressed the importance of addressing the clinical and research needs of frequently ignored populations, including specific race and ethnic groups in the LGBT communities. Research affirms that many mental health risk and resilience factors may differ between segments of the lesbian and gay community based on race and ethnicity. For example, immigration is an important factor in mental health risks and resilience among Latina lesbians.³² A study of substance abuse among Latina lesbians suggests connections between heterosexism and lesbiaphobia, ethnocentrism and racism, and the excessive use of alcohol and other drugs.³³ Mays, Cochran and colleagues' studies of both African American lesbians and gay men suggest unique strengths and challenges in a number of areas including access to social support for lesbian and bisexual alcoholics, choices in disclosing sexual orientation, risks for depression, and issues in connecting to community.³⁴⁻³⁷ Hildalgo identifies an important theme in writings about lesbians of color and social and human services: the multi-oppression of lesbians of color and the effects of these interlocking oppressions in daily life and in the development of self-identity and self-worth.³⁸

Health Insurance and Access to Health Care and Preventive Services

Lesbians and gay men may be more likely to face barriers in access to care and preventive services. Dr. Diamant reported on her study on health care and health among lesbians and heterosexual women that included examination of access and barriers to health care as well as use and receipt of health care. In general, the findings suggest that:

- Lesbians were more likely to report being uninsured at sometime during the past year and were less likely to have continuity of care from a regular physician.
- Lesbians were more likely to have had problems in obtaining care in the prior year in comparison to heterosexual women.
- Lesbians were significantly more likely to have been unable to obtain care for financial reasons, particularly in relation to seeing a physician or obtaining mental health services.
- Lesbians were less likely to receive preventive health services (Pap smears, clinical breast exams).

Dr. Stall reported on access to health care among men who have sex with men. The data from the Urban Men's Health Study is particularly useful because it is based on a random household sample of men in census tracts (1980 census) with high proportions of gay men. Citywide datasets have been given to each of the cities that were selected for the study (San Francisco, New York, Los Angeles, and Chicago) and should be useful for local research and planning.

Key findings from the study suggest that:

- About 16 percent of men who have sex with men in America's largest cities do not have any form of health insurance and about 13 percent do not have a health care provider.
- About 20 percent have not told their health care providers that they have sex with men.
- Economic privilege seems to predict having insurance/health care provider.
- Being out to one's provider seems to be strongly related to being out in general.

The degree to which a lesbian or gay man feels comfortable disclosing her/his sexual orientation appears to be related to health care access. Dr. Diamant found that disclosure of sexual orientation to a provider was a positive predictor for obtaining cervical cancer screening within two years among lesbians. Stall also found a positive relationship between access to health care among men who have sex with men and provider knowledge that the study participants have sex with men.¹³

Issues in Advancing Lesbian and Gay Health Research

Several research issues and methodological challenges in research on health issues of men who have sex with men and women who have sex with women were delineated by panelists and discussed by all Roundtable participants. Several themes emerged in this discussion.

Methodological Issues. Several methodological problems need to be addressed in research on LGBT populations. First, measures used to define the population often vary between studies. For example, some studies define sexual orientation based on measures of identity while others obtain larger numbers by using measure of sexual behavior and/or desire. Second, it is often difficult to obtain population-based data on largely invisible and stigmatized populations; and the

ability to generalize with nonprobability samples is limited. This is particularly a problem for gathering information and telling the stories of populations that are often neglected in studies such as LGBT youth, LGBT seniors, African Americans, Asian/Pacific Islanders, Latino/as, Native Americans, people with disabilities, and LGBT individuals in rural areas. Other problems include lack of control or comparison groups and lack of standard measurements between studies (e.g., studies on substance abuse that may use different time frames for reporting quantity and frequency of alcohol or drug consumption).

Lack of Support from Mainstream Research. National, state and local research projects rarely include questions about sexual orientation or sexual behavior in their demographic questions. Although Roundtable participants stressed the importance of having researchers that are reflective of the community in studies targeting LGBT communities and specific cultural groups within LGBT communities, they also emphasized the importance of having LGBT questions included in general studies, particularly large population-based studies. For example, Massachusetts opted to include questions about sexual identity in a statewide youth study that provided valuable information. However, this was voluntary and the federal government cannot require states to include such questions. The Office of Women's Health, California Department of Health Services, included a sexual behavior question in its statewide Women's Health Survey. Unfortunately, many state, university, and private researchers do not know about or fail to emulate such positive examples.

Need for Strengthening Connections between Community, Clinics and Research. Research endeavors (such as that conducted at Fenway) often do not establish strong and productive linkages to communities and community based organizations. Participants named several problems they had observed or experienced in this area including take the data and run practices that leave communities (often communities of color) disenfranchised. Other problem practices include obtaining use of client data or clients themselves without sharing skills that would enable community organizations to conduct their own research and design of research studies with no input from communities targeted for study about their priority questions. One participant mentioned a document suggesting protocols for conducting research among African American men who have sex with men that was developed in response to these problems. Standards and models for conducting culturally appropriate, respectful, empowering research are not widely disseminated or adopted.

Workforce Issues: Development of Research Capacity. Roundtable participants discussed the fact that research is often an elite type of occupation and not all community members potentially interested in research have access to learning these skills. Investment and support in development of a workforce — part of and reflective diverse LGBT communities — is an important gap in the research landscape. In particular participants placed importance on developing researchers that understand and represent different racial and ethnic groups in LGBT communities.

Paucity of Research on Health Related Risk and Protective Factors. Roundtable participants identified a number of gaps in research examining factors that may differ among LGBT populations and sub-groups in the LGBT community. Topic areas mentioned included greater examination of high smoking rates, health risks for lesbians including sexual behavior/practices,

substance abuse, depression, eating disorders, biological/genetic factors, and rates of health care access/utilization. Questions were also raised about how we motivate populations to seek health care. In addition, there is a lack of research examining some of the resilience factors that may be specific to LGBT communities. There is indication that, in some areas, lesbians may report more favorable overall mental health than their heterosexual counterparts and development of a unique sense of identity may be a source of resilience in youth. Participants called for a greater focus on developing individual strengths and community assets that may help to mediate and improve health.

Need to Address Under-Researched Topics and Communities. Several areas of research have received inadequate attention including research inclusive of rural areas, research in domestic violence beyond prevalence (e.g., how domestic violence may play a role in increasing health problems or interfering with treatment compliance), and aging within the LGBT community. There is little research into the early development of gender identity, health issues of transgender individuals, and how gender identity intersects with lesbian, gay and bisexual health. Adolescents remain underserved and under-studied in relation to health risks, resilience, identity development and coming out. Participants discussed the importance of partnering with national centers (NIH/CDC) to obtain representative samples and also for the credibility and political acceptance required to study this population. Family relationships and family support as they relate to health were also identified as important sources for future study. Topics might include the effect of family of origin support on outcome of illness, child well-being in LGBT families, support and caregiving among older lesbians and gay men, issues for LGBT step-parents or blended families, and the impact on health of break-ups on family members compared to heterosexual divorced families.

Clinical Practice in the LGBT Community

Health Care Delivery Systems

Stephen Boswell, M.D., Executive Director of the Fenway Community Health Care Center, and Stephanie Roberts, M.D., Medical Director of Lyon-Martin Women's Health Services, discussed health care delivery to LGBT communities. Both presenters discussed the struggles and strategies for surviving and providing LGBT sensitive services in a changing health care environment. Dr. Boswell pointed out that community health centers are the most vulnerable health centers in a managed care environment. The special role of LGBT clinics as centers of excellence will not survive without an aggressive approach that includes having a diverse source of funding; specialized funding will not be as available and agencies must prepare for this reality. Fenway developed a number of strategies for surviving in a managed care environment including joining a hospital provider network, developing systems for reimbursement based upon severity of illness, and developing systems to monitor both the cost and quality of care (that may be used to access data for research). Clinic representatives have also been part of overall discussions of statewide and regional health care delivery and the development and implementation of standards of care.

Dr. Roberts of the Lyon-Martin clinic described the challenges that organization has had in a managed care environment. Lyon-Martin chose to remove entirely financial barriers to care by

seeking a combination of federal, state, city and private funding for different programs that are earmarked for different clients and services. Funding and management of the complexities of different contracts has been difficult. The agency also removed barriers to care based on race and ethnicity by hiring staff who are representative of the communities served. Spanish speaking staff are on-site and translation services and interpreters are available. Approximately 99 percent of patients at Lyon-Martin are low-income women. Many are disabled physically or mentally and require high levels of care. In the past, approximately half the client population was lesbian-identified and currently the numbers have dropped to 25 percent lesbians, with younger women particularly interested in lesbian-specific STD information and older women especially interested in cancer screening. The clinic has received funding for research on breast and ovarian cancer, but still requires funding to conduct broader research and meet the clinical needs of diverse patients that cannot access or are not served appropriately in other health care systems.

In addition to preventive screening and health care, some of the special clinical needs of the LGBT community include alternative insemination, family support groups, hepatitis vaccines, female to female transmission of sexually transmitted disease, anal PAPs particularly for gay men, high quality and responsible transgender health care, and prevention in the context of ethnic and cultural differences within community (e.g., the Fenway Sisters Advocating for Safe Sex Information and Education or SASSIE project).³⁹ LGBT communities also need appropriate substance abuse prevention and treatment and access to LGBT sensitive mental health services.

In addition to the provision of quality care, LGBT-specific health care centers have an important role in teaching health professionals to provide appropriate, quality care. In general, there are two models for training health professionals: 1) education in medical, nursing, physician assistant and other schools for health professionals and 2) provision of training in settings that provide practice opportunity in working with diverse patients. Centers that focus on LGBT health are ideal sites for research and teaching. The care of LGBT communities should be integrated into the larger discussion of providing medical care. Ideally, a mixed model that incorporates LGBT training in all health care education as well as teaching on the community level should be adopted.

Training for Culturally Competent Health Care

Jeffrey Akman, M.D., Associate Dean for Student and Faculty Affairs, George Washington University, addressed medical student education and the care of LGBT patients. Dr. Akman stated that homophobia and heterosexism continue to be problematic in health care. This assertion is affirmed by research. For example, a recent study of a sample of medical students found that approximately 25 percent believed homosexuality to be immoral and expressed aversion to interacting with homosexuals, 9 percent believed homosexuality to be a mental disorder, and 14 percent reported feeling more homophobic since the advent of AIDS.⁴⁰ There is also evidence of bias against LGBT medical students in medical education.⁴¹ Curriculum content on homosexuality and bisexuality in medical curricula is often absent or inadequate.⁴²

Dr. Akman pointed out that a study of medical schools found that training on LGBT issues consisted of one lecture on homosexuality in 80 percent of the schools and a lecture/panel

presentation in 40 percent of schools. Physicians are generally untrained and ill-prepared to address issues of sexuality; many receive only a one-hour lecture in school. LGBT should be addressed in two ways: as a dedicated part of health professional training and as an integral part of substantive training on sexuality and taking an effective sex history.

Possible curricula elements to enhance student capacity to provide sensitive care include didactic instruction, discussion, simulated patient interactions, and supervised work with patients.⁴³ Dr. Akman outlined a number of opportunities for teaching about LGBT issues in medical school that are integrated into the George Washington School of Medicine curriculum. These include didactic courses on sexuality, problem-based learning, patient interviewing practicums, clinical rotations where students work with LGBT patients, role modeling and supervision, mentoring LGBT medical students, use of informal opportunities to teach, and contact with physicians conducting LGBT research. The school also has LGBT faculty and provides opportunities for clinical clerkships and electives at a local LGBT clinic. Educational strategies that are critical to health education include development of clear educational objectives and creating time for curriculum content on LGBT issues and sexuality. Important institutional strategies for medical schools and other health profession education programs include identification of sensitive and knowledgeable faculty, faculty development regarding the importance of academic and clinical exposure to LGBT issues, faculty modeling of competent care, support of LGBT students, and affiliation with local LGBT community agencies.

In addition to training students in medical school, there is a demonstrated need for training existing health care providers and other professionals such as health social workers.^{16, 17, 44-46} Bias against LGBT adults among health care professionals and other ancillary health providers are common.⁴⁷ There is also a documented need for pediatricians and other health providers to better address the health needs, gender specific issues, and confidentiality concerns of adolescent LGBT or questioning youth.⁴⁸⁻⁵⁰ In addition, physicians often need to overcome additional layers of bias and unfounded assumptions when working with LGBT Latino, African American, Native American or Asian patients.⁵¹ The impact of the bias among health care professionals is voiced by the author of a qualitative study of lesbians of color in health care interactions who concludes that, In the midst of any single encounter with a health care provider, they might have to decipher heterosexist remarks, steel themselves against racist epithets, counter undermining remarks insinuating gender inferiority, and heal from blows to their self esteem as they are badgered about their deservedness as uninsured clients.⁵²

Funding and Mobilization of Resources

Funding of research, services, and organizing to advance LGBT health as a whole is inadequate. Although the need for funding of HIV/AIDS research and services remains important to LGBT communities as well as communities of color that are disproportionately impacted by HIV/AIDS, funding for broader health issues is sorely needed. For example, Silvestre conducted an analysis of NIH-sponsored research between 1974 and 1992.⁵³ Homosexual projects unrelated to HIV averaged on \$532,000 per year compared to about \$20 million per year since 1982 for HIV projects. The author points out that this funding is inadequate considering the range of health needs of the community.

Roundtable participants discussed working with government agencies to fund LGBT health research and projects by demonstrating that LGBT individuals and communities are included in the groups for which mainstream funding is targeted. Federal funds are available in several areas relevant to LGBT communities: primary care funds for expanded capacity, early intervention planning grants for ethnic minority groups at high risk for HIV, and planning dollars for capacity building. The Office of Community Service supports community development activities aimed at low-income communities. The Office of Minority Health has coalition constituency grants for organizations that work in communities of color. State resources are available for children and families that might help serve LGBT families (Prop. 10 funds in California for children 0-5 years of age, children's health insurance program, and CalWorks funds for long-term family self-sufficiency). States are considering allocation of tobacco settlement dollars and LGBT representatives should be at the table. While seeking inclusion in national and state dialogues, LGBT organizations must take care to preserve a focus on their primary mission.

Private funders and foundations have an important role in advancing LGBT health. Some foundations, such as the Gill Foundation, have invested in LGBT community efforts, including health projects. Foundation funding is critical for capacity building, for efforts to build the capacity of communities to engage in applied research, and for expanding diversity in the service and research workforce. Private funding needs to be directed to strengthen and support community organizations and culturally specific health projects and organizing in the LGBT community (e.g., health advocacy in Latino/a and Asian/Pacific Islander Communities). Even those foundations interested in funding LGBT projects often do not hear from or work closely with community members to help determine how to leverage the best results with their resources. Foundations interested in health should be educated about opportunities to integrate LGBT constituents into their general grantmaking strategies. Roundtable participants suggested that LGBT health advocates need to become more effective at reaching private funders for both national organizing and local LGBT health efforts.

Participants also discussed the importance of mobilizing existing resources, whether or not additional funding is available. A local government representative pointed out that their agency, if asked, would state that they do not fund research. However, there are, in fact, a number of opportunities that they can be helpful in research. For example, Los Angeles County conducted a health survey and, with the addition of a couple of questions about sexual orientation/behavior suggested by a local researcher, it was possible to extract valuable data about lesbian health. Encouraging existing population-based survey research projects to include questions on sexual identity and behavior, as exemplified by the California Women's Health Survey, represents another opportunity.

Recommendations

Several overall principles emerged during discussions and brainstorming of recommendations. First, Roundtable participants affirmed the importance of forwarding inquiry and interventions in areas that have traditionally been associated with gay and lesbian health concerns (e.g., HIV/AIDS and breast cancer) while expanding support for a broader health agenda. Second, participants called for increased support, not just for large LGBT institutions, but for smaller organizations and community groups to define and address their specific research needs, health concerns, and policy issues. In particular, participants identified African American, Asian/Pacific Islander, Latino/a, Native American, rural, and youth segments of LGBT communities as important populations that should be targeted for research, service and capacity building resources. Finally, resources and support are best directed to individuals and organizations that are grounded in, representative of, and have a history of involvement in the LGBT communities that they hope to research, serve or organize.

I. Research

- A. **Government resources should be made available to study health disparities and health interventions in LGBT communities as a whole and among specific racial, ethnic, age, transgender, and disabled populations.** Requests for applications (RFAs) for such studies should require demonstrated history and meaningful connections to the communities to be studied.
- B. **Government and/or private funding should be directed to evaluate outcomes of LGBT specific/sensitive services.** Direct service health, mental health and substance abuse organizations should be able to obtain funding to evaluate efficacy of accessing care from non-gay clinic vs. gay specific/sensitive services.
- C. **Applicants for research funding from the federal government should justify exclusion of LGBT populations.** Because of past exclusions of women and people of color in research projects and clinical trials, prospective grantees are required to describe if, and why, these populations are excluded from their proposed research. Similar explanations should be made for exclusion of LGBT populations.
- D. **Organizations representing diverse segments of LGBT communities should have a voice in national research agendas as they evolve.** In addition, LGBT communities should have input on social policy/health policy decision-making at federal/state/local government levels.
- E. **Foundations committed to LGBT populations and those committed to health should support community-based action research.** This would include funding different LGBT communities on how to gather data and how to speak to policy makers and department heads about key health disparities and health issues.

- F. **Foundations should invest in building an infrastructure for community-based research and evaluation.** First, foundations should support greater diversity in the research and evaluation workforce through scholarships, training programs, and support of mentors. For example, researchers who are part of communities of color could provide planning and technical assistance to community groups seeking to gather data from under-researched populations and groups deemed hard to reach. In addition, there is a need to provide incentives for partnerships between researchers/research organizations and communities to help build the research/evaluation capacity of community organizations. Foundations should also invest in projects designed to make research funding accessible and useful to communities/community organizations that may use information in both program planning and advocacy. Finally, models and methodologies for creating do-able project evaluations and community studies that are not overly ambitious for community organizations should be compiled, disseminated and used in the context of technical assistance and collaboration between organizations to help answer questions of both local and national concern.
- G. **LGBT community centers could serve as a resource for building capacity in the community for developing researchers.** Often, community-based centers have data and access to clients for quantitative or qualitative studies. The compilation of information from these sources would be beneficial for the clients and community members interested in developing research skills as well as for the agencies.
- H. **Standards or best practices for research in LGBT communities, particularly communities of color should be developed and widely disseminated.** These communities are often research subjects, but are excluded from framing, directing or responding to studies. Funders of research and evaluation should use these standards in the grant review and oversight process. Researchers, community organizations, and funders must recognize the importance of true collaboration in research. Building the infrastructure and capacity of communities to understand and conduct their own research (as recommended above) is an important factor in reducing vulnerability to data raiders.
- I. **Government and/or foundation sources should invest in methodological research to determine how to best interpret results from under-represented groups for whom it is difficult or impossible to obtain population-based data.** A group of researchers should be convened to address these issues and/or conduct a meta-analysis of studies that draw on non-probability samples. There are many ways to take samples of LGBT people: over the telephone, face-to-face interviews, and samples from community institutions such as churches or bars. Development of a strategy to account for bias (e.g., calculating bias in drinking patterns in a bar sample or characteristics likely to differ in a church sample) would provide a structured way to interpret findings from populations that are generally not reached in traditional sampling. Population-based strategies, that are considered superior for being able to generalize findings to a population, are not currently possible for many segments of LGBT communities. This methodological work could help under-funded communities that need to take convenience samples and report results in a way that could be interpreted and used for planning and advocacy.

- J. **Government organizations should collaborate with researchers based in LGBT communities to address barriers to conducting research with adolescents.** Researchers and community groups often face tremendous opposition to conducting research that touches on issues of sexuality among adolescents. Strategies for addressing these issues in smaller research studies should be made available and opportunities for inclusion of sexuality questions on large surveys of youth sponsored by government institutions (e.g., NIH and CDC) should be sought.
- K. **Government funded survey research should include questions about sexual orientation and sexual behavior.** National and state datasets from survey research should include variables that will allow for studying health risk, resilience, and behaviors of LGBT adults and youth. Development of research guidelines describing measurements of sexual orientation might facilitate inclusion of such questions in surveys.

II Education and Training of Health Professionals

- A. **Accreditation bodies for medical schools and other health profession schools should require information on LGBT health issues in school curricula.** Specific context on LGBT health should be taught and expanded training on human sexuality, including LGBT issues, should be required. In addition, content on cultural competence in training should include sensitive treatment of LGBT patients as a facet of cultural competence and the humanization of care. Such training should integrate consideration of LGBT patients from different ethnic, racial, and cultural backgrounds.
- B. **Medical Boards and other bodies that license other health practitioners should include questions on LGBT health issues in their examinations.** Inclusion of such questions would affirm institutional commitment to sensitive and appropriate care for LGBT populations and would motivate students to learn about LGBT health care.
- C. **Academic health centers should include training and practice experience in LGBT health.** Academic health centers should provide on-site training, linkages and learning opportunities with community health agencies serving LGBT populations, and should hire LGBT staff/faculty to teach all students and to mentor LGBT students.
- D. **Models for training health providers in LGBT-sensitive care should be collected and disseminated.** The American Psychological Association has formal curricula on LGBT mental health. Several schools of medicine, nursing, physician assistant training, and social work have developed curricula and practice models that could be adopted or adapted by other schools. Materials, and contact information for experienced leaders in this area, should be provided to all health profession training programs.
- E. **LGBT health content should be required for continuing education of existing providers.** Training on LGBT issues should be included as required curricula for continuing education for all health professionals. Health care institutions should provide in-service training on specific facets of LGBT care and updates on research in LGBT health.

- F. **Effective models for training health professionals in LGBT-sensitive care should be identified, developed and disseminated.** Specific strategies for promoting culturally competent care among diverse populations, including LGBT populations should be identified. The focus should be on identifying and disseminating methods of instruction and practice that have a measurable impact on practice. Evaluations of promising teaching methods should be conducted and information on best practices in teaching should be widely disseminated.
- G. **Universities and community-based agencies should seek opportunities to collaborate to provide training opportunities for students and quality care for LGBT clients.** Through special funding or leveraging of existing resources, community clinics should be encouraged to find practical ways to work with universities. Models currently in use by some LGBT health providers include having staff physicians who are faculty at a local medical schools and provision of supervised rotations of students through a LGBT health clinic.

III Health Care Systems and Direct Services

- A. **Government and foundation resources should be directed to assisting community health centers, including LGBT providers, survive and thrive in the current health environment.** Technical assistance and training should be provided to help community health agencies develop the expertise, linkages to HMOs/PPOs, and administrative infrastructure to continue to provide safe, affordable, appropriate services to the LGBT populations they serve.
- B. **Government agencies and foundations should respond to opportunities to support new and continuing health services in LGBT communities.** LGBT communities should be active players in overall and community-specific efforts to address the needs of uninsured populations, reach under-served communities and insure appropriate access to care. Funding for the training of interns, the provision of services through safety net providers, and access to special services such as outreach to youth at risk for HIV are diminishing. Culturally specific programs may be lost unless community groups participate in the discussion of general health care issues and the need for specific services. Many counties and states have community planning processes and advisory bodies that should represent the concerns of LGBT constituents in the context of the larger health environment. For example, the Office of Multicultural Health and the Office of Women's Health in California were named as advisory bodies with the capacity to address LGBT health concerns. An assessment of existing services should be conducted to identify where HHS capacity-building dollars, and other potential resources, might be invested.
- C. **Efforts to create and disseminate standards of care should be supported by government health agencies and foundations.** The Massachusetts Department of Public Health and the San Francisco Lesbian, Bisexual, Transgendered Women's Health Forum have launched efforts to develop standards of care for LGBT populations in

collaboration with community groups and individual experts in LGBT health. Development of standards should be adopted by other government health agencies and foundations should support compilation and dissemination of model policies that could be used by advocates to promote adoption of standards in different states and counties.

- D. **LGBT community centers and social service organizations should help educate their constituents about advocating for their own health.** Community organizations are an important vehicle for teaching health consumers how to advocate for their own health care, educate their own health providers, and become voices for structural change in health care. Organizations concerned with civil rights issues, such as legal sanctioning of LGBT relationships, can make the connection between these issues and health such as access to coverage, financial status, and social support.
- E. **LGBT community and advocacy organizations should work with the federal government to insure inclusion of LGBT health issues in the Healthy People 2010 goals and strategies.** Healthy People 2010 offers an important opportunity to include sexual orientation into the national health agenda. Specific goals related to reducing disparities in LGBT health (e.g., related to tobacco and alcohol use) provide an opportunity to leverage mainstream support and funding that will provide interventions and prevent health problems in LGBT communities. In this context, public health officials and policy makers need to be educated about gaps and disparities in LGBT health and connections between LGBT disparities in health and disparities related to race, ethnicity and other factors.
- F. **LGBT community organizations should support and communicate with government agency representatives and policy makers that are openly LGBT and other allies.** LGBT representatives should be invited to the table by government entities to represent their LGBT constituents. Community organizations should work closely with LGBT staff, legislators and other allies to be informed about emerging policy issues and to have a voice in policy changes. Many other elected officials and staff of government health agencies are proven allies to LGBT communities. These relationships should be cultivated and communities should recognize that constituent activism is critical to support changes that these allies are often unable to effect without outside support.
- G.

IV Other Funding and Mobilization of Existing Resources

- A. **Foundation and government support is critical to advancing LGBT health through national and regional convening of stakeholders.** National convening is critical to building a LGBT health agenda, disseminating research, and sharing effective models for the provision of care and training of health professionals. Regional and local convenings are also essential for addressing state-specific and local opportunities and issues.
- B. **Funding, in connection with linkages between research and advocacy organizations, should be invested in a clearinghouse for LGBT health information.** Whether housed in one or several organizations, communities and policy makers need access to current and emerging information about LGBT health research, practice standards and advocacy.

- C. **Resources from government sources should be leveraged to summarize research information into a readily distributed format.** The public sector can provide human or financial resources to create summary documents, tables, and other information that can be disseminated to health institutions and providers to support overall efforts to advance sensitive, quality care to LGBT clients.

- D. **Government projects underway should integrate LGBT concerns.** Various government initiatives that are already underway should help advance LGBT health. For example, subsequent to the release of the Institute of Medicine Report (IOM) on Lesbian Health in 1999, there are federally supported efforts underway to develop a lesbian health research agenda. Participation of community voices in the formation of this agenda could be supported in the context of these efforts. Local states and counties should, similarly, use the IOM report as a foundation for examining current and planning future research efforts. Findings of a Surgeon General's report on mental health discrimination, bias, and stigma will be addressed in a national Anti-Stigma campaign. There is interest in addressing discrimination based on race, ethnicity, sexual orientation, and disability. LGBT community organizations can work with the Surgeon General's Office and with local state agencies to develop strategies for preventing and reducing harm associated with discrimination and bias.

- E. **LGBT media should increase coverage of health-related issues.** National and local publications need to improve their coverage of LGBT health issues, emerging health research, health policies that impact LGBT communities, and opportunities to affect health policy.

Conclusion

The LGBT community has demonstrated tremendous past resilience in addressing health problems, and currently possesses many assets for addressing emergent health issues. The shifting health care delivery environment, inadequate support for research, and heterosexism and homophobia in health care represent challenges to the health of LGBT communities. Ultimately, addressing these issues will benefit LGBT consumers and the larger community. Critical goals for advancing the health of LGBT communities involve inclusion in mainstream federal, state and local health initiatives, expansion of health care resources sensitive to diverse LGBT communities, and development of a broader research agenda with greater involvement of community organizations. Research and health care efforts must include and directly support populations that have been frequently neglected in research such as LGBT communities of color and rural communities. National and local advocacy efforts need to be supported, expanded, and coordinated. Recommendations forwarded through the Gay and Lesbian Health Roundtable, along with the proposals of many other LGBT health advocates, provide concrete ideas for operationalizing the overall goal of advancing LGBT health.

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The L.A. Gay & Lesbian Center is the world's largest gay and lesbian organization and is recognized as a powerful, nonprofit force for gay and lesbian civil rights. The Gay & Lesbian Center is home to a wide array of free or low-cost health, legal, employment, educational, cultural and social programs designed especially for lesbians and gay men. The Gay & Lesbian Center is staffed by 250 employees and is supported by approximately 3,000 volunteers.



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