

Trans Populations and HIV: Time to End the Neglect

Of all populations affected by HIV worldwide, evidence suggests that trans populations may be the most heavily burdened. Due to stigma, neglect, and institutionalized discrimination, the HIV response has largely failed to address the needs of trans people. Achieving an AIDS-free generation will demand more effective, sustained, rights-based programs for this at-risk population.

Gender Identity: Evolving Terminology

Increasingly, ‘trans*’ is being used typographically as an umbrella term to refer to the diverse communities and individuals living or identifying beyond strict gender binaries. The addition of the asterisk is intended to expand the boundaries of the commonly used *transgender* characterization to be fully inclusive of nontraditional cisgender individuals—those who identify with the gender they are assigned at birth.¹ Examples of identities included under the trans* neologism are hijra (a South Asian cultural category in the trans feminine spectrum), two-spirit (an umbrella term for North American native gender identities), cross-dressers (a Western term mostly used for male-assigned people who occasionally wear clothing typically associated with women), drag performers, travesti (a Latin American term for people in the trans feminine spectrum, usually from low-income backgrounds), and transgender (a Western term mostly used for people who live, or desire to live, permanently in a gender other than the one assigned to them at birth). There are many more terms used by various communities, including some that carry different meanings in different locations.

Trans Populations

Trans people have a gender identity or expression that differs from their assigned sex at birth. Trans individuals may be male or female, or identify as a different gender or no gender at all. Gender identity is distinct from sexual orientation, as trans people may identify as gay/lesbian, heterosexual, bisexual, or none of these. Trans populations may include a wide variety of identities, some of which may have specific local connotations that are not easily translatable to other cultural or religious settings.

Trans people may express their gender identity through various means, including wearing clothing and adopting mannerisms and speech usually associated with the gender with which they identify, and/or using hormones or surgery to modify their bodies. Due to the costliness of many medical procedures desired by some trans people, as well as the common failure of public and private payers to cover such procedures, many trans people cannot obtain or afford medical interventions by licensed practitioners. As a result, many self-medicate with black market hormones or amateur silicone injections, sometimes with deadly outcomes.²

Studies indicate that all societies include trans people.³ General population research indicates that 0.8–1.1% of the population of the Netherlands⁴ and 0.5% of residents in Massachusetts (U.S.)⁵ identify as transgender.

Due to the stigma associated with trans identities or expressions, trans people are often socially marginalized.⁶ Many trans people drop out of school, limiting their economic prospects.² Trans people frequently experience discriminatory treatment with respect to housing, employment, and access to public services, and many are shunned by their families. As a result of these barriers, many trans people live in poverty.³

HIV and Trans Populations

A systematic review of available evidence from 2000 to 2011 found that 19.1% of trans women (male-to-female, or MtF) worldwide are estimated to be living with HIV, with median HIV prevalence somewhat higher in the U.S. (21.6%) than in low- and middle-income countries (17.7%).⁷ The rate of HIV infection among trans people is higher than other most-at-risk groups, such as men who have sex with men, people who inject drugs, and sex workers, yet most tracking systems do not record data on trans people systematically.⁸ Globally, limited available evidence suggests that trans women are 49 times more likely to be living with HIV than the general population.⁷

Although definitive evidence is not available worldwide, one study in the U.S. found that HIV prevalence was much lower among trans men (female-to-male) compared to trans women, though it was still higher than that of the general population.⁹ Emerging, still unpublished evidence suggests that trans men often engage in high levels of sexual risk behavior. In general, understanding of HIV-related risk behaviors among trans men is limited by a lack of existing research; a recent CDC analysis of 29 studies involving trans people found only five collected data on trans men specifically.¹⁰

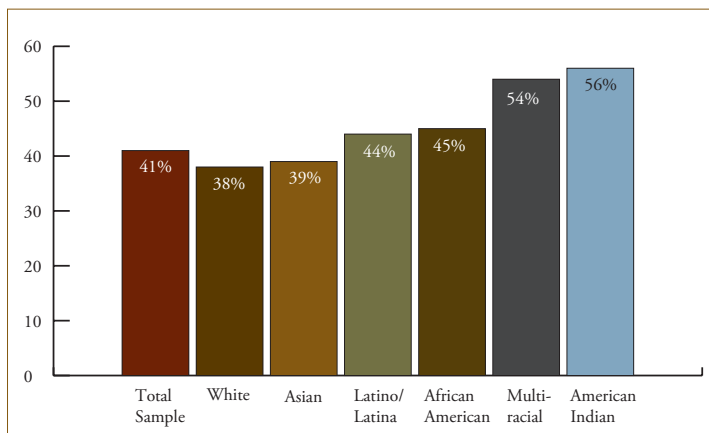
Within trans populations, certain groups appear to be at especially high risk for acquiring HIV. In the U.S., for example, HIV prevalence is more than three times higher among black MtF trans people than among white or Latina MtF trans people.⁹ Many trans individuals become infected with HIV while they are young.¹¹ Trans men who have sex with men, engage in sex work, or inject drugs may also be at higher risk.

Numerous factors increase the risk of HIV acquisition for trans people:

Low Self-Esteem and Body Issues

Many trans individuals harbor low self-esteem (commonly exacerbated by discrimination, violence, and rejection), often with concurrent body image issues. Both lower the priority many trans people place on protecting their bodies and physical health from harm, and some may even engage in self-destructive behavior as a result. High rates of suicide, attempted suicide, or suicidal ideation are an expression of this problem. One study in the U.S. found that 41% of trans respondents had attempted suicide.¹²

Figure 1. Trans Suicide Attempts Broken Down by Race in the U.S.



Source: Grant J, et al; NCTE, National Gay and Lesbian Task Force. National transgender discrimination survey report on health and healthcare.

Sexual Risk Behaviors

Surveys indicate that many trans people frequently engage in sexual risk behaviors with cisgender men, especially unprotected receptive anal and/or vaginal intercourse.^{2,9} Much of the disproportionate HIV burden among trans people who have sex with men may be explained by the frequency of unprotected receptive anal or vaginal intercourse, which has a much higher per-act probability of transmission than other forms of sexual intercourse.¹³

HIV Acquisition During Injecting Drug Use

Especially in cases where trans individuals rely on the black market for the purchase of hormones, sharing injecting equipment may result in HIV transmission. Amateur injections of silicone or other materials for body contouring may pose similar issues, along with other potentially deadly threats to the individual's health. In addition, various studies have detected high rates of drug and alcohol use, including injecting drug use, among trans populations.^{3,14}

Sex Work

It is not uncommon for trans individuals in some settings to engage in sex work to earn money—in many cases due to the lack of other employment opportunities.³ A survey of trans women in Latin America found that 95% of respondents were engaged in sex work.¹⁵ Sex work, which by definition involves sex with multiple partners, increases the risk of HIV acquisition. A recent multi-country analysis determined that 1) HIV prevalence was nearly twice as high among MtF trans sex workers than in trans women

not engaging in sex work; and 2) trans women engaging in sex work were six times more likely to be living with HIV than non-trans female sex workers.¹⁶ No data is available for trans men engaged in sex work, who may be at specific risk and may not be reached through outreach geared towards ciswomen sex workers.

Sexually Transmitted Diseases

Untreated STDs significantly increase the risk of both HIV acquisition and transmission.¹⁷ In the U.S., trans people have STD rates four times higher than the general population.¹⁰ Due to the lack of trans-affirming health services and often transphobic attitudes among healthcare providers, many trans people avoid seeking sexual health services until they have a symptomatic STD.²

Violence

In 2008–2011, at least 831 trans people were murdered worldwide, with the number of reported homicides increasing each year.¹⁸ This growing and troubling trend continued in 2013, with a reported 238 trans people being murdered globally.¹⁹ In a survey of trans women in Latin America, 80% reported having experienced violence or threats of violence at the hands of government employees, with most acts of violence occurring in the context of sex work.¹⁵ Emerging evidence strongly links experience of gender-based violence with HIV infection.²⁰

Perpetrators of violence against trans people are rarely brought to justice. According to activists, 60 trans women in Colombia were murdered between 2005 and 2012, and no one has been convicted of any of these crimes.¹⁵

Impediments to an Effective HIV Response for Trans People

Lack of Attention to the Trans Population's HIV-Related Needs

In the HIV-related policy discourse, trans people have often been treated as a subset of men who have sex with men. Not only is this approach fundamentally at odds with the gender identity of trans women and typically fails to take account of the needs and experiences of trans men who have sex with men, but this tendency has served to limit attention to the unique HIV-related needs of trans people.^{2,21}

Programs in countries where specific HIV services are available for trans people are highly dependent on international donors. In 2012, only 43% of countries addressed trans people in their national strategic HIV plans.⁸ There are, however, encouraging signs in some settings that policy makers are beginning to recognize the need to focus attention on HIV among trans individuals. In South Africa, for example, the national strategic HIV plan now acknowledges the trans population as an HIV risk group.²¹

Inadequate Access to Quality Healthcare

Many trans people have multiple healthcare needs.²² According to the “Standards of Care” developed by the World Professional Association for Transgender Health, some trans patients require services specific to their gender identity and individual needs, including access to hormones, surgical transition, and voice and communication therapy. In addition to the comprehensive array of services required by all other patients, trans individuals are frequently in need of mental health and substance abuse services.²³

Surveys indicate that trans people frequently have unsatisfactory experiences with mainstream health services.^{2,21} Problems faced by trans patients include providers and administrative staff using improper pronouns to address them,²¹ lack of preparedness to address their unique health needs,²⁴ and/or denial of health services entirely.^{21,24} As a result, many trans people either forgo health services altogether—sometimes even in life-threatening situations—or must travel considerable distances to obtain care from a knowledgeable and qualified provider.²⁴

Difficulties in obtaining official identification that reflects an individual's gender identity often impede access to health and social services and can make it challenging to vote, cross a national border, or even obtain a mobile phone. Registration with national authorities often occurs at birth or early in life, and most countries make it difficult for trans people to amend their identification documents, typically requiring applicants to navigate a complicated process of medical verification.²⁵

Hostile health services and lack of access to transition-related care, combined with the struggles of day-to-day living, diminish health outcomes among HIV-positive

trans people. Trans individuals living with HIV are less likely than their non-trans counterparts to have favorable interactions with healthcare providers and are less likely to adhere to prescribed antiretroviral regimens.²⁶ Impediments to meaningful healthcare access undermine the ability to reach trans people with highly effective biomedical prevention tools, including HIV treatment-as-prevention and oral pre- and post-exposure (antiretroviral) prophylaxis. The failure of mainstream health providers to address the needs of the trans population, including transition-related needs, has led to the creation of trans-specific health centers in different parts of the world.²⁴

Experience indicates that focused training programs can resolve misconceptions and build the capacity of healthcare providers to deliver quality care to trans patients. In the Dominican Republic, the Comunidad de Trans-Travestis Trabajadoras Sexuales Dominicana (COTRAVETD) trains medical personnel on trans issues and aims one day to create a network of trans-specific health and community centers.²⁵

Stigma and Discrimination

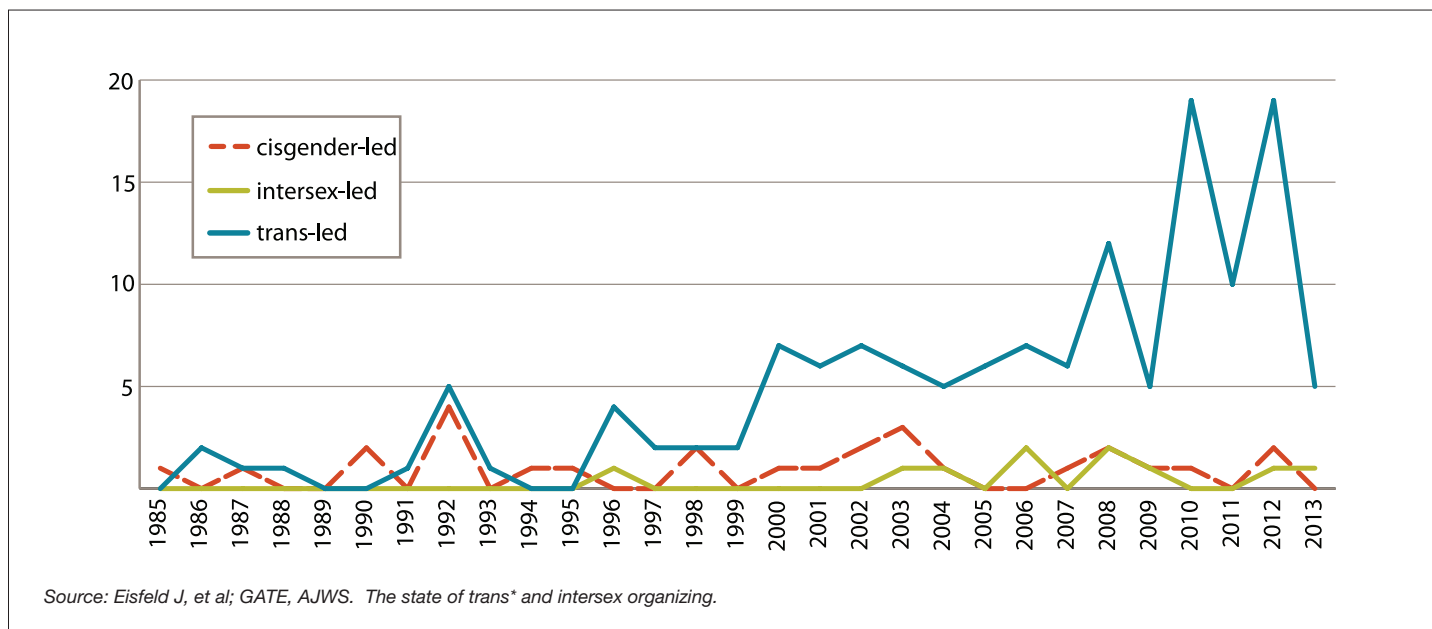
Discriminatory practices deter trans individuals from seeking the treatment and prevention services they need. In the U.S., 58% of trans people surveyed said it was reasonable to avoid getting tested for HIV where laws criminalize HIV exposure, transmission, or non-disclosure, with 44% saying such laws justified avoidance of HIV treatment altogether.²⁷

Although the social and legal environment for trans people worldwide remains deplorable, some positive signs have emerged. In 2011, The United Nations Human Rights Council passed a resolution condemning extrajudicial executions based on gender identity and other grounds. California, the most populous state in the U.S., now prohibits insurance plans from excluding coverage based on gender identity or expression,²⁸ and Argentina in 2012 enacted legislation providing legal protections based on gender identity.²⁹

Insufficient Support for Community Systems Strengthening

While trans issues were largely invisible only 20 years ago, recent years have witnessed an extraordinary growth in the visibility, activism, and organization of trans communities.^{25,30} Across the world—from Eastern Europe to South Asia to Latin America—trans communities have mobilized to deliver essential services and to advocate for their rights. In Argentina, the Asociación de Travestis, Transexuales y Transgéneros de Argentina (ATTTA) and other trans organizations played a key role in the successful passage of a gender identity law in 2011 by the national Chamber of Deputies.³⁰ In Bangladesh, the hijra-managed organization Shustha Jibon, has two clinics that serve more than 1,000 clients each month.²⁵ In Ecuador, in response to the country's acute shortage of specialized endocrinologists, Asociación Silueta X

Figure 2. Number of New Trans Groups Founded Globally, by Leadership Demographics





ASPIDH members at a booth advocating for trans healthcare rights.

assists young trans people in the proper and healthy use of feminizing hormones.³⁰ The Asociación Solidaria Para Impulsar El Desarrollo Humano (ASPIDH) has implemented comprehensive HIV prevention and health promotion activities for trans women in El Salvador.³⁰ In Nicaragua, nine organizations joined forces to develop a Strategic Plan of Comprehensive Care for the Transgender Population, which calls for advocacy for legal reform, training workshops, health literacy programs, and behavior change interventions.²⁰

Although a growing number of trans communities are mobilizing to address their health needs, they typically lack essential financial resources.²⁵ A 2012 survey of 20 philanthropic and bilateral donors found that less than \$2.4 million was available to support trans-related work outside the U.S.³¹ Even where funding is available, many grassroots organizations are unaware of funding opportunities or lack the capacity to complete funding applications.²⁵ Relatively little funding is available for community systems strengthening generally, and even less to bolster direct services (including health and social services), advocacy, mobilization, and other service delivery by trans communities. Many countries permit civil society organizations to receive funding only if they are registered—yet another barrier for small grassroots organizations that have difficulty navigating national bureaucracies.²⁵

Inadequate Research Focus

Comparatively little research has focused on trans people, with much of the available research emanating from the U.S.³² Inadequate information is available on the size of trans populations in different settings, and few studies have

focused on interventions to prevent new infections or improve health outcomes among trans people.² Core indicators to monitor progress towards the goals and targets set forth in the 2011 UN General Assembly's Political Declaration on HIV/AIDS generally ignore HIV-related issues among trans populations.

Conclusion

To make HIV transmission a rare event, it will be critical to reach all communities with proven prevention and treatment services. This is certainly true for trans populations, which may carry the heaviest HIV burden worldwide.

- *Leadership:* Trans issues must be elevated on the HIV agenda, and trans people should be supported to lead these efforts.
- *Funding:* New funding must be mobilized to support HIV prevention and treatment for and by trans people, with particular steps to ensure ready access to trans-supportive healthcare settings, transition-related healthcare, condoms, mental health services, highly effective biomedical prevention tools, and support for risk reduction.
- *Research:* A comprehensive trans-specific research agenda addressing behavioral, biomedical, legal, and structural challenges should be formulated and fully implemented.
- *Healthcare Capacity:* Focused training programs should build the capacity of healthcare workers to provide high-quality, appropriate, non-judgmental health services, including transition-related healthcare.
- *Stigma, Discrimination, and Structural Barriers:* Laws prohibiting discrimination on the basis of gender identity or expression should be enacted. Trans individuals should have access to gender-appropriate identity documentation and to legal services, and harassment by law enforcement personnel must be eradicated. Specific investments are needed to increase trans people's educational and employment opportunities.
- *Community Systems Strengthening:* Decision makers also need to invest in trans community infrastructure, provide financial means to advocate for their needs, and deliver community-centered services.

References

- Ryan H. What does trans* mean, and where did it come from? Slate. http://www.slate.com/blogs/outward/2014/01/10/trans_what_does_it_mean_and_where_did_it_come_from.html. Updated January 10, 2014. Accessed February 2014.
- Winter S; UNDP, Asia Pacific Transgender Network. Lost in transition: transgender people, rights and HIV vulnerability in the Asia-Pacific region. <http://www.undp.org/content/dam/undp/library/hiv/aids/Lost%20in%20translation.pdf>. Published May 2012. Accessed February 2014.
- Keller K. Transgender health and HIV. The Body. <http://www.thebody.com/content/art54537.html>. Updated Summer/Fall 2009. Accessed February 2014.
- Kuyper L, Wijzen C. Gender identities and gender dysphoria in the Netherlands. *Arch Sex Behav*. 2014;43:377–385. doi:10.1007/s10508-013-0140-y.
- Conron KJ, Scott G, Stowell GS, Landers SJ. Transgender health in Massachusetts: results from a household probability sample of adults. *Am J Public Health*. 2012;102:118–122. doi:10.2105/AJPH.2011.300315.
- American Psychological Association. Module nine: HIV/AIDS and the transgender population. <http://www.apa.org/pi/aids/programs/hope/training/hiv-transgender.pdf>. Published 2010. Accessed February 2014.
- Baral SD, Poteat T, Strömdahl S, Wirtz AL, Guadamuz TE, Beyrer C. Worldwide burden of HIV in transgender women: a systematic review and meta-analysis. *Lancet Infect Dis*. 2013;13:214–222.
- UNAIDS. Global report: UNAIDS report on the global AIDS epidemic 2012. http://www.unaids.org/en/media/unaids/contentassets/documents/epidemiology/2012/gr2012/20121120_UNAIDS_Global_Report_2012_with_annexes_en.pdf. Published November 2012. Accessed February 2014.
- Herbst JH, Jacobs ED, Finlayson TJ, et al. Estimating HIV prevalence and risk behaviors of transgender persons in the United States: a systematic review. *AIDS Behav*. 2008;12:1–17.
- Centers for Disease Control and Prevention. HIV among transgender people. <http://www.cdc.gov/hiv/risk/transgender>. Accessed February 2014.
- Wilson E. Addressing HIV risk among trans youth. Presented at the XIX International AIDS Conference; July 22–27, 2012; Washington D.C.
- Grant JM, Mottet, LA, Tanis J, et al; National Center for Transgender Equality, National Gay and Lesbian Task Force. Injustice at every turn: a report of the national transgender discrimination survey. http://www.thetaskforce.org/downloads/reports/reports/ntds_full.pdf. Published 2011. Accessed February 2014.
- Beyrer C, Baral SD, van Griensven F, et al. Global epidemiology of HIV infection in men who have sex with men. *Lancet*. 2012;380:367–377.
- American Psychological Association. Report of the APA task force on gender identity and gender variance. <http://www.apa.org/pi/lgbt/resources/policy/gender-identity-report.pdf>. Published January 2009. Accessed February 2014.
- REDLACTRANS, International HIV/AIDS Alliance, What's Preventing Prevention. The night is another country: impunity and violence against transgender women human rights defenders in Latin America. <http://www.aidsalliance.org/includes/Publication/Violencia-e-impunidad-English.pdf>. Published December 2012. Accessed February 2014.
- Operario D, Soma T, Underhill K. Sex work and HIV status among transgender women: systematic review and meta-analysis. *J Acquir Immune Defic Syndr*. 2008;48:97–103.
- Centers for Disease Control and Prevention. The role of STD detection and treatment in HIV prevention - CDC fact sheet. <http://www.cdc.gov/std/hiv/stdfact-std-hiv.htm>. Accessed February 2014.
- Balzer C, Hutta JS; Transrespect Versus Transphobia Worldwide, Transgender Europe. Transrespect versus transphobia worldwide: a comparative review of the human-rights situation of gender-variant/trans people. http://www.transrespect-transphobia.org/uploads/downloads/Publications/TvT_research-report.pdf. Published November 2012. Accessed February 2014.
- Transrespect Versus Transphobia Worldwide. TDOR 2013. http://www.transrespect-transphobia.org/en_US/tvt-project/tmm-results/tdor-2013.htm. Accessed February 2014.
- UNAIDS. Global report: UNAIDS report on the global AIDS epidemic 2013. http://www.unaids.org/en/media/unaids/contentassets/documents/epidemiology/2013/gr2013/UNAIDS_Global_Report_2013_en.pdf. Published November 2013. Accessed February 2014.
- Stevens M; Gender Dynamix, amFAR. Transgender access to sexual health services in South Africa: findings from a key informant survey. <http://www.genderdynamix.org.za/wp-content/uploads/2012/10/Transgender-access-to-sexual-health-services-in-South-Africa.pdf>. Published September 2012. Accessed February 2014.
- Center of Excellence for Transgender Health, University of California San Francisco. Primary care protocol for transgender patient care. <http://transhealth.ucsf.edu/trans?page=protocol-00-00>. Accessed February 2014.
- Coleman E, Bockting W, Botzer M, et al; World Professional Association for Transgender Health. Standards of care for the health of transsexual, transgender, and gender-nonconforming people, version 7. *Int. J. Transgenderism*. 2011;13:165–232.
- Open Society Foundations. Transforming health: international rights-based advocacy for trans health. <http://www.opensocietyfoundations.org/sites/default/files/transforming-health-20130213.pdf>. Published February 2013. Accessed February 2014.
- Eisfeld J, Gunther S, Shlasko D; Global Action for Trans* Equality, American Jewish World Service. The state of trans* and intersex organizing: a case for increased support for growing but under-funded movements for human rights. http://ajws.org/who_we_are/publications/special_reports/trans-intersex-funding-report.pdf. Published January 2014. Accessed February 2014.
- Sevelius JM, Carrico A, Johnson MO. Antiretroviral therapy adherence among transgender women living with HIV. *J Assoc Nurses AIDS Care*. 2010;21:256–264.
- Transgender Law Center. HIV criminalization discourages HIV testing, disclosure and treatment for transgender and third sex individuals. <http://transgenderlawcenter.org/archives/8538>. Accessed February 2014.
- Transgender Law Center. FAQ: California's ban on transgender exclusions in health insurance. <http://transgenderlawcenter.org/archives/4273>. Accessed February 2014.
- Transgender Europe. Argentina gender identity law. http://www.tgeu.org/Argentina_Gender_Identity_Law. Published September 2013. Accessed February 2014.
- UNAIDS, REDLACTRANS, International HIV/AIDS Alliance. Making rights a reality: a compilation of case studies: the experiences of organizations of transgender people. <http://www.aidspace.org/getDownload.php?id=1825>. Published April 2012. Accessed February 2014.
- Open Society Foundations, Global Action for Trans* Equality, American Jewish World Service. Mapping donors on the state of funding on trans* and intersex issues. Presented at Advancing Trans* Movements Worldwide; December 3–4, 2013; Berlin, Germany.
- Lombardi E. Transgender health: a review and guidance for future research – proceedings from the summer institute at the center for research on health and sexual orientation, University of Pittsburgh. *Int. J. Transgenderism*. 2010;12:211–229.



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