

When Health Care Isn't Caring

Lambda Legal's Survey on Discrimination Against
LGBT People and People Living with HIV

Lambda Legal
making the case for equality

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Lambda Legal is a national organization committed to achieving full recognition of the civil rights of lesbians, gay men, bisexuals, transgender people and those with HIV through impact litigation, education and public policy work.

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For more information on the National Health Care Fairness Survey and to view the original survey, visit www.lambdalegal.org/health-care-fairness.

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EXECUTIVE SUMMARY

Many of us are vulnerable when we are ill or seeking health care services. For lesbian, gay, bisexual and transgender (LGBT) people and those living with HIV, that vulnerability is often exacerbated by disrespectful attitudes, discriminatory treatment, inflexible or prejudicial policies and even refusals of essential care. These barriers, in turn, can result in poorer health outcomes and often have serious and even catastrophic consequences.

This survey is the first to examine refusal of care and barriers to health care among LGBT and HIV communities on a national scale. We hope that these data will influence decisions being made about how health care is delivered in this country now and in the future.

In spring 2009, Lambda Legal and over 100 partner organizations distributed the survey to LGBT people and people living with HIV nationwide. The information in this report is gleaned from 4,916 respondents.

The respondents were not drawn from a random sample, but instead are people who chose to respond to the survey after it was promoted online and at events. The results are a rich and informative picture of the experiences of thousands of LGBT people and people living with HIV, but cannot be used to draw conclusions about the proportion of all LGBT people and people living with HIV who have had similar experiences. The data are powerful because they represent a diverse sampling of the LGBT and HIV communities with respect to sexual orientation, gender identity, HIV status, race and ethnicity, age and geography.

Discrimination and Barriers to Care

The results of this survey highlight enormous challenges that remain for LGBT communities and those living with HIV in accessing quality, non-discriminatory health care services. More than half of all respondents reported that they have experienced at least one of the following types of discrimination in care: being refused needed care; health care professionals refusing to touch them or using excessive precautions; health care professionals using harsh or abusive language; being blamed for their health status; or health care professionals being physically rough or abusive. **Almost 56 percent of lesbian, gay or bisexual (LGB) respondents had at least one of these experiences; 70 percent of transgender and gender-nonconforming respondents**

had one or more of these experiences; and nearly 63 percent of respondents living with HIV experienced one or more of these types of discrimination in health care.

- **LGBT people and people living with HIV are too often denied the care they need because of their sexual orientation, gender identity and/or HIV status.** Almost 8 percent of LGB respondents reported that they had been denied needed health care outright. Over a quarter of all transgender and gender-nonconforming respondents (almost 27 percent) reported being denied care and 19 percent of respondents living with HIV also reported being denied care.
- **LGBT people and people living with HIV are frequently treated in a discriminatory manner while trying to obtain care, including providers using harsh language, refusing to touch patients and blaming them for their health status.**
 - f* Just over 10 percent of LGB respondents reported that health care professionals used harsh language toward them; 11 percent reported that health professionals refused to touch them or used excessive precautions; and more than 12 percent of LGB respondents reported being blamed for their health status.
 - f* Almost 36 percent of respondents living with HIV reported that health care professionals refused to touch them or used excessive precautions and nearly 26 percent were blamed for their own health status.
 - f* Nearly 21 percent of transgender and gender-nonconforming respondents reported being subjected to harsh or abusive language from a health care professional, and almost 8 percent

reported experiencing physically rough or abusive treatment from a health care professional. Over 20 percent of transgender and gender-nonconforming respondents reported being blamed for their own health conditions.

- **In almost every category measured in this survey, transgender and gender-nonconforming respondents reported experiencing the highest rates of discrimination and barriers to care.** Transgender and gender-nonconforming respondents reported facing barriers and discrimination as much as two to three times more frequently than lesbian, gay or bisexual respondents.
- **In nearly every category, a higher proportion of respondents who are people of color and/or low-income reported experiencing discriminatory and substandard care.** For example, close to 33 percent of low-income transgender and gender-nonconforming respondents reported being refused care because of their gender identity and almost a quarter of low-income respondents living with HIV reported being denied care.
- **Respondents reported a high degree of anticipation and belief that they would face discriminatory care and such concerns were a barrier to seeking care.** Overall, 9 percent of LGB respondents are concerned about being refused medical services when they need them, and 20 percent of respondents living with HIV and over half of transgender and gender-nonconforming respondents share this same concern.

Survey respondents were somewhat more privileged than the LGBT population as a whole, with higher proportions having obtained advanced degrees, reporting higher household incomes and having better health insurance coverage. **Since these factors tend to improve access to care, this report likely understates the barriers to health care experienced by all LGBT people and those living with HIV.**

Key Recommendations

Health care institutions should:

- Establish nondiscrimination, fair visitation and other policies that prohibit bias and discrimination based on sexual orientation, gender identity and expression and HIV status, recognize families of LGBT people and their wishes and provide a process for reporting and redressing discrimination if it occurs.
- Develop and implement goals and plans to ensure that LGBT people and people living with HIV are treated fairly.
- Require health profession students and health professionals to undergo significant cultural competency training about sexual orientation, gender identity and expression and HIV status.
- Include training about the specific ways LGBT people and people living with HIV who are also people of color, low-income, seniors or members of other underserved populations may experience discrimination in health care settings and establish policies to prevent them.
- Advocate for laws and accreditation standards that require all providers to deliver to LGBT people and people living with HIV the same level of high-quality care afforded others.

Our federal, state and local governments should:

- Include coverage of LGBT people and those living with HIV in all antidiscrimination and equal opportunity mandates.
- Require all health care facilities and education programs that receive government funding to develop and implement goals, policies and plans to ensure that LGBT people and people living with HIV are treated fairly and provide ongoing cultural competency training for all health care profession students and staff.

- Change laws to require recognition of the families of LGBT people, including those who live within less common family structures, and require health care providers to do the same.
- Eliminate overly broad religious exemptions that purport to exempt medical care from nondiscrimination laws.
- Prohibit discriminatory practices by insurance providers that deny or limit coverage for needed care by LGBT people and people living with HIV.
- Ensure that government-funded health research and surveys include sexual orientation and gender identity issues and demographic analysis so that more can be known about the health care discrimination experienced by our communities as well as about our communities' health care needs.

Individuals and organizations should:

- Educate themselves, each other and, when possible, health care providers about the rights and needs of LGBT patients and those living with HIV.
- Advocate for improved laws and policies.
- Use existing mechanisms that are appropriate — such as medical powers of attorney and other legal documents as well as formal legal relationships where that is a couple's choice — to create as much protection as possible for themselves and their loved ones.
- Fight back when discrimination occurs, including reporting discriminatory practices, sharing stories and contacting Lambda Legal and other advocacy organizations and/or attorneys.

About Lambda Legal and the Study

Lambda Legal is the oldest and largest national legal organization committed to achieving the full recognition of the civil rights of lesbians, gay men, bisexuals, transgender people and those living with HIV. This survey was designed

as part of Lambda Legal's national Health Care Fairness Campaign launched in 2009. The goals of the campaign are to bring together advocates, partners and consumers to educate policy-makers, health care providers and the general public about the need for health care fairness and to advocate for reforms that address the issues of greatest concern to LGBT people and people living with HIV. Chronicling the types and prevalence of barriers to care faced by the range of groups in our communities is a vital part of helping to address and eliminate them.

For more information about Lambda Legal, visit www.lambdalegal.org

HEALTH CARE FAIRNESS: A PERSONAL ISSUE, A NATIONAL CAMPAIGN

Lambda Legal has been advocating for health care fairness through impact litigation, education and public policy work to make sure that LGBT people and those living with HIV have full and equal access to all medically appropriate health care without discrimination based on sexual orientation, gender identity or expression, HIV or family status. Some of the key components of health care fairness we have outlined include:

- privacy and confidentiality for all, including LGBT people and those living with HIV;
- recognition and respect for all families including same-sex couples and their children;
- equal access to affordable health care insurance for same-sex spouses, partners and their children, and elimination of discriminatory insurance policy exclusions for transgender care, reproductive health care or care based on HIV status;
- fair and comprehensive health care services for LGBT youth and adults in custody as well as those living with HIV;
- informed consent for HIV testing;
- protection of the rights of LGBT patients and those living with HIV to seek and obtain all medically appropriate care without restrictions based on the personal or religious views of providers;
- equal access to mental health and substance abuse treatment and services for LGBT people and people with living with HIV; and
- fair and compassionate services for LGBT seniors and older people living with HIV.

Because issues of health care access and fairness are so critical to the well-being of the LGBT and HIV communities, Lambda Legal made health care fairness one of our ten priority issue areas and in 2009 we chose to highlight these issues with a national **Health Care Fairness Campaign**. The goals of the campaign are to bring together advocates, partners and consumers to educate policy-

makers, health care providers and the general public about the need for health care fairness and to advocate for reforms that address the issues of greatest concern to LGBT people and people living with HIV.

Why This Survey?

Anecdotal evidence suggests that LGBT individuals and people living with HIV in the United States — from all backgrounds — have less access to health care and face greater obstacles to navigating health care systems than do heterosexual people. For over three decades, Lambda Legal has been at the forefront of establishing recognition of the legal rights of LGBT people and people living with HIV. The organization's impact litigation cases present examples of the kinds of challenges many LGBT people and people living with HIV experience while trying to receive needed health care services every day. Our Legal Help Desk also consistently receives calls from LGBT people and people living with HIV with questions and concerns about how they have been treated by health care and health insurance providers.

Although there have been studies finding health disparities by sexual orientation in cancer screening, mental illness, substance abuse, smoking and some other commonly measured health status indicators, there are very few, if any, survey reports about the types of health care-related discrimination LGBT people and those living with HIV face, how common such experiences are and what impact this discrimination has on their care. Designed as part of Lambda Legal's national Health Care Fairness Campaign, this survey is the first to examine experiences with refusal of care and barriers to health care access among LGBT and HIV communities on a national scale.

With the nation in the midst of a vigorous debate about reforming the way health care is delivered, we at Lambda Legal and our partners want to ensure that the needs of LGBT people and those living with HIV are an integral part of the discussion. Chronicling the barriers to care faced by the range of groups in our communities and the scope of these problems is a vital part of helping to address these needs. We hope that these data will influence decisions being made now and in the future.

WHAT WE FOUND: WHEN HEALTH CARE ISN'T CARING

Enormous challenges remain for lesbian, gay, bisexual and transgender (LGBT) communities and people living with HIV. Experiences of bias and outright hostility remain common in all areas of our lives. When those experiences occur in the context of obtaining health care, they are not only deeply distressing but potentially life-threatening.

The essential bond of trust between clinician and patient that many in the United States take for granted is not a given for LGBT people or people living with HIV. Whether because of prejudices, ignorance, outdated systems or short-sighted policies, many people across our communities are not receiving the health care they need.

The tables on the following pages, which present data from our health care fairness survey, illustrate this problem from two perspectives. Tables 1 to 5 show **patterns of discrimination and substandard care** experienced in specific interactions with medical providers. Table 6 deals with personal fears and alienation from the health care system. Such prevalent fears and alienation are **barriers to care**.

Discrimination and Substandard Care

The responses we received are disturbing and require action. Respondents were asked to report whether they believed they received discriminatory care because of their sexual orientation, gender identity or HIV status. All the data reported below represent experiences that respondents felt were motivated by prejudice against lesbian, gay, bisexual, transgender people or people living with HIV. (Please note that the “transgender” category in the following charts includes both transgender and gender-nonconforming respondents because of the high visibility that puts both groups at a high risk for discrimination based on gender identity.)

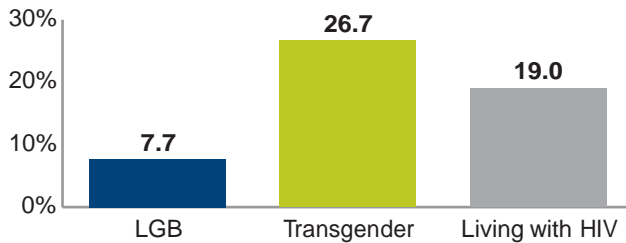
More than half of all respondents reported that they have experienced at least one of the following types of

In 2008, Janice Langbehn (second from left) and Lisa Pond were about to depart from Miami on a family cruise with their three children. Pond suddenly collapsed and was rushed to Jackson Memorial Hospital. Janice was informed that she was in an antigay city and state, and she could expect to receive no information or acknowledgment as Lisa’s partner or family. Hospital personnel would not allow Janice or their children to see Lisa until nearly eight hours after their arrival as Lisa slipped into a coma, even though Lisa’s sister was allowed to visit as soon as she arrived. The next day, Lisa died. In 2008, Lambda Legal filed a lawsuit on behalf of the family. The court dismissed the case, agreeing with Jackson Memorial that the hospital has no obligation to allow their patients’ visitors in their trauma unit. Lambda Legal and our partners continue to fight for fair visitation policies.

Langbehn v. Jackson Memorial Hospital



Table 1: I was refused needed health care



Guadalupe “Lupita” Benitez (left) was denied infertility treatment by the North Coast Women’s Care Medical Group because she is a lesbian. Her former doctors are conservative Christians who claimed their religious beliefs gave them a right to withhold care from Benitez that they routinely provide to heterosexual patients. In 2001, Lambda Legal filed a lawsuit on behalf of Benitez fighting for the basic right of LGBT people to receive equal access to treatment from health care providers and tackling the issue of religiously motivated discrimination. In 2008, the California Supreme Court unanimously ruled in favor of Benitez, making clear that California’s state law prohibiting discrimination must be followed.

Benitez v. North Coast Women’s Care Medical Group

discrimination in care: being refused needed care; health care professionals refusing to touch them or using excessive precautions; health care professionals using harsh or abusive language; being blamed for their health status; or health care professionals being physically rough or abusive. **Almost 56 percent of lesbian, gay or bisexual (LGB) respondents had at least one of these experiences; 70 percent of transgender and gender-nonconforming respondents had one or more of these experiences; and almost 63 percent of respondents living with HIV experienced one or more of these types of discrimination in health care.**

Almost 8 percent of LGB respondents reported that they had been denied needed health care because of their sexual orientation. Over a quarter of all transgender respondents (nearly 27 percent) reported being denied care and 19 percent of respondents living with HIV also reported being denied care because of their transgender or HIV status, respectively.

Many of our survey respondents also reported that they have been treated in a discriminatory manner while trying to receive care. Nearly 11 percent of LGB respondents have interacted with health care professionals who have used harsh language. That same percentage have encountered health care professionals who refused to touch them or used excessive precautions. More than 12 percent of LGB respondents were blamed for their health status.

Our survey showed that persons living with HIV are still facing ignorance, lack of respect and overt discrimination when accessing health care, with 19 percent of respondents reporting being refused needed health care. **Respondents living with HIV were most likely to report that health care professionals refused to touch them or used excessive precautions (nearly 36 percent) and blamed them for their own health status (nearly 26 percent).** And over 4 percent of respondents living with HIV reported being treated in a physically rough or abusive manner by health care providers.

The picture is even more disturbing for transgender and gender-nonconforming respondents, who experienced

Table 2: Health care professionals refused to touch me or used excessive precautions

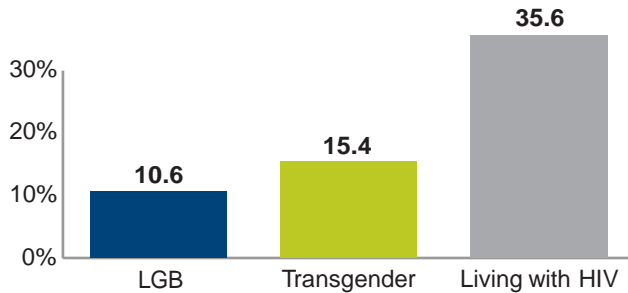


Table 4: Health care professionals blamed me for my health status

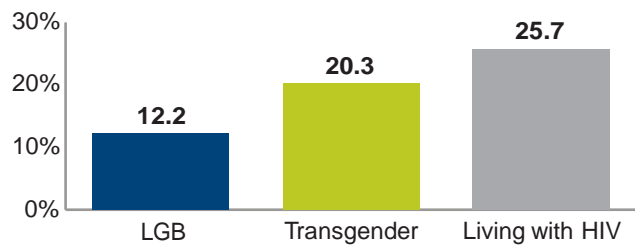


Table 3: Health care professionals used harsh or abusive language

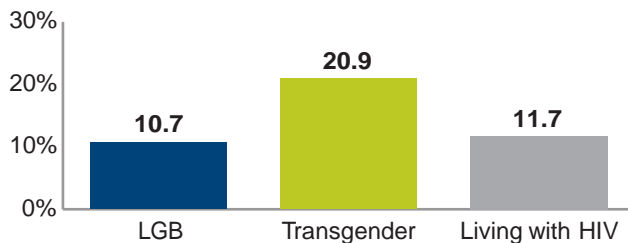
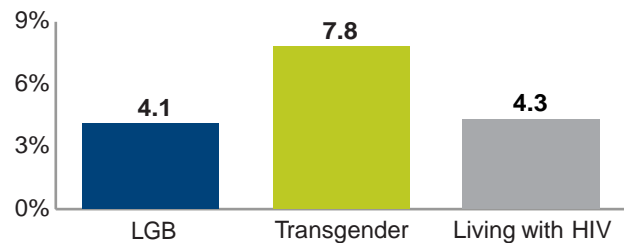


Table 5: Health care professionals were physically rough or abusive



the highest rates of being refused care (nearly 27 percent), being subjected to harsh language (nearly 21 percent) and experiencing physically rough or abusive treatment (nearly 8 percent). Over 20 percent of transgender and gender-nonconforming respondents reported being blamed for their own health problems and illnesses.

In addition to the overall rates of substandard care, respondents of color and low-income respondents (defined in this survey as having a household income under \$20,000) in nearly every category experienced higher rates of discrimination and substandard care. For example, while transgender respondents as a whole reported a care-refusal rate of almost 27 percent, low-income transgender respondents reported a rate of almost 33 percent. Over a quarter of low-income respondents living with HIV were refused care compared to 19 percent of respondents living with HIV overall. Almost 11 percent

of low-income LGB respondents and LGB respondents of color were refused care compared to almost 8 percent of LGB people overall.

Nearly half of low-income respondents living with HIV reported that medical personnel refused to touch them while the overall rate among those with living with HIV was nearly 36 percent. Over 35 percent of low-income respondents living with HIV were blamed for their health status, in contrast to about a quarter of those living with HIV overall.

Low-income respondents and respondents of color often reported harsh language by medical providers. Almost 17 percent of low-income LGB respondents and 14 percent of LGB respondents of color reported experiencing harsh language compared to almost 11 percent of LGB respondents overall. Over a quarter of transgender respondents of color and 28 percent of low-income

transgender respondents reported harsh language compared to 21 percent of transgender respondents overall. And nearly 13 percent of respondents of color living with HIV and 19 percent of low-income respondents living with HIV experienced harsh language compared to almost 12 percent of respondents living with HIV overall.

People of color living with HIV and LBG people of color were at least twice as likely as whites to report experiencing physically rough or abusive treatment by medical professionals. Of the LGB respondents, 3 percent of whites and almost 7 percent of people of color reported experiencing such treatment; among those living with HIV, the figures were just over 3 percent for whites and nearly 8 percent for people of color.

Barriers to Care

In addition to asking about specific encounters with health care providers and systems, the Lambda Legal health care fairness survey also asked respondents about their fears and concerns about obtaining health care. Personal beliefs and perceptions about whether one can access quality health care have been shown to strongly affect whether and how individuals seek medical care and interact with medical

professionals. Past experiences of bias, humiliation, harsh treatment and isolation as well as perceived bias by health care providers can cause LGBT people and people living with HIV to become alienated from the health care system and even reluctant to seek care. Such reluctance can in turn result in poorer health outcomes because of delays in diagnosis, treatment or preventive measures.

Overall bias and stigma in our society — conveyed through negative family, community, institutional and cultural messages about our lives, combined with discriminatory policies and practices — can result in unwillingness for LGBT people and people living with HIV to disclose to clinicians personal information that can be essential to proper diagnosis and/or treatment. At times, disclosure can be a catch-22 — that is, lack of disclosure about one’s sexual orientation or gender identity can lead to inadequate care, while disclosure can make LGBT people more vulnerable to discrimination and denial of care. For transgender individuals, disclosing one’s gender identity may result in discriminatory practices by insurance companies who refuse to cover necessary cross-gender health care, such as pap smears for transgender men or prostate screenings for transgender women.

Table 6: Fears and concerns about accessing health care

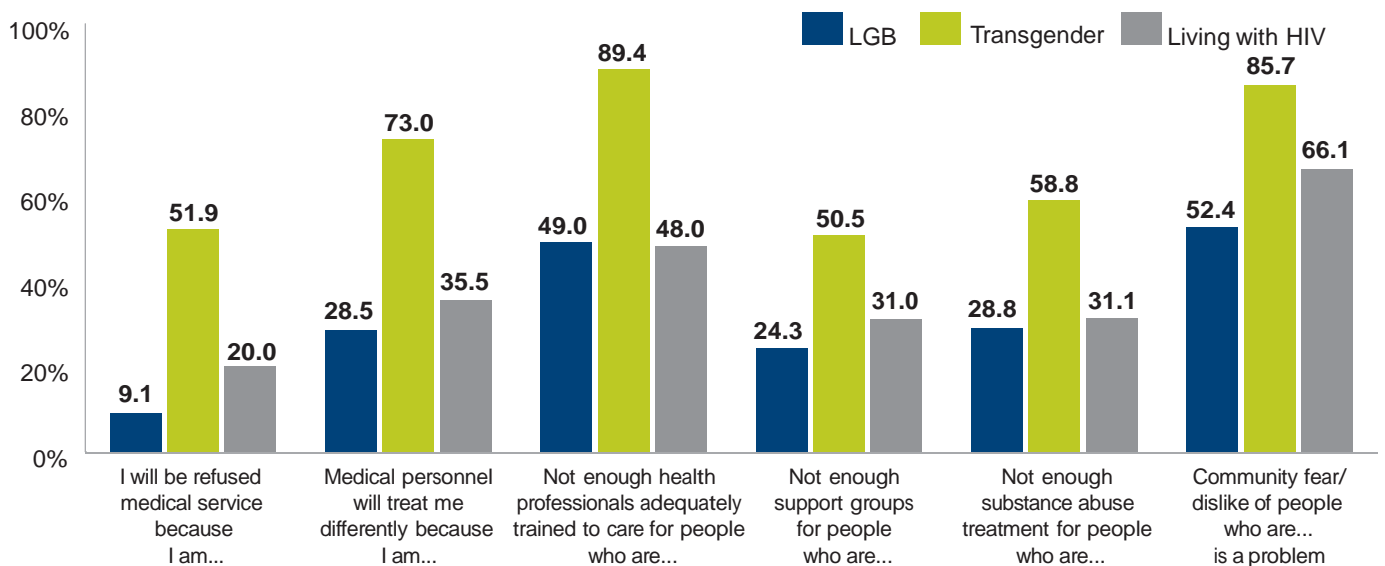


Table 6 shows the depth of the need for greater cultural competency throughout our health care systems to reduce serious barriers to care.

Survey respondents were asked to rate how much various factors make it hard for them to receive the care they need. Percentages reflect how many respondents designated each factor as “somewhat of a problem” or a “major problem” and indicate alarming amounts of perceived bias and barriers to care for LGB people and even greater alienation for people living with HIV and transgender people. (Please note: Only the responses from members of each group were counted in these statistics. For instance, the transgender group only includes responses from people who are transgender and gender non-conforming.)

Overall, nine percent of LGB respondents are concerned about being refused medical services when they need them. Over half of transgender respondents and 20 percent of respondents living with HIV share this concern. When asked about more specific concerns, the reports of perceived bias are even more disturbing. **For instance, nearly half of LGB respondents and respondents living with HIV and almost 90 percent of transgender respondents believe there are not enough**

medical personnel who are properly trained to care for them. Mental health issues were also of particular concern to LGB people, transgender people and those living with HIV, with almost 28 percent of the respondents concerned that not enough mental health professionals are available to help them. **Over half of LGB respondents, two-thirds of respondents living with HIV and almost 86 percent of transgender respondents indicated that overall community fear or dislike of people like them is a barrier to care.**

In this survey, we also examined barriers to care based on gender expression. Regardless of their sexual orientation or gender identity, people who are gender-nonconforming— men who appear more feminine, women who appear more masculine and people who have a more androgynous appearance — often face bias, harassment and discrimination in our society. In fact, one of the common ways many LGBT people experience discrimination in our society is based on their gender expression. This was a particular concern for the people who answered our survey. **Thirty percent of all respondents stated that they fear medical personnel will treat them differently based on their gender expression and presentation.**



I called a gynecologist's office trying to schedule a hysterectomy. I told the receptionist that I was a transgender male. Two days later, I received a phone call telling me that the doctor did not take cases like mine and referring me to a hospital. I remember feeling like a freak. I called the second number. The receptionist told me they didn't deal with transgender men either. After I got over the hurt, I called another doctor's office. The receptionist told me that their office welcomed transgender clients. I told the doctor that I wanted a full hysterectomy. She performed an exam, Pap smear and ultrasound. She told me that the results showed that I was fine. I asked her again about the hysterectomy, this time telling her I would pay for it out of pocket. She continued to say that it would be unethical because there was nothing wrong with me. She was hiding her transphobia behind a bogus argument and dismissing a very real medical need. I told her that there was something wrong: "I am a man with a uterus. I need to have all female reproductive parts removed. I AM A MAN!" She refused. I left her office feeling like a freak again, vulnerable and depressed.

Tony Ferraiolo/ New Haven, CT

THE PATH TO HEALTH CARE FAIRNESS: RECOMMENDATIONS FOR PROVIDERS, POLICY-MAKERS AND COMMUNITY MEMBERS

The findings in this survey raise serious concerns about the state of health care for the lesbian, gay, bisexual and transgender (LGBT) and HIV communities that must be addressed. Remediating the problems outlined in this report requires systemic change: an integrated combination of enforcement of legal protections that already exist, progressive legislation, thoughtful policy-making and ongoing education and training, all carried out with opportunities for community input.

The Critical Role of Cultural Competency

Increasing cultural competency should be one of the main methods for health care providers to address the discrimination experienced by LGBT people and people living with HIV and to close the gap in access to health care. Cultural competence is the integration and transformation of knowledge about individuals and groups of people into specific standards, policies, practices and attitudes used in appropriate cultural settings to increase the quality of health care, thereby producing better health outcomes.¹ According to the U.S. Department of Health and Human Services' Office of Minority Health, "It's the way patients and doctors can come together and talk about health concerns without cultural differences hindering the conversation, but enhancing it."²

Policies about discrimination, visitation, patients' rights, employment and other matters should clearly communicate that bias and discrimination of LGBT people and people living with HIV will not be tolerated. Policies should also outline a grievance process and provide access to redress if the policies are violated. Health care providers should also recognize and honor the wishes of the families of LGBT people. Even though our survey did not ask about discriminatory behavior and attitudes towards the families of LGBT people (questions were about individual interactions with health care systems and providers), such attitudes contribute significantly to creating an unwelcoming environment for all LGBT people.

1 In Diane L. Adams, ed., *Health Issues for Women of Color: A Cultural Diversity Perspective* (Thousand Oaks, CA: Sage, 1995).

2 U.S. Department of Health and Human Services, Office of Minority Health, "What is Cultural Competency," <http://minorityhealth.hhs.gov/templates/browse.aspx?lvl=2&lvlID=11> (accessed January 10, 2010).

Institutions should also clearly inform patients of their policies and practices and regularly solicit input from the LGBT and HIV communities.

Education is another important component to cultural competency. Institutions should provide initial training as a part of orientation for new staff and require ongoing education for all staff. The optimal provision of health care and prevention services to sexual and gender minorities requires providers to be sensitive to historical stigmatization, to be informed about continued barriers to care and to become aware of the cultural aspects of their interactions with LGBT patients.³

Forms, questionnaires and other written materials should be sensitive to and inclusive of LGBT people and their families and communicate the institution's commitment to providing an environment that meets the needs of all patients including LGBT people and people living with HIV. Where appropriate, institutions should also provide and advertise LGBT and HIV-specific services and specialized care such as support groups or HIV prevention programs.

When fully implemented, cultural competency can reduce the systemic health care discrimination experienced by LGBT people and people living with HIV. The Mautner Project, a national lesbian health organization, has a training curriculum, "Removing the Barriers: Providing Culturally Competent Care to Lesbians and Women Who Partner with Women," that explains the benefits of culturally competent care as including: increased access to

3 K. H. Mayer, J.B. Bradford, H. J. Makadon, R. Stall, H. Goldhammer, and S. Landers, "Sexual and Gender Minority Health: What We Know and What Needs to be Done," *American Journal of Public Health*, 98, no. 6 (2008): 989-995.

services; improved prevention and early intervention; more accurate diagnoses; improved treatment adherence and compliance and increased patient retention.

By focusing on cultural competence for all LGBT people and people with HIV, providers, policy-makers and members of the community can begin taking steps to address substandard and discriminatory care as well as additional barriers that prevent LGBT people and people living with HIV from obtaining quality health care.

Our Recommendations

Health care institutions and providers should:

- **Establish nondiscrimination, fair visitation and other policies that:**
 - f* prohibit bias and discrimination based on sexual orientation, gender identity and expression and HIV status including refusal of care, disrespectful or abusive treatment, the use of excessive precautions and blaming patients for their health conditions;
 - f* convey a commitment to equally serve and provide culturally competent care to LGBT and HIV communities;
 - f* recognize families of LGBT people and their wishes; and
 - f* provide a process for reporting and redressing discrimination if it occurs.
- **Develop and implement goals and plans to ensure that LGBT people and people living with HIV are treated fairly, including strategies to maintain diverse staff, complete an initial assessment of services for LGBT patients, collaborate with LGBT and HIV community partners and implement culturally sensitive grievance procedures.**
- **Require health profession students and health professionals to undergo significant cultural competency training about sexual orientation, gender identity and expression and HIV status so they will**

be able to provide respectful and nondiscriminatory care to LGBT people and people living with HIV.

Cultural competency needs to be implemented at both an institutional and individual level. Unfortunately, many professional schools and continuing education programs do not provide the training needed to teach culturally competent care for LGBT people and those living with HIV.⁴ Ensuring that all medical, nursing, dental and other health profession students are trained in these issues as a mandatory part of the curriculum will increase the likelihood that they will have a basic understanding of the needs of the LGBT and HIV communities. Making cultural competency a key part of ongoing staff training and continuing education programs is equally important for ensuring that the inclusive policies of institutions are carried out consistently and uniformly.

- **Include training about gender identity and expression to ensure that the unique needs of transgender and gender-nonconforming people are addressed.**

In almost every category measured in this survey, proportionately more transgender respondents reported discrimination in care and barriers to care. Providers need to take particular care to address the issues of transgender and gender-nonconforming people.

- **Include training about the specific ways LGBT people and people living with HIV who are also people of color, low-income, seniors or members of other underserved populations may experience discrimination in health care settings and establish policies to prevent discrimination.**

Providers must address the discrimination experienced by low-income people and people of color and ensure that care is delivered in a culturally competent way to people who are part of more than one marginalized community. (For more discussion about the impact of health care discrimination on low-income people and people of color and the intersectionality of multiple

⁴ Ibid., 989-995.

forms of oppression, see Lambda Legal's supplemental health care fairness survey fact sheets.)

- **Advocate for laws and accreditation standards that require all providers to deliver to LGBT people and people living with HIV the same level of high-quality care afforded others.** Laws and standards that mandate LGBT and HIV-inclusive practices are needed so that all providers will offer the same level of care.

Federal, state and local governments should:

- **Include coverage of LGBT people and those living with HIV in all antidiscrimination and equal opportunity mandates including laws related to employment discrimination, access to public accommodations, harassment and freedom of expression.**
- **Require all health care facilities and educational programs that receive government funding to develop and implement goals, policies and plans to ensure that LGBT people and people living with HIV are treated fairly and require that they provide ongoing cultural competence training for all health care profession students and staff.**
- **Change laws to require recognition of the families of LGBT people, including those who live within less common family structures, and require health care providers to do the same.**
- **Eliminate overly broad religious exemptions that purport to exempt medical care from nondiscrimination laws.**

Although questions about religion were not part of the survey, we know that, in an increasingly worrisome trend, some health care providers have claimed that their religious beliefs or affiliations allow them to deny providing the same care to LGBT individuals that they routinely offer to others. Providers should not be allowed to use their religious views or affiliations to circumvent antidiscrimination laws, medical ethics rules and professional standards of care.

- **Prohibit discriminatory practices by insurance providers that deny or limit coverage for needed care by LGBT people and people living with HIV, such as basic and/or gender transition care for transgender individuals or reproductive health care for LGBT people.**
- **Ensure that government-funded health research and surveys include sexual orientation and gender identity issues and demographic analysis so that more can be known about the health care discrimination experienced by our communities as well as about our communities' health care needs.**

Individuals and organizations should:

- **Educate themselves and each other about LGBT rights, and when possible, educate health care providers about the needs of LGBT patients and those living with HIV.**
- **Advocate for improved laws and policies.**
- **Report unfriendly and discriminatory practices and share referrals to friendly providers and institutions.**
- **Share stories of health care discrimination with organizations like Lambda Legal, as well as with policy-makers, friends, relatives and trusted co-workers.**
- **Create as much protection as possible for themselves and their loved ones using appropriate, existing mechanisms such as advance directives, medical powers of attorney and other legal documents as well as formal legal relationships such as domestic partnerships, civil unions and marriage, where that is a couple's choice.**
- **Fight back when discrimination occurs and contact Lambda Legal, other legal and advocacy organizations or a local attorney.**
- **Continue to fight attempts to roll back LGBT rights.**

METHODOLOGY: HOW WE CONDUCTED THE SURVEY

In the spring and summer of 2009, Lambda Legal invited lesbian, gay, bisexual and transgender (LGBT), HIV and other partner organizations to join the national Health Care Fairness Campaign, asking them to promote the health care fairness survey and encouraging their participation in other aspects of this initiative. With the help of over 100 such organizations located in 35 states, the survey was distributed to LGBT people and people living with HIV nationwide. Participants included 25 national organizations and 75 local, state and regional organizations. Thirteen groups were specifically people of color organizations and 12 specifically focused on people living with HIV. Groups promoted the survey in various ways, including email requests to members and supporters; posting survey links on their websites and their social networking sites and distributing and collecting paper surveys where feasible.

Lambda Legal sent survey announcements and reminders to our email list, featured the survey on our web page and publicized the survey in Lambda Legal's *Impact* magazine and monthly eNews. Ads were placed on various LGBT

blogs, web sites and in a few LGBT newspapers, and the survey was promoted on Facebook and Twitter. Wallet cards announcing the survey were distributed at 15 Pride festivals and several other LGBT events around the country. In a few cities, Lambda Legal staff and/or interns collected surveys at locations in the LGBT community. All survey promotional and informational materials were available in both English and Spanish, as was the survey itself. The survey was not based on a random sample, but used "convenience sampling" and "snowball sampling," which means that responses came from those who chose to take the survey and many learned about it through e-mails and blog posts.

A total of 5,941 people took the survey from June 10 to July 14, 2009. The information in this report is gleaned from the 4,916 surveys that remained after invalid surveys (postal codes outside the U.S., missing key demographic info, not LGBT or living with HIV) were excluded from the sample.

WHO RESPONDED

The tables below provide demographic information about the 4,916 individuals whose responses are reflected in this report. Because of the complexity of our communities, checking more than one category was an option for several of the demographic questions, so that some results add up to more than 100 percent.

Sexual Orientation

Slightly over half the respondents, or 2,727 people, identified as gay, with just fewer than 30 percent, or 1,453 people identifying as lesbian. The categories of queer (nearly 16 percent or 774 people) and same-gender loving (just over 5 percent or 261 people) include both women and men, as does the bisexual category (just over 11 percent or 542 people). A very small number of responses came from heterosexuals (just over 1 percent or 66 people), who are either living with HIV or transgender.

Gender Identity

Table 8 shows that almost 56 percent of all respondents identified as male and almost 38 percent of all respondents identified as female. These numbers include transgender and nontransgender respondents. Almost 53 percent (2,593 people) identified as non-transgender male and nearly 33 percent (1,614) as non-transgender female; 8 percent (397) as transgender (either transfeminine or transmasculine); just over 4 percent (220) as gender-nonconforming; and almost 2 percent (83) as two-spirit.

“Transgender” is an umbrella term that refers to people whose gender identity and/or gender expression differs from the sex they were assigned at birth. In general use, the term may include but is not limited to transsexuals, cross-dressers and other gender-variant people. In the related chart (Table 8), transgender respondents are listed as either “transmasculine” (individuals who were assigned the sex “female” at birth, but whose gender identity is along the masculine spectrum of gender) or “transfeminine” (individuals who were assigned the sex “male” at birth, but whose gender identity is along the feminine spectrum of gender). “Gender-nonconforming” (GNC) refers to individuals whose external manifestation of their gender identity does not conform to society’s expectations of gender roles. A gender-nonconforming person may or may not identify as transgender, gay, lesbian or bisexual but may

identify as gender-free, androgynous or moving back and forth between gender identities. The term “two-spirit” is a culturally specific category related to traditions among Native Americans/American Indians.

Race and Ethnicity

Eighty-six percent of all respondents or 4,241 people identified as White and slightly over 18 percent or 892 people identified as people of color – meaning that they selected a racial/ethnic category other than or in addition to White. These numbers add up to more than 100 percent because some of the multiracial people selected white and another race or ethnicity.

Table 9 displays the racial and ethnic distribution of the people of color who completed the survey. Of the total survey respondents, almost 8 percent or 373 people were Latina/o; close to 5 percent or 231 people were Black; almost 4 percent or 176 people were American Indian; 3 percent or 153 people were Asian; and 1 percent or 48 people were Middle Eastern. Again, the numbers add up to more than 100 percent because respondents could choose more than one category. Almost 6 percent of all survey respondents, or 285 people, identified as multiracial. While Asians and American Indians who responded to the survey were proportionately represented compared to the overall population in the United States, Blacks, Latina/os and Middle Eastern respondents were underrepresented compared to their representation in the U.S. population as a whole. This underrepresentation indicates an ongoing need for more consistent and better-targeted outreach to communities of color.

Table 7: Sexual orientation

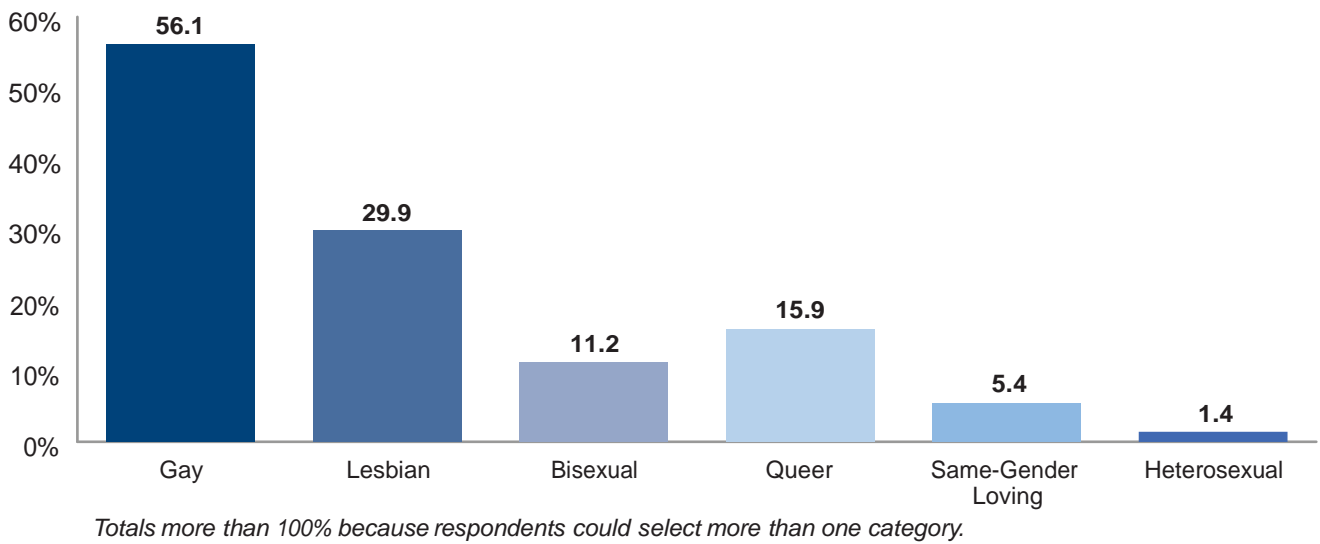


Table 8: Current gender identity

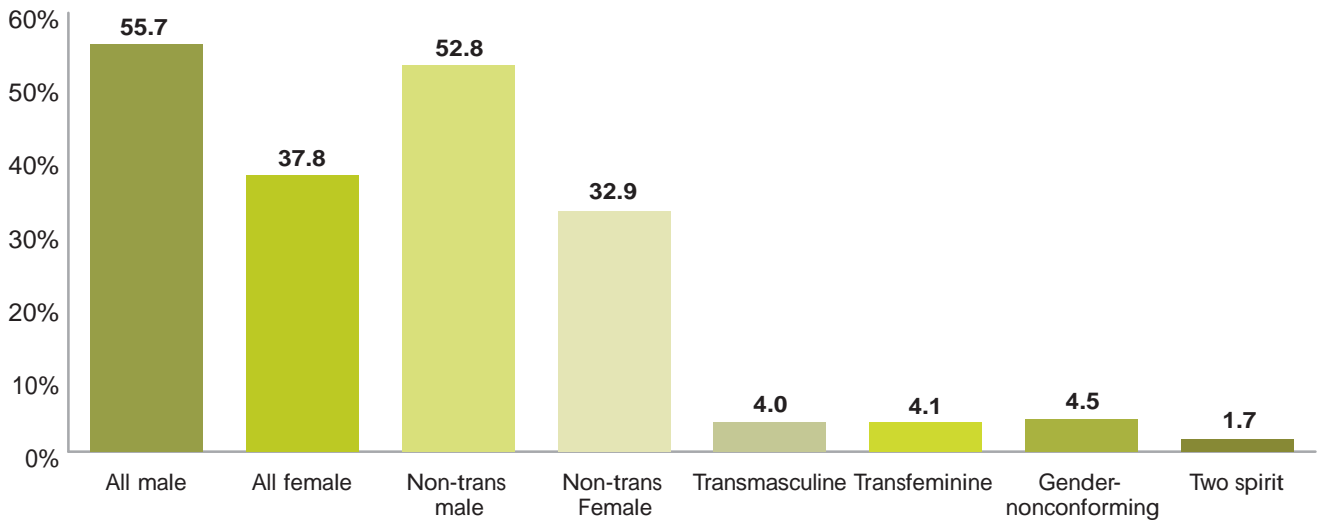
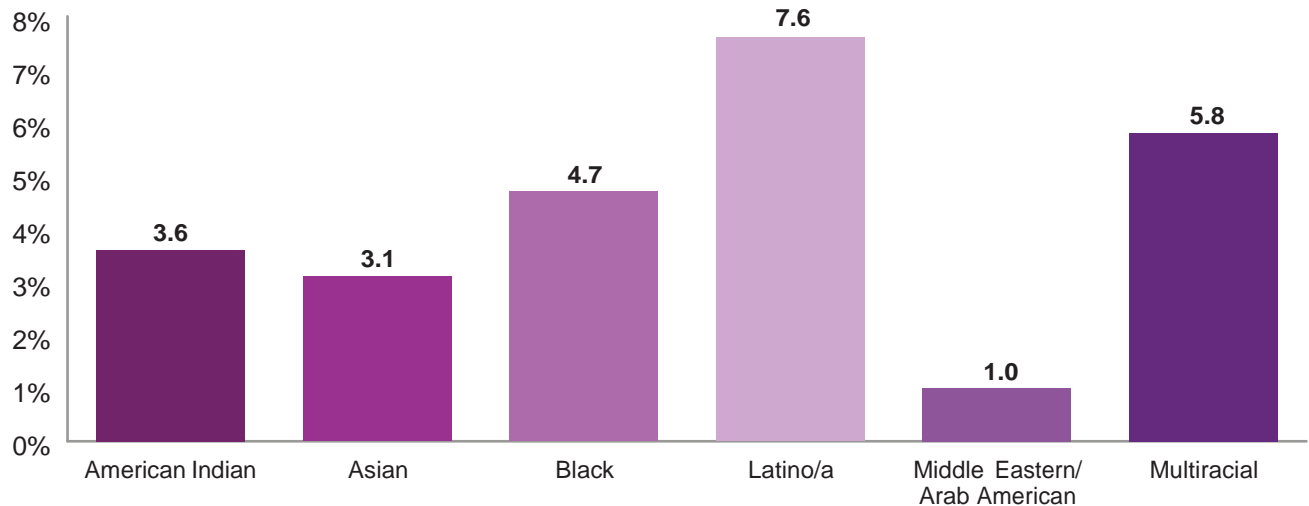


Table 9: Race and ethnicity of people of color respondents



Other Demographics

All age groups are represented in the survey with responses somewhat skewed towards the 25-44 age group.

The survey generally achieved geographic distribution, with respondents from all fifty states and Washington, DC, although California provided a disproportionate number of respondents (nearly 21 percent or 985 people).

Individuals living with HIV were over 13 percent of the sample, or 662 people.

An important fact to note is that survey respondents were somewhat more privileged than the LGBT population as a whole, with higher proportions having obtained college, graduate and professional degrees; reporting higher household incomes and having better health insurance coverage. According to a groundbreaking study by the Williams Institute of the University of California School of Law, the stereotype of LGBT people as an affluent elite with high levels of education and income is debunked by more than a decade of research showing that LGBT people actually have lower incomes than comparable heterosexual individuals and households

and that existing research strongly hints at a sizable presence of LGBT people among the low end of the income distribution in the United States.⁵ A recent study conducted by the National Center for Transgender Equality and the National Gay and Lesbian Task Force also found that transgender respondents experience poverty at a much higher rate than the general population, with more than 15 percent reporting incomes of \$10,000 or lower, double the rate of the general population.⁶

Since people who are affluent, educated and insured are more likely to be well-served by health care systems, this report likely *understates* the barriers to health care experienced by LGBT people and those with living with HIV.

⁵ R. Albeda, M. V. L. Badgett, A. Schneebaum, and G. J. Gates, "Poverty in the Lesbian, Gay, Bisexual and Transgender Community," <http://www.law.ucla.edu/WilliamsInstitute/pdf/LGBPovertyReport.pdf> (accessed November 23, 2009).

⁶ National Center for Transgender Equality and National Gay and Lesbian Task Force, "National Transgender Discrimination Survey," http://www.thetaskforce.org/downloads/release_materials/tf_enda_fact_sheet.pdf (accessed December 28, 2009).

Table 10: Age

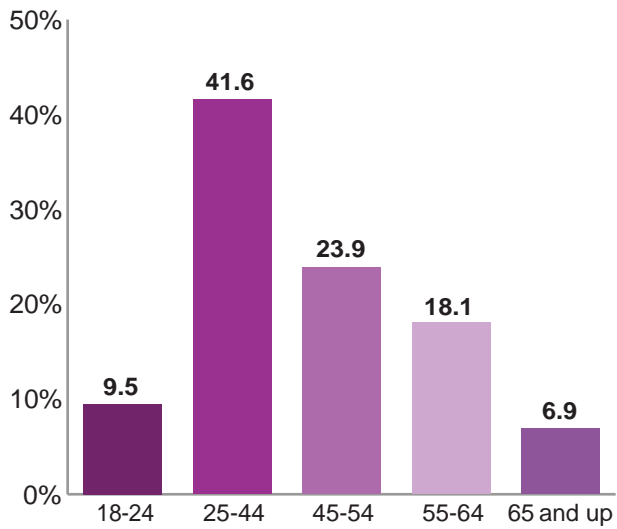


Table 11: HIV status

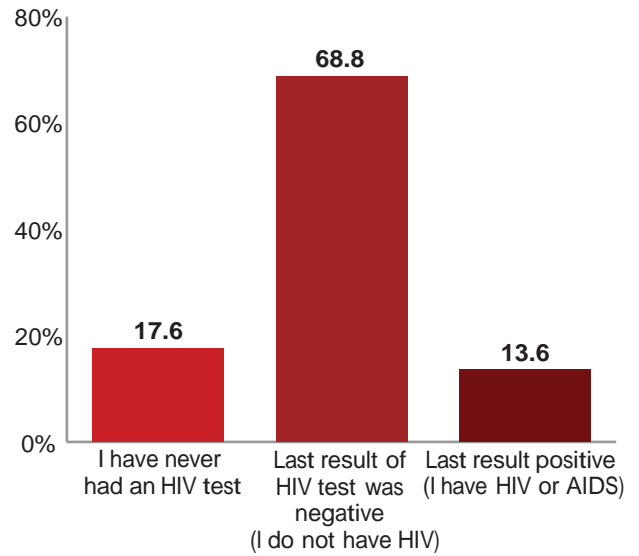


Table 12: Employment status

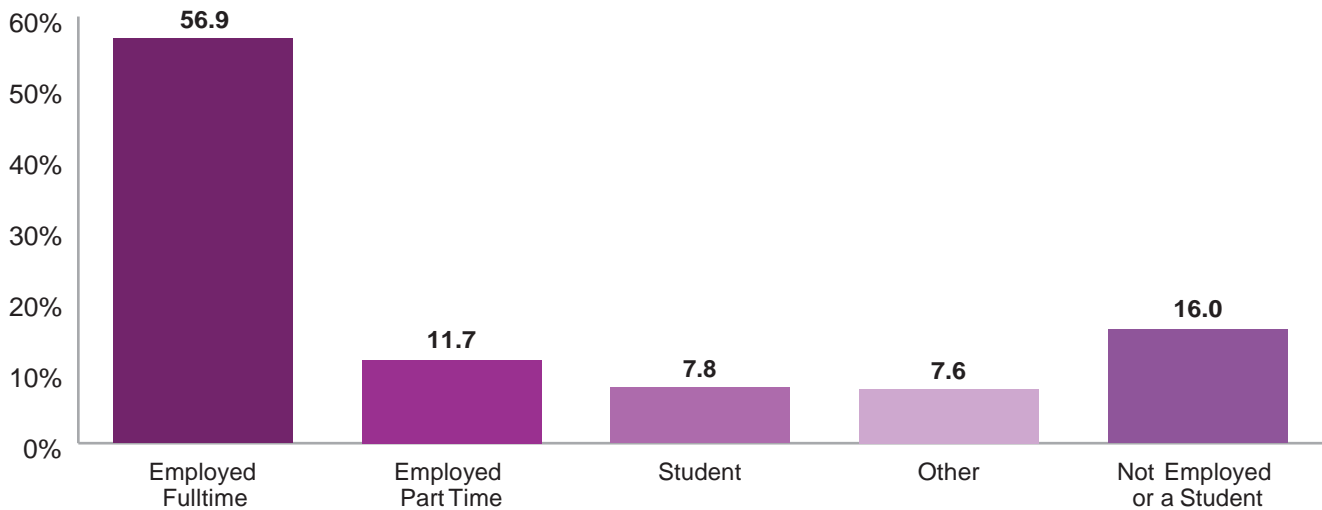


Table 13: Household income

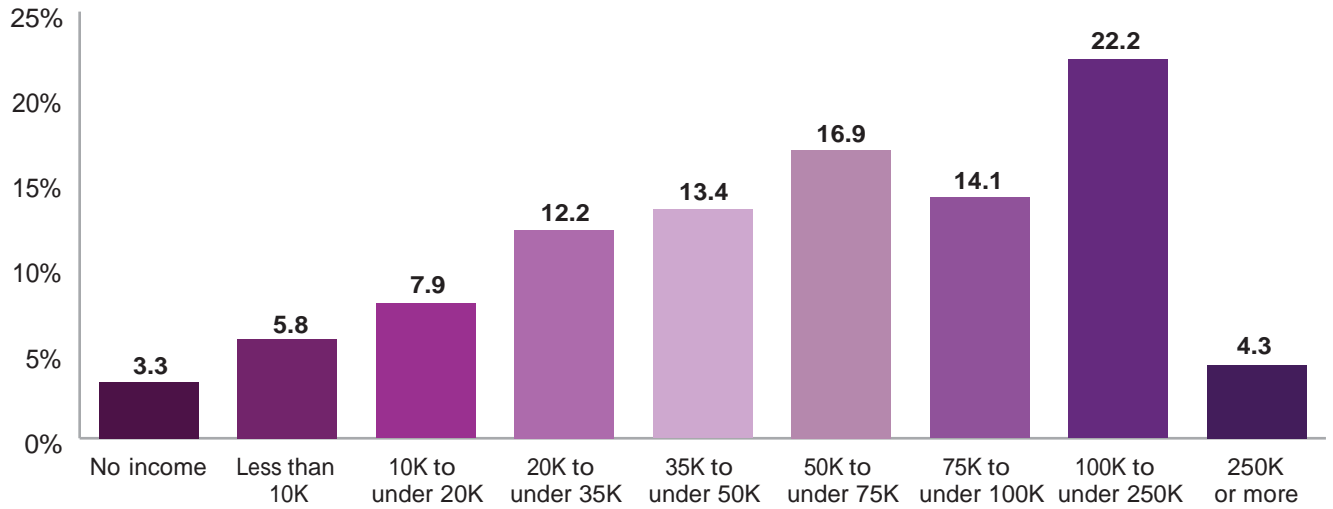
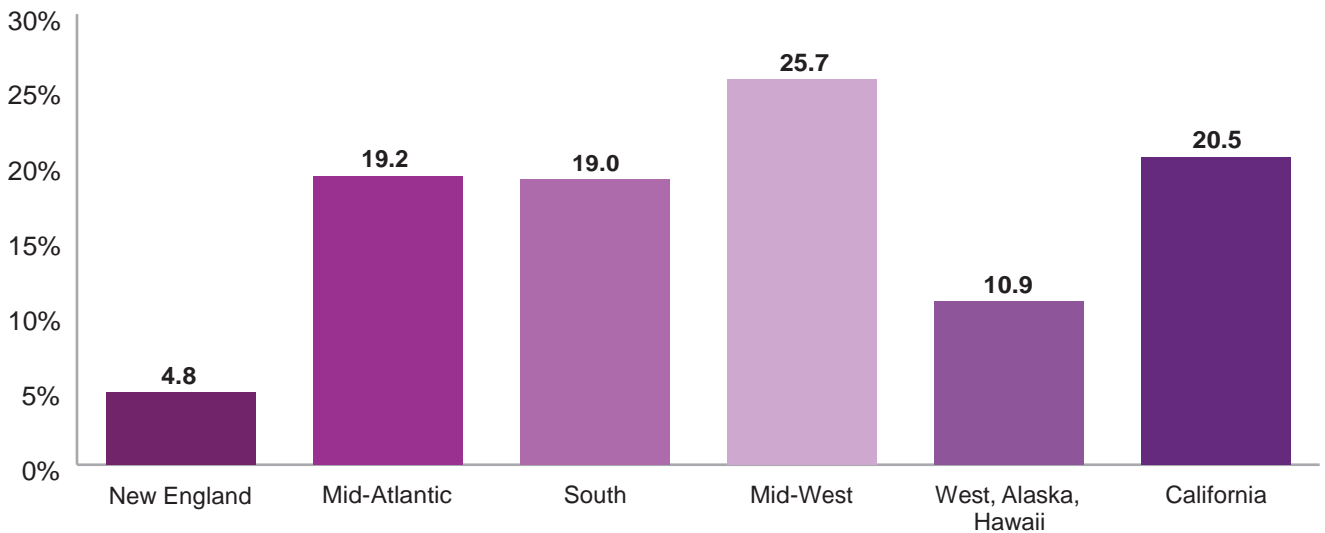


Table 14: Geographic distribution of responses



GLOSSARY: EXPLANATION OF SURVEY TERMS

This section was created to enhance understanding of the terms in this report. However, it's important to remember that people defy labels. Identity is fluid and self-defined. Not everyone will fit into a definition, label or box, no matter how large we make it.

Advance directive, also known as a living will, is a legal document that gives instructions specifying what medical actions should be taken in the event that a person is no longer able to make decisions due to illness or incapacity.

AIDS or Acquired Immune Deficiency Syndrome is generally used to refer to the most advanced stages of HIV progression in which the human immune system becomes compromised, leaving the body susceptible to opportunistic infections it could otherwise defeat. There is some debate among medical professionals as to what actually constitutes a progression to AIDS and whether the term should continue to be used at all.

Bisexual people are attracted to and/or sexually active with people regardless of gender.

Convenience sampling is a technique for developing a research sample which involves drawing from that part of the population which is close to hand, readily available or convenient. This technique is different from random sampling.

Cultural competence is the integration and transformation of knowledge about individuals and groups of people into specific standards, policies, practices and attitudes used in appropriate cultural settings – in the context of this study, to increase the quality of health care, thereby producing better health outcomes.

Gay people are people who are romantically and/or sexually attracted to and/or sexually active with people of the same gender. “Gay” can refer either to women or men, but for the purposes of this report refers to men unless otherwise specified.

Gender expression refers to the way a person expresses gender through dress, grooming habits, choice of name and pronoun, mannerisms, activities, etc.

Gender identity is an individual's emotional and psychological sense of being male or female. Gender identity is not necessarily the same as an

individual's biological identity. In this survey, when the terms “male” and “female” are used alone, they refer to people who do not have transgender and gender-nonconforming identities, while transgender and gender-nonconforming people are identified by their current gender and the terms “transgender” and/or “gender non-conforming.”

Gender-nonconforming (GNC) refers to individuals whose external manifestation of their gender identity does not conform to society's expectations of gender roles. A gender-nonconforming person may or may not identify as transgender, gay, lesbian or bisexual.

HIV or human immunodeficiency virus (HIV) is a retrovirus that targets the human immune system. Progression of HIV infection can lead to a serious compromise of immune system function, leaving the body open to opportunistic infections against which it could normally defend.

HIV positive people are living with HIV, although they might not have AIDS.

Homophobia refers to hatred, fear of or discrimination against lesbian, gay or bisexual people based on their sexual orientation.

Lesbians are people who are romantically and/or sexually attracted to and/or sexually active with people of the same gender. “Lesbian” refers exclusively to women while “gay” can refer either to women or men.

LGBT stands for lesbian, gay, bisexual or transgender.

Low-income is defined for the purposes of this report as having an annual household income of less than \$20,000.

Medical power of attorney is a legal document that gives someone the legal authority to act on an individual's behalf regarding health care decisions if they ever become incapacitated or unable to communicate.

People living with HIV includes all people who are infected with HIV, including people who have been diagnosed with AIDS and those who are HIV positive.

Queer is an identity used by people who reject conventional categories such as “LGBT” or embrace a political identity as ‘queer’ in addition to being LGB and/or T. It also may include heterosexuals who embrace a non-normative or counter-normative sexual identity.

Same-gender loving is a term most often used in communities of color to describe people with same-sex attractions since gay, homosexual, bisexual or lesbian can carry negative connotations to some people.

Sexual orientation generally refers to people’s sexual behavior or attraction.

Snowball sampling is a technique for developing a research sample where existing study subjects recruit future subjects from among their acquaintances. Thus the sample group appears to grow like a rolling snowball. As the sample builds up, enough data is gathered to be useful for research. This sampling technique is often used in hidden populations which are difficult for researchers to access.

Transsexual is an older term which originated in the medical and psychological communities. Many transgender people prefer the term “transgender” to “transsexual.” Some transsexual people still prefer to use the term to describe themselves. However, unlike transgender, transsexual is not an umbrella term, and many transgender people do not identify as transsexual.

Transfeminine is a broad term used to describe individuals who were assigned the sex “male” at birth, but whose gender identity is along the feminine spectrum of gender. This can encompass those who have medically transitioned and those who have not, and may include (but is not limited to) those who identify as transwomen, MTF (male-

to-female), transgender female, transexual female, genderqueer, etc.

Transgender is a word commonly used to describe people who live in a gender different from the one assigned to them at birth. People often use this word to describe not only people who have changed their gender through surgery or cross-gender hormone treatment, but also people who have non-medical gender transitions or identify as transgender but do not seek to change their gender legally or medically. For the purposes of this report, “transgender” categories include people who self-identified as transgender and those who indicated a current gender identity that is different from what they stated was the sex on their birth certificate.

Transmasculine is a broad term used to describe individuals who were assigned the sex “female” at birth, but whose gender identity is along the masculine spectrum of gender. This can encompass those who have medically transitioned and those who have not, and may include (but is not limited to) those who identify as transmen, FTM (female-to-male), transgender male, transexual male, genderqueer, etc.

Transphobia refers to hatred, fear of or discrimination against transgender people based on their gender identity or expression.

Two-spirit is a culturally-specific gender-nonconforming identity within the culture and heritage of American Indian/Native American.

OUR PARTNERS

We'd like to thank the following groups that have joined as partners in Lambda Legal's national Health Care Fairness Campaign for helping to promote the health care fairness survey and disseminate and utilize these findings. We would not have been able to collect responses from such a large and diverse group of people without their help and support. It should be noted that our partners did not participate in the writing of this report nor the development of the policy recommendations.

9 to 5 California	Circle of Voices
9 to 5 National Association of Working Women	COLAGE
Adolescent AIDS Program	Community HIV/AIDS Mobilization Project (CHAMP)
Aeromestiza	Crossdressers International
Affirmations	Dr. Maxwell Anderson & Associates
AIDS Legal Referral Panel	Emotional Healing and Empowerment Center
AIDS Project El Paso	Entre Hermanos
Al Gamea	Equality North Carolina
Allgo	Equality Texas
Alliance for Full Acceptance	Family Equality Council
American Friends Service Committee	Feminist Health Center
Asian Pacific Islander Coalition on HIV/AIDS (APICHA)	Gay & Lesbian Center of South Nevada
Atlanta Lesbian Health Initiative	Gay and Lesbian Medical Association
Basic Rights Oregon	Gay, Lesbian and Straight Education Network
BCC (Beth Chayir Chadoshim)	Gender Just
Best Koeppel APLC	Gender Rights Advocacy Association of New Jersey
BGLAD @ SCU Law	Georgia Equality
Bienestar	Giovanni's Room
Boston Alliance of LGBT Youth, Inc. (BAGLY)	Glory To God Christian Church
Bronx Pride	Human Rights Campaign
Brothas & Sistas, Inc.	Identity, Inc
CAEAR Foundation	Indiana Equality
Cascade AIDS Project	International Federation for Gender Education
Center for Medicare Advocacy, Inc.	International Gay & Lesbian Human Rights Commission
Centerlink	Kentucky Fairness Alliance

Knoxville/Knox County, Department of Air Quality
Management

Latino Commission on AIDS

Legal Voice

LGBT Center New Orleans

LGBT Community Center of Greater Cleveland

LGBT Center, UCSF

Life Healing Center

Lighthouse Community Center

Love Makes a Family

Lotus Monk

Mautner Project

Metropolitan Community Church of Louisville

Missoula AIDS Council

Mocha Center

More Light Presbyterians

National Coalition for LGBT Health

National Gay & Lesbian Task Force

National Senior Citizens Law Center

National Youth Advocacy Coalition

Nevada Association of Latin Americans (NALA)

NIA Collective

New York Association for Gender Rights Advocacy

Northern Colorado AIDS Project

One Iowa

Our House

OUTLaw

Palm Beach County Human Rights Council

PFLAG National

PFLAG Bozeman

PFLAG Omaha

PFLAG Tulsa

Planned Parenthood of Southern
Finger Lakes

Pride Collective & Community Center

Pro Latino

PROMO

Public Health - Seattle & King County

Rainbow Access Initiative

Rainbow Center

Rainbow Community Center

Raising Women's Voices for the Health Care We Need

Tennessee Transgender Political Coalition

The Butch/Femme Society

The MergerWatch Project

The Sperm Bank of California

The Wall - Las Memorias

Tomboy Magazine

Topeka AIDS Project

Transgender Individuals Living Their Truth (TILTT)

Transgender Legal Defense Fund

Triangle Foundation

Tri-City Health Center

Two Spirit Society of Denver

UCC Coalition for LGBT Concerns

Utah Pride Center

Ventura County Rainbow Alliance (VCRA)

Whitman-Walker Clinic

Wilson Resource Center

Workmen's Circle, So California Arberter Ring Education
Center

Zuna Institute

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Lambda Legal is a national organization committed to achieving full recognition of the civil rights of lesbians, gay men, bisexuals, transgender people and those with HIV through impact litigation, education and public policy work.

If you feel you have been discriminated against, please call Lambda Legal's Help Desk at (866) 542-8336 or visit www.lambdalegal.org/help/online-form

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