

The Legal Needs of Transgender Women Living with HIV

Evaluating Access to Justice in Los Angeles

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I. INTRODUCTION

Los Angeles County (“LAC”) is home to the second largest community of people living with HIV/AIDS (“PLWH”) in the U.S. Currently, an estimated 58,000 PLWH reside in the county, a figure that has steadily increased over time.¹ Epidemiological data confirms 558 transgender individuals are documented as living with HIV throughout Los Angeles County.² Because gender identity data was not collected by the state in the HIV/AIDS Case Report Form prior to 2002, LAC estimates the number of transgender individuals living with HIV to be closer to double that figure.³ Prevalence rates of HIV among transgender individuals cannot be calculated due to a lack of data regarding the total size of the transgender population in LAC.⁴ Using population estimates from four previous studies, however, the County estimates there to be 14,428 transgender persons living in LAC, half of whom, or 7,214, are presumed to identify as transgender women.⁵ Based on these assumptions, the estimated HIV prevalence among transgender women in LAC is 15.1%.⁶

In 2013, the Williams Institute designed the Legal Assessment of Needs Study (“LeAN Study”) to examine the legal needs of PLWH in LAC. The study focused on particularly vulnerable members of the HIV-positive community, including low-income and unemployed individuals. Almost all respondents were accessing community-based social services and safety net programs at the time of the study. Research studies focused on legal services for PLWH are limited, and to date, little research has been done to assess the unmet legal needs of transgender women living with HIV.

A. Legal Assessment of Needs (“LeAN”) Survey

This report summarizes findings of the LeAN Study for transgender women living with HIV in Los Angeles County. We describe respondents’ legal needs,⁷ respondents’ experiences getting assistance for identified legal needs from both legal and non-legal sources, and barriers respondents faced in accessing assistance from both legal and non-legal sources. We describe differences and similarities between transgender women and all other respondents. Finally, we discuss how these legal needs may relate to health access and health status.

The LeAN Study survey included 387 respondents who identified as PLWH. Overall, respondents identified as cisgender men (69%), cisgender women (21%), and transgender women (9%) with a mean age of 49 years (SD = 10.6, age range 20-77 years). Almost half of the respondents (48%) reported living with AIDS. Respondents identified their race/ethnicity as Hispanic, Latino or of Spanish origin (44%), Black or African American (37%),

¹ DIV. OF HIV & STD PROGRAMS, L.A. CNTY. DEP’T OF PUB. HEALTH, 2013 ANNUAL HIV SURVEILLANCE REPORT 2 (2014), available at <http://publichealth.lacounty.gov/dhsp/Reports/HIV/2013AnnualHIVSurveillanceReport.pdf>.

² *Id.*

³ DIV. OF HIV & STD PROGRAMS, L.A. CNTY. DEP’T OF PUB. HEALTH, LOS ANGELES COUNTY TRANSGENDER POPULATION ESTIMATES 2012 (2012), available at <http://publichealth.lacounty.gov/wwwfiles/ph/hae/hiv/Transgender%20Population%20Estimates%202-12-13%20pub.pdf>.

⁴ 2013 ANNUAL HIV SURVEILLANCE, *supra* note 1, at 12.

⁵ LOS ANGELES COUNTY TRANSGENDER POPULATION, *supra* note 3, at 4.

⁶ *Id.* at 5.

⁷ For this study, a “legal need” was defined as any issue or problem experienced by the respondent that legal services are known to cover, such as problems in housing, health care access, and employment. It is understood that these needs may not be conceptualized by respondents or others as inherently legal in nature. The list of issues with legal implications was developed by a team of attorneys and HIV/AIDS researchers within the Williams Institute.

White (17%), American Indian/Alaskan Native (6%), and Asian/Pacific Islander (1.6%).⁸ Respondents resided in 111 unique zip codes spread across LAC, including the Metro (43%), South L.A. (20%), South Bay (16%) and San Fernando (11%) areas.

Thirty-four of the total respondents, or 9%, identified as transgender women.⁹ This cohort represents approximately 6% of the total population of confirmed HIV-positive transgender individuals living with HIV in LAC. Of these women, 79% identified as being Hispanic, Latino or of Spanish origin, and over 70% indicated being foreign born. Their mean age was 46 (SD= 10.4, range 21-73 years). Transgender women respondents reported residing in 24 unique zip codes spread across the following areas: the Metro (44%), South L.A. (21%), South Bay (15%), San Fernando (9%), East L.A. (6%), San Gabriel (3%) and West L.A. (3%) areas. These areas were generally the same areas where other respondents reported residing.

More than 90% of transgender women indicated not having children, and household size for transgender women was smaller on average than for other respondents. As compared to all other respondents, transgender women reported a lower level of formal education (74% received a high school education or below compared to 55% of non-transgender identified respondents). Transgender women were less likely to report being disabled and living on disability benefits than non-transgender respondents (18% vs. 51%, respectively) and more likely to have worked sometime in the past five years than non-transgender respondents (56% vs. 37%, respectively).

No significant differences were observed between transgender and non-transgender respondents with regard to self-reported income. Fifty percent of respondents reported household incomes of less than \$10,000 per year, and 78% of respondents reported household incomes under \$20,000 per year. For transgender women 64% reported household incomes of less than \$10,000 per year, and 79% of respondents reported household incomes under \$20,000 per year.¹⁰ Encouragingly, similar to the survey respondents as a whole, transgender women also reported high rates of being linked to care (100%), retained in care (97%), being prescribed anti-retroviral medication in the last year (97%) and being informed as having an undetectable viral load in the past year (85%).

II. MAIN FINDINGS

A. Legal Needs

The survey questionnaire elicited responses that indicated the likely presence of a legal need.¹¹ The study showed that PLWH in LAC have a diverse array of legal needs. Ninety-one percent of transgender women also reported a legal need in at least one other remaining legal issue area. On average, transgender women reported experiencing

⁸ Respondents were first asked whether they identified as Hispanic, Latino or of Spanish origin, and then were asked a second question about their race that allowed them to select all racial categories that they identified with. All figures above include any respondent who selected that racial/ethnic option, regardless of whether they also identified as other races/ethnicity. White, as defined in the figure above, only includes respondents who identified as non-Hispanic monoracial White. Thirty-two percent of respondents identified as monoracial non-Hispanic Black or African American, 1% of respondents identified as monoracial non-Hispanic American Indian/Alaskan Native, and .3% of respondents identified as only non-Hispanic Asian/Pacific Islander. Thirty-nine percent of respondents identified as White, regardless of whether they identified as other racial/ethnic identities.

⁹ Zero respondents identified as transgender men.

¹⁰ This figure indicates that the majority of respondents have a household income that falls under the median household income for Los Angeles County. See United States Census Bureau, *Los Angeles County, California*, STATE AND COUNTY QUICKFACTS, <http://quickfacts.census.gov/qfd/states/06/06037.html> (last updated Dec. 4, 2014) (stating median household income at \$55, 909, 3.01 persons per household, thus averaging approximately \$18,636 per person).

¹¹ The evaluation asked questions about legal needs in the following legal issue areas: public benefits, private insurance, health care access, housing, immigration, testamentary documents and directives, tort (i.e. personal injury), family law, criminal law, consumer law, tax, improper disclosure of HIV status, and experiences of being physically attacked, harassed or subjected to another crime.

an average of six distinct legal needs ($SD=4.2$) in four legal issue areas ($SD=2.5$) in the year prior to taking the survey. The most highly prevalent legal issue areas were:

Among transgender women surveyed, the most prevalent legal issue areas reported were in immigration (50%), health care access (44%), victimization (44%), consumer law (41%), criminal law (41%), housing (29%), discrimination in employment, health care, or housing (24%), public benefits (21%), and private insurance (21%).

Table 2.1 describes the legal needs transgender women faced in the year prior to the interview, arranged according to legal issue area. A large percentage of non-transgender respondents (84%), and 94% of transgender women, reported not having a testamentary will and/or an advanced health care directive. These documents help facilitate end of life decisions related to assets and health care decisions. Not having these documents was a common legal issue among respondents across all categories of gender, sexual orientation and race/ethnicity. However, because this may be an important legal document that many respondents may not have identified on their own as a legal need, outside of being asked by the survey, we also examined the percentage of respondents who reported legal needs besides not having a testamentary will and/or an advanced health care directive.

Figure 2.1: Most Prevalent Legal Issue Areas Reported for Transgender Women

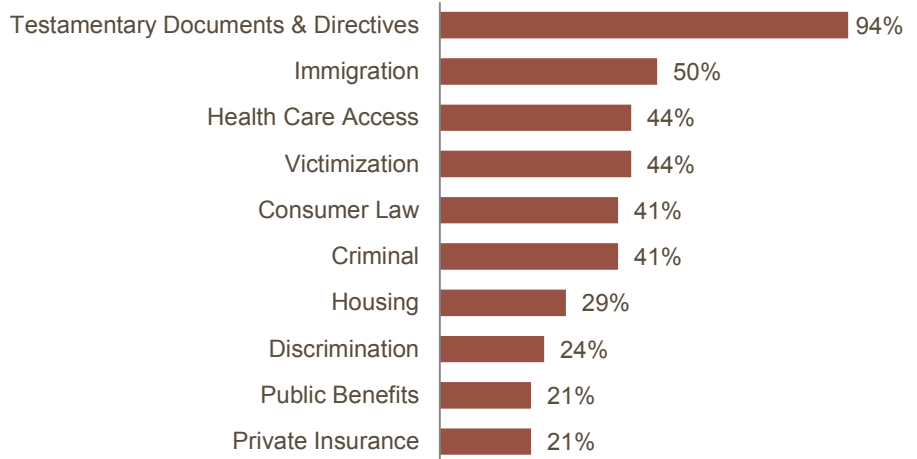


Table 2.1: Identified Legal Needs in Year Prior by Legal Issue Area

Legal Issue Area	Transgender Women	All Respondents
Testamentary Documents & Directives ¹²	94%	85%
Immigration ¹³	50%	19%
Health Care Access ¹⁴	44%	47%
Consumer Law ¹⁵	41%	49%
Criminal ¹⁶	41%	28%
Housing ¹⁷	29%	42%
Discrimination ¹⁸	24%	21%
Public Benefits ¹⁹	21%	30%
Private Insurance ²⁰	21%	12%
Taxes ²¹	9%	14%
Tort (Injury) ²²	9%	11%
Family ²³	3%	6%
Improper Disclosure of HIV Status ²⁴	3%	4%

¹² Includes responses indicating respondents did not have a will or an advanced health care directive in place.

¹³ Includes responses indicating needing help with a green card, citizenship, a visa, document renewals, other immigration papers, and/or any experience with Immigration Customs and Enforcement including getting stopped at the border upon entry.

¹⁴ Includes responses indicating not getting medical care or medication when needed, not having health coverage in the year or five-year period prior to the survey, and/or not seeking routine HIV care for lack of money or health insurance.

¹⁵ Includes responses indicating respondents experienced bankruptcy, having money deducted from government benefits due to debt, receiving harassing telephone calls or letters regarding past due debt, and/or being three or more months behind in payments for student loans, medical bills, credit cards, child support or a car loan.

1. Immigration

Half of all transgender women reported a legal need in immigration law. While only 19% of respondents overall reported a legal need related to immigration, this difference is likely influenced by the fact that transgender women were more likely to report being foreign-born than their non-transgender counterparts (71% versus 30% respectively). These issues included needing assistance with a green card (29%); coming into contact with Immigration and Customs Enforcement (29%); citizenship (24%); needing assistance with a visa (18%); needing assistance with document renewals (6%); and needing assistance with other immigration papers (35%).

2. Health Care Access

Measures in the survey regarding access to medical care, medication, health insurance or health coverage indicated that 44% of transgender women experienced some challenges accessing health care in the year prior to the survey. Among those who had issues accessing health care, 67% did not get medication when they needed it in the year prior to the survey, 47% reported they did not get medical care when they needed it, and 27% experienced a lapse in health insurance/health coverage in the five-year period prior to the survey.

3. Victimization and the Criminal Justice System

Nearly half (44%) of transgender women reported being harassed, attacked with violence, and/or subjected to another crime in the past year. Looking at violent attacks specifically, transgender women were particularly vulnerable (29%) and were significantly more likely to report being violently attacked than straight cisgender men (7%).

Additionally, 41% of transgender women reported coming into contact with the criminal justice system in the five years prior to the survey. Transgender women were also significantly more likely to report having been incarcerated in the five years prior to the survey than cisgender women (26% versus 12%, respectively). Among transgender women who reported being incarcerated for a week or more during the five-year period prior to the survey, 56% reported having problems accessing HIV medication, being separated from others due to HIV status, and/or being denied access to services in the jail or prison while incarcerated.

¹⁶ Includes responses indicating experience of a sex partner threatening to contact the police because of the respondent's HIV status, being accused of committing a crime, arrested, charged with a crime in court or in a hearing before a judge, receiving a sentence or probation related to being accused of committing a crime, and/or being incarcerated.

¹⁷ Includes responses indicating experiences of homelessness or unstable housing, landlord refusal to fix habitability issues, receipt of notice to leave the home (eviction), owning a home that has gone into foreclosure or sold in a short sale, and/or being three or more months behind in rent or mortgage payments.

¹⁸ Includes responses indicating experiences of housing discrimination (refused housing because of HIV status or respondent's landlord refused to make requested adjustments to their living arrangements because of their HIV status), employment discrimination (not hired for a job, removed from direct contact with people at work, denied a promotion, fired from a job, harassed by someone at work, attacked with violence while at work, asked inappropriate questions by employer about their HIV/AIDS, told by employer that they could not take time off work for a necessary medical appointment, and/or refused other necessary adjustments at work because of their HIV status), health care discrimination (denied dental care, denied care by a doctor, nurse or medical specialist, and/or treated differently than other patients by a health care provider because of HIV status) or other discrimination in the year prior to the survey.

¹⁹ Includes responses indicating respondents were denied disability, general income or health care benefits and/or were informed of a benefits overpayment.

²⁰ Includes responses indicating difficulty in getting private insurance or termination of private insurance due to HIV status.

²¹ Includes responses indicating respondents owed or had been told they owe money for taxes for past years.

²² Includes responses indicating experiences of being badly injured due to someone else's fault including bad medical treatment.

²³ Includes responses indicating needing help with a divorce, separation, child custody or adoption.

²⁴ Includes responses indicating experiences in which a current manager/supervisor, doctor, pharmacist, health care provider, or lawyer may have disclosed HIV status improperly or without needed consent.

4. Discrimination on the Basis of HIV Status

Overall, 21% of respondents reported experiencing discrimination in the year prior to the interview and 31% of respondents reported experiencing discrimination over a five -year period prior to the survey. Similarly for transgender women, 24% reported experiencing discrimination in the year prior to the interview and 32% of respondents reported experiencing discrimination over a five -year period prior to the survey. Table 2.2 describes the reported experiences of transgender women with regard to HIV-related discrimination in housing, employment and health care settings.

Table 2.2: Experiences of HIV-Related Discrimination in Various Settings

		Transgender Women	All Respondents
Housing	One year ²⁵	3%	10%
	Five Years ²⁶	9%	13%
Health Care ²⁷	One Year	9%	8%
	Five Years	15%	16%
Employment ²⁸	One Year	9%	5%
	Five Years	12%	10%

B. Barriers to Accessing Assistance for Legal Needs

Seventy-one percent of all respondents who answered follow up questions regarding their most recent legal need reported not looking for a lawyer or legal advisor for help.²⁹ As a result, among all respondents who identified a legal need, only 16% reported receiving legal assistance.³⁰ The majority of transgender women surveyed also indicated they did not look for legal help (63%).

Some of the information provided by respondents regarding their most recent legal need may explain common barriers for accessing assistance for a legal need. Of the transgender women who did not look for help, 53% experienced barriers to seeking help. These barriers include not knowing whether a lawyer could help, not being able to afford legal services, not knowing who or where to call, fear of being treated badly because of HIV status or for other reasons, and lack of transportation. Among those transgender women who did not look for help, 26% indicated they did not seek help because they could not afford legal services, 16% did not know if a lawyer could help them, 11% indicated not knowing who or where to call, and 5% were afraid of being treated badly because of their HIV status. For transgender women, similar to all other respondents, affordability and awareness of legal services was a barrier to getting legal assistance. Table 2.3 describes respondents' experiences with regard to barriers to accessing legal assistance.

²⁵ Includes responses indicating that respondent was refused housing because of their HIV status or respondent's landlord refused to make requested adjustments to their living arrangements because of their HIV status (such as to being allowed to have a companion animal, a long-term caregiver, or for a change in rent due dates) in the year prior to the survey.

²⁶ Includes responses indicating that respondent was refused housing because of their HIV status in the five years prior to the survey and responses indicating that respondent's landlord refused to make requested adjustments to their living arrangements because of their HIV status in the year prior to the survey. The survey did not ask about housing accommodations over a five-year period.

²⁷ Includes responses indicating that respondent was denied dental care because of HIV status, denied care by a doctor, nurse or medical specialist because of HIV status, and/or treated differently than other patients by a health care provider because of HIV status.

²⁸ Includes responses indicating respondent was not hired for a job because of HIV status, removed from direct contact with people at work, denied a promotion, fired from a job, harassed by someone at work, attacked with violence while at work, asked inappropriate questions by employer about their HIV/AIDS, told by employer that they could not take time off work for a necessary medical appointment, and/or refused other necessary adjustments at work such as an adjustable workstation, rest breaks for fatigue or a modification of work schedule.

²⁹ One percent of respondents indicated they did not know if they looked for help from a lawyer or legal advisor to help with their most recent legal need.

³⁰ Indicates that respondent reported that the person assisting them was a lawyer.

Table 2.3: Barriers to Accessing Legal Assistance for Most Recent Legal Need

	Transgender Women	All Respondents
For those who did not look for help (n=223; 19 Transgender)		
I could not afford legal services	26%	26%
I did not know if a lawyer could help me	16%	19%
I did not know who or where to call	11%	15%
I was afraid of being treated badly because of my HIV status	5%	6%

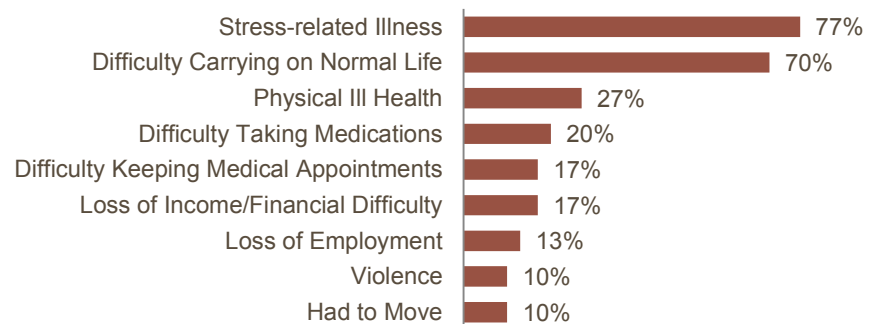
C. Accessing Assistance for Legal Needs

Of all respondents who answered follow up questions about their most recent legal need, 28% indicated they looked for a lawyer or legal advisor to help with their most recent legal need, 21% found some form of assistance, 16% found help from a lawyer, and 13% reported that they found that legal assistance helpful. For transgender women, the figures were different. While over 63% of transgender women reported not looking for legal help, the 37% of those who did seek help all reported being successful in accessing some kind of assistance (82% legal help, 18% non-legal help). Among those who reported receiving assistance, 82% found the assistance was helpful, 9% found the assistance was not helpful, and 9% did not know if the assistance was helpful.

At the time of survey, 50% of transgender women indicated the identified problem was resolved, and 50% indicated that they still had the problem, regardless of whether they had received assistance. Among transgender women who still had the problem, 33% felt the situation had gotten worse, 27% felt the situation had gotten better, and 40% felt there was no change with the problem. Overall, 15% of all transgender women indicated they either helped themselves or solved the identified problem on their own.

D. Impact of Legal Needs

Based on the impact of their most recent legal need, transgender women reported impacts on their lives from not receiving legal assistance. These included stress-related illness (77%), difficulty carrying on normal life (70%), physical ill health (27%), difficulty taking medications (20%), difficulty keeping medical appointments (17%), and loss of income or financial difficulty (17%). Other impacts reported experiencing loss of employment (13%), violence (10%), and having to move (10%) as a result of their recent legal need.

Figure 2.2: Reported Impacts of Most Recent Legal Need for Transgender Women

III. POLICY, PRACTICE, AND RESEARCH IMPLICATIONS

It appears that low-income PLWH have numerous legal needs in a broad range of legal issue areas. This is true of transgender women who were surveyed for the LeAN Study. Thus, addressing all legal needs of PLWH requires significant resources. Given the relative scarcity of funding for legal services, these findings provide a list of commonly experienced issues that could be used by providers to target appropriate services to transgender women living with HIV (e.g. immigration, health care access, victimization, consumer law, criminal, housing, discrimination, public benefits, and private insurance). Specific legal needs in the area of victimization and immigration indicate that transgender women have needs which may be different and apart from the needs of other subgroups. Legal services providers will need to consider how these specific needs can be met.

Study findings indicate that transgender women who experienced incarceration in the five years prior to the study also experienced high levels of separation, denial of services and lack of access to medications during confinement. This was concerning for transgender women, who reported particularly high incarceration rates, with more than one in four reporting incarceration in the previous five years. Traditional legal services providers do not typically provide counsel, advice, or representation on criminal law issues, so this area represents an area of need that are likely unmet by current civil legal assistance structures. Meeting this need may require HIV legal service providers to broaden the scope of legal services by shifting legal service delivery methods. Doing so may require exploring policy changes necessary to effect change.

The majority of respondents did not seek legal assistance, and this was, in part, because they did not know if a lawyer could help them. The findings indicate that educating transgender women living with HIV about how to identify a legal need would, in part, address this particular gap. The study shows that this is true of all PLWH facing vulnerable circumstances in LAC—they need more information on the availability of legal resources that are low to no cost.

Finally, the self-reported impacts which transgender women reported as resulting from unmet legal needs indicate more research is necessary to explore the relationship between the presence of legal needs and its impact on the health of transgender women living with HIV. Because all transgender women who sought legal help found help, some respondents seemed to have demonstrated a level of resilience which may have influenced their ability to engage in self-advocacy. More research is necessary to understand how resilience may or may not play a role in how unmet legal needs impact the health of transgender women.

IV. METHODOLOGY

From July through October, 2014, in-person computerized surveys were administered in conjunction with AIDS Project Los Angeles' community-based food pantry program, Bienestar, and other HIV service providers throughout LAC. The final data set includes 387 total complete surveys of which 21% were completed in Spanish.

To be eligible to take the survey, a respondent had to consent to the study, be 18 years of age or older, living with HIV, and reside in LAC at the time of the survey. Respondents were asked to complete a series of questions focused on: demographic information, a legal needs evaluation, questions about health coverage, current health and wellbeing, knowledge about California laws related to HIV/AIDS, and experiences with discrimination, privacy and confidentiality of HIV status. Respondents who completed the survey received a \$5 incentive. Study procedures were approved by the UCLA Institutional Review Board.³¹

³¹ For a full description of study methods and the survey tool, see AYAKO MIYASHITA, AMIRA HASENBUSH, BIANCA D.M. WILSON, ILAN H. MEYER, SHEILA NEZHAD & BRAD SEARS, THE WILLIAMS INST. UNIV. OF CAL. L.A. SCH. OF LAW, HIV LEGAL ASSESSMENT OF NEEDS STUDY: A COMPREHENSIVE SURVEY OF PEOPLE LIVING WITH HIV/AIDS IN LOS ANGELES (2015), available at <http://williamsinstitute.law.ucla.edu/wp-content/uploads/Legal-Needs-People-Living-with-HIV-Los-Angeles-County-April-2015.pdf>.

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Research Team

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Partners

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