

# Lesbian, Gay, Bisexual, and Transgender Health: Findings and Concerns

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## I. INTRODUCTION/BACKGROUND

### A. Definitions and Scope

This report discusses the health of lesbian, gay male, bisexual, and transgender (LGBT) individuals. This grouping includes diverse and varied populations that often share little more than society's stigma and prejudice. Stigma, however, as well as a range of other social and cultural factors are forces that impact both the health of LGBT people and the ability of health care providers to care for them in myriad ways.

Like the general U.S. population, LGBT people are diverse in terms of cultural background, ethnic or racial identity, age, education, income, and place of residence. The degree to which sexual orientation or gender identity is central to one's self-definition, the level of affiliation with other LGBT people, and the rejection or acceptance of societal stereotypes and prejudice vary greatly among individuals. These differences parallel the diversity among members of other minority groups.

#### *Lesbian, Gay, and Bisexual Populations*

Lesbian, gay, and bisexual (LGB) people are defined by their sexual orientation, a definition that is complex and variable. Throughout history and among cultures the definition of sexual orientation shifts and changes. While sexual orientation is not easily defined, a generally accepted definition of an LGB person is one with an orientation toward people of the same gender in sexual behavior, affection, or attraction, and/or self-identity as gay/lesbian or bisexual.

Varied definitions of sexual orientation and research methodologies have resulted in differing estimates of the number of lesbians and gay men in the United States. Many scientists now concur with estimates derived from Laumann *et al.*'s (1994) well-designed survey of the U.S. population, though the authors note that these numbers may be low due to the limited ability of survey research to capture sensitive information from sexual minorities. Laumann *et al.* used varied definitions of sexual orientation to offer a range for the prevalence of homosexuality. Lower-end estimates were derived from reports of those people who self-identified as homosexual, gay, lesbian, or bisexual, while upper-end estimates were derived from those reporting any sexual behav-

ior with a person of the same gender since puberty. Using these definitions, between 1.4% and 4.3% of women and 2.8% and 9.1% of men in the United States are classified as lesbian, gay, or bisexual. Because of the concentration of LGB people in larger urban centers, these estimates increase sharply when the 12 largest cities in the United States are considered separately. In these areas, estimates of homosexuality or bisexuality range from 2.6% (identity) to 4.6% (sex since puberty) for women, and from 9.2% (identity) to 15.8% (sex since puberty) for men.

#### *Transgender Populations*

Definitions and scope of transgender populations are even less adequately researched. Gender is increasingly being understood as having a strong cultural definition in addition to precise biological and extensive psychosocial components. Studies frequently and incorrectly include gender-nonconformist individuals under the rubric of gay men or lesbians in spite of the fact that gender identity is clearly distinct from sexual identity (Israel and Tarver, 1997). Other studies have focused on health concerns of transsexuals alone, while ignoring intersex individuals, androgynes, transvestites, and a range of other individuals whose behavior and identity make them identify as transgender (Cohen *et al.*, 1997; Gagne *et al.*, 1997; Israel and Tarver, 1997; Mason-Schrock, 1996).

### B. Stigmatization of LGBT Populations in the United States

Despite a steady increase in the acceptance of homosexuality over the past two decades (Herek, 1999), there still is great stigma surrounding homosexuality in the United States. A recent poll found that the majority of Americans view homosexuality as morally wrong, in the same category as adultery (Ungvarski and Grossman, 1999).

"Homophobic" and "antigay" are terms commonly used in this document and elsewhere to describe negative attitudes toward lesbians and gay men. "Heterosexist" is used to refer to characteristics of an ideological system that denies, denigrates, and stigmatizes any nonheterosexual form of behavior, identity, relationship, or community.

*Lesbian, Gay, and Bisexual Stigmatization*

Homophobia and heterosexism play a role in the inadequate assessment, treatment, and prevention of lesbian, gay, and bisexual health problems. LGB individuals suffer from discrimination in housing, employment, and basic civil rights. Homosexuality is still criminalized through sodomy laws in 16 states of the United States, which is used not only to arrest LGB people, but to deny them jobs, child custody, or participation in the political process (Lambda Legal Defense and Education Fund, 1999). Insurance companies, government, hospitals, and health clinics often fail to recognize committed lesbian and gay relationships, and deny gay and lesbian partners the privileges granted to married heterosexual couples (O'Hanlan *et al.*, 1997).

Many LGB people, rejected by or uncomfortable with their families of origin, lose traditional social support after disclosure of their sexual identity (Vincke *et al.*, 1993). In addition, disproportionate numbers move to large urban centers with concentrated health risks.

*Transgender Stigmatization*

Research on the effects of stigma, violence, social attitudes, and gender bias on the lives of transgender individuals is even less available than for LGB populations. Preliminary reports and existing studies suggest that the problems above may be even more severe for transgender individuals. They frequently face marginalization from gay and lesbian communities as well as from heterosexual communities and providers, and in many instances are regarded as pathological or unhealthy *per se* (Israel and Tarver, 1997).

**C. Health of Lesbian, Gay, Bisexual, and Transgender Populations**

Social conditions impact the health of LGBT populations in a variety of ways. The areas affected can be conceptualized as ranging from the direct impact of stigmatization and prejudice (e.g., exposure to violence, stress, poor access to care) to failure adequately to address special needs of LGBT populations (e.g., gay-specific sexually transmitted disease, fertility challenges, genital reassignment surgery). The diverse public health areas of impact are the

substance of this report, though two general themes running throughout include the following:

1. *Research and evaluation.* Because of stigma and prejudice, and because LGBT people represent a minority of the U.S. population, clinical and public health studies and program evaluation have been scarce in all sectors of health delivery and research. For example, population-based national health surveys virtually never include ways to assess sexual orientation, and those that have sought federal support have been denied funding (Laumann *et al.*, 1994). In addition to stigmatization and political obstacles, methodological challenges, including problems in recruitment of subjects and definitions of homosexuality or transgender identity, have thwarted research on LGBT public health issues (Solarz, 1999). With virtually no large-scale random surveys of LGBT populations, public health researchers and planners must turn to small studies that often use convenience samples. Such data are often biased and uninformative for public health purposes. Areas where lack of representative samples has frustrated researchers recently include the association of sexual orientation with incidence and natural history of cancer (e.g., breast cancer in lesbians and anal cancer in gay men), mental health of gender-variant adolescents, and sexually transmitted disease (STD) rates among gay men.

2. *Health care delivery and access to care.* Because of negative attitudes prevalent in the U.S. public as well as among physicians and other medical staff, LGBT individuals are subject to discrimination and bias in medical encounters. Moreover, they are likely to receive substandard care, or remain silent about important health issues they fear may lead to stigmatization (Schatz and O'Hanlan, 1994; Bradford and Ryan, 1988; Bockting *et al.*, 1998). Bias from health care professionals and perception of such bias have been identified as personal and cultural barriers to care, leading to reduction in help-seeking and quality of care (Millman, 1993). In addition, stereotyping and lack of education may lead health care providers to ignore known special preventive care and treatment needs of LGBT people (e.g., provision of Pap smears to lesbians, pain management after genital reassignment surgery, examination for infections of the anal canal, and others). Medical forms and the format of medical intake and history are often insensitive to the experience of LGBT patients, and likely to discourage disclosure of sexual orientation and behavior.

In mental health care, stigma, lack of cultural sensitivity, and unconscious and conscious reluctance to address sexuality may all hamper effectiveness of care. An extreme example is found in “reparative” therapy, which seeks to reverse sexual orientation or gender identification, an approach that may lead to increased self-hatred and mental health problems (CC Ryan *et al.*, 1999). Treatment modalities that rely on group therapies and support groups are also vulnerable to the effects of discrimination, with participants often forming a justifiable fear that full disclosure of personal details may adversely affect their standing in the group or health care setting. LGBT people report discriminatory treatment following disclosure of sexual orientation in paramedical and auxiliary care settings, including nursing homes, domestic violence centers, senior centers, and others (Wolfe, 2000).

Barriers to care for LGBT people include systemic bias in health insurance and public entitlements, which routinely fail to cover gay and lesbian partners or to provide reimbursement for procedures of particular relevance to LGBT populations (e.g., fertility services to lesbians, surgical procedures required by transsexuals). Obstacles to LGBT care are likely to increase as greater numbers of employers move toward self-insurance and as health maintenance organizations (HMOs) require more detailed reports for ongoing mental health care. These and other trends will increase LGBT individuals’ fears of breaches in confidentiality and consequent stigmatization.

#### *Social Origins of Health Concerns*

This report covers a wide variety of health concerns of particular relevance for LGBT populations, organized by health topic. It is also important to consider these health outcomes in the context of their social origins. Table I conceptualizes health outcomes and their putative relationship to social/behavioral factors specific to LGBT populations, listing social/behavioral factors (across the top) and health outcomes specific to each (below each factor). While not an exhaustive list of either, the table may serve as a useful heuristic in considering the relationship of social/behavioral factors and LGBT health concerns.

#### *Threshold Issues*

While knowledge of and standards of care for particular conditions prevalent among LGBT popu-

lations vary widely, several threshold areas impact LGBT health delivery generally and provide important opportunities to enhance delivery of care to LGBT populations. These topics are summarized in Section II, and include the following:

- Public health infrastructure
- Access to quality health services
- Health communication
- Educational and community-based programs

#### *LGBT Health Concerns*

Although there are many common issues affecting LGBT communities, transgender concerns present unique health challenges that merit separate discussion. Subject-specific summaries of leading lesbian, gay, and bisexual health concerns (e.g., cancer, substance abuse, etc.) are found in Section III. Section IV provides an overview of some of the complex issues related to transgender individuals.

#### *Methodologic Challenges*

Central to the study of LGBT health concerns are the methodologic challenges posed by studies of these populations. Relevant issues include definition and measurement of critically unexamined and socially constructed categories, as well as challenges of sampling rare and hidden populations concerning sensitive topics. These methodologic challenges are examined in Section V.

Many topics of concerns to the health of LGBT individuals are not addressed here. While this report summarizes existing research findings, clinical and public health research for these populations has been scarce (Bradford and White, 2000). In addition, there is currently no public health infrastructure for funding and supporting research on the health of LGBT communities. Coordination of research into LGBT health and systemic reform and education toward elimination of antigay bias and insensitivities remain imperative.

While this report is brief, its findings will prove useful if it engenders increased dialogue, understanding, concern, and support for research, education, and training with respect to LGBT health concerns. These are among the steps necessary for increasing knowledge about LGBT health and LGBT access to health services, for improving the health of members

**Table I.** Social/Behavioral Factors and Health Concerns Relevant to LGBT Populations

Sexual Behavior	Cultural Factors	Disclosure of Sexual Orientation, Gender Identity	Prejudice and Discrimination	Concealed Sexual Identity
HIV/AIDS	Body culture: eating disorders	Psychological adjustment, depression, anxiety, suicide	Provider bias, lack of sensitivity	Reluctance to seek preventive care
Hepatitis A and B	Socialization through bars: drug, alcohol, and tobacco use	Conflicts with family of origins, lack of social support	Harassment and discrimination in medical encounters, employment, housing, and child custody	Delayed medical treatment
Enteritis (e.g., giardia, amoeba)	Nulliparity: breast cancer	Physical/economical dislocation	Limited access to care or insurance coverage	Incomplete medical history, (e.g., concealed risks, sexually related complications, social factors)
Human papillomavirus	Parenting: insemination questions, mental health concerns		Pathologizing of gender-variant behavior	
Bacterial vaginosis	Gender polarity in dominant culture: conflicts for transgender and intersex persons		Violence against LGBT populations	
Anal cancer				
Other STDs				

of lesbian, gay, bisexual, and transgender communities, for addressing health disparities in the United States, and for ensuring the health of all U.S. residents.

## II. THRESHOLD ISSUES

### A. Public Health Infrastructure

Efforts to research and address the health needs of LGBT populations are hampered by a lack of infrastructure to support and direct funded initiatives. Currently there is no identified agency within the Public Health Service with responsibility to oversee and/or coordinate such initiatives. Various agencies have funded competitive research and policy studies, but these efforts have been scattered and without central, overarching guidance relevant to population health. For gay and bisexual men, competitive research grants have been funded primarily in areas related to HIV/AIDS. For lesbians, several grants have been awarded in the areas of substance abuse, health care, and mental health (Solarz, 1999). While useful, these uncoordinated studies do not comprise an organized program of population-based research, nor is it easy to understand how they may mature into such a program without the intentional development of support structures. Research and public health interventions targeted to transgender individuals have lagged even more seriously.

Recent reports on LGBT health, most notably

the Institute of Medicine's (IOM) landmark report on lesbian health, contain a number of recommendations that will be difficult to implement without significant infrastructure development (Solarz, 1999). Political constraints may limit the feasibility of creating an LGBT-dedicated research organization within the federal bureaucracy. However, alternatives such as cooperative planning and funding of critical population-based research and initiatives may be feasible. The IOM study on lesbian health, supported by funding from two agencies in the federal public health infrastructure—the Office of Research on Women's Health in the Department of Health and Human Services (DHHS) and the Office of Women's Health at the Centers for Disease Control and Prevention (CDC)—represents one example of such a collaboration.

Other promising cooperative efforts followed publication of the IOM report. In September 1999, the National Institute of Mental Health (NIMH) collaborated with the American Psychological Association to present and host a 2-day workshop on current research regarding LGBT populations. A current collaboration of DHHS with the Gay and Lesbian Medical Association/Lesbian Health Fund (GLMA/LHF) to implement a March 2000 scientific meeting as follow-up to the IOM report is another related endeavor. Cooperative efforts such as these can help fill gaps in the infrastructure, and can provide a foundation on which to create an enduring structure with appropriate sharing of responsibility among public and private organizations.

## B. Access to Quality Health Services

LGBT individuals face financial, structural, personal, and cultural barriers as they attempt to access competent, sensitive health care services (Millman, 1993). These barriers and anxiety about facing them prevent LGBT individuals from receiving the screening and prevention services they need, and cause delays in receiving care for acute conditions.

Provider attitudes, communication difficulties, and systemic obstacles pose major impediments for sexual minorities to access care. LGBT persons, despite generally higher educational levels, have a lower socioeconomic status than their heterosexual counterparts. Many are self-employed, work as artists or craftspersons, or work part-time; consequently, many have few or no health insurance benefits (Badgett, 1998; Bradford and Ryan, 1988).

An analysis of data from the National Lesbian Health Care Survey (NLHCS) (Bradford and Honnold, 1994) suggests that subgroups of lesbians may be at particularly high risk of negative health consequences due to lack of insurance coverage. Within the NLHCS sample, lack of health insurance was significantly correlated with being younger, unemployed, in school, of lower income, and African American. Mental health issues were more prominent among uninsured respondents, many of whom reported significantly higher levels of anxiety and suicide ideation. Uninsured respondents are also more likely to have experienced physical and/or sexual abuse and reported much greater concern about sometimes feeling unable to meet their routine responsibilities. Certain physical health conditions were also more prominent, including ulcers and other intestinal disorders, substance abuse, and eating disorders. There was a statistically significant correlation for this sample between not having health insurance and believing that being lesbian affected their access to health care.

Both gay men and lesbians in committed relationships are at a disadvantage compared to married heterosexuals because many insurance companies and employers deny spousal benefits to unmarried partners (Denenberg, 1995; Stevens, 1995). Systemic bias in favor of heterosexuals is also found in regulations allowing one member of a married heterosexual couple to retain a jointly owned house without jeopardizing the other's right to Medicaid coverage. Moreover, married heterosexuals receive a spouse's Social Security payments following his or her death.

While some 30 states have passed constitutional amendments barring recognition of gay marriage

even if found legal by their courts, a recent ruling in Vermont provides a promising model. The State's highest court has instructed legislators to recognize gay marriage or to structure domestic partnership regulations affording committed gay and lesbian couples benefits equivalent to those of heterosexual spouses. A number of local municipalities and private corporations have also widened insurance coverage for their employees to include unmarried domestic partners, both homosexual and heterosexual.

LGBT populations may also find it difficult to access other publicly supported programs. While many localities offer critical low-cost or free health care and screening to women who are seeking birth control, lesbians who do not need birth control find it hard to locate affordable health care services. Men, already less likely to seek out such services than women, may be further impeded by reluctance to reveal their sexual practices or fear of homophobia in medical settings.

Additionally, same-sex partners are denied rights granted to married heterosexuals in hospitals and clinics. Unless a gay or lesbian couple has signed legal papers (e.g., durable power of attorney, health proxy, etc.) authorizing mutual medical decision making, blood relatives, including those who know less about the patient's ethical, medical, or religious preferences, can override decisions by a homosexual partner. Some health care settings also limit visits or participation in medical consultations to legally recognized spouses or blood relatives, a practice particularly damaging to the many LGBT people who prioritize families of choice over families of origin (O'Hanlan *et al.*, 1997).

Even those LGBT individuals who have individual private insurance may be reluctant to use it to access care. The vast majority of U.S. employers who have more than 1000 employees now self-insure, which means they have access to employee health care records and claims (Wolfe, 2000). For some LGBT persons, disclosure of information about sexual orientation or gender identity would be an unacceptable consequence of seeking care. Similar confidentiality concerns may impede LGBT individuals from seeking counseling or support, or care for stigmatized conditions such as HIV infection, through HMOs, which often require detailed justifications to ensure continuation of benefits.

In response to poor access to the health care system, during the past two decades LGBT communities have begun building elements of their own system. Systemic reform and the elimination of antigay

bias in health care and social service settings remain essential goals for the health of LGBT communities. These goals are critical both to address medical concerns with unique effects for LGBT populations—detailed in the pages that follow—and to address general medical concerns shared with Americans at large.

### C. Health Communication

#### *Personal and Cultural Barriers*

In addition to difficulties in accessing health care, lesbian, gay, bisexual, and transgender individuals face significant obstacles in communication with health care providers. First and most challenging are negative attitudes toward homosexual, bisexual, and transgender persons held by many providers. Forty percent of physicians in one study were sometimes or often uncomfortable providing care to lesbian or gay patients (Matthews *et al.*, 1986). In a nonrandom survey of members of the Gay and Lesbian Medical Association (GLMA), 67% of respondents believed they had seen gay or lesbian patients receiving “substandard” care because of their sexual orientation (Schatz and O’Hanlan, 1994). Many lesbians and gay men have reported that their doctors are not sensitive to or knowledgeable about their particular health risks and needs, and do not disclose pertinent information about treatments or prevention (EM Smith *et al.*, 1985; Trippet and Bain, 1992; Schatz and O’Hanlan, 1994).

Whether patients disclose their sexuality and sexual practices to providers may depend in part on where patients are in their coming out process. For example, gay and lesbian adolescents, who often lack structural supports such as financial independence and social networks that can sustain older gay men and lesbians (LB Allen *et al.*, 1998; D’Augelli and Hershberger, 1993; Newman and Muzzonigro, 1993), are likely to delay disclosure of sexuality to clinicians. Homosexually active men and women who identify as heterosexual, or those who are at the early stages of the distinct developmental processes theorists have associated with coming out (Brady and Busse, 1994), may also choose not to disclose their sexual histories to a health care provider.

Still, even individuals who enjoy significant social support as openly gay men and lesbians may find it difficult or imprudent to reveal their sexuality in a doctor’s office. Intake forms covering sexual

history rarely include the option for providing information on same-gender sexual partners. Physicians and researchers routinely ask heterosexually biased questions, such as, “Are you married, single, widowed or divorced?” or “What kind of birth control do you use?” Consequently, disclosure of sexual orientation in a health care setting remains infrequent for the majority of gay men and lesbians (Robertson, 1998; White and Dull, 1997; LB Allen *et al.*, 1998; Cochran and Mays, 1988; Siegel *et al.*, 1994). In a survey of lesbians in Michigan, 61% felt unable to disclose their sexual orientation to their providers (Bybee and Roeder, 1990). Some 9% of respondents reported that their health care providers had not allowed their female partners to stay with them during treatment or see them in a treatment facility; 9% also said that providers had not included their partners in discussion about treatment (Bybee and Roeder, 1990).

The medical educational system has failed to educate providers and researchers regarding the unique aspects of lesbian and gay health (Wallik *et al.*, 1992), including examination techniques, taking of patient histories, and preventive recommendations. Although homosexuality has been removed from the list of diagnoses in the diagnostic manual of the American Psychiatric Association, the relationship between homosexuality and sickness has proved more enduring in the minds of many providers. A variety of studies describe provider hostility (Hayward and Weissfeld, 1993; Gerbert *et al.*, 1991) or instances of gay men or lesbians being described as “deserving” of illness or unworthy of treatment (Schatz and O’Hanlan, 1994). Tellingly, stigma can be most pronounced in those instances where sensitive treatment is needed. A number of respondents to the GLMA survey, for example, said they had seen doctors performing “rough” or “violent” digital rectal exams on patients after discovering that they were gay (Schatz and O’Hanlan, 1994).

Many clinicians sympathetic to gay men or lesbians may lack a repertoire of questions about social and sexual history appropriate to homosexuals, or be unaware of why they might be necessary. Among physicians interviewed for a cancer screening project conducted by the Mautner Project for Lesbians with Cancer, approximately one half stated that they assumed lesbians were in their practices, but did not see any reason to address this in a direct way (Bradford and Dye, unpublished). These providers expressed an eagerness to learn more about the needs of lesbians and stated emphatically that they would

make changes when they had information about what steps would be appropriate (Bradford and Dye, unpublished).

Physicians are not alone among health care providers in facing difficulties in communication with gay and lesbian patients. In a random sample survey of Virginia mental health providers, respondents acknowledged having lesbians in their practices, yet had little or no training about the special needs of these clients (CC Ryan *et al.*, 1999). Some mental health practitioners continue to practice "reparative" therapy for homosexuality (J Berger, 1994), to use inadequate or inappropriate definitions for lesbians and gay men, and/or state that they do not think the concerns of gay or lesbian clients are different from those of heterosexuals (Robertson, 1998; CC Ryan *et al.*, 1999). Findings were similar in a California study of physicians dealing with lesbians and gay men (Mathews *et al.*, 1986).

Barriers to communication about the needs and realities of gay and lesbian life are manifested at the systemic as well as individual level. In hospitals, emergency rooms, and intensive care units, visitation and medical decision-making policies frequently exclude partners of lesbian or gay patients. In the wake of Congressional disapproval of explicit safer sex campaigns, the 1987 Helms Amendment prohibited funding any public health or educational material, that "promote or encourage, directly or indirectly, homosexual sexual activities" (Andriote, 1999). While that prohibition has since been struck down in court, the CDC still requires that materials undergo community review, with no guarantee that review panels include gay men or lesbians or knowledgeable experts. Public ambivalence toward homosexuality continues: as late as 1998, a poll found that the majority of the public considered homosexuality a moral wrong in the same category as adultery (Ungvarski and Grossman, 1999). This situation may create censorship or self-censorship of information critical to vulnerable populations.

Finally, gay men and lesbians themselves, when faced with an uncomfortable interaction with a clinician, may lack the skills or self-efficacy to defend against negative experiences. They may feel unable to change physicians' conduct, to resolve an uncomfortable situation, or to speak openly with a clinician about their discomfort. This may stem from a history of discrimination and the power imbalance traditionally experienced between clinician and patient, and/or from past memories of difficult experiences.

### *Health Consequences of Poor Communication*

Disclosure of sexual orientation in the health care setting is crucial to the provision of appropriate, sensitive, and individualized care. Failure to establish rapport and communication between physicians and patients is associated with decreased levels of adherence to physician advice and treatment plans, and decreased rates of satisfaction (Inui and Carter, 1989). Additionally, clinicians unaware of their patients' sexual orientation may fail accurately to diagnose, treat, or recommend appropriate preventive measures for a range of conditions. While more research is needed on the effects of communication related to sexual orientation and medical care, small surveys suggest that successful communication and ease of sexual orientation disclosure may positively affect health risks and screenings. In a study of lesbians in Oregon (White and Dull, 1997), 90% disclosed their sexual orientation to providers, and of these, 92% raised the issue themselves (White and Dull, 1998). Communication style of the provider was rated by respondents as the most important characteristic in determining ease of discussion about difficult issues. The lesbians who disclosed their sexual orientation were more likely to seek health and preventive care, to have a Pap test, to be nonsmokers, and to report comfort in communication with providers. By contrast, difficulty communicating with the primary care provider was associated with delay in seeking health care (White and Dull, 1998).

### **D. Educational and Community-Based Programs**

Lesbian, gay, bisexual, and transgender communities and their allies began to promote LGBT health concerns in the United States in the 1950s when educational, healthcare, and other government and private systems proved inadequate. Organizing began with efforts to have homosexuality declassified as a mental illness. These efforts extended through the 1960s and intensified in the 1970s, with successful advocacy to remove homosexuality from the *Diagnostic and Statistical Manual of Mental Disorders* (DSM) of the American Psychiatric Association (Bayer, 1981). In related early efforts, LGBT communities created a variety of professional and volunteer health care initiatives to offer nonjudgmental treatment and education about sexually transmitted diseases (STDs) and mental health issues related to coming out and stigmatization. Lesbian health initiatives



included the creation of “lesbian health nights” at women’s health clinics (Plumb, 1998). Gay counseling sessions, peer education groups, and STD screenings at ordinarily nongay community health facilities were also organized. Then, as the gay community faced the HIV epidemic, work ensued to expand the focus of mainstream organizations, and to create new and powerful lesbian and gay-focused health education, treatment, and advocacy organizations (Deyton and Lear, 1988; Andriote, 1999).

Today, a variety of LGBT organizations, some of which are now celebrating their 25th anniversary, deal in a comprehensive manner with HIV/AIDS, mental health, cancer, violence, and other issues. Clinics and volunteer initiatives providing community-based primary health care services directly to LGBT communities are found throughout the United States. Among the largest and most notable of these are the Callen-Lorde Community Health Center in New York, the Fenway Community Health Center in Boston, the Whitman-Walker Clinic in Washington, D.C., and the Howard Brown Memorial Clinic in Chicago, whose services include screening, testing, and care for HIV, breast cancer, and STDs, mental health services, family planning services, including artificial insemination and adoption, and support services related to violence and coming out.

Lesbian and gay community centers, of which there are over 100 in 33 states, may provide similar or additional services to those offered by health care clinics. These community centers range from the modest Up the Stairs Community Center in Fort Wayne, Indiana, and the Panhandle Gay & Lesbian Support Services in Scottsbluff, Nebraska, to the much larger centers serving the gay and lesbian communities of Los Angeles, Chicago, and New York City. Many of these offer counseling and support for people in crisis, youth, the elderly, people living with HIV and AIDS, people struggling with substance abuse, and survivors of antigay violence. For example, the Los Angeles Gay and Lesbian Center, founded in 1971 as the nation’s first lesbian and gay community services center and now the nation’s largest, offers primary care counseling, addiction recovery groups, testing and treatment for sexually transmitted diseases, and shelter for homeless youth (Burns and Rofes, 1988). Others, such as the New York Lesbian and Gay Community Services Center, serve as focal points for hundreds of support groups, and host cultural events and political advocacy efforts centered around LGBT health issues. New York City’s community services center is home to the nation-

ally recognized Gender Identity Project, providing counseling, advocacy, social support, and training for transgender individuals and their providers. Many community centers provide a “safe space” to diminish the sense of isolation and self-judgement that are among the particular stresses of minority sexual orientation.

### *Impact of HIV/AIDS*

Not surprisingly, in the 1980s and 1990s, the HIV/AIDS epidemic forced a restructuring of existing educational and community-based programs in LGBT communities and the creation of new LGBT health-focused organizations (Altman, 1994; E Drucker, 1994; Jonsen and Stryker, 1993; Van Vugt, 1994). The first of these new organizations and prototype for many others was Gay Men’s Health Crisis (GMHC), founded in New York City in 1982. Formed by a group of gay men before there was a name for AIDS, GMHC was a community effort to educate and care for itself as a growing number of its members became ill and died (Reinfeld, 1994). GMHC and many other AIDS organizations have grown from all-volunteer efforts to professionally staffed, nonprofit organizations that provide services such as support and advocacy, primary and secondary risk reduction, and community education. Other leading AIDS organizations include the AIDS Project Los Angeles, the San Francisco AIDS Foundation, and the AIDS Action Committee in Boston. Gay men and lesbians have also played prominent roles in the organizations formed to advocate for particular needs and concerns of people of color with HIV, including, for example, the National Minority AIDS Council, the National Latino/a Lesbian and Gay Organization, the National Native American AIDS Prevention Center, the Latino Commission on AIDS, the Black Leadership Commission on AIDS, Us Helping Us, African American AIDS Support Services and Survival Institute, the Minority AIDS Project, Bienestar, the Asian and Pacific Islander Wellness Center, the Asian Pacific Islander AIDS Intervention Team, and the Asian and Pacific Islander Coalition on HIV/AIDS.

The onset of the HIV/AIDS epidemic strengthened the gay health movement’s emphasis on patient self-determination, and broadened its focus to include the previously ignored arena of clinical trials and medical research. The Community Consortium (CC) in San Francisco and the Community Research Initiative

(CRI) of the People with AIDS Coalition in New York City were created in the 1980s to increase community involvement in the testing of HIV drugs (Andriote, 1999). The AIDS Coalition to Unleash Power (ACT-UP), with chapters across the country, focused its early efforts on increased scrutiny of governmental agencies and privately held companies perceived to be impeding the development of or access to potentially lifesaving AIDS medications. While tactics differed, CRI and CC helped establish a network of community clinical trials sites, and ACT-UP used public education and civil disobedience to achieve greater scientific accountability and patient involvement in research. Advocates for a range of illnesses have since adopted similar approaches and goals.

### *Services Throughout the Lifespan*

Efforts to foster health as well as combat illness have expanded to address the needs of LGBT individuals across the lifespan. For example, the Gay, Lesbian, and Straight Education Network (GLSEN) works to create a safe learning environment for lesbian and gay students in K-12 schools. GLSEN currently has a network of 85 chapters whose members work to educate school officials about nondiscrimination policies. They also train teachers to prevent anti-gay attacks and create nonhostile environments. Other organizations working to protect and advocate for LGBT youth are the Hetrick-Martin Institute in New York City and Horizons Community Services Center in Chicago (C Ryan and Futterman, 1998). For older gay men and lesbians, a number of organizations, many of which participate in a network organized by Senior Action in a Gay Environment (SAGE), now provide support groups, social support, provider education, and advocacy.

### *Professional Organizations*

LGBT professional organizations, or committees and working groups within larger professional organizations, serve as important resources for health care provision and social support efforts. Both the American Psychological Association and the American Society on Aging have committees or working groups focused on gay and lesbian concerns. LGBT professional organizations include the Gay and Lesbian Medical Association (GLMA), the Association for Gay, Lesbian, and Bisexual Issues in Counseling,

and the National Association of Lesbian and Gay Addiction Professionals. The mission of GLMA, for example, is “to combat homophobia within the medical profession and in society at large, to promote quality health care for LGBT and HIV-positive people, to foster a professional climate in which our diverse members can achieve their full potential, and to support members challenged by discrimination on the basis of sexual orientation” (Gay and Lesbian Medical Association, 1999).

### *Governmental Agencies*

In some locations, governmental entities have been created to promote the health of LGBT people beyond concerns of HIV/AIDS. For example, New York City established the Office of Gay and Lesbian Health Concerns (OGLHC) in 1983 in response to the AIDS crisis and redefined it in 1985 to address all lesbian and gay health concerns. The OGLHC has addressed the lack of health care services for lesbian and bisexual women, anti-gay and lesbian violence, gay and lesbian suicide, and chemical dependency and substance abuse among gays and lesbians. Similarly, in San Francisco a Coordinator of Lesbian and Gay Health Services was created in the early 1980s (Vachon, 1988).

Other governmental agencies extended their reach to LGBT people by collaborating with existing community organizations. In 1996 the Massachusetts Department of Public Health, in conjunction with the Justice Resource Institute, the Medical Foundation, and the JSI Research and Training Institute, created the Gay, Lesbian, Bisexual and Transgender Health Access Project (GLBTHAP). The project works “to strengthen the Massachusetts Department of Public Health’s ability to foster the development of comprehensive, culturally appropriate health promotion policies and health care services for gay, lesbian, bisexual and transgender people through a variety of venues including community awareness, policy development, advocacy, direct service and prevention strategies” (Gay, Lesbian, Bisexual and Transgender Health Access Project, 1999).

In conclusion, while some governmental agencies, professional organizations, and mainstream health care entities have begun to address and respond to the concerns of lesbian, gay male, bisexual, and transgender individuals, LGBT people still largely depend upon self-created community-based and professional organizations to address their spe-

cial health care needs. In addition, no federal infrastructure exists to facilitate the creation of LGBT health initiatives or research.

### III. LESBIAN, GAY, AND BISEXUAL HEALTH CONCERNS

#### A. Cancer

While definitive studies are lacking, preliminary data lend credence to the suggestion that gay men and lesbians are at increased risk for certain cancers, and that more research is needed to understand the natural history of disease in LGB populations. Innovative studies in psychoneuroimmunology further suggest a direct association between psychological phenomena, reduced immunity, and tumor growth; thus, gay men and lesbians who do not disclose their sexual orientation may be at increased risk for melanoma or other cancers due to psychogenic suppression of the immune response (SW Cole *et al.*, 1996).

Breast cancer is probably the most researched topic in lesbian health. Several investigators have hypothesized that lesbians are at higher risk for breast cancer than are heterosexual women due to higher rates of risk factors such as obesity, alcohol consumption, nulliparity, and lower rates of breast cancer screening (Haynes, 1994; Denenberg, 1995). While definitive studies in this area have yet to be completed, data on prevalence of each of the risk factors confirm the plausibility of this hypothesis (Dibble *et al.*, 1997; Valanis *et al.*, in press). Lesbians also receive less frequent gynecologic care than do heterosexual women (Robertson and Schacter, 1981) and therefore might also be at greater risk for mortality and morbidity from gynecologic cancers. Both of these risks are likely compounded by the difficulties many lesbians experience in communicating with or receiving standard clinical care from physicians and health care systems (Trippet and Bain, 1992). Little is known about prevalence and incidence of other cancers among lesbians.

Among gay men, a high rate of Kaposi's sarcoma (KS) was among the first described indicators of AIDS (Centers for Disease Control and Prevention, [CDC] 1981). Estimated risk for KS among gay and bisexual men was thousands of times higher than in the general population prior to approval of highly active antiretroviral therapies (Koblin *et al.*, 1996). This was a by-product both of HIV's weakening of

the immune system and of the sexually transmitted nature of the herpes virus (HHV-8) now thought to cause the cancer (JN Martin *et al.*, 1998). The risk for AIDS-related non-Hodgkin's lymphoma is also elevated among gay men, although at lower magnitudes (Koblin *et al.*, 1996). Between 1973 and 1987 non-Hodgkin's lymphoma incidence increased 10-fold and Kaposi's sarcoma incidence increased over 5000-fold in single San Francisco men ages 20–49 years (Rabkin *et al.*, 1991). While highly active antiretroviral therapies have significantly reduced KS rates (Buchbinder *et al.*, 1999), non-Hodgkin's lymphoma remains among the AIDS-related malignancies that continue to occur at sharply higher rates among HIV-positive individuals. An increase in the incidence of Hodgkin's disease has also been observed, but its association with HIV/AIDS is equivocal and the disease is not included in the AIDS case definition (Koblin *et al.*, 1996).

In a cohort design, using studies of records in New York and California cancer registries and the National Death Index, Koblin and colleagues (1996) found gay and bisexual men to be at excess risk for anal cancer (standardized incidence ratio [SIR] = 24.2), non-Hodgkin's lymphoma (SIR = 12.7), and Hodgkin's disease (SIR = 2.5). These accounted for an increased risk for all cancers in this population (SIR = 1.6). The authors found no difference in the incidence of cancers in any other site, including lip, oral cavity, and pharynx; digestive system and peritoneum; respiratory; bone and connective tissues; skin; genitourinary; multiple myeloma; leukemia; or other and unspecified sites. While Koblin and colleagues determined that the increase in risk for both non-Hodgkin's lymphoma and Hodgkin's disease was related to increased incidence of HIV/AIDS among homosexual men, they found the increased risk for anal cancer was unrelated to HIV/AIDS.

Evidence increasingly suggests that gay men are at increased risk for anal cancer. Higher risk for anal cancer among gay and bisexual men was demonstrated by Daling *et al.* (1987) in a case-control study of anal cancer. Daling *et al.* (1987) found that history of anal intercourse was associated with anal cancer (RR = 33.1) in men. History of STDs was also a risk factor for the disease.

Research suggests that risk factors for the excess incidence of anal cancer among homosexual men included increased rates of human papillomavirus (HPV) and anal squamous intraepithelial lesions (ASIL), both putative anal cancer precursors (Beckman *et al.*, 1989; Breese *et al.*, 1995; Daling *et al.*,

1987; Melbye *et al.*, 1990; Palefsky *et al.*, 1998). HPV has been found in both HIV-positive and HIV-negative men, but prevalence of infection is higher among HIV-positive men, with highest prevalence associated with latest stages of HIV disease (Breese *et al.*, 1995; Melbye *et al.*, 1990). In a study of HIV-positive and HIV-negative gay and bisexual men, Palefsky *et al.* found high prevalence of HPV (93% and 61%, respectively), most of subtype HPV-16. Infection with multiple HPV types was found in 73% of HIV-positive and 23% of HIV-negative men. Higher risk for HPV has been related to a history of receptive anal intercourse, rectal administration of recreational drugs (Palefsky *et al.*, 1998), and a higher number of lifetime sexual partners (Breese *et al.*, 1995). In addition to sexual behavior, smoking—prevalence of which is sharply higher among gay men—increases risk of anal cancer (Daling *et al.*, 1987).

Survival time among gay men with cancer may also be lower than the general population. Koblin *et al.* (1996) found 5-year survival rates for non-Hodgkin's lymphoma (9.8%) and Hodgkin's disease (32.8%) much shorter than the expected national rates (50.2% and 75.7%, respectively). The shorter-than-expected survival rate is probably related to HIV/AIDS comorbidity. Additional reasons for the lower survival rate may include delay in detection and treatment, possibly related to barriers in accessing care or communication with health care providers. The disparity in survival rate "highlights the need for rapid identification of such patients, and more effective approaches to detection and treatment of malignancies" (Koblin *et al.*, 1996). The use of rectal Pap smear for detection of HPV infections has been suggested (e.g., Palefsky *et al.*, 1998) as one such intervention, although further research needs to assess the association of HPV subtypes and anal cancer and the efficacy of Pap smear in detection.

Finally, difficulty in assessing sexual orientation in the general population may lead to bias in studies of gay/bisexual men and cancers. Available studies typically use urban, highly sexually active men, usually of midlife age. It is not known to what extent the results are applicable to less sexually active, older, or younger populations of gay and bisexual men.

## B. Family Planning

Fear of discrimination—particularly among lesbian and gay parents, who may face loss of child custody or visitation rights as a result of their sexual

orientation—has made it difficult for researchers to produce reliable figures on how many lesbians or gay men are currently raising children (Patterson, 1996; Havemann, 1997). Estimates of the number of children being raised by lesbian or gay parents in the United States range from 6 to 14 million (Patterson, 1996; Havemann, 1997).

At one time most children parented by lesbians or gay men were conceived during a previous heterosexual relationship. That is now changing. The newly coined phrase "lesbian baby boom" describes the increasing numbers of lesbians who are now choosing to have children after coming out, a pattern also reported to a lesser extent among gay men (Patterson, 1996). In 1990, it was estimated that 5000–10,000 lesbians had chosen to have children after coming out (Patterson, 1996), and the phenomenon has continued to grow. In addition to the donor inseminations that make up the majority of such pregnancies among lesbians, increasing numbers of gay men and lesbians are exploring other routes to parenthood, including foster care, adoption, and coparenting (Patterson, 1999; Cowan and Cowan, 1999).

Gay and lesbian parents have been routinely threatened by courts as being unfit *per se*, simply by virtue of their sexual orientation. Perhaps this explains why much of the limited research on lesbian and gay parenting is focused on the question of whether there are adverse effects to children of gay and lesbian parents. The literature does not show any negative outcomes for children raised by lesbian or gay parents (Patterson, 1994; N Allen and Burrell, 1996), nor does it demonstrate that those children are more likely to become gay or lesbian themselves (Patterson, 1996). Golombok's research showed that lesbian families had a greater mother-child interaction than heterosexual families in the sample, and greater psychological well-being in families where there was no genetic link to the child (Golombok *et al.*, 1997). National organizations that have policy statements supporting gay and lesbian parents include the American Academy of Matrimonial Lawyers, the American Psychological Association, the American Academy of Child and Adolescent Psychiatrists, and the National Association of Social Workers (Patterson, 1996).

Gay and lesbian families have few if any legal protections. The courts rule frequently in favor of biological parents and against the interests of the nonbiological parent in custody cases (Editors of the *Harvard Law Review*, 1990; Pollikoff, 1990). Agreements between known sperm donors and les-

bian mothers, too, are rarely recognized as legally binding; courts fail to recognize any role for known donors except that of parent, an interpretation which is often unsatisfactory to both the donor and the mothers raising the child (Bernstein, 1998). Gay and lesbian families, particularly nonbiological parents, face a range of systemic impediments to care and custody of children, including exclusion from a spouse's health insurance coverage and hostility in school systems and health care settings. Some states expressly prohibit gay men and lesbians from adopting or serving as foster parents, and other agencies advise gay men and lesbians to pursue those options as single parents rather than introducing the subject of sexual orientation (Patterson, 1996; AM Martin and Hetrick, 1993).

Little research has addressed the effects of stress produced by such institutionalized discrimination, or the ways in which gay and lesbian families must struggle with many psychosocial factors related to their alternative status. Factors include whether the nonbiological parent will be recognized by others as a parent, how the extended families will react to the new family structure, how to deal with a surrogate mother or a known-donor father, whether to choose a sperm donor who allows himself to be known later in the child's life, how to provide the children with peers who have similar families, and what and when to tell children about donors.

In addition, evidence suggests that communication difficulties between lesbians and health care providers may impede screening and care commonly delivered through family planning clinics or by ob-gyn physicians. In the National Lesbian Health Care Survey, 27% of respondents said their current providers had assumed they were heterosexual, 16% felt they could not come out to their providers, and 11% said providers had "forced" birth control on them. One in seven of these lesbians (14%) said they had difficulty talking to their ob-gyn providers (Bradford and Ryan, 1988).

### C. HIV/AIDS

See also Section III E on Mental Health and Mental Disorders, Section III G on Substance Abuse.

#### *Epidemiology*

In 1981, reports of unusual cancers and pneumonias among gay males were the first hint of the HIV

pandemic to come (CDC, 1981). Researchers looked to the number of sexual partners, recreational drug use, and other factors to identify the cause of what was originally known as GRID, or gay-related immunodeficiency. However, it was anal sex, a common sexual practice among men who have sex with men, that proved to be the most common means of transmitting the virus that caused the symptoms now known as AIDS. The history and future of LGBT communities will forever be shaped by the decimation experienced as a result of HIV.

Since 1981, it is estimated that more than 702,000 Americans have been diagnosed with AIDS (CDC, 1999b). Of those, 54% are reported to be men who have sex with men (MSM) (CDC, 1999b). While the popular image of a person with AIDS remains that of the White gay man, African American and Latino men have constituted the majority of AIDS cases among MSM since 1998 (CDC, 2000). In the states that report HIV infection, men who have sex with men (including those cross-listed as MSM and injecting drug users) constitute 38% of all newly reported cases (CDC, 1999b), with African American and Latino MSM becoming infected in greater numbers, and at a younger age, than White men (CDC, 2000).

#### *Gay Identity and HIV*

Growing understanding of HIV transmission has underscored the importance of distinguishing between sexual identity and sexual behavior. As indicated by the category "men who have sex with men," those at risk for HIV infection through homosexual sex include men who describe themselves as gay, bisexual, or heterosexual, and those who reject such categories altogether. Cultural differences in assessing sexuality, differences in homophobia levels within cultural and ethnic groups, and conflicts between racial and sexual identity may also contribute to reluctance to identify as gay, particularly for African American and Latino men (Diaz *et al.*, 1996; Stokes and Peterson, 1998; Jonsen and Stryker, 1993; Icard, 1986). One recent study of more than 8000 MSM of color with HIV found that as many as 24% of homosexually active African American men with HIV identified themselves as heterosexual (CDC, 2000). Some 15% of Latino men who had contracted HIV through homosexual sex identified themselves as heterosexual (CDC, 2000). The threat of HIV, or actual infection with the virus, may itself complicate

the process of disclosure of sexual identity and identification with a gay community. This situation can increase an individual's belief in negative stereotypes about gay men, binding attachment and intimacy to fears of illness, death, and loss of self and others (Saddul, 1996).

Many HIV research and prevention materials for homosexually active men have focused on men who identify as gay or bisexual, or have grouped bisexual and homosexual men together as a single group (Heckman *et al.*, 1995). In fact, this elision may have most serious consequences precisely in those men of color at highest sexual risk for HIV. Studies of bisexual behavior in men have found it to be correlated with lower intention to use condoms, knowing fewer HIV-positive people, weaker perceived norms for safer sex (Heckman *et al.*, 1995), and higher rates of sex that is high-risk for HIV (Doll and Beeker, 1996).

In addition, several studies have found that bisexually active men are often unlikely to disclose their bisexuality to female partners (Kalichman *et al.*, 1998b; Weatherburn *et al.*, 1998). It is difficult to tell how many heterosexual female exposures are a result of sex with undisclosed bisexual males. Community planners have identified the role that "survival" behaviors—including convenience sex, sex for drugs, or sex for food—all play in the transmission patterns of the pandemic. These factors underscore the need for greater research and educational materials aimed at homosexually active men who do not identify as gay. In addition, some bisexual men, if infected with HIV, may encounter difficulties in accessing care because the ability to identify with the gay community has been a proven predictor of supportive social relationships and subsequent health benefits in coping with HIV (Chapple *et al.*, 1998; Jonsen and Stryker, 1993).

### *Risk Behaviors*

Behavioral interventions to reduce risk for HIV/AIDS are currently the only effective way of slowing the spread of HIV infection (National Institutes of Health, 1997). Gay communities have pioneered strategies to successfully lower risk of HIV exposure through community-based education (Coates and Collins, 1998; Kalichman and Hospers, 1997; Jonsen and Stryker, 1993; Saddul, 1996). In the aggregate, research has shown that while most gay men have protected sex all or most of the time, a significant

percentage of MSMs—as many as one in three—have some incidence of unprotected anal sex (Hickson *et al.*, 1996; Meyer and Dean, 1995). Reasons for and context of this unprotected sex, and perceived risk for HIV involved in it, vary widely. Studies show some gay men to engage in selective risk reduction strategies such as unprotected sex only or primarily with partners they believe to be of the same serostatus (both HIV-positive or both HIV-negative) (Kippax *et al.*, 1997; Elford *et al.*, 1999). In addition, a wide and sometimes contradictory range of other psychosocial factors have been shown to influence sexual risk-taking, among them self-esteem, social supports or lack thereof, mood prior to sexual encounter, optimism, fatalism, age, education, and alcohol or drug use (Hospers and Kok, 1995). A growing body of literature suggests the importance of moving beyond informational prevention education to consideration of mental health models and support in the service of effective HIV prevention.

### *Treatment for HIV-Related Illness*

Health implications of the HIV epidemic for gay men are myriad, ranging from life-threatening opportunistic infections and malignancies to mental health challenges noted above and elsewhere in this paper. While the advent of highly active antiretroviral treatments (HAART) has sharply reduced AIDS deaths and opportunistic infections (CDC, 1999c), long-term effects of the combination anti-HIV drug regimens are unknown. Recent years have seen increasing reports of high cholesterol, diabetes, and redistribution of body fat known as lipodystrophy (Kaul *et al.*, 1999), raising questions about the treatment's long-term viability.

Gay men may also face particular obstacles in accessing health care, or in achieving the communication with health care providers that is critical to adherence to treatment regimens. The implications of failure to adhere, as well as of saturation in some gay communities of earlier, less effective treatment regimens, are only now beginning to be gauged by research. Studies have already documented passage of a drug-resistant virus from one gay man to another, and one recent study among newly infected gay men found that as many as 16% had HIV that was somewhat resistant to one or more AIDS drugs (Boden *et al.*, 1999).

HAART's efficacy may also impact HIV prevention efforts and other health supports for homosexu-

ally active men. Fueling the perception that AIDS has become a manageable, chronic infection, advent of HAART has been accompanied by reports of sharp drops in funding for community-based AIDS prevention and service organizations serving gay men and increases in high-risk behavior. One study, for example, found that 18% of HIV-positive gay men were now practicing safe sex less often because of treatment advances (Kelly *et al.*, 1998).

While the long-term treatment effects of HAART are not fully understood, neither are its effects on HIV transmissibility. Some research points to a reduction of HIV in seminal fluid associated with a reduction in viral load (Gupta *et al.*, 1997). Based on the CDC's retrospective case-control study of HIV-exposed health workers and extrapolation from the use of antiretrovirals to interrupt perinatal transmission, a number of urban centers have begun offering gay men and others postexposure prophylaxis in an effort to contain viral replication for those thought to have experienced recent exposure (Kowng *et al.*, 1999). While these findings and efforts are preliminary and inconclusive, they suggest possibilities for future HIV prevention strategies.

#### *Adolescents: Leading Edge of the Epidemic*

Youth represent a subgroup of all MSM who are particularly likely to engage in high-risk behavior, and so are particularly at risk for HIV. Adolescents and young adults (ages 13–24 years) are the single most likely group to contract an STD (CDC, 1998a). Among this same group, the rate of HIV infections is growing particularly rapidly, with 31% of all new infections being reported as MSM. In a sample of young MSMs (ages 15–22 years) in six urban counties, between 5% and 9% were found to be infected with HIV, with a significantly higher percentage of African American youth and Latino youth being infected than White youth (CDC, 1999a). Other studies have shown that adolescent MSMs show markedly higher rates of unprotected receptive anal sex than do older MSMs and that sex with older people is highly correlated with exposure to HIV (Morris *et al.*, 1995). One study of inner-city youth attending a gay community center program reported consistent condom use in only 13% of adolescent MSMs, while one fourth engaged in prostitution, and all reported sexual activity (Rotheram-Borus *et al.*, 1992).

#### *Lesbians and HIV*

The impact of HIV on the lesbian community, and the risks of female–female HIV transmission, remain underresearched. Since people with HIV are categorized by the highest risk group to which they belong, lesbians with HIV who have had any heterosexual contact or injection drug use history are usually classed as heterosexual or injectors, regardless of their personal sexual identification or history (Cohen *et al.*, 1993). While small studies among serodiscordant lesbians have found no evidence of female-to-female HIV transmission (Raiteri *et al.*, 1994), numerous health advocates have urged for greater research, as well as consideration of broader assessment of HIV risk for lesbians; in 2000, the Centers for Disease Control will fund a 200-participant study of lesbians and HIV with cohorts in Washington, D.C., San Francisco, and New York (R Smith, 2000). Fears of elevated risk for HIV among some lesbians are not restricted to their sexual contact with women: HIV-positive women reporting female sexual partners in one San Francisco study, for example, were twice as likely to have used drugs and significantly more likely to have engaged in anal intercourse with a man than those not reporting female sexual partners (Young *et al.*, 1992).

#### **D. Immunization and Infectious Diseases**

Vaccination recommendations for gay and lesbian people do not differ significantly from those for the general population, with notable exceptions for gay men, who are at increased risk of contracting viral hepatitis. (McDonnell and Askari, 1997). Immunization against hepatitis B virus (HBV) for all homosexually active men has been recommended since the 1980s, and vaccination against hepatitis A virus (HAV) was recommended in 1996 by the Advisory Committee on Immunization Practices (ACIP) for gay and bisexual men, as well as for certain other high-risk groups (CDC, 1997).

Although HAV and HBV vaccination is recommended for gay and bisexual men, national prevalence rates for these vaccinations are currently unknown, hampering efforts to assess the successful implementation of vaccination campaigns for these men. However, available data suggest that rates of vaccination for men who have sex with men are low. In 1996, the Centers for Disease Control found that only 3% of the sample of young MSM were vacci-

nated against HBV (CDC, 1996c). The CDC analyzed serologic data from the 1992–1993 Young Men’s Survey (YMS) conducted by the San Francisco Department of Public Health to estimate hepatitis B vaccination coverage among young MSM. The survey used a targeted sampling method to enroll MSM aged 17–22 years at selected public venues in San Francisco and Berkeley, California. Of the 385 young MSM eligible for the study, 20% had evidence of previous or current HBV infection, while an additional 3% were positive for anti-HBs alone, suggestive of hepatitis B vaccination. Of the remaining 77% who lacked evidence of vaccination or infection, 80% reported having had anal sex or having injected drugs during the preceding 6 months. Of these, 86% reported receiving one or more types of health care (CDC, 1996c).

### E. Mental Health and Mental Disorders

See also Section IIIC on HIV/AIDS, Section IIIG on Substance Use, Section IIII on Violence and Sexual Assault, and Section IV on Transgender Health Concerns.

#### *Overview*

Most studies of mental disorders among gay, lesbian, or bisexual people in the 1960s and 1970s addressed issues related to the status of homosexuality as a mental disorder (Bayer, 1981; Gonsiorek, 1991; Morin, 1977). Such studies helped lead to the declassification of homosexuality as a mental disorder in 1973 and the removal of “ego-dystonic homosexuality” from the 1986 *Diagnostic and Statistical Manual of Mental Disorders* (DSM-III). Epidemiologic advances of the past two decades, including the recognition of the importance of population surveys (rather than clinical studies) of mental disorders, the introduction of an improved psychiatric classification system, and the development of measurement tools and techniques for epidemiologic research have made earlier research on mental health among LGBT populations virtually obsolete.

Few recent studies have used these advances to focus needed research on gay men, lesbians, or bisexuals. For example, no information on LGBT individuals has been provided by either of two recent large-scale, national psychiatric epidemiological surveys conducted in the United States, the Epidemio-

logical Catchment Area study (Robins and Regier, 1991) and the National Comorbidity Survey (Kessler *et al.*, 1994). LGB populations may be at increased risk for mental distress, mental disorders, substance use, and suicide because of exposure to stressors related to societal antigay attitudes. Known social stressors include prejudice, stigmatization, and antigay violence (Meyer, 1995; Rosario *et al.*, 1996; Gonsiorek and Rudolph, 1991). Internalization of negative social attitudes (internalized homophobia) in particular has been related to intimacy and sexual problems and other adjustment difficulties (Meyer and Dean, 1998), as well as high HIV risk-taking behaviors among young gay and bisexual men (Meyer and Dean, 1995). Understanding patterns of and risk factors for mental disorders in LGB individuals is important for tailoring proper mental health treatment and for designing effective public health intervention and prevention programs (Council on Scientific Affairs, American Medical Association, 1996).

#### *Rates of Mental Disorders*

As noted above, methodologically sound studies of mental disorders in LGB populations are lacking. Many studies used symptom scales in which the relationship to psychopathology is unclear (Bradford *et al.*, 1994b; Cochran and Mays, 1994; Gonsiorek, 1991); included no comparison group (Bradford *et al.*, 1994b; Tross *et al.*, 1987; Williams *et al.*, 1991; JL Martin and Dean, 1990); employed convenience samples unlikely to be representative of LGBT populations (Saghir and Robins, 1973; Pillard, 1988; Atkinson *et al.*, 1988); or expressed potential bias in their definition or detection of homosexuality (Fergusson *et al.*, 1999; Cochran and Mays, 2000). Most studies fail to distinguish between findings on gay or lesbian individuals and those on bisexuals, making comparisons of gay men and lesbians with bisexual men and women difficult.

A number of studies have used criteria-based case diagnoses to study mental illness among gay men and used a comparison group to assess differences between gay and heterosexual men. Pillard (1988) found elevated rates of bipolar disorders among gay men; Atkinson *et al.* (1988) found elevated rates for most mental disorders among gay men; and Cochran and Mays (2000) found homosexual men to have higher rates of major depression disorder than heterosexuals. Fergusson *et al.* (1999) found lesbians, bisexuals, and gay men to have higher rates of major



depression disorder, generalized anxiety disorder, and conduct disorders than a heterosexual sample, though the authors did not disaggregate data by gender. Other studies using case diagnoses included no explicit comparison group. Compared with estimates of U.S. rates of disorders reported by the Epidemiologic Catchment Area study (ECA; Robins and Regier, 1991), Williams *et al.* (1991) found a high lifetime prevalence of affective disorders, but no elevated prevalence of current disorders; Tross *et al.* (1987) found a slightly elevated prevalence for current major depressive disorder; and JL Martin (1990) found no increased prevalence of alcohol abuse/dependence among gay and bisexual men.

Mental health among lesbians, too, has gone largely unstudied or been inadequately researched. As recently as 1990, the Women and Depression Task Force Report of the American Psychological Association (McGrath *et al.*, 1990) reviewed several hundred studies on women and depression, none of which focused on lesbians. The largest and most comprehensive survey of lesbian mental health to date is the National Lesbian Health Care Survey (NLHCS) (Bradford *et al.*, 1994b) with a sample of 1925 lesbians. Symptoms of depression in the study were roughly equivalent to those in studies among heterosexual women (McGrath *et al.*, 1990). Similarly, Cochran and Mays (1994) reported similar levels of depressive symptoms among African American lesbians and gay men as those found in studies of African Americans in the general population.

### *Gender Identity Disorder*

While homosexuality has been removed from the American Psychiatric Association's diagnostic manual, gender identity disorder (GID) remains. As defined in the *Diagnostic and Statistical Manual of Mental Disorders-IV* (DSM-IV), GID is "strong and persistent cross-gender identification, which is the desire to be, or the insistence that one is, of the other sex," and "persistent discomfort about one's assigned sex or a sense of inappropriateness in the gender role of that sex" (American Psychiatric Association, 1994).

While not necessarily involving sexual attraction to the same gender, a GID diagnosis is seen by some gay and lesbian health professionals as reinforcement for normative gender standards that are hostile to feminist or gay-affirmative values (Corbett, 1999). A child or adult who perceives that he or she is attracted to a person of the same sex may experience some

gender identity "confusion" because by definition their sexuality deviates from assigned gender roles. For example, a boy who feels same-sex attraction, having internalized societal values, may feel that he is girl-like in that attraction. This may indicate nothing but the beginning of a process of questioning social norms, but can be labeled a disorder according to the DSM-IV's categories. Similarly, the diagnosis may "punish" innovators who challenge existing gender roles (e.g., a girl who wants to be on a football team, a boy who wants to grow up to be a mom) by stigmatizing them.

Sensitive to critiques of diagnosis as a means of social control, authors of the DSM-IV make "clinically significant distress or impairment in social, occupational, or other important functioning" a requirement for GID diagnosis. However, distress is subjective, and widely defined. For example, subjective distress could simply be the interpersonal problems one has with parents because of one's nonconforming behavior. It is hard to imagine any person who is somewhat different not experiencing some distress, at least related to others' reactions to his or her nonnormative behavior. A child who is taunted for being a "sissy," or who is socially isolated because she is "masculine," will clearly experience subjective distress, but the source of the distress is oppression and intolerance, not an inherent disorder. This is analogous to ethnically based taunting.

Small, nonrandom studies of boys with childhood GID indicated that 75% of boys with GID may grow up to be homosexual men (DSM-IV). This may heighten concerns that parents and physicians will see GID as a precursor, or even a "risk factor," for homosexuality, and, if seen as a problem, may seek to treat it aggressively. All these have been discussed as reasons for the declassification of GID as a mental disorder. Against this, some transgender advocates argue for maintaining the classification, suggesting that the inclusion of GID in the DSM-IV may allow for insurance reimbursement and treatment for transgender people seeking psychiatric therapy or hormonal treatment. Investigation is needed to determine how such third-party payments can be appropriately authorized without unnecessarily stigmatizing children and adults for gender roles that do not fit the dominant norm.

### *Mental Health and HIV Risk-Taking Behaviors*

Stress and mental health raise important practical public health issues related to HIV risk-taking

behavior, particularly as prevention research has begun to move from purely cognitive explanatory models of risk-taking behavior to the consideration of affective and nonrational processes among gay men (McKirnan *et al.*, 1996; Kelly *et al.*, 1993; National Institutes of Mental Health, 1999). Mental health problems, including substance use and personality and psychological constructs (e.g., low self-esteem, sensation seeking), have been associated with HIV-related risk-taking behavior (Bartholow *et al.*, 1994; Graham *et al.*, 1998; Strathdee *et al.*, 1998; Hays *et al.*, 1997b; Kalichman *et al.*, 1996, 1997b, c; Diaz *et al.*, 1996; Chesney *et al.*, 1998; Leviton, 1989; National Institutes of Health, 1997). Research has also described high-risk behavior as an emotion-focused coping strategy to reduce stress (Folkman *et al.*, 1992).

Alcohol and drug use, in combination with emotion-focused coping, serve a disinhibiting function leading to more risk taking (Folkman *et al.*, 1992; Meyer and Dean, 1995, 1998). The convergence of internalized homophobia, drug problems, and AIDS-related traumatic stress response are related to increased risk taking (Meyer and Dean, 1998). In addition, in the context of reports of increased risk for suicide among gay and bisexual men, the relationship of mental health and HIV risk taking is of particular concern. Some researchers have suggested that high-risk sexual behavior among young gay and bisexual men may be related to a sense of hopelessness and suicidal tendencies (Frances *et al.*, 1985; Odets, 1996; Flavin *et al.*, 1986).

### *Suicide*

Whether gay men, lesbians, and bisexual individuals have higher rates of suicidal behavior has been widely debated in recent years, and research evidence is mixed (Muehrer, 1995). Studies of suicide ideation and attempts found elevated lifetime prevalences for gay/bisexual men and lesbians (e.g., D'Augelli and Hershberger, 1993; Kruks, 1991; Remafedi *et al.*, 1991; Schneider *et al.*, 1989; Pillard, 1988; Bell and Weinberg, 1978; Saghir and Robins, 1973), but studies of completed suicides found no evidence for elevated rates (e.g., Rich *et al.*, 1986; Shaffer *et al.*, 1995). Results of the NLHCS found that more than half the sample had had thoughts about suicide at some time, and 18% had attempted suicide (Bradford *et al.*, 1994b). This compares with 33% and 4%, respectively, for women in the United States as reported in

the ECA studies (Robins and Regier, 1991; Moscicki, 1994). Several recent studies of gay youth populations continue to report alarmingly high rates of suicide ideation and attempts among gay and bisexual youth. For example, Faulkner and Cranston (1998), Remafedi *et al.* (1998), and Fergusson *et al.* (1999) found that rates of various measures of suicide ideation and attempts were three to seven times higher among gay and lesbian youth compared with heterosexual youth.

Both types of studies—of completed suicides and of suicide ideation and attempts—have severe methodological limitations. The former uses samples biased toward underestimating rates of completed suicides because of difficulties in post-mortem classification of sexual orientation; the latter uses samples biased toward overreporting of suicide ideation and attempts because more vulnerable gay youth may be identified at younger ages. These problems have led members of a workgroup convened by the NIMH and the CDC to recommend epidemiologic study of mental disorders and suicide as an important priority (Working Groups, Workshop on Suicide and Sexual Orientation, 1995).

### *Body Image and Eating Disorders*

Social stressors may impact body image and eating patterns among gay and lesbian adolescents. Significant literature suggests that adolescence and the social stress that accompanies it may place gay men in particular at increased risk for body dissatisfaction and problem eating behaviors. The onset of these disorders commonly occurs during this period.

In addition to this social stress hypothesis, other research suggests a sociocultural hypothesis linking body image dissatisfaction and eating disorders with the cultural valuation of a thin body (Silberstein *et al.*, 1989; Hefferman, 1994). According to this view, emphasis on thinness normally placed on feminine bodies may also influence gay men, who are more likely to demonstrate atypical gender role behavior (Fichter and Daser, 1987), and may place greater cultural emphasis on appearance (Herzog *et al.*, 1991; Siever, 1994). In contrast, a decreased emphasis on physical appearance among lesbians may be protective against the development of weight concern, body dissatisfaction, and disordered eating behavior (Siever, 1994; Beren *et al.*, 1996).

Studies of clinical samples, assessing whether homosexuality is overrepresented among patients with eating disorders, have found sexual orientation to be

a significant predictor of eating disorders among men, though not among women. A study of the 135 men treated for eating disorders at Massachusetts General Hospital from 1980 to 1994 showed 27% of all men reported homosexual orientation and 42% of bulimic patients identified as homosexual or bisexual (Carlat *et al.*, 1997). These results are consistent with other, smaller studies, which found association between male homosexuality and eating disorders, showing that a higher proportion of anorectic or bulimic men than would be expected were gay (Herzog *et al.*, 1984; Schneider and Agras, 1987; Robinson and Holden, 1986; Fichter and Daser, 1987).

Nevertheless, assessing the validity and generalizability of these conclusions is difficult. With an overall prevalence of less than 1% for bulimia and 3% for anorexia (American Psychiatric Association, 1994; Hall *et al.*, 1985), eating disorders are rare, and men account for less than 10% of total cases (American Psychiatric Association, 1994; Carlat and Camargo, 1991). In addition, research on the association of eating disorders and homosexuality has used varying definitions of both eating disorders and homosexual tendencies, sometimes equating lack of heterosexual experience or atypical gender behavior with homosexuality (Fichter and Daser, 1987). The effect of comorbid psychiatric disorders (e.g., depression) is largely ignored in these studies. Differences by gender in reporting of eating habits may also bias results. For example, women are more likely than men to label eating a large amount of food as a “binge” (Carlat and Camargo, 1991). To the extent that this bias in reporting style is also characteristic of gay men, it may lead to overreporting and increased detection of anorexia and bulimia among gay men as compared with heterosexual men. Heterosexual men may be more reluctant than homosexual men to seek help for eating disorders because the disorders are perceived, and thus stigmatized, as “feminine” (Carlat and Camargo, 1991). Finally, while many clinical studies report an association with male homosexuality, several found no such association (Turnbull *et al.*, 1987; Pope *et al.*, 1986; Herzog *et al.*, 1991).

Community studies, which have typically sampled college students or participants in gay and lesbian organizations, have often found significant association between sexual orientation and negative body image among gay men (Silberstein *et al.*, 1989; Beren *et al.*, 1996; Herzog *et al.*, 1991), but drawing clear conclusions from them is impossible. These studies typically used small samples of easily recruited subjects, and their generalizability to the general gay

population is questionable. Also, some studies show that heterosexual men with eating disorders have similar problems in body image, exercise, and dieting behavior (Olivardia *et al.*, 1995). Among women, while being female was related to concerns about dieting and being fat, lesbians were less likely to be preoccupied with weight and body image than heterosexual women (Siever, 1994; Brand *et al.*, 1992).

The Minnesota Adolescent Health Survey (Neumark-Sztainer *et al.*, 1998), a survey of more than 30,000 Minnesota students (grades 7–12), was the only one to use a random community sample. In that study, homosexual boys were more likely than heterosexual boys to report a poor body image (28% vs. 12%), frequent dieting (9% vs. 6%), binge eating (25% vs. 11%), and purging behaviors (e.g., vomiting: 12% vs. 4%) (French *et al.*, 1996). Homosexual girls, by contrast, were more likely than heterosexual girls to report a positive body image (42% vs. 21%), though no less likely to report disordered eating behaviors such as binge eating or purging. (Rogers *et al.*, 1997). While random, the sample did identify adolescents of high school age or younger. Because many gay men and lesbians do not know or disclose their sexual orientation until older, it may be difficult to generalize the results more broadly to gay men and lesbians.

It is important to note that significant gender differences related to eating problems hold true for gay and lesbian populations (Saewyc *et al.*, 1998). Young boys (15%) in the Minnesota sample were less likely than young girls (27%) to rate themselves low on body image. A greater proportion of older females (38%) than males (22%) considered themselves to be overweight. In each group more girls than boys reported dieting in the last year, at all levels of frequency. Despite increased risk among homosexual men compared with heterosexual men, women (both lesbian and heterosexual) are at greater risk for body dissatisfaction and disordered eating.

#### *Ameliorative Factors: Coping and Social Support*

Like members of other minority groups, LGBT populations are not passive recipients of stigma and discrimination, but engage in active coping to counter the ill effects of negative social stressors. Such positive coping has been shown to be beneficial to members of minority groups (Shade, 1990). Minority status is related not only to stigma and discrimination (stress), but also to structural resources, such as group

solidarity and cohesiveness, that protect minority members from the adverse mental health effects of social stress (Crocker and Major, 1989; Kessler *et al.*, 1985). Even exposure to antigay violence, while creating a crisis with potential adverse mental health outcomes, also presents “opportunities for subsequent growth” (Garnets *et al.*, 1990). Jones and colleagues (1984) described two functions of minority-related coping, cohesiveness and support, to (1) allow stigmatized persons to experience social environments in which they are not stigmatized by others, and (2) provide support against the negative evaluation of the stigmatized minority group. Social evaluation theory suggests another plausible mechanism for minority coping. In-group support can provide a reappraisal (Lazarus and Folkman, 1984) of the stressful environment, yielding it less injurious to psychological well-being. Through reappraisal, the minority group validates its experiences (Thoits, 1985; Crocker and Major, 1989).

Oetjen and Rothblum (in press) used a standardized measure to examine the effect among lesbians of factors consistently cited in the women and depression literature (relationship status, relationship satisfaction, social support from friends, and social support from family), and two unique factors (outness and relationship status satisfaction), to determine their ability to predict depression among lesbians. Perceived social support from friends, relationship status satisfaction, and perceived social support from family were found to be significant predictors, accounting for 17.8% of the variance in depression. Among those lesbians in committed relationships, social support from friends was the only predictor, accounting for 5.8% of the variance in depression. A similarly designed study among Canadian lesbians found lower depression rates among women in relationships, lesbians who had more social support from friends and family, and those who were more open about their sexual orientation. Some 38% of the variance in depression scores could be predicted from the four variables (Ayala and Coleman, in press).

## F. Sexually Transmitted Diseases

In addition to HIV, men who have sex with men (MSM) are at increased risk of certain sexually transmitted diseases relative to heterosexual men (Council on Scientific Affairs, 1996; Harrison and Silenzio, 1996; Ungvarski and Grossman, 1999). The stigmas associated with sexually transmitted infections in gen-

eral and with homosexual acts make accurate estimates of the prevalence rates for these conditions in MSM almost completely unavailable. STDs for which homosexually active men are at risk include urethritis, proctitis, pharyngitis, prostatitis, hepatitis A (HAV) and B (HBV), syphilis, gonorrhea, chlamydia, herpes, genital warts, and HIV infection. MSM are believed to be at generally increased risk for these infections, although additional data on patterns of infection and definitive prevalence data are needed. MSM with HIV are in danger of chronic or life-threatening complications from sexually transmitted infections that are harmless or self-limiting in HIV-negative individuals, including cytomegalovirus, herpes, and anal cancer associated with strains of the human papillomavirus. In spite of availability of vaccines to prevent hepatitis A and B, and recommendations calling for vaccination of sexually active MSM against these viral infections, rates of vaccination for these diseases remain low.

After sustained declines in rates of STDs in gay and bisexual men since the beginning of prevention programs aimed at HIV/AIDS, recent data from many U.S. and international cities indicate that rates of unprotected anal sex and STDs may be increasing (CDC, 1999f; Community Disease Report Weekly, 1999). STD clinics and public health departments have reported increases in rectal gonorrhea rates among MSM in San Francisco (CDC, 1999d) as well as increases in syphilis rates among MSM in Seattle. Community-based clinics reported epidemic rates of HAV in 1998 and 1999 among gay men in New York, Boston, Atlanta, and various cities outside the United States (Wolfe, 2000). These increased STD rates are coincident with the decline in the number of MSM reporting that they “always used condoms,” and an increased proportion of MSM reporting unprotected and sex. This points to a clear need for renewed efforts to reduce the rates of STD and HIV transmission among MSM, and for the development of new surveillance techniques to assess the efficacy of these efforts.

No known gynecologic problems are unique to women who have sex with women, and none are believed to occur more often in lesbians than in bisexual or heterosexual women. STDs appear to be less common in women who identify as lesbian and in women who are sexually active only with women than in either heterosexual women or gay men. This may be due in part to a relative epidemiologic isolation of this group from men and the lack of penile-vaginal intercourse.

Human papillomavirus and bacterial vaginosis have been shown to be transmissible between women and do occur in lesbians (Marrazzo *et al.*, in press; Berger *et al.*, 1995). Candidiasis and *Trichomonas vaginalis* infections do occur in lesbians and appear to be transmissible between women (Degen and Waitkevicz, 1982). Women who are sexually active only with women appear to have a lower incidence of syphilis and gonorrhea than any other group except those who have never been sexually active. Infections with chlamydia or herpes virus disease appear to be less common in lesbians who have been sexually active exclusively with women, but both are theoretically transmissible (Johnson *et al.*, 1987; Robertson and Schachter, 1981; Degen and Waitkevicz, 1982). Hepatitis A, amebiasis, shigellosis, and helminthiasis also have a low prevalence in these women. Hepatitis B and C occur only when other risk factors are present (Walter and Rector, 1986; William, 1981).

### G. Substance Abuse

Epidemiologic studies on alcohol and other drug abuse have rarely asked about sexual orientation. When focusing on gay and lesbian populations, the studies have exhibited serious methodologic flaws. Early studies, for example, recruited gay and lesbian subjects in bars, a sample which not surprisingly showed higher rates of heavy alcohol and drug use than the general population (Fifield *et al.*, 1977; Lorenz *et al.*, 1978, Saghir and Robins, 1973). These and other opportunistic samples have frequently shown the prevalence of excessive or problem drinking among gay men, lesbians, and bisexuals to be near 30%, as compared to 10% among the general population (Paul *et al.*, 1991).

#### *Alcohol*

Subsequent studies, recruiting subjects via other means, have generally disputed claims that the alcoholism rate among gay men and lesbians reaches 30%. McKirnan and Peterson (1989), surveying the readership of a Chicago gay newspaper, found rates of heavy drinking among gay men and lesbians to be comparable to those in the general population. Bloomfield (1993), using random phone surveys in the San Francisco area, reported that there were no significant differences in levels of drinking and bar-going behavior between lesbian/bisexual and heterosexual

women. Skinner (1994) found higher rates of drinking among lesbians than among women in a geographically matched sample. Stall and Wiley (1988), comparing alcohol use patterns of heterosexual and homosexual males in San Francisco, found no significant differences in quantity and frequency of alcohol consumption overall, though differences at the extreme patterns of use were noted. Gay and bisexual men were approximately twice as likely to be heavy drinkers or abstainers as heterosexual men. Lesbians and bisexual women, too, report higher rates of abstinence than heterosexual women in some studies (Bloomfield, 1993).

#### *Other Substance Use*

Sound data about substance use among lesbians is even more scarce, though McKirnan and Peterson (1989) found that rates of marijuana and cocaine use were higher among lesbians than among heterosexual women and that differences between light and heavy use were smaller than those found in the general population. Skinner and Otis (1996), surveying gay men and lesbians, found few gender differences in substance use, though lesbians in some age groups reported somewhat higher rates of marijuana and cocaine use, as well as higher rates of smoking. Gay men reported higher rates of use of inhalants such as amyl or butyl nitrite ("poppers"), hallucinogens, and illicit drugs overall. LGB health researchers and advocates have called for greater research into the effects of recreational drugs common in nightclubs and dance parties (e.g., ketamine, MDMA, etc.), and for research into the potential consequences of chronic pharmacologic manipulation of neurotransmitters (Abrams to Leshner, 1999).

Belief in a direct causal relationship between substance abuse and unsafe sexual behavior has caused the phenomenon of substance use to be better documented among gay men since the advent of HIV (Stall *et al.*, 1986). Though the assumption that substance use causes unprotected sex has been critically challenged (Bolton *et al.*, 1992; Bux, 1996), a wide body of evidence suggests that there is an association between recreational drug use and high-risk sexual behavior and that gay men use particular drugs more often than their heterosexual counterparts. Stall and Wiley (1988) found gay men significantly more likely to have used marijuana and psychedelics in the last 6 months, three times as likely to have used barbiturates, five times as likely to have used MDMA, and

58 times more likely to have used “poppers.” It is important to note, however, that while this study found gay men more likely to have used more drugs, it did not demonstrate higher levels of dependence or addiction.

Adolescent and young adult gay men and lesbians appear to be especially at risk for substance abuse, with important health consequences. With the exception of popper use, differences in drug use between heterosexual and homosexual men noted by Stall and Wiley (1988) were largely attributable to higher rates of drug use among the youngest cohort. Data from the 18- to-25-year-old cohort of gay men in the Trilogy Project (Skinner and Otis, 1996) found rates of 87.1%, 78.5%, 31.5%, 57.0%, and 33.3% respectively, for alcohol, marijuana, cocaine, inhalants, and hallucinogens, with an overall rate of 87.1% for any illicit drug use. Young lesbians, too, report overall rates of substance use in excess of 80%. Given the association between substance use and a variety of adverse health consequences for which young gay men and lesbians are at increased risk, including HIV infection and suicide, greater attention is needed to the problem and prevention of substance abuse by young gay men and lesbians.

Finally, though data are not yet conclusive, research suggests that a number of illicit substances may speed replication of HIV or have an immunosuppressive effect, a fact which may impact significantly on the health of the disproportionate number of gay men who are at risk for or are infected with HIV (Seage *et al.*, 1992; Basgara and Pomerantz, 1993). Further, adverse interactions have been documented between recreational drugs and other medications. Poppers, for example, cause potentially fatal drops in blood pressure when combined with the common erectile dysfunction medication sildenafil citrate (Viagra). Following the death of a British gay man in 1997, community publications alerted gay men to the possibility that Ritonavir, a common anti-HIV medication, might inhibit the liver’s ability to process the drug MDMA, boosting levels of the recreational drug to potential fatal levels (Wolfe, 2000).

#### *Cultural Issues in Diagnosis and Treatment*

Evidence suggests that gay men and lesbians may perceive themselves to be at increased risk for alcoholism and substance abuse, that they have increased need for drug and alcohol treatment, and that they face particular barriers in accessing such

treatment. McKirnan and Peterson (1988, 1989) found that while heavy drinking patterns did not differ significantly by sexual orientation, gay men and lesbians reported rates of alcohol problems nearly twice as often as heterosexuals. Drinking rates among gay men and lesbians do not appear to decrease with age as quickly as they do in heterosexual populations (Skinner, 1994; McKirnan and Peterson, 1988; Stall and Wiley, 1988; Bradford *et al.*, 1994b). Gay and lesbian Alcoholics Anonymous meetings have become the largest special interest group within the self-help fellowship (Paul *et al.*, 1991). Assessments of alcohol and drug treatment facilities have documented lack of staff training in treatment issues for gay and lesbian alcoholics, and few or no gay staff (Hellman, 1991; Garnets *et al.*, 1991), in spite of evidence that gay, lesbian, and bisexual clients are more willing to attend treatment programs that address gay issues and less likely to comply with treatment from homophobic mental health providers (Paul *et al.*, 1991; O’Hanlan *et al.*, 1997).

Effective research into the treatment needs of gay men and lesbians should include enhanced understanding of the role of subcultural factors in forming and influencing patterns of both substance use and sexual behavior. Such factors, including the reliance on bars for socialization, stress caused by discrimination, and targeted advertising by liquor companies in gay and lesbian publications, have been documented, but remain inadequately understood (Hughes and Wilsnack, 1997; Nardi, 1991).

#### **H. Tobacco Use**

Adverse health effects of tobacco use among gay and lesbian populations are similar to those among the general population. Evidence suggests, however, that the rates of tobacco use among sexual minority men and women may exceed those of the general population, ultimately leading to increased rates of tobacco-related disease.

As with surveys of alcohol use among gay men, lesbians, and bisexuals, studies of tobacco use in these populations tended to use nonrandom samples, often drawn from bar patrons, and to report rates of tobacco use sharply higher than those of their heterosexual counterparts (Stall *et al.*, 1999). Unlike studies of alcohol use, however, later, more representative studies of tobacco use seem to support earlier reports that the prevalence rate is strikingly higher among gay men than in the general male population. Using

a household-based sample, Stall *et al.* (1999) found 41.5% of gay adults to be smokers, a rate far in excess of the national rate of tobacco use by men generally (28.6%) CDC, 1994). DuRant *et al.* (1998) found that adolescent males who engage in same-sex sexual behavior also have increased rates of tobacco use relative to their peers and that higher numbers of male sexual partners correlated with higher rates of tobacco use, drug use, victimization, and the use of violence.

As with alcohol use, representative studies of lesbian tobacco use have yet to be completed. Cardiovascular diseases (e.g., heart, stroke, arteriosclerosis), however, represent the leading causes of death for women in general. Existing nonrandom studies indicate that lesbians may smoke more and have a higher body mass index than heterosexual women and thus may be at higher risk for cardiovascular disease and cancers (Bradford *et al.*, 1994a; White and Dull, 1997; Moran, 1996). Because lesbians appear to seek health care less often, they are less likely to receive blood pressure and cholesterol screening, further compounding their risk. In addition, comparisons between young gay men and lesbians (Skinner and Otis, 1996) have found that lesbians actually smoke more than their gay male counterparts, furthering concern about their risk and the need for greater research in this area.

## I. Violence and Sexual Assault

### *Hate and Bias Crimes*

A report on the response of the criminal justice system to bias crimes concluded that lesbians and gay men are among the most frequent victims of hate violence in the United States and as a group they “are probably the most frequent victims” (Finn and Mcneil, 1987). Acts of aggression, denigration, and violence against LGBT people have been documented in a variety of settings: schools and colleges, the armed services, jails and prisons, at homes, in work places, and in public places (American Psychiatric Association, 1997; Bradford *et al.*, 1994b; D’Augelli, 1989; Garnets *et al.*, 1991; Herek, 1989; Levine and Leonard, 1984; Rothblum, 1994; Wolfe, 1998; Wooden and Parker, 1982).

Antihomosexual violence may differ from generic violence in several qualitative ways. Homicides committed against LGBT individuals, for example, are frequently more violent than in the general popu-

lation (B Miller and Humphreys, 1980; Comstock, 1991), carry a very high likelihood that the assailant and victim are strangers to one another, and have a high ratio of number of assailants to victims (Bohn, 1984; LeBlanc, 1991). In addition, because LGBT persons often step outside the regular course of their lives to pursue sexual activities, they are more likely to have sexual encounters with persons previously unknown and therefore are at a higher risk of being victimized.

Antihomosexual hate crimes are also distinguished by their early onset. While hate violence occurs against GLBT of all age groups, there is evidence that the young are particularly vulnerable (Dean *et al.*, 1992). In addition, perpetrators of homophobic hate crimes often include family members and community authorities (Herek, 1989), and many gay and lesbian adolescents have been forced out of their homes or schools because of abuse related to their sexual orientation (American Academy of Pediatrics, 1993; Bidwell, 1992; Gonsiorek, 1988). Though the actual number of lesbian and gay runaways and “throwaways” is not known, local reports indicate that GLBT youth are disproportionately represented among these groups. In Seattle, for example, 40% of homeless youth are estimated to be lesbian or gay (Kruks, 1991).

Law enforcement data—a traditional source of information on hate crime violence—is likely to underreport antigay violence. Dean *et al.* (1992) found that only 13–14% of violent incidents that were experienced annually were reported to the police in each year of their longitudinal study. Fearing that discussion of their sexuality will subject them to further punishment, victims are often reluctant to disclose it. This fear may be well founded because a summary of antigay violence/victimization surveys conducted between 1988 and 1991 showed that between 16% and 30% of LGBT victims had been victimized by the police (Berrill, 1992).

Surveys of victim populations, while varying widely in quality, show violence to be a significant mental and physical health issue for lesbians and gay men. Many, however, fail to disaggregate data by gender (National Gay and Lesbian Task Force [NGLTF], 1984; Comstock, 1989), thereby obscuring information about the prevalence and impact of hate crimes against lesbians and gay men. There is only one published study focused exclusively on the prevalence and impact of antilesbian hate crimes (von Schulthess, 1992). A larger lesbian health survey that included questions about violence and hate crimes

showed that more than one half of respondents (Bradford and Ryan, 1988) had experienced a verbal hate crime. About 1 in 20 had been physically assaulted because of her sexual orientation. Other research has found that about three fourths of lesbians experienced at least one verbal hate crime and about 1 in 10 reported a history of hate-motivated physical assault (Comstock, 1989; Jay and Young, 1977; NGLTF, 1984).

While surveys among gay men are also limited, there is evidence that they, too, experience victimization and hate-motivated assault at high rates. A longitudinal study of 746 New York City gay/bisexual men showed that an estimated 20–26% of the men were the victims of antigay violence or discrimination annually (1985–1991). Half of the men in this study experienced at least one such event in at least one of the years, while 26% of the sample reported violent events in 2 or more years of the study (Dean, 1995).

#### *Childhood Sexual Abuse and Adult Sexual Assault*

It is believed that the stigma associated with sexual abuse combined with that of being a member of a sexual minority group complicates the study of this phenomenon (Klinger and Stein, 1996). In addition, both the conceptualization and definition of sexual abuse and assault vary widely from study to study, making comparisons and the estimation of prevalence and incidence of these behaviors across populations almost impossible. Existing data, however, suggest that childhood sexual abuse and adult sexual assault are certainly no less a problem in sexual minority groups than in the larger population. Also, gay men may in fact be at elevated risk for sexual abuse and assault. Moreover, data indicate that these experiences may impact on other health-related concerns such as mental health, substance use, and HIV risk behavior.

Research on sexual abuse and assault refutes the once-common assertion that lesbians choose their sexual orientation as a direct consequence of assaultive sexual experiences with men (Gundlach, 1977; Herman and Hirschman, 1981; Meiselman, 1978). Data from the National Lesbian Health Care Survey (NLHCS) indicate that the rate of child sexual abuse (18.7%) and adult sexual assault (34%) for lesbians up to the age of 25 years (Bradford and Ryan, 1988) is similar to rates of abuse and assault for the general female population (16% and 34%, respectively [Russel, 1984]). Similarly, the lifetime preva-

lence of attempted and completed rape among the lesbians in the NLHCS (32%) parallels rates found in samples of heterosexual women (36% by Kilpatrick *et al.*, 1988; 27% by Koss *et al.*, 1987). As with heterosexual women, younger lesbians report more child sexual abuse and rape than older lesbians. Several researchers have suggested that increases are due to changing social roles and consequent actual increases in abuse rates (Russell, 1982; Winfield *et al.*, 1990) rather than biases due to recency effect or greater comfort in reporting. More evidence is needed, however, to understand the reasons for the increase.

NLHCS findings with respect to ethnicity, while preliminary because of the small number of lesbians of color in this sample, run counter to previous research with heterosexual women. Studies among heterosexual women have shown either no differences across ethnic groups (Finkelhor *et al.*, 1990) or that White women report higher rates of these forms of violence (Russell, 1982; Sorenson *et al.*, 1987; Wyatt, 1998). In NLHCS findings, Black lesbians reported the highest rates of childhood sexual abuse and rape, and White lesbians the lowest rates of both child sexual abuse and rape (Bradford and Ryan, 1988). Latina lesbians experienced child sexual abuse at a rate more similar to Black than White lesbians, and rape rates similar to White lesbians, i.e., significantly lower than those reported by Black lesbians.

Rates of sexual abuse and assault experienced by gay men may be higher than those found in studies of men generally. Investigators of one large study ( $N = 1001$ ) of gay and bisexual men 18 years and older (Doll *et al.*, 1992) observed that more than one third (37%) of the men reported having a sexual encounter with an older or stronger partner (usually a man) before the age of 17 years. About one half (51%) of these early encounters involved the use of force, and almost all (93%) met the investigators' definition of sexual abuse, which was based on a developmental criterion. This study also indicated that the risk of sexual abuse was higher for the young men who had stereotypical feminine characteristics. Wooden and Parker (1982) showed that male homosexuals in prisons are disproportionately victimized by heterosexual men.

Sexual abuse among these men may have significant health consequences. In one study comparing sexually abused and nonabused gay men, sexually abused men showed higher levels of internalized homophobia and an earlier onset of sexual activity than did the men who did not report a history of sexual abuse (Knisely, 1992). Further, there is evidence that



gay and bisexual men who have a history of childhood sexual abuse also have higher rates of HIV risk taking (Bartholow *et al.*, 1994), and this has also been documented in studies of Latinos and African American men (Carballo-Diegeuz and Dolezal, 1995; Doll *et al.*, 1992). Sexual abuse during childhood and adolescence has also been shown to be associated with substance abuse, depression, suicide ideation, and a need for mental health services (Remafedi *et al.*, 1991).

Studies of male–male rape perpetrated on adolescent and adult gay men, while also difficult to study due to the double stigma of being gay and the male victim of assault, have found that gay men are more likely to be assaulted than heterosexual men (Scarce, 1997). Where race was noted in research studies, African American male rape survivors are overrepresented relative to the percentage of African Americans in communities in which the studies were conducted (Scarce, 1997). In addition, male–male assault on adults and adolescents almost always involves unprotected anal intercourse, exacerbating the trauma of sexual assault with anxiety about HIV transmission (Kalichman and Rompa, 1995). While the number of male–male assaults is small, accounting for some 5–10% of overall rape cases reported (Sorenson *et al.*, 1987; Bureau of Justice Statistics, 1996; Geist, 1988), rape crisis centers and medical personnel remain unfamiliar with the psychological or physical examination needs of male victims (Scarce, 1997; King, 1990).

#### *Intimate Partner Violence and Sexual Assault*

There is little empirical research on intimate partner violence or sexual assault in the lives of lesbians and gay men. The few studies of intimate partner violence in lesbian relationships are limited by small or specialized samples (Brand and Kidd, 1986; Renzetti, 1992; Schilit *et al.*, 1990), but reveal rates of intimate partner violence at rates slightly lower (e.g., 11.4% [Bradford and Ryan, 1988]) than those experienced by heterosexual women (e.g., 17% [Russell, 1982]). A nonempirical study by Island and Letellier (1991) attempted to extrapolate the number of gay males who are victims of partner abuse by combining information from a variety of sources. They based their estimate of the number of gay men who are annual victims of partner abuse upon their untested and most likely inaccurate assumptions that gay men couple at similar rates as heterosexuals and that they batter their partners at similar rates.

Further complicating the situation of gay and lesbian victims of domestic violence is the lack of training on the dynamics and realities of homosexual intimate partner violence among police, health, and social service providers. Shelters for battery victims, for example, are rarely able to accommodate men. Groups for batterers, already uncommon, are unlikely to be open to women. Both gay men and lesbians are forced to confront myths about gender roles and violence, e.g., that men should be strong enough to protect themselves or that women are incapable of doing serious physical harm (Island and Letellier, 1991).

## IV. TRANSGENDER HEALTH CONCERNS

### A. Overview and Definitions

#### *Introduction*

The medical literature on gender identity, sex, and sexuality lags significantly behind the gender-focused scholarship in history, literature, anthropology, philosophy, cultural studies, gender studies, and other disciplines (Elliott, 1998). Researchers and scholars in the latter fields have undertaken theoretical analyses and presented extensive cross-cultural and historical evidence extending beyond the narrow horizons of western and particularly U.S. definitions of gender (Chauncey, 1994; Devor, 1997; Herdt, 1994; Ekins and King, 1996; Feinberg, 1996; Gagne and Tewksbury, 1998; Garber, 1992; Garfinkel, 1967). This scholarship has paralleled the efforts of transgender activists, who have facilitated a shift in perspective away from notions of gender pathology to gender nonconformity, and who have emphasized the problems inherent in narrow and rigid societal definitions of gender.

Gender is now commonly understood to have strong cultural components, in addition to biological and psychosocial components. The public health needs of transgendered populations should be considered with this interdisciplinary definition in mind. In particular, the existence of specific health issues related to gender nonconformity should not be interpreted as a confirmation that transgendered identities or behaviors are inherently pathological. Rather, such health issues are more likely to be either normal components of the various stages of gender change specific to transgendered individuals, or the result of prejudice, discrimination, or other culturally based

stressors (Cohen *et al.*, 1997; Gagne *et al.*, 1997; Israel and Tarver, 1997; Mason-Schrock, 1996).

### Definitions

Transgendered individuals are those who live full- or part-time in the gender role opposite to the one in which they were born (Lawrence *et al.*, 1996), or who display gender characteristics that are not typical of their assigned sex. Some categories of transgendered persons include transsexuals, crossdressers or transvestites, transgenderists, androgynes, intersexed persons, hermaphrodites, and drag kings and queens (American Public Health Association, 1999; Israel and Tarver, 1997). As cultural definitions of gender and sex change and expand, additional categories of transgendered persons are likely to emerge. At present, the predominant *gender vectors* transgendered individuals take are either from female-to-male (FtM) or from male-to-female (MtF).

Some current definitions of transgendered identities include the following:

- *Transsexuals* are individuals who desire to live full time as members of the opposite sex, and who usually seek hormone therapy, cosmetic surgery, and genital surgery in order to approximate more completely the appearance of the gender in which they choose to live (Lawrence *et al.*, 1996).
- *Crossdressers* (transvestites) are individuals who dress in clothing of the opposite sex for emotional satisfaction, erotic pleasure, or both.
- *Transgenderists* are individuals who live full- or part-time as members of the opposite gender.
- *Androgynes* are those with androgynous presentations, who deliberately adopt characteristics of both genders or strive to attain a gender-neutral or nongendered status.
- *Intersexed persons* (hermaphrodites) are individuals with medically documentable physical or hormonal attributes of both sexes. Examples of intersex conditions include androgen-insensitivity syndrome, Klinefelter syndrome, and congenital adrenal hyperplasia.
- *Drag queens and kings* are individuals who crossdress to entertain, to challenge gender stereotypes, or for personal satisfaction.

### Transgender and Sexual Orientation

In many cases it is difficult to distinguish transgender issues from those related to sexual orientation since the affected groups overlap so significantly.

Many persons who identify as transgendered also identify as gay or lesbian, or did so at one time, and most persons who are visibly transgendered are rightly or wrongly regarded as homosexual by health care providers as well as by the public at large. Moreover, transgendered persons whose gender identities are ambiguous, androgynous, or fluid challenge existing categories of sexual orientation or identity, making it problematic even to define what “same sex” or “opposite sex” might mean in some cases.

Childhood gender nonconformity is argued to be the strongest single predictor of adult homosexuality (Bell *et al.*, 1981), and while not all lesbians and gay men are visibly transgendered, a substantial number are, or once were. Even if gender nonconformity is not part of a gay, lesbian, or bisexual person’s identity, the centrality of gender to definitions of sexual orientation essentially defines gay, lesbian, and bisexual persons as transgressors of gender norms. From this viewpoint, they, too, are transgendered. Indeed, some gay activists believe that homosexuality will soon be seen as just one specific manifestation of gender nonconformity, and that eventually most lesbians and gay men will also identify as transgendered (Rotello, 1996).

### The APHA Statement

In 1999, the American Public Health Association (APHA) addressed the special public health needs of transgendered persons. In their statement, “The Need for Acknowledging Transgender Individuals within Research and Clinical Practices,” the Association:

1. Urges the National Institutes of Health and the Centers for Disease Control and Prevention (as well as individual researchers and health care workers) to categorize MtF [Male to Female] and FtM [Female to Male] transgendered individuals as such and not equate them with gay men or lesbians (unless as appropriate to an individual’s sexual orientation in their preferred gender) as well as acknowledging the variation that exists among transgendered individuals.

2. Urges researchers and health care workers to be sensitive to the lives of transgendered individuals and treat them with dignity and respect, and not to force them to fit within rigid gender norms. This includes referring to them as the gender with which they identify.
3. Urges researchers, health care workers, the National Institutes of Health, and the Centers for Disease Control and Prevention to be aware of the distinct health care needs of transgendered individuals, and
4. Urges the National Institutes of Health, and the Centers for Disease Control and Prevention to make available resources that will enable a better understanding of the health risks of transgendered individuals, especially the barriers they experience within health care settings.

## B. Barriers to Care

### *Prejudice and Discrimination*

Prejudice against transgendered individuals is pervasive within American medicine (Lawrence *et al.*, 1996). Most U.S. medical providers and researchers, as well as the public at large, believe that transgendered behavior is pathological. This in itself constitutes one of the most significant barriers to care.

As a result of this prejudice, transgendered individuals underutilize medical and social services. A survey of transgendered men and women in San Francisco reported that many are chronically underserved with regard to basic medical and psychological support services (Clements *et al.*, 1999). Transgendered individuals frequently resort to self-medication with black market hormones, or visit irresponsible practitioners who offer hormone administration without appropriate medical follow-up, or dangerous treatments such as silicone injections. Few resources exist that address transgendered persons' special needs, or provide necessary consumer education and regular medical follow-up (Asian AIDS Project, 1995; San Francisco Human Rights Commission, 1994).

In addition to the prejudice experienced because of their gender nonconformity and perceived sexual orientation, many male-to-female MtF transgendered persons are subject to sexism, based on their gender presentation. For example, mental health providers and researchers have noted that (MtF) trans-

gendered persons are often not prepared to experience the sexual harassment routinely faced by women. In the female role, these individuals sometimes also fear for their physical safety (Bockting *et al.*, 1998).

### *Community Responses to Prejudice*

A small group of transgender activists and their supporters have organized efforts to challenge societal stigma and discrimination. Members of transgender communities have become increasingly public, and are working to dispel myths and prejudices through an increasing number of publications and public appearances and in-service presentations to the staffs of health and social service delivery agencies involved their care.

Community-based transgender organizations are receiving increasing attention, and representatives of these organizations continue to work with public health, medical, and mental health researchers. The emergence of transgendered celebrities, and positive representations of transgendered individuals and communities in the media, increasingly contribute to increased public awareness and understanding of gender identity issues. Such awareness and understanding are essential if prejudice and stigma are to be reduced. These movements, organizations, community collaborations, and increased media presence constitute a substantial infrastructure that, with adequate funding, could become a significant foundation for public health initiatives designed to meet the needs of transgendered individuals.

### *Economic Barriers*

Transgendered persons frequently experience social and economic marginalization. Those rejected by family and community and with reduced educational and employment opportunities because of harassment and discrimination commonly experience unemployment, poverty, and homelessness. Unemployment and underemployment result in no or inadequate health insurance, and thus many transgendered persons are unable to afford basic medical and mental health services (Clements *et al.*, 1999; Xavier, 2000). A disproportionate number of these individuals are people of color, HIV-positive, or youth, thereby increasing the likelihood they are socially

marginalized and medically underserved (Israel and Tarver, 1997).

The combination of these factors contributes to the numbers of transgendered sex workers, who engage in survival sex, sex for drugs, or trade sex for services. As with other sex workers, they face many barriers to obtaining appropriate care.

#### *Lack of Insurance Coverage*

Although a large body of evidence demonstrates that effective treatments are available for transsexualism and other severe gender identity disorders (Kuiper and Cohen-Kettenis, 1988; Mate-Kole *et al.*, 1990; Green and Fleming, 1990; Pfafflin and Junge, 1992; Eldh *et al.*, 1997; Landen *et al.*, 1998; Rehman *et al.*, 1999), public and private insurers often specifically exclude coverage on the grounds that the treatments are either cosmetic or experimental (Seil, 1996). Transgendered individuals, even when they receive a formal psychiatric diagnosis such as gender identity disorder (GID), are denied the legal protections such a diagnosis ordinarily provides. Although gender identity disorders “cause clinically significant distress or impairment in social, occupational, or other important areas of functioning” (American Psychiatric Association, 1994), individuals with GID are specifically excluded from the Americans with Disabilities Act and thus do not receive its benefits or protections (Gordon, 1991; Israel and Tarver, 1997).

U.S. attitudes toward insurance coverage of transgender care are different from those found in a number of other countries, such as Great Britain, the Netherlands, and Australia. In these countries, sex reassignment surgery is accepted as a standard of care, and is paid for by national health insurance. Although in the United States, Medicaid could theoretically pay for sex reassignment surgery, the courts have usually ruled only that states cannot promulgate regulations that absolutely exclude such funding. Judgements in such cases have not guaranteed funding, but have merely ensured that the requests will be evaluated on an individual basis (Gordon, 1991). The final decisions are not always favorable to transgendered persons; moreover, the necessary legal process is beyond the means of the vast majority of transgendered persons.

#### *Provider Ignorance and Misconduct*

One of the most significant barriers to care is that most health professionals lack the knowledge

about transgender identity and sexuality necessary for them to respond adequately to their patients. As a result, patients are usually required to educate health care providers about transgender issues (Bockting *et al.*, 1998; Xavier, 2000). Other factors that limit access to care include low self-esteem from a negative body image, and the fear of their transgendered status being revealed.

These experiences contribute to some of the most significant health deficits faced by transgendered individuals—feelings of shame, low self-esteem, isolation, loneliness, anxiety, and depression (Prieur, 1990). As a result of the financial barriers to quality medical care, many transgendered individuals, particularly minority subpopulations, are victimized by unscrupulous providers who offer hormones, silicone injections (illegal in the United States), and surgical procedures without informed consent, appropriate standards of care, or adequate follow-up (Israel and Tarver, 1997).

### **C. Mental Health Needs**

#### *Transgenderism as a Mental Disorder*

The *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition* (DSM-IV; American Psychiatric Association, 1994) offers four specific diagnoses which are potentially applicable to transgendered persons. These are Gender Identity Disorder (GID) in adolescents and adults (302.85) and in children (302.6), Gender Identity Disorder Not Otherwise Specified (GIDNOS; 302.6), and Transvestic Fetishism (302.3). The diagnosis of GID is generally reserved for the most severely gender dysphoric adults and adolescents, persons who usually meet the criteria for transsexualism (Harry Benjamin International Gender Dysphoria Association, 1998). Transvestic fetishism, a paraphilia, could be the diagnoses given some crossdressers. GIDNOS is the most general of the DSM-IV diagnoses, and is potentially applicable to a wide variety of transgendered persons (Harry Benjamin International Gender Dysphoria Association, 1998). Under DSM-IV, any of these diagnoses requires evidence of distress, or impairment in functioning; functional impairment that is solely due to societal prejudice based on perceived social deviance does not meet this criterion (American Psychiatric Association, 1994, p. xxii). It is thus important to emphasize that *being transgendered does not in itself constitute a mental disorder* under DSM-IV.

Nevertheless, the diagnoses of GID and Transvestic Fetishism are still considered pejorative by many in the transgendered community. They see the diagnosis of GID in particular as stigmatizing of nonnormative gender behavior, in much the same way that homosexuality was pathologized prior to its removal from the list of mental illnesses by the American Psychiatric Association in 1973.

### *Other Mental Health Problems*

While research is inadequate, the little that has been done suggests that transgendered persons exhibit mental health problems that are comparable to those seen in other persons who experience major life changes, relationship difficulties, chronic medical conditions, or significant discrimination on the basis of minority status. These mental health problems include adjustment disorders, anxiety disorders, post-traumatic stress disorders, and depression. Substance abuse also is a serious related concern among transgender persons.

Some studies have suggested that there may be an increased incidence of severe personality disorders, psychoses, and other severe mental illnesses in clinical samples of transgendered persons (Derogatis *et al.*, 1978; Dixen *et al.*, 1984; Beatrice, 1985; Hartmann *et al.*, 1997). But more recent studies have revealed no relationship between gender dysphoria and other psychiatric diagnoses. This has been demonstrated both in clinical samples (C Cole *et al.*, 1997) and in nonclinical ones (G Brown *et al.*, 1996). More rigorous research will be required to determine the actual incidence of mental health disorders in transgendered persons (Lothstein, 1984). Israel and Tarver (1997) suggest that transgendered persons frequently avoid seeking treatment for depression out of concern that their gender issues will be assumed to be the cause of their symptoms, and that they will be judged negatively. Because of these and other factors, depression associated with gender transition may be underdiagnosed.

### *Victimization and Posttraumatic Stress*

Virtually every transgendered person is likely to experience some form of victimization as a direct result of his or her transgendered identity or presentation. A link between these experiences and mental health disorders such as posttraumatic stress disorder

is widely suspected, but has not been adequately documented. This work is urgently needed.

Victimization includes subtle forms of harassment and discrimination as well as blatant verbal, physical, and sexual assault. The last may include physical and sexual assault and even homicide. The majority of assaults against transgender persons are never reported to the police. This situation exists because transgender individuals have little societal support or access to legal recourse. Sexual violence against MtF transgendered individuals is common, but incidents are rarely prosecuted in the criminal justice system (Feinberg, 1996). Of the transgendered individuals sampled in the Washington Transgendered Needs Assessment Survey (WTNAS), 13.5% reported having been victims of sexual assault (Xavier, 2000).

### *Self-Harm*

Both suicide attempts and completed suicides are common in transgendered persons. Dixen and colleagues (1984) found that among 479 MtF and 285 FtM transsexuals seen in the Palo Alto program, about 25% and 19%, respectively, had attempted suicide prior to transition. Most other studies report a pretransition suicide attempt rate of 20% or more, with MtFs relatively more suicide-prone than FtMs (Pfafflin and Junge, 1992). In the WTNAS, the suicidal ideation rate was 35% and the attempt rate was 16% (Xavier, 2000). Van Kesteren and colleagues (1997) reported a disproportionately high number of deaths due to suicide in MtF transsexuals compared to the general population. Pfafflin and Junge (1992) found reports of only 16 possible suicide deaths following surgical sex reassignment, among over 2000 cases reviewed. These results suggest that posttransition, suicidal tendencies probably get no worse, and may actually improve.

Another form of self-harm in transgendered persons is attempted or completed autocastration or genital mutilation. This is most common among transsexuals and transgenderists, although crossdressers have done this as well. A study of a cohort of transgendered individuals who applied for services at gender identity clinics reported that genital mutilation was attempted by 9% of the males and breast mutilation was attempted by 2% of the females (Dixen *et al.*, 1984).

### *Mental Health Issues in Transgendered Youth*

Almost all research on transgendered youth combines them with gay and lesbian youth in the catchall category, lesbian-gay-bisexual-transgender (LGBT). Moreover, many youth who appear transgendered, and who may later identify as transgendered, initially identify as gay or lesbian. Consequently, little is known about the prevalence of mental health disorders among transgendered youth specifically. In a study of psychological functioning in 29 adolescent transsexuals in the Netherlands, Cohen *et al.* (1997) found little evidence of more frequent mental health disorders than in nontranssexual youth. They did, however, find some evidence of lower levels of reality testing in adolescent transsexuals than in nontranssexuals.

It is assumed that, like lesbian, gay, and bisexual youth, transgendered youth are at increased risk for low self-esteem, depression, suicide (Remafedi *et al.*, 1991), substance abuse, school problems, family rejection and discord, running away, homelessness, and prostitution (Kruks, 1991; Remafedi, 1990; Savin-Williams, 1994). The transgendered youth suicidal ideation rate is reported as 33% in the WTNAS (Xavier, 2000). Transgendered youth are likely to be the victims of social stigma, hostility, isolation, and alienation, as are gay and lesbian youth (American Academy of Pediatrics, Committee on Adolescence, 1993), and to experience higher rates of substance use and suicidal ideation.

### *Mental Health Issues in Partners*

The impact of transgender-related issues on the partners of transgendered individuals has received almost no attention (S Cole, 1999). There is evidence that changes related to gender identity do impact partners and could unsettle relationships, causing significant emotional stress to both individuals (Doctor and Prince, 1997). When initially introduced to their partner's transgendered status, spouses, partners, and significant others often question their own sexual orientation, at the same time expressing the same concerns with respect to their partners. Partners' symptoms can be severe, and sometimes resemble those of posttraumatic stress disorder (S Cole, 1999).

## **D. HIV/AIDS and Other STDs**

### *Limitations in Knowledge*

Limited information is currently available on HIV/AIDS prevalence and risk in transgendered

populations, although both are believed to be significantly elevated relative to nontranssexuals. For example, a study of transgendered individuals seeking hormone therapy at a San Francisco public health clinic found that 15% were HIV-positive (Peterson *et al.*, 1996). Using self-report, the WTNAS recorded an HIV-positive rate of 25% among those surveyed (Xavier, 2000).

The majority of the literature focuses on the impact the AIDS epidemic has had on transsexual sex workers. The health concerns of HIV-positive transgendered individuals also remain largely unexplored by many of the nation's leading AIDS service organizations, including those based in or primarily serving gay communities.

An unknown number of male-to-female transgendered persons engage in sex work; as a group, they are considered at increased risk for infection and transmission of HIV and other STDs.

As noted previously, the cost of sex reassignment surgery is high, and is rarely covered by insurance. Sex work is one of the few means of obtaining the necessary money for many preoperative transsexuals (Pang *et al.*, 1994).

### *HIV/STDs in Sex Workers*

Increased prevalence rates of HIV (Elifson *et al.*, 1993; Modan *et al.*, 1992), syphilis, and hepatitis (Elifson *et al.*, 1993) have been reported among transgendered sex workers in comparison to female sex workers. This may be the result of certain sexual practices specifically engaged in by transgendered individuals. Transgendered persons often begin sex work prior to undergoing sex reassignment surgery, and are therefore more likely to engage in receptive anal intercourse (Pang *et al.*, 1994; Tsoi, 1990). After surgical reassignment, transgendered individuals are at risk for contracting HIV/STDs through both vaginal and anal intercourse (Pang *et al.*, 1994). Transgendered sex workers are usually at the bottom of the hierarchy of prostitution. They work in the least desirable locations, earn the least money, and are stigmatized by nontransgendered sex workers (Cohen, 1980; Garber, 1992). Therefore, they are more inclined to engage in unprotected sex because of client demand and the prospect of being paid additional money for unprotected sex (Asian AIDS Project, 1995; Boles and Elifson, 1994; Gattari *et al.*, 1992). The WTNAS reported that 11.5% of its respondents mentioned sex work as a reason for having unprotected sex (Xavier, 2000).

### *Risk Factors for HIV and STDs*

One study examining HIV knowledge and risk behavior in a transsexual sample not limited to sex workers reported that 24% of sexually active respondents engaged in receptive anal sex and only 19% of those reported condom use; 4% reported drug use (Avery *et al.*, 1995, cited in Bocking *et al.*, 1998). In the WTNAS, 14% of all transgendered individuals surveyed reported having engaged in unprotected anal intercourse in the last month, 32% in the last year, and 54% in their lifetime. Of respondents, 36% reported that they had a drug problem (Xavier, 2000).

Other common risk factors in transgendered persons include multiple sexual partners, irregular condom use, and drug and injecting needle use (Boles and Elifson, 1994; Elifson *et al.*, 1993; Galli *et al.*, 1991; Gattari *et al.*, 1991; Inciardi and Surratt, 1997; Modan *et al.*, 1992; Ratnam, 1996; Tirellie *et al.*, 1991). One of the factors encouraging needle use, and consequently increasing the likelihood of needle sharing, is the belief that injecting hormones is more efficacious than taking pills (Nemoto *et al.*, 1999).

A study investigating HIV risk behaviors among 53 “transvestite” commercial sex workers in Atlanta revealed that 68% of the sample were HIV-positive. HIV seroprevalence rates were higher among those who had engaged in receptive anal sex and used crack cocaine (Elifson *et al.*, 1993).

### *HIV Prevention Education*

Focus on transgendered persons and their sexual partners is largely absent from most HIV/AIDS interventions, whether for prevention or for the provision of care. Bocking *et al.* (1998) report that transgender individuals find that existing HIV prevention education is not inclusive of transgendered people, and often makes assumptions about sex and gender that are not applicable to their situation. In addition, transgendered persons involved in the injection of black market hormones and silicone may neither identify as drug users nor perceive their behavior as drug use, and hence are unlikely to identify themselves as being at risk, despite frequent needle sharing. Prevention education needs specifically to target transgendered persons and their unique combination of risk factors.

### *HIV and Sex Reassignment*

The usual sense of urgency felt by those waiting for sex reassignment surgery can be heightened by

the presence of HIV infection. Research suggests that this group has a greater level of anxiety, hopelessness, and loneliness than matched controls (Kok *et al.*, 1990). Patients in this situation may be reluctant to express their anxiety for fear of jeopardizing their chances of surgery (Pang *et al.*, 1994).

Providing sex reassignment surgery and related support services for HIV-positive individuals can be undertaken with confidence, following the recent publication of guidelines for care (Kirk, 1999) and the reports of a series of patients demonstrating acceptable morbidity and mortality (Wilson, 1999). A resolution by the Harry Benjamin International Gender Dysphoria Association in 1997 declared that it is unethical to deny eligibility for sex reassignment surgery solely on the basis of seropositivity for infections such as HIV. However, these recommendations and policy statements are not widely known, and are too often ignored even by providers who are familiar with them.

Studies of the effects of hormones on the progression of HIV/AIDS are also needed. Some practitioners believe that hormone administration in HIV-positive transgendered individuals may have immune-enhancing effects. Hormone-induced side effects, particularly those affecting psychological well-being, may be exacerbated in HIV-positive individuals. There is little information on the potentially compounded side effects of simultaneously undergoing hormone and HIV drug therapies (Israel and Tarver, 1997). However, it has been reported (by the Gay Men’s Health Crisis of New York) that antiretroviral medications lower the amounts of circulating hormones in the body, and there is anecdotal evidence to suggest that various health complications arise from the simultaneous administration of HIV/AIDS medications and estrogen (Xavier, 2000).

## **E. Transsexualism and Sex Reassignment**

### *Phenomenology of Transsexualism*

Transsexualism is the most severe form of gender dysphoria, or gender identity disorder.

Transsexualism is relatively rare. In the Netherlands in 1993, its prevalence was reported as 1 per 11,900 for males and 1 per 30,400 for females (Bakker *et al.*, 1993). In 1952, after the well-publicized case of Christine Jorgensen revealed that sex reassignment surgery was possible, patients started requesting the procedure. By conservative estimates, since the late 1970s approximately 10,000 sex reassignment surger-

ies have been successfully performed worldwide. This figure includes approximately 4500–6000 surgeries performed on U.S. residents (Landen *et al.*, 1996; Midence and Hargreaves, 1997). The accuracy of these figures is disputed by some in the transsexual movement. They note that the caseloads reported by individual surgeons, one of whom claims to have performed 4000 sex reassignment surgeries alone, suggest that the number of reassignment operations performed may be far higher.

### *Standards of Care*

The Harry Benjamin International Gender Dysphoria Association (HBIIGDA) was formed in 1979 by an international group of professionals who dealt with transsexual patients. One of HBIIGDA's first acts was to formulate guidelines for caregivers and patients regarding the treatment of persons seeking sex reassignment. These guidelines are called the Standards of Care (SOC), and are widely regarded as authoritative by providers working in this field. However, a recent survey of European and North American gender-identity clinics found that only 9 of 19 clinics that responded to the survey adhered to the HBIIGDA standards entirely (Petersen and Dickey, 1995). Moreover, individual caregivers often will not use the HBIIGDA standards, and in a recent survey (Xavier, 2000), over 90% of its transgendered respondents did not know what the HBIIGDA standards were.

The Standards of Care have been revised five times since their initial release in 1979. The latest published revision was in 1998, and a new revision is expected to be released in 2000.

### *Outcomes of Sex Reassignment*

Because reimbursement for and performance of sex reassignment surgery has been a subject of controversy, evaluation of its effectiveness is important. Since the 1960s, over 70 follow-up studies have been published on transsexual patients' satisfaction with their sex reassignment, and all but 1 concluded that the surgery was satisfactory (Seil, 1996), and that patients were highly satisfied with surgical outcomes (Pfafflin and Junge, 1992). Psychological functioning, as measured by the MMPI and by clinical measures has been shown to improve after surgery (Fleming *et al.*, 1981; Mate-Kole *et al.*, 1990).

### *Medical Complications of Sex Reassignment*

The most frequent complication of hormone therapy in transgendered women (MtF) is venous thromboembolism—blood clots, usually in the legs, which can sometimes lead to pulmonary embolism or other complications (Harry Benjamin International Gender Dysphoria Association, 1998). In their study of mortality and morbidity in transsexual subjects, van Kesteren *et al.* (1997) reported a 20-fold increase in venous thromboembolism relative to the general population. Smoking increases the risk of blood clots with estrogen therapy, particularly after age 40. Transdermal estradiol administration may considerably reduce the risk of venous thromboembolism (van Kesteren *et al.*, 1997).

Other complications of male-to-female hormone therapy include infertility, weight gain, emotional lability, liver disease, and the development of benign pituitary tumors (Harry Benjamin International Gender Dysphoria Association, 1998). There are reports in the literature of four MtF transsexuals developing breast carcinoma following estrogen administration (Ganley and Taylor, 1995; Kirk, 1996).

The major risks associated with administration of testosterone in transgendered men (female-to-male) are increased cholesterol and lipid levels, heart disease, including myocardial infarction, mood changes, liver disease, including hepatic tumors, male pattern baldness, and acne (Harry Benjamin International Gender Dysphoria Association, 1998). Smoking increases the risk of coronary heart disease in individuals using testosterone (Israel and Tarver, 1997).

## **F. Transgendered Youth**

The health-related needs and experiences of transgendered youth have received very little examination. For the most part, the literature does not distinguish these individuals from lesbian and gay youth. Scientific investigation of the specific and unique needs of transgender youth is urgently needed.

Most transgendered youth are relatively invisible, as they strive to appear indistinguishable from their nontransgendered peers, in order to avoid physical and emotional abuse. The impact of the various urban GLBT youth service organizations is beginning to be felt, however. By offering transgendered youth safe spaces that are sources of support, information,



and referrals, they are making it possible for a larger number of such youth to be out. MtF youth tend to remain more closeted for reasons of physical safety. FtM youth tend to be much more visible and out about themselves.

Isolation keeps most transgendered youth from seeking essential mental health and medical care until crises occur. The consequences of such crises can be enormous. They are not just medically destabilizing, but often led to rejection and further isolation from family and peers. As a result of family and social abandonment, many transgendered youth encounter victimization through homelessness, drug use, and prostitution (Israel and Tarver, 1997; Kral *et al.*, 1997a).

Within the health care system, transgendered youth probably encounter ignorance and prejudice similar to or greater than that experienced by lesbian and gay youth. In an unpublished 1995 study conducted by Blanco (cited in Kreiss and Patterson, 1997), LGBT youth in Washington State were asked to assess their access to health care and the quality of care they received. The study found that 66% of youth stated that their health provider had never brought up issues of sexual orientation. Many received inappropriate treatment and health education based on their provider's heterosexual assumptions and ignorance of their true sexual orientation. One can only speculate that gender identity issues were either confused with sexual orientation or not asked about at all.

Since most studies have tended to conflate sexual orientation and gender identity, HIV/AIDS prevalence is unknown for transgendered youth. Given the high rates of homelessness and substance use among LGBT youth, high rates of sex work among transgendered individuals, and high rates of HIV risk among homeless or runaway LGBT youth, transgendered youth are likely to be at greatly elevated risk for HIV infection.

For the most severely gender-dysphoric transgendered youth, early intervention with puberty-delaying hormones can safely buy time to explore gender issues in therapy while preventing the irreversible hormone-induced physical changes that make passing in the desired gender so difficult for most adult transsexuals (Gooren and Delemarre-van de Wall, 1996; Cohen-Kettenis and van Goozen, 1998; Harry Benjamin International Gender Dysphoria Association, 1998). Transsexuals who have been treated early at the Amsterdam Gender Clinic pass very easily as members of the opposite gender (Cohen-Kettenis &

Goozen, 1997). As a result, these individuals may suffer less stress as adults. Further research on the relationship between the age at which an individual receives sex reassignment and long-term outcomes would be extremely beneficial to both consumers and medical providers, and is urgently needed.

## G. Special Populations

### *Ethnic and Racial Minorities*

As in the general population, transgendered persons of color are more likely to be economically disadvantaged, and to face disproportionately higher rates of victimization, unemployment, substance abuse, HIV infection, prostitution, and other difficulties. Transgendered persons of color also report a loss of community identity if their true gender identity becomes known. In most communities of color, heterosexual males and females commonly regard gay males and lesbians as no longer a part of their ethnic community because they assume that all people of color are or should be heterosexual. This ostracism also extends to transgendered individuals (Israel and Tarver, 1997).

### *Incarcerated and Institutionalized Individuals*

Transgendered individuals who are incarcerated or institutionalized often become victims of physical and sexual assault as a result of their gender presentation. This has sometimes resulted in the death of transgendered persons from homicide or suicide. Israel and Tarver (1997) report that victimization is common in institutional settings. Sexual assault systematically occurs in jails and prisons. Guards and administrators either ignore these events or even encourage them, because keeping violent criminals in "relationships" tends to make populations more manageable. As a result, transgendered individuals frequently become victimized by aggressive prisoners, or are pressured into providing sexual services for one or more individuals. Rape under similar circumstances is also prevalent in institutionalized mental health populations.

Victimization of prisoners and other institutionalized persons also includes withholding hormones. Withdrawal of hormones has been linked to an increased risk of self-mutilation or autocastration, clinical depression, behavioral difficulties, illegal drug

use, and suicide attempts (Harry Benjamin International Gender Dysphoria Association, 1998; Israel and Tarver, 1997).

## H. Intersex

It is conservatively estimated that 1 in 2000 newborns are found to have ambiguous external genitalia. Although some conditions do require surgical or hormonal intervention for genuine medical indications, the majority of intersex conditions are found to be physiologically benign (Diamond and Sigmundson, 1997; Kessler, 1998). Nevertheless, it is estimated that 100–200 pediatric surgical sex reassignments are performed in the United States annually. Thousands of these procedures have been performed since the practice was institutionalized in the 1950s with the intention of precluding the stigma arising from the lack of clearly defined male or female genitalia (Kipnis and Diamond, 1998; Preves, 1998). It has been standard practice to recommend surgery for infants with ambiguous genitalia. The parents of these patients are told to raise them unambiguously as boys or girls. As a result, many adults who have had these operations in infancy have never been candidly informed of their medical histories (Elliott, 1998; Kipnis and Diamond, 1998).

Kipnis and Diamond (1998) identified a number of limitations to the current clinical management of intersexuality. First, the line that decisively and non-arbitrarily separates male from female is unclear, and perhaps nonexistent. Second, the development of gender identity is not always alterable in these children, despite alteration of their genitalia. Third, it is not possible to predict confidently the gender—male, female, or transgendered—that an intersexed child will find comfortable in adulthood.

Whether to surgically alter ambiguous genitalia in infants and children is an increasingly controversial issue, which highlights the conflict between our cultural and biological definitions of gender. Intersexuality, the biologically variant sexual anatomy known more commonly as hermaphroditism, disturbs the distinction between male and female persons which is so fundamental to self-identification and social status, particularly in the United States (Chase, 1998).

In a recent and ongoing study, Reiner (1997) tracked six boys who had lost their penises in infancy by accident or through surgery and were being reared as girls. These children behaved more like boys than girls and, in two cases, the children autonomously

changed gender and assumed male roles. In interviews with intersexed adults, Preves (1998) found that many of those who had genital surgery emphasized that the very operations that were intended to assuage their feelings of difference only served to highlight their stigma. More extensive follow-up studies are required to determine the clinical benefits and harms of early surgery on intersexed individuals. The ethical implications of concealing information from patients also requires further analysis (Nelson, 1998). A review of current standards of care for intersexed individuals is urgently required.

## I. Selected Professional and Consumer Organizations

These include the Harry Benjamin International Gender Dysphoria Association (HBIGDA), Gender Education and Advocacy (GEA), the Intersex Society of North America (ISNA), the International Foundation for Gender Education (IFGE), and the Gender Public Advocacy Coalition (GenderPAC).

## V. METHODOLOGIC CHALLENGES TO STUDYING LESBIAN, GAY, BISEXUAL, AND TRANSGENDER HEALTH

### A. Overview

The public, government officials, health care providers, and researchers have only recently begun to recognize the many important, yet largely overlooked, links among health, sexual orientations, and transgender identity (Solarz, 1999; Scarce, 1999; Ryan and Futterman, 1998; Joint Policy Committee, American Public Health Association, 1998; Council on Scientific Affairs, American Medical Association, 1996). In order to improve the health of the U.S. population as a whole these concerns can no longer be neglected. However, as researchers have begun to hypothesize and study these links, unresolved scientific methods have presented serious challenges to the collection of reliable and valid information.

These difficulties include defining, measuring, and sampling individuals using largely critically unexamined and socially constructed categories, as well as sampling rare and hidden populations concerning sensitive topics (Solarz, 1999; Sell, 1997; Gonsiorek *et al.*, 1995). Not surprisingly, these difficulties mirror similar problems that have been recognized and ex-

amined related to the classification of people based upon race and ethnicity. To understand the very real health needs of individuals related to their sexual orientations and/or transgender identity, research must mount a similar effort to the one that has examined race and ethnicity.

While there are many challenges surrounding the collection of data concerning sexual orientation and transgender identity, four require immediate attention:

- Defining the populations to be studied
- Constructing valid and reliable measures of sexual orientations and transgender identity representative of these definitions
- Sampling rare and hidden populations
- Sampling and studying sensitive topics

These four areas are often ignored or left unresolved, and the resultant research has therefore shown significant variation in how sexual orientations and transgender identity are defined, measured, and sampled (Israel and Tarver, 1997; Shively *et al.*, 1985; Sell and Petruccio, 1996). For example, a review of published public health research articles that sampled homosexuals, lesbians, gays, and/or bisexuals between 1990 and 1992 found that research publications rarely provided a conceptual definition of the population they sampled, used a range of incompatible methods and measures of sexual orientation to identify and select participants, sampled from settings representative of dramatically different populations, and rarely used probability sampling (Sell and Petruccio, 1996). This is not to say that none of the studies reviewed were methodologically sound nor that the studies did not produce important results. To better understand and monitor the public health concerns of lesbian, gay, bisexual, and transgender people, steps must be taken to standardize definitions, measures, and methods. Each of the above four topics is briefly reviewed here.

## B. Defining the Populations

Different definitions and measures of sexual orientations have been proposed and used to develop study populations since the 1860s when sexual orientations first gained widespread research interest (Sell, 1997). In fact, many different terms were used to label sexual orientations before the terms “heterosexual,” “homosexual” “bisexual,” “gay,” and “lesbian” slowly came into widespread use from the 1920s

through the 1960s. Unfortunately there is still no general consensus on the definitions of these terms, although each includes components of at least one of three dimensions: (1) sexual orientation identity, (2) sexual behavior, and/or (3) sexual attraction (Laumann *et al.*, 1994). For example, one study might define sexual orientation as a form of identity (as self-identified heterosexual, homosexual, bisexual, gay, or lesbian), while another defines it as gender choice in sexual partners, and yet another as the gender of those to whom one is sexually attracted (Sell, 1997).

Within each of the above three dimensions there is even further variation. One researcher might define sexual behavior as any relationship between two people resulting in sexual arousal (not necessarily including physical contact), while another researcher’s definition may specify physical contact resulting in orgasm. Consensus is required to develop valid and reliable measures.

Recent national studies estimating the percentage of the population that falls into each of the three broad dimensions of identity, behavior, and attraction show that 1–4% of the population identifies as lesbian or gay, 2–6% of the population reports some same-sex behavior in the previous 5 years, and up to 21% of the population reports same-sex attraction at least once in adulthood (Sell *et al.*, 1995; Laumann *et al.*, 1994; Billy *et al.*, 1993; TW Smith, 1991; Harry, 1990; Fay *et al.*, 1989). Therefore, depending upon how it is defined and measured, 1–21% of the population could be classified as lesbian or gay to some degree, with the remainder classified as bisexual or heterosexual to some degree.

The research definition of the term “transgender” is even more treacherous and less examined than that of sexual orientation. Israel and Tarver (1997) point out that “the term ‘transgender’ has become the word of choice for both professionals and consumers when referring to individuals or the community as a whole.” The term itself, however, encompasses a number of populations and communities including transsexuals, crossdressers, and the intersexed. See Section IV, Transgender Health Concerns, for full definitions of the subgroups within the transgender population. Each subpopulation presents definitional challenges.

## C. Measuring the Populations

There is also much confusion about measures of sexual orientation and transgender identity. This is

not surprising considering that valid measures should first and foremost be based upon conceptual definitions of the populations in question, and no such definitive definitions exist (Streiner and Norman, 1989; Sudman, 1976).

Existing measures of sexual orientation range in complexity from simple dichotomous measures in which subjects report they are or are not heterosexual or homosexual, to more complex scales as developed by Kinsey *et al.* (1948), Klein *et al.* (1985), Shively and DeCecco (1977), and Sell (1996) (for a description of each see Sell, 1997). There exists no consensus and virtually no literature discussing when and where each of these measures should be used. Therefore, their use and value for research is uncertain at best. Only common sense and the health question before the researcher provide any guidance as to which measure, if any, should be chosen. For example, questions that pertain to biomedical pathogenesis, disease prevalence, health care access, or prevention efforts may all require the measurement of different dimensions of sexual orientation. For instance, self-identification may be best for studying access to health care, sexual behavior may be best for studying STDs, while sexual attraction may be best for examining some mental health issues. How well each of the existing measures captures these dimensions of sexual orientation must be taken into consideration.

Measures to identify transgender individuals are, not surprisingly, less well described and developed. While measures of sexual orientation generally assess identity, behavior, and/or sexual attractions, the term “transgender” has been constructed and is usually defined as a form of identity. That is, individuals are transgender if they choose to identify as such. Self-identification as transgender then generally serves as a marker for one of the related communities, such as a transsexual, crossdresser, or intersexed individual. Of course, most researchers wanting to examine the health of transgender populations would want to further classify individuals into each of these categories or perhaps single out one of these populations for study (Israel and Tarver, 1997).

Measures of sexual orientation and transgender identity must also take into account racial, ethnic, and age differences among research participants, which may affect measure validity and reliability (Solarz, 1999; C Ryan and Futterman, 1998). Substantial variation exists across racial and ethnic groups concerning the social acceptability of exact orientations and identities, and consequently the reporting and understanding of these constructs varies across com-

munities. The terminology to discuss human interactions similarly varies and must be taken into consideration when developing and choosing measures of sexual orientation and transgender identity.

#### D. Sampling Rare Populations

In addition to the above research challenges, researchers studying relationships among health, sexual orientations, and transgender identity are faced with the difficulty of sampling and studying rare populations. Rare populations, often geographically dispersed and hidden, present certain methodologic and financial challenges to researchers wanting to construct samples, and in particular representative samples (Sell *et al.*, 1995; JL Martin and Dean, 1990; Sudman *et al.*, 1988; Sudman, 1976). To a larger extent, unlike in the areas of defining and measuring the populations as discussed above, there is research outside the field of sexual orientations and transgender identity that can be examined, modified, and applied to the construction of research samples (Lee, 1993; Renzetti and Lee, 1993).

The methods that have been used most often to study LGBT populations include the following:

- *List sampling*—when a sample is derived from a list, such as members of an LGBT organization. Sometimes the entire list is used for this selection of subjects, while at other times the list may be sampled.
- *Multipurpose sampling*—when a sample constructed for another purpose is expanded to study issues related to LGBT health. For example, a study designed to examine women and cancer, by stratifying the sample by sexual orientation, can be expanded to examine the relative risks of various cancers by sexual orientation.
- *Screening sampling*—when a larger general population sample is screened in order to identify LGBT people for inclusion into the research study. Because the populations are rare, it is sometimes necessary to screen study participants by sexual orientation or transgender identity using a screening to determine inclusion.
- *Network or snowball sampling*—when the researcher identifies members of the populations of interest or key informants who then identify other members of the populations who are

consequently contacted and included in the study. These additional individuals can then be asked to identify additional participants and so forth, resulting in a “snowballing” effect.

- *Outcropping sampling*—when individuals of rare populations are identified and recruited into the sample at locations frequented by the population. For example, lesbian and gay pride events, lesbian and gay bars, or lesbian and gay neighborhoods serve as locations for outcropping samples.
- *Advertising sampling*—when the researcher places advertisements to recruit subjects. The advertisements can be placed in newspapers and/or periodicals catering to the population or can be posted in locations frequented by the population. For example, transgender subjects may be recruited through postings on transgender-related web pages or publications.
- *Servicing sampling*—when a service is offered to the study subject as a method of recruitment. For example, transsexuals may be recruited by offering free hormone replacement counseling, or gay men may be recruited by offering free or reduced-price hepatitis vaccinations.

The above methods of course can and often are mixed and matched to construct samples. Each of the methods introduces biases, too numerous to discuss here, into the study that must be addressed when interpreting findings. Despite these biases, however, the above methods are generally used because they are feasible, considering the limited resources generally available to study these populations.

### E. Sampling Sensitive Topics

The final concern to address when studying LGBT health is the sampling and studying of “sensitive” topics. Sieber and Stanley (1988) define sensitive research as “studies in which there are potential consequences or implications, either directly for the participants in the research or for the class of individuals represented by the research.” Research on LGBT health, by any definition, must be considered sensitive.

The revelation of sexual orientation or transgender identity by study subjects can be difficult because of cultural taboos or because some subjects may have

unresolved issues relating to their sexual orientation or gender identity (C Ryan and Futterman, 1998; Sell *et al.*, 1995). The subjects may also place themselves at risk for violence and discrimination if responses are not kept confidential (Lee, 1993). The revelation of sexual orientation by study participants may also imply the conduct of certain sexual behaviors classified as criminal in some jurisdictions in the United States (Hunter *et al.*, 1992). Research concerning how to conduct studies on sensitive topics must therefore be refined and examined in the context of research on LGBT health (Lee, 1993; Renzetti and Lee, 1993). In fact, the sensitive nature of LGBT health affects the entire research process, from the formulation of the research question, to the design and conduct of the study, to the publication and dissemination of the results. These problems, in addition to presenting methodologic challenges, can present ethical, political, and legal challenges the researcher must address. This paper, however, only attempts to address some of the methodologic challenges.

The following is a brief review of methods that have been shown successfully to assist the conduct of research on sensitive topics and specifically the development of survey questions:

- *Loading questions*—Loading questions refers to the process of biasing a question to influence the subject’s comfort with providing a response. For example, a question can be phrased to imply, using an authoritative source, that a certain behavior is common or socially acceptable. The question can also be worded to assume that respondents have participated in specific behaviors forcing the subject to respond in the negative if they have not (Lee, 1993).
- *Familiar words*—Using familiar words has been shown to assist in understanding and increasing comfort with questions. Familiar words are those commonly used by the subject or the population to describe the sensitive topic being explored by the researcher (Bradburn and Sudman, 1979).
- *Long questions*—Short questions are almost always preferable to long questions; however, long questions can be used to provide memory clues to the respondent or to give the respondent more time to recall past experiences on sensitive topics (Bradburn and Sudman, 1979).
- *Embedded questions*—Questions that are sensitive can be embedded into the questionnaire

in such a way as to decrease any threats they may pose. For example, a question about same-sex sexual behavior is less threatening in a survey concerning sexual behavior in general. Because questions about past behavior or practice tend to be less threatening than those about current behavior or practice, questions about the past can be asked first. Questions concerning the present would then only be asked if a respondent reports “ever” expressing the behavior (Lee, 1993).

In addition to paying particular attention to the wording and placement of questions, researchers can modify other aspects of the research process to better examine sensitive topics. The following are some of the techniques described elsewhere that can be used: randomized response, nominative techniques, and microaggregation techniques (Lee, 1993; Duffy and Waterton, 1984; Bradburn and Sudman, 1979; Boruch and Cecil, 1979).

Finally, when studying sensitive topics, assuring research subjects that their responses will be kept confidential can improve both response rates and the validity of responses. Confidentiality assists with the research process by convincing respondents that they can trust the researcher. The process of assuring confidentiality can be complex. However, every researcher studying LGBT health should be aware of procedures to do so and must take them seriously (Boruch and Cecil, 1979).

## F. Summary

Despite the challenges of defining, measuring, and sampling sexual orientation and transgender identity discussed above, researchers are forging ahead with studies that provide important information concerning the links between health, sexual orientation, and transgender identity as well as providing valuable insights into the conduct of such research (Israel and Tarver, 1997; Meyer and Colten, 1999; Faulkner and Cranston, 1998; Remafedi *et al.*, 1998; Binson *et al.*, 1995). The most impressive work has perhaps been done in conjunction with the Nurse’s Health Study and the Women’s Health Initiative, both of which have now included items of sexual orientation in their data collection (Solarz, 1999). The field experience of these researchers should be examined to provide a framework for the conduct of future studies and to begin to resolve the challenges presented in this paper.

The most important constraint limiting our knowledge concerning the health of lesbian, gay, bisexual, and transgender people is the collection of data from large national on-going population-based surveys funded by the federal government. To monitor the health of LGBT populations, it is necessary to include measures of sexual orientation and transgender identity on surveys such as the National Health Interview Survey (NHIS), the National Health and Nutrition Examination Survey (NHANES), and the Youth Risk Behavior Surveillance System (YRBSS) among many others. The three mentioned here each have had some experience measuring sexual orientation, with NHANES and YRBSS each addressing one core aspect of sexual orientation, that is, sexual orientation identity.

Most impressively, NHANES, starting in the year 2000, began asking all adult respondents, using audio computer-assisted self-interview techniques, the following question: “Do you think of yourself as . . . Heterosexual or straight (that is, attracted to only persons of the opposite sex); homosexual, lesbian, or gay (that is, attracted to only persons of the same sex); bisexual (that is, attracted to persons of both the same and opposite sex); something else; or you’re not sure?” The experience of NHANES, including any information for future researchers concerning the validity and reliability of its measure of sexual orientation, and the findings concerning the health of lesbian and gay people, will undoubtedly improve many lives in the United States. With the addition of sexual orientation as a demographic variable on additional large federally funded surveys and the collection of transgender identity data as well, life-saving knowledge that has long been considered unimportant or irrelevant will finally be made available.

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