

When Health Care Isn't Caring: People Living with HIV

Results from Lambda Legal's Health Care Fairness Survey

Key Findings

In 2009, Lambda Legal conducted a survey with the help of over 100 partner organizations as part of a national Health Care Fairness Campaign. **This survey is the first to examine refusal of care and barriers to health care among lesbian, gay, bisexual and transgender (LGBT) and HIV communities on a national scale.** The information in this report is gleaned from 4,916 completed surveys. Almost 14 percent of the total survey respondents (669 people) indicated that they are living with HIV.

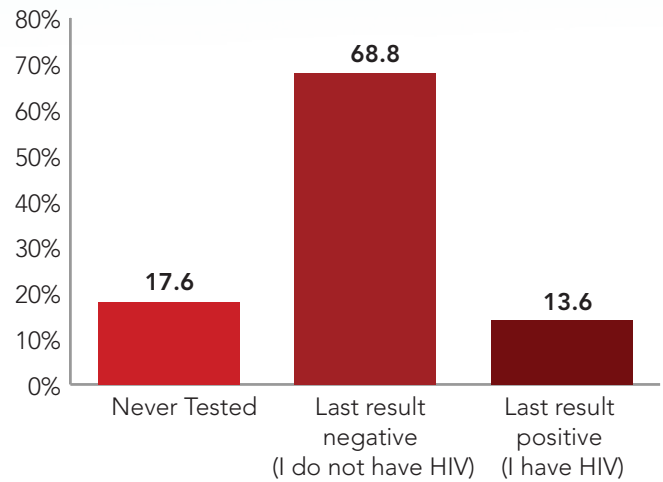
The respondents living with HIV reported that they have experienced various types of **discrimination and substandard care**, including:

- being refused needed medical care (19 percent);
- being blamed for their own health status (over 25 percent);
- health care professionals who refused to touch them or took excessive precautions such as wearing extra pairs of gloves when examining them (nearly 36 percent); and
- being treated in a physically rough or abusive manner by providers (over 4 percent);

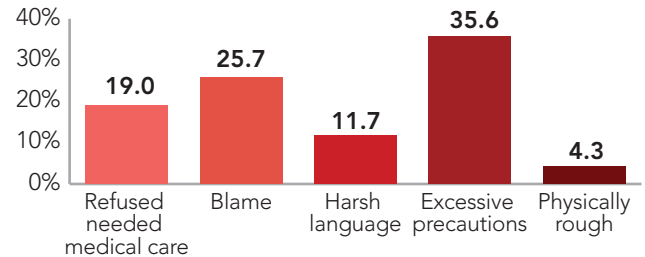
Respondents living with HIV also reported concerns about their ability to obtain needed health care. These concerns are **barriers to care** and can lead to a reluctance to seek care, and, as a result, poorer health outcomes.

- Two-thirds of respondents reported that community fear or dislike of people living with HIV had been a problem or major problem for them in accessing health care.
- Nearly half believe that there are not enough medical personnel who are properly trained to care for them.

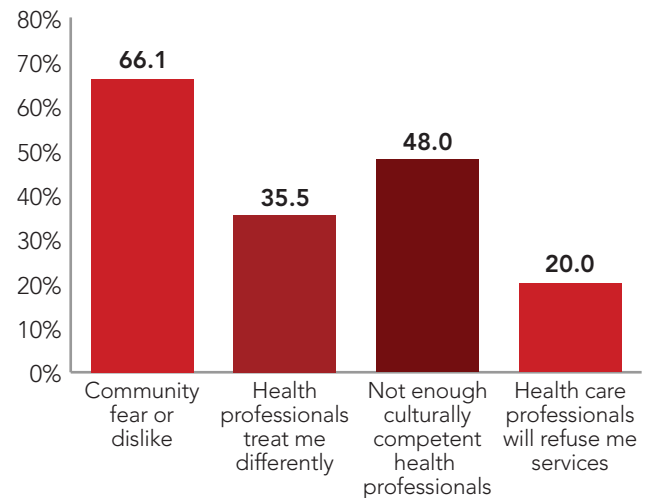
HIV Testing Status



Types of Discrimination and Substandard Care Experienced by People Living with HIV



Fears and Concerns about Accessing Health Care



Key Recommendations

Health care institutions and providers should:

- Educate all staff about HIV transmission and treatment, to reduce stigma and misinformation.
- Educate all staff about the importance of enhanced sensitivity to confidentiality when dealing with patients living with HIV, and about the rights of people living with HIV to be free from discrimination.
- Ensure that the confidentiality wishes of patients with HIV are respected.
- Provide culturally competent care for people living with HIV.
- Advocate for improved laws and accreditation standards to enhance the level of care provided.
- Require health profession students and health professionals to undergo HIV cultural competency training.

Governments should:

- Include coverage of people with living with HIV in all anti-discrimination and equal opportunity mandates.
- Require all health care providers to treat people living with HIV fairly and provide culturally competent care.
- Prohibit discriminatory practices by insurance providers that deny or limit coverage for needed care by people living with HIV.

Individuals and organizations should:

- Educate themselves and each other about the legal rights of people living with HIV, and when possible, educate health care providers about the needs and rights of patients living with HIV.
- Advocate for improved laws and policies.
- Report unfriendly and discriminatory practices, share stories of health care discrimination, and pass on referrals to friendly providers and institutions.

Demographics

Ninety three percent of all people living with HIV who took this survey were non-transgender men; 2 percent were non-transgender women; 2 percent were transgender women; and the remainder were transgender men, gender-nonconforming or two-spirit. Ninety percent of those who were living with HIV identified as gay, nearly 8 percent as queer, 6 percent as same-gender loving and the remainder as bisexual, lesbian, heterosexual or another identity.

Nearly 80 percent of respondents living with HIV identified as White, while about 20 percent identified as a person of color. Just over 9 percent were born outside the US.

Most respondents who were living with HIV were in their middle years, with 35 percent aged 25 to 44, 37 percent aged 45 to 54 and almost 23 percent aged 55 to 64. Forty-four percent were single – not partnered or dating.

While these respondents represent a diverse sampling of the larger community of people living with HIV, survey respondents were somewhat more privileged than the LGBT population as a whole (in terms of income level, educational level, and access to health insurance).

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

From *When Health Care Isn't Caring: Lambda Legal's Survey of Discrimination Against LGBT People and People with HIV* (New York: Lambda Legal, 2010). Available at www.lambdalegal.org/health-care-report.

For the complete survey report, visit www.lambdalegal.org/health-care-report

If you feel you have been discriminated against, contact Lambda Legal's Help Desk at 866-542-8336 or send an email via our web form at www.lambdalegal.org/help/online-form