

# The Legal Needs of Cisgender 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.<sup>1</sup> Epidemiological data confirm that 5,322 females<sup>2</sup> are documented as living with HIV throughout Los Angeles County.<sup>3</sup> The 2013 HIV transmission rate in LAC among cisgender<sup>4</sup> (non-transgender) women was three in 100,000.<sup>5</sup>

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 PLWH, including cisgender women living with HIV.

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

This report summarizes findings of the LeAN Study for cisgender women living with HIV in Los Angeles County. We describe respondents’ legal needs,<sup>6</sup> 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 cisgender women and all other respondents. Finally, we discuss how these legal needs may relate to health care 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%), White (17%), American Indian/Alaskan Native (6%), and Asian/Pacific Islander (1.6%).<sup>7</sup> Respondents resided in 111 unique zip codes spread across LAC, including the Metro (43%), South L.A. (21%), South Bay (16%) and San Fernando (11%) areas.

Eighty-two of the total respondents, or 21%, identified as cisgender (non-transgender) women. Of these women, nearly half (49%) identified as monoracial Black or African American, compared to only 27% of male and transgender

<sup>1</sup> 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>.

<sup>2</sup> Because Los Angeles County reported a separate number for the prevalence of HIV among transgender individuals, we assume that the female count includes only cisgender (non-transgender women).

<sup>3</sup> DIV. OF HIV & STD PROGRAMS, *supra* note 1 at 2.

<sup>4</sup> Cisgender women include individuals whose sex is assigned female at birth and who currently identify as female.

<sup>5</sup> DIV. OF HIV & STD PROGRAMS, *supra* note 1 at 2.

<sup>6</sup> 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.

<sup>7</sup> 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.

respondents. Cisgender women also identified as Hispanic, Latina or of Spanish origin of any race (34%), monoracial White (10%), and multiracial (7%). Cisgender women were also much more likely to identify as straight than other survey respondents (88% versus 21%, respectively). Five percent of cisgender women respondents identified as gay/lesbian, and 5% identified as bisexual. Their mean age was 52 (SD= 10.2, range 28-70 years), about four years older on average than the rest of the survey respondents.<sup>8</sup> Cisgender women respondents reported residing in 49 unique zip codes spread across the following areas: South L.A. (37%), Metro (29%), South Bay (22%), San Fernando (4%), East L.A. (4%), San Gabriel (4%) and West L.A. (1%) areas. These women reported living in South L.A. more often than expected compared to the rest of the survey respondents, of whom only 17% reported living in South L.A.

Cisgender women were significantly more likely to report having children than other survey respondents (84% versus 22%, respectively). As compared to all other respondents, cisgender women reported a lower level of formal education (67% received a high school education or below compared to 54% of other respondents). Cisgender women were less likely to report being currently employed than other respondents (9% vs. 20%, respectively) and more likely to report being homemakers than other respondents (11% vs. 1%, respectively).

No significant differences were observed between cisgender women and other 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.<sup>9</sup> For cisgender women 53% reported household incomes of less than \$10,000 per year, and 75% of respondents reported household incomes under \$20,000 per year. Encouragingly, similar to the survey respondents as a whole, cisgender women also reported high rates of being linked to care (99%), retained in care (95%), being prescribed anti-retroviral medication in the last year (94%) and being informed as having an undetectable viral load in the past year (88%).

## II. MAIN FINDINGS

### A. Legal Needs

The survey questionnaire elicited responses that indicated the likely presence of a legal need.<sup>10</sup> The study showed that PLWH in LAC have a diverse array of legal needs. All cisgender women reported having at least one legal issue in the year prior to the survey. Most cisgender women (83%) said that they did not have a testamentary will and/or an advanced health care directive. Ninety-three percent of cisgender women reported a legal need in at least one other remaining legal issue area. On average, cisgender women reported experiencing an average of six distinct legal needs (SD=3.5) in four legal issue areas (SD=1.9) in the year prior to taking the survey.

Among cisgender women surveyed, the most prevalent legal issue areas reported were in health care access (49%), consumer law (48%), housing (39%), public benefits (28%), victimization (24%), criminal law (23%) and discrimination in employment, health care or housing (18%).<sup>11</sup>

<sup>8</sup> All differences are reported at the  $p < .05$  level.

<sup>9</sup> 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).

<sup>10</sup> 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.

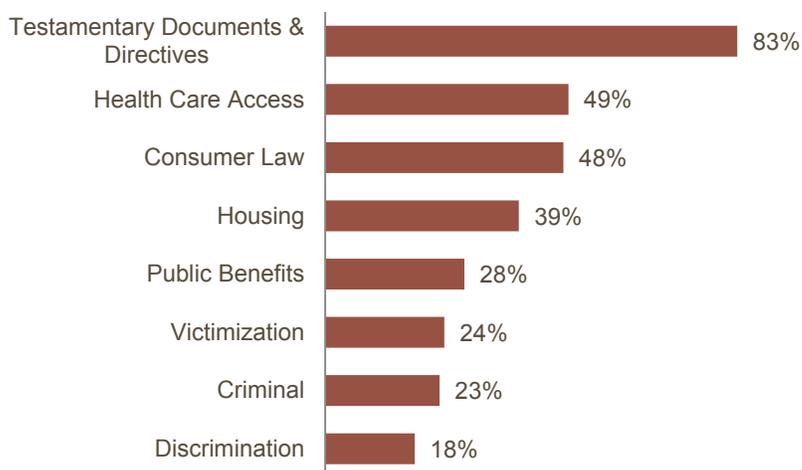
<sup>11</sup> For a description of these legal issue areas, see *infra* notes 12–28.

Table 1 describes the legal needs cisgender women faced in the year prior to the interview, arranged according to legal issue area. A large percentage of cisgender women (83%), and 85% of other respondents, 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.

### 1. Health Care Access

Measures in the survey regarding access to medical care, medication, health insurance or health coverage indicated that 49% of cisgender women experienced some challenges accessing health care in the year prior to the survey. Among those who had issues accessing health care, 55% did not get medication when they needed it in the year prior to the survey, 48% reported they

**Figure 1: Most Prevalent Legal Issue Areas Reported for Cisgender Women**



**Table 1: Identified Legal Needs in Year Prior by Legal Issue Area**

	Cisgender Women	All Respondents
Testamentary Documents & Directives <sup>12</sup>	83%	85%
Health Care Access <sup>13</sup>	49%	47%
Consumer Law <sup>14</sup>	48%	49%
Housing <sup>15</sup>	39%	42%
Public Benefits <sup>16</sup>	28%	30%
Victimization <sup>17</sup>	24%	35%
Criminal <sup>18</sup>	23%	28%
Discrimination <sup>19</sup>	18%	21%
Taxes <sup>20</sup>	12%	14%
Tort (Injury) <sup>21</sup>	11%	11%
Family <sup>22</sup>	11%	6%
Immigration <sup>23</sup>	10%	19%
Private Insurance <sup>24</sup>	9%	12%
Improper Disclosure of HIV Status <sup>25</sup>	4%	4%

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

<sup>13</sup> 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.

<sup>14</sup> 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.

<sup>15</sup> 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.

<sup>16</sup> Includes responses indicating respondents were denied disability, general income or health care benefits and/or were informed of a benefits overpayment.

<sup>17</sup> Includes responses indicating respondents were harassed, attacked with violence, and/or were a victim of any other crime.

<sup>18</sup> 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.

did not get medical care when they needed it, 18% reported having no health coverage at the time of the survey, and 35% experienced a lapse in health insurance/health coverage in the five-year period prior to the survey.

## 2. 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 cisgender women, 18% reported experiencing discrimination in the year prior to the interview and 26% reported experiencing discrimination over a five-year period prior to the survey. Table 2 describes the reported experiences of cisgender women with regard to HIV-related discrimination in housing, employment and health care settings. There were no statistically significant differences between cisgender women's reported experiences of discrimination and other respondents. While employment discrimination numbers may have appeared slightly lower among cisgender women, when controlling for employment status, cisgender women were no less likely to report experiencing employment discrimination than other respondents.

**Table 2: Experiences of HIV-Related Discrimination in Various Settings**

		Cisgender Women	All Respondents
Housing	One year <sup>26</sup>	11%	10%
	Five Years <sup>27</sup>	12%	13%
Health Care <sup>28</sup>	One Year	6%	8%
	Five Years	12%	16%
Employment <sup>29</sup>	One Year	4%	5%
	Five Years	6%	10%

<sup>19</sup> 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.

<sup>20</sup> Includes responses indicating respondents owed or had been told they owe money for taxes for past years.

<sup>21</sup> Includes responses indicating experiences of being badly injured due to someone else's fault including bad medical treatment.

<sup>22</sup> Includes responses indicating needing help with a divorce, separation, child custody or adoption.

<sup>23</sup> 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.

<sup>24</sup> Includes responses indicating difficulty in getting private insurance or termination of private insurance due to HIV status.

<sup>25</sup> 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.

<sup>26</sup> 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.

<sup>27</sup> 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.

<sup>28</sup> 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.

<sup>29</sup> 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.

### 3. Family Law

While family law was not a legal issue for the majority of cisgender women who responded to the survey, cisgender women as a whole were more likely than expected to report legal needs in the area of family law compared to the other survey respondents (11% versus 5%, respectively). This is reasonable, considering that cisgender women were significantly more likely to report having children than other respondents (84% versus 22%, respectively). Overall, 6% of cisgender women respondents reported needing assistance with child custody, 5% reported needing assistance with a divorce, and 1% reported needing assistance with an adoption in the year prior to the survey.

#### B. Barriers to Accessing Assistance for Legal Needs

Seventy 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.<sup>30</sup> As a result, among all respondents who identified a legal need, only 16% reported receiving legal assistance.<sup>31</sup> A similar percent of cisgender women surveyed also indicated they did not look for legal help (77%), and overall, 11% of cisgender women reported receiving legal assistance.

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 cisgender women who did not look for help, 45% experienced barriers to seeking help. These barriers included 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 cisgender women who did not look for help, 24% indicated they did not seek help because they could not afford legal services, 16% indicated not knowing who or where to call, 14% did not know if a lawyer could help them, 6% were afraid of being treated badly because of their HIV status, 6% were afraid of being treated badly for other reasons, and 4% reported not having access to transportation. For cisgender women, similar to all other respondents, affordability and awareness of legal services were barriers to getting legal assistance. Table 3 describes respondents' experiences with regard to barriers to accessing legal assistance.

**Table 3: Barriers to Accessing Legal Assistance for Most Recent Legal Need**

	Cisgender Women	All Respondents
<b>For those who did not look for help (n=222; 51 Cisgender Women)</b>		
I could not afford legal services	24%	26%
I did not know who or where to call	16%	15%
I did not know if a lawyer could help me	14%	19%
I was afraid of being treated badly because of my HIV status	6%	6%

<sup>30</sup> 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.

<sup>31</sup> Indicates that respondent reported that the person assisting them was a lawyer.

## C. Accessing Assistance for Legal Needs

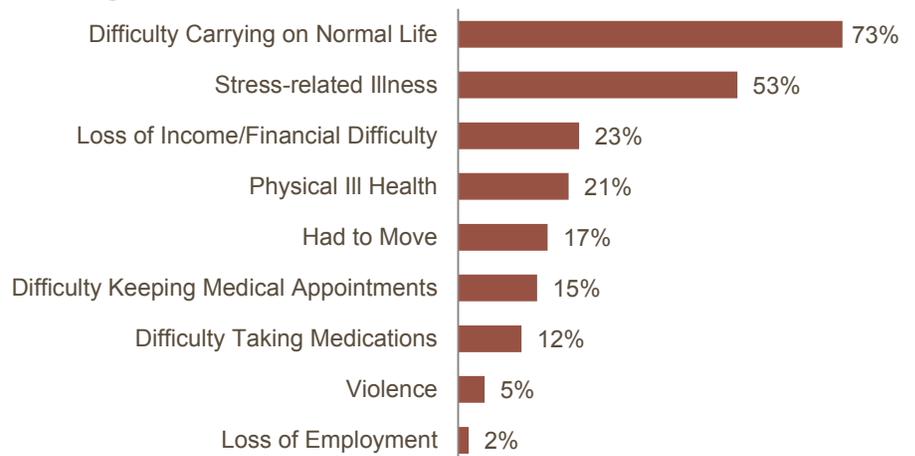
Of all respondents who answered follow up questions about their most recent legal need, 28% indicated they looked for a lawyer or legal advisor to help with their most recent legal need, 21% found some form of assistance, 16% found help from a lawyer, and 13% reported that they found that legal assistance helpful. For cisgender women, the figures were similar: 23% indicated that they looked for a lawyer or legal advisor to help with their most recent legal need, 14% found some form of assistance, 11% found help from a lawyer and 8% reported that they found the legal assistance helpful

At the time of survey, 32% of cisgender women indicated the identified problem was resolved, and 68% indicated that they still had the problem, regardless of whether they had received assistance. Among cisgender women who still had the problem, 16% felt the situation had gotten worse, 4% felt the situation had gotten better, and 80% felt there was no change with the problem. Overall, 29% of all cisgender women indicated they either helped themselves or solved the identified problem on their own.

## D. Impact of Legal Needs

Based on the effects of their most recent legal need, cisgender women reported impacts on their lives from not receiving legal assistance. These included difficulty carrying on normal life (73%), stress-related illness (53%), loss of income or financial difficulty (23%), physical ill health (21%), having to move (17%), difficulty keeping medical appointments (15%) and difficulty taking medications (12%). Other impacts reported included experiencing violence (5%) and loss of employment (2%), as a result of their recent legal need.

**Figure 2: Reported Impacts of Most Recent Legal Need for Cisgender 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 cisgender 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 cisgender women living with HIV (e.g. health care access, consumer law, housing, public benefits, victimization, criminal law, and discrimination).

The legal needs identified through the LeAN Survey with regard to limitations in health care access may be significant given that cisgender women living with HIV tend to experience unique health problems.<sup>32</sup> Chief among these concerns include gynecological and reproductive health concerns. For example, cisgender women who do not receive proper prenatal care face increased risks of transmitting HIV to their unborn children. Thus it is especially important for cisgender women to receive the health care and treatment both desired and needed, in a timely manner.

Specific legal needs in the area of family law also indicate that cisgender women have needs which are different and apart from the needs of other subgroups. Family law and legal matters with regard to custody, in particular, are considered especially critical matters as low-income individuals often go unrepresented.<sup>33</sup> Because there is a limited amount of civil legal assistance provided in these matters, generally, legal services providers will need to consider how to coordinate with existing programs and leverage state-level efforts to address this justice gap.<sup>34</sup>

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 cisgender 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 cisgender 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 women living with HIV.

## 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.<sup>35</sup>

<sup>32</sup> AIDS.GOV., WOMEN'S HEALTH (2015), <https://www.aids.gov/hiv-aids-basics/staying-healthy-with-hiv-aids/taking-care-of-yourself/womens-health/>.

<sup>33</sup> LEGAL SERVICES CORPORATION, DOCUMENTING THE JUSTICE GAP IN AMERICA: THE CURRENT UNMET CIVIL LEGAL NEEDS OF LOW-INCOME AMERICANS (2009), available at <http://www.americanbar.org/content/dam/aba/migrated/marketresearch/PublicDocuments/JusticeGapInAmerica2009.authcheckdam.pdf>.

<sup>34</sup> See Sargent Shriver Civil Counsel Act (codified in CAL. GOV'T CODE §68650 et. seq.); See also CALIFORNIA COURTS, SARGENT SHRIVER CIVIL COUNSEL ACT PILOT PROJECTS (2016), available at <http://www.courts.ca.gov/15703.htm> (describing three of seven projects dedicated to custody matters).

<sup>35</sup> 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>.

## V. ACKNOWLEDGEMENTS

### Research Team

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