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# The Legal Needs of People Living with HIV

Evaluating Access to Justice in Los Angeles

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## I. EXECUTIVE SUMMARY

### A. 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> 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. Needs assessments in other jurisdictions have been broad and focused on a variety of service categories including legal services. The most recent legal needs assessment focused on PLWH in LAC was completed in 1998, over 15 years prior to this study.<sup>2</sup> Since that time, the medical and legal frameworks in addition to funding sources for HIV legal services have changed drastically. In May 2012, LAC’s legal services provider dedicated solely to PLWH, the HIV & AIDS Legal Services Alliance, closed its doors. This closure raised questions about whether the changing medical and legal landscape for PLWH in LAC had reduced HIV-specific legal needs and whether such legal needs were being met by other legal services providers. This study was designed to answer these questions.

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

This report summarizes findings of the LeAN Study – an online survey with 387 respondents who identified as PLWH. We describe respondents’ legal needs,<sup>3</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 among subpopulations that are traditionally underserved and understudied, including gay and bisexual men (“GBM”), people of color, and cisgender and transgender women. Finally, we discuss how these legal needs may relate to health access and health status.

### C. Main Findings

- Almost all respondents had a legal need.
  - Ninety-eight percent of respondents reported they had a legal need in the year prior to the survey.
  - Almost all of those with a legal need said that they did not have a testamentary will and/or an advanced health care directive.
  - Ninety-one percent of all respondents reported a legal need in at least one other remaining legal issue area.

<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> HIV & AIDS LEGAL SERV. ALLIANCE, 1998 HALSA LEGAL NEEDS ASSESSMENT (1998), *available at* [http://www.bc.edu/content/dam/files/schools/law\\_sites/library/pdf/content/tremblay\\_schulman/1998.HALSA.Legal%20Needs%20Assessment.Excerpt.pdf](http://www.bc.edu/content/dam/files/schools/law_sites/library/pdf/content/tremblay_schulman/1998.HALSA.Legal%20Needs%20Assessment.Excerpt.pdf).

<sup>3</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.

- On average, respondents had more than one legal need in more than one legal issue area.
  - An average of six distinct legal needs in four legal issue areas in the year prior to taking the survey were reported.

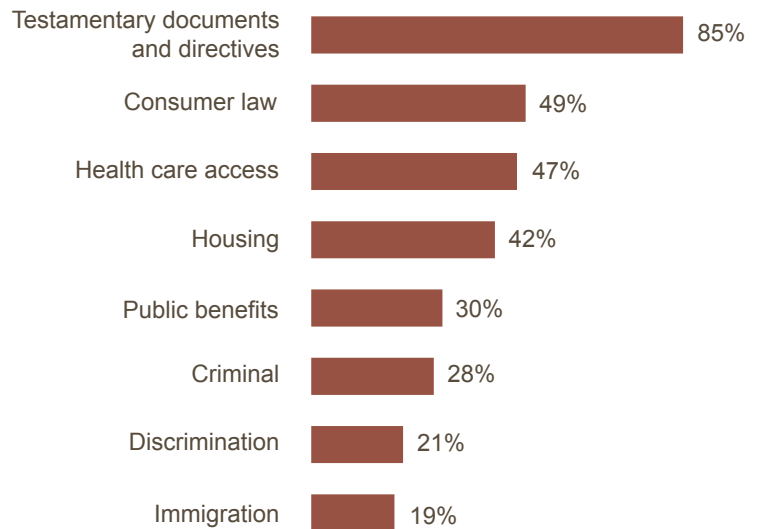
- Many respondents did not look for legal help and those that did look did not always find qualified legal assistance.

- Twenty-eight percent of respondents who had a legal need sought help.
- Among the respondents who had a legal need and looked for help, 26% were unable to find assistance.
- Of those individuals who did not get assistance, 22% reported not finding help because they felt that the provider was insensitive to their needs as a PLWH.
- Among respondents who did not seek assistance for their most recent legal need, six percent reported that one of the reasons they did not seek assistance was because they were afraid of being treated badly because of their HIV status.

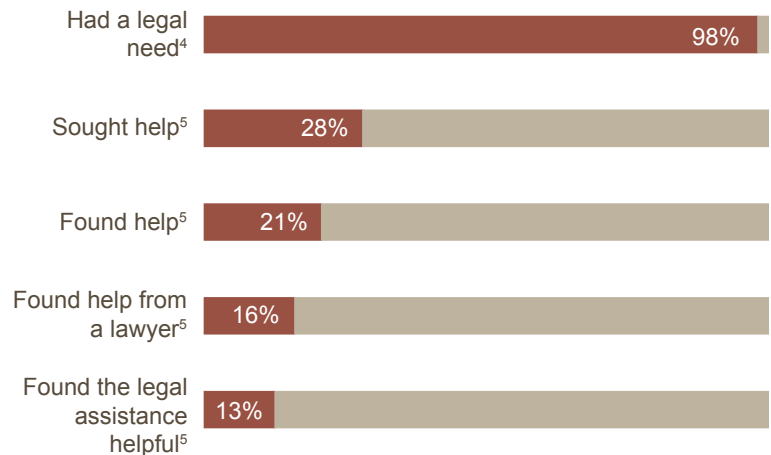
- Only 16% of the respondents who reported having a legal need were successful in receiving assistance from a lawyer.

- Immigration was an area of legal need for a significant subgroup of the study sample.<sup>45</sup>
  - Nineteen percent of respondents reported a legal need in immigration law, 93% of whom identified as Hispanic, Latino or of Spanish origin.
  - Legal issues in immigration included:
    - needing assistance with a green card (49%)
    - citizenship (22%)
    - coming into contact with Immigration and Customs Enforcement (22%)

**Figure 1.1: Most Prevalent Legal Issue Areas Reported**



**Figure 1.2: Help Seeking Behavior and Assistance Received**



<sup>4</sup> The existence of a legal need was measured out of the entire study sample (n=387).

<sup>5</sup> All other responses were measured out of those who answered follow up questions about their most recent legal need (n=316).

- Gender and sexual minority statuses were a factor in some of the legal issue areas.
  - Nearly half of all transgender women reported experiences of being harassed, attacked with violence, and/or subjected to another crime in the past year (44%).
    - 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%).
  - When compared to cisgender women and straight cisgender men, gay and bisexual men were significantly more likely to report being harassed, attacked with violence, and/or subjected to another crime in the past year (41%).
  - Transgender women were significantly more likely to report having been incarcerated in the five years prior to the survey than cisgender women (26% versus 12%, respectively).
- HIV-related discrimination was reported by participants in several areas.
  - In the five years prior to the survey, 31% of respondents reported experiencing HIV-based discrimination in housing, employment and/or health care settings.
  - Among those 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.
- Affordability and awareness of legal services was a barrier to getting legal assistance.
  - Among the 71% of respondents who had a legal need and did not look for legal assistance, 26% indicated they did not seek help because they could not afford legal services, and 15% indicated not knowing who or where to call.
- Respondents reported impacts on their lives from not receiving legal assistance.
  - Respondents described the impact of their most recent legal need, including difficulty carrying on normal life (70%), stress-related illness (59%), physical ill health (25%), difficulty keeping medical appointments (19%), difficulty taking medications (17%), and loss of income or financial difficulty (19%).

## **D. Policy, Practice, and Research Implications**

- It appears that low-income PLWH have numerous legal needs and in a broad range of legal issue areas. Thus, addressing all legal needs of PLWH would require 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 serving PLWH to prioritize areas of legal practice (e.g. testamentary documents and directives, consumer law, health care access, and housing).
- Given that immigration law is an area of high need among Latinos, legal services providers may consider prioritizing legal resources for immigration law in order to fully serve the legal needs of Latino PLWH.
- Transgender women and GBM represent especially vulnerable communities with specific legal needs in areas of physical victimization and criminal law. Legal service providers may want to consider implementing targeted programming to address the needs of this population.
- It appears that many PLWH in LAC continue to face HIV-related stigma and experience HIV-based discrimination in different aspects of daily life. To bolster existing HIV non-discrimination law, steps taken to reduce stigma and discrimination may include providing continuing education on HIV/AIDS

issues and law to service providers who serve PLWH in these contexts (e.g. health care providers, housing providers, employers, corrections officers, legal services providers and law enforcement officers). Further, research on best practices for delivering culturally competent legal services would be a useful next step for the field.

- 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 PLWH about how to identify a legal need would, in part, address this particular gap. Further, the study shows that vulnerable PLWH in LAC need more information on the availability of legal resources that are low to no cost. Increased outreach about available resources could influence help-seeking behavior among PLWH with legal needs.
- Finally, these self-reported impacts resulting from legal needs indicate more research is necessary to explore the relationship between the presence of legal needs and its impact on the health of PLWH.

## **E. 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.

## II. 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>6</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 HIV legal services and the legal needs of PLWH are limited.<sup>7</sup> Needs assessments in other jurisdictions have been broad and focused on multiple service categories such as primary care services, oral health, medication, case management, mental health, food, emergency financial assistance, housing, and psychosocial support, in addition to legal services. While these assessments highlight the overall need for legal assistance among PLWH in their jurisdictions, the assessments do not capture the exact nature of those legal needs.<sup>8</sup>

The most recent legal needs assessment focused on PLWH in LAC was completed in 1998, over 15 years prior to this study.<sup>9</sup> Since that time, the medical and legal frameworks in addition to funding sources for HIV legal services changed drastically. New medications have increased survival rates, reduced transmission, and improved the quality of life for many PLWH. Since 1998, the Supreme Court has ruled that discrimination against all PLWH because of their HIV status is prohibited under the federal Americans with Disabilities Act,<sup>10</sup> and the federal government has removed its ban on immigration for PLWH.<sup>11</sup> That is, laws are in place to protect PLWH. However, as in many other areas of discrimination, existing laws do not guarantee that discrimination will not happen. Legal assistance is still needed to access justice under the law. Further, a number of areas in which PLWH are likely to experience legal needs at higher rates (housing, health care, employment) may also require legal assistance to resolve.

Unfortunately, in LAC, a significant amount of federal funds ceased being allocated to the provision of HIV legal services.<sup>12</sup>

In May 2012, LAC’s HIV legal services provider, the HIV & AIDS Legal Services Alliance, closed its doors. This closure called into question whether the changing medical and legal landscape for PLWH in LAC had reduced

<sup>6</sup> DIV. OF HIV & STD PROGRAMS, L.A. CNTY. DEP’T OF PUB. HEALTH, *supra* note 1.

<sup>7</sup> See e.g. CTR. FOR HIV LAW & POLICY, SEND LAWYERS, GUIDES AND MONEY: THE LEGAL SERVICES NEEDS OF PEOPLE LIVING WITH HIV IN THE SOUTHERN UNITED STATES (2010), <http://www.hivlawandpolicy.org/sites/www.hivlawandpolicy.org/files/Southern%20Survey%20Report%20Final.pdf>; JEFFREY A. MENZER ET. AL., LEGAL SERVICES NEEDS OF FAMILIES AFFECTED BY HIV/AIDS (2001), <http://www.familytiesproject.org/Documents/legalneeds.pdf>.

<sup>8</sup> See e.g. LA. DEP’T OF HEALTH AND HOSP., OFFICE OF PUB. HEALTH, PEOPLE LIVING WITH HIV NEEDS ASSESSMENT (2013), [http://new.dhh.louisiana.gov/assets/oph/HIVSTD/RFI/PLWHA\\_Statewide\\_Report\\_DRAFT.pdf](http://new.dhh.louisiana.gov/assets/oph/HIVSTD/RFI/PLWHA_Statewide_Report_DRAFT.pdf); MICHAEL DEMAYO ET AL., 2011 ATLANTA EMA HIV/AIDS CONSUMER SURVEY (2011), [http://www.seatec.emory.edu/documents/ema\\_consumer\\_rpt.pdf](http://www.seatec.emory.edu/documents/ema_consumer_rpt.pdf); FLA. DEP’T OF HEALTH, BUREAU OF HIV/AIDS AND PATIENT CARE PLANNING GROUP, FLORIDA’S 2012-2015 STATEWIDE COORDINATED STATEMENT OF NEED AND COMPREHENSIVE PLAN(2012), [http://www.floridahealth.gov/diseases-and-conditions/aids/patient-care/\\_documents/Floridas-2012-15-SCSN-Comprehensive-Plan.pdf](http://www.floridahealth.gov/diseases-and-conditions/aids/patient-care/_documents/Floridas-2012-15-SCSN-Comprehensive-Plan.pdf); JSI RESEARCH AND TRAINING INST., MASSACHUSETTS AND SOUTHERN NEW HAMPSHIRE HIV/AIDS CONSUMER STUDY (2011), <http://www.mass.gov/eohhs/docs/dph/aids/consumer-study-june-2011.pdf>.

<sup>9</sup> HIV & AIDS LEGAL SERV. ALLIANCE, *supra* note 2.

<sup>10</sup> *Bragdon v. Abbott*, 524 U.S. 624 (1998).

<sup>11</sup> Medical Examination of Aliens-Removal of Human Immunodeficiency Virus (HIV) Infection from Definition of Communicable Disease of Public Health Significance, 74 Fed. Reg. 56547 (Nov. 9, 2009).

<sup>12</sup> In 2012, the Los Angeles County Commission on HIV ceased allocating significant Ryan White CARE funds for the provision of HIV legal services. The only significant federal funding source remaining is a grant from Housing Opportunities for People with AIDS (HOPWA).



HIV-specific legal needs and whether such legal needs were being met by other legal services providers. This study was designed to answer those questions.

This report summarizes findings of the LeAN Study. We describe respondents' legal needs,<sup>13</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 in these findings among subpopulations that are traditionally underserved and understudied, including gay and bisexual men ("GBM"), people of color, and cisgender and transgender women. Finally, we discuss how these legal needs may relate to health access and health status.

### III. SURVEY

The research team, including Williams Institute scholars, staff, attorneys, graduate students, and various stakeholders in the HIV-positive community, engaged in a year-long process to develop a unique legal needs assessment tool. Prior to launching the LeAN Study, the survey instrument was pilot tested and revised according to findings of the pilot. Questions focused on the following topic areas: demographic information, a legal needs evaluation focused on legal needs in the year and five years prior to the survey, 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. The aim of the survey was to examine experiences in multiple areas of conflict or concern in which PLWH may have needed legal assistance, rather than narrowly focus on issues that the average citizen identifies as a "legal issue."

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. The interview was offered in English and Spanish and could be completed online or in-person. In-person respondents had the option to complete the web survey independently on a laptop provided by the study researchers, or orally with assistance from a survey administrator. Respondents who completed the survey received a \$5 incentive. Study procedures were approved by the UCLA Institutional Review Board.

From July through October, 2014, the research team conducted 52 outreach sessions throughout LAC in locations run by organizations and service providers catering to lower income PLWH. Of the 52 outreach sessions, surveys were administered during 43 of those sessions, over half of which were conducted in conjunction with AIDS Project Los Angeles' community-based food pantry program, established to provide free groceries to low-income PLWH throughout LAC. Other participating locations included Bienestar, L.A. Family AIDS Network, Skid Row Housing Trust, LAMP Community, JWCH Institute, Harbor-UCLA, and large gatherings of PLWH at the L.A. HIV Women's Task Force Annual Conference, Strength for the Journey, and CHIRP L.A.'s Annual Housing Resource Fair. The final dataset<sup>14</sup> includes 387 total complete surveys, of which 21% were completed in Spanish.

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<sup>13</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. The list of issues with legal implications was developed by a team of attorneys and HIV/AIDS researchers within the Williams Institute.

<sup>14</sup> All statistical analyses were completed with Stata version 13.0. Any comparisons drawn throughout the report have been found to be statistically significant at the  $p=.05$  level unless otherwise indicated.

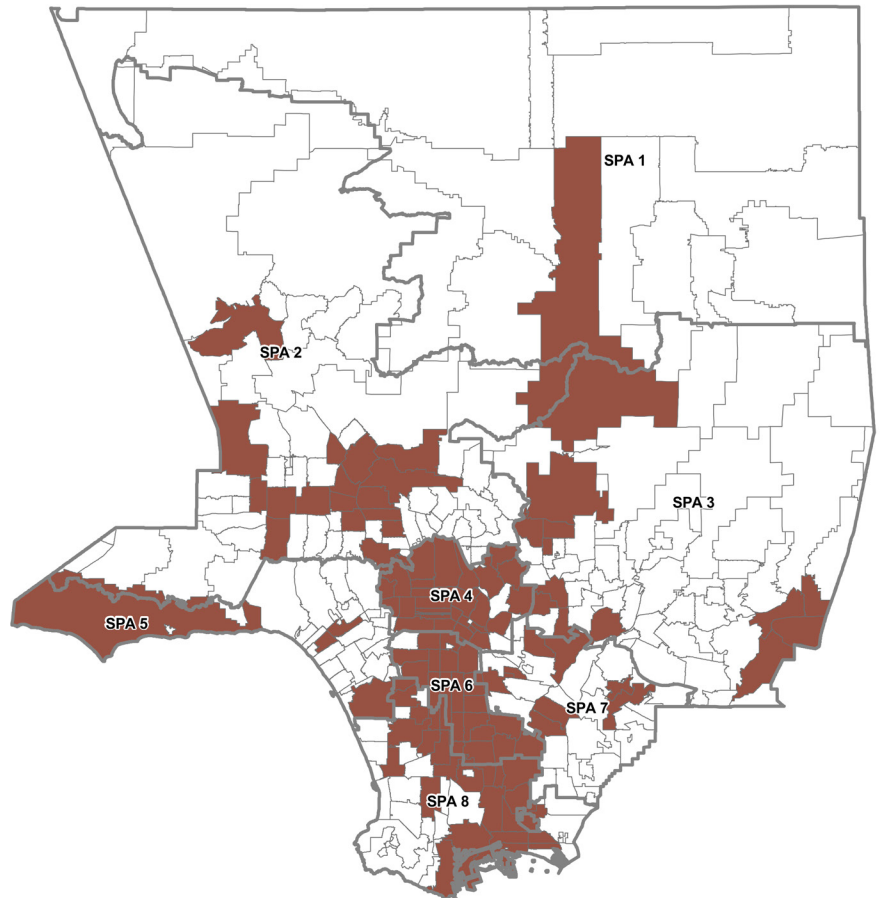


## IV. DEMOGRAPHICS

Respondents were 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>15</sup> 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. Figure 4.1 shows a map with the distribution of respondents' reported residential zip codes according to Special Planning Areas ("SPA") of LAC.

The study sample included 35% straight-identified individuals and 61% lesbian, gay or bisexual ("LGB")-identified individuals, most of whom were assigned male at birth. When asked about current employment status, 18% of respondents reported being currently employed, 48% reported not working due to disability, and 24% of respondents indicated they were unemployed and looking for work. Overall, 26% of respondents reported less than a high school education, 31% reported having a high school diploma or equivalent, and 43% indicated attending college or graduate school. 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>16</sup> Over 75% of respondents reported receiving a public benefit of some kind. Sixty-six percent of respondents reported being born in the United States.

**Figure 4.1: Respondents' Reported Residence by Zip Code and SPA**



<sup>15</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.

<sup>16</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).

## V. LEGAL NEEDS

The questionnaire elicited responses that indicated the likely presence of a legal need.<sup>17</sup>18192021222324252627282930

**Table 5.1: Identified Legal Needs in Year Prior by Legal Issue Area**

	GBM	Cisgender women	Transgender women	All respondents
Testamentary documents & directives <sup>18</sup>	84%	83%	94%	85%
Consumer law <sup>19</sup>	50%	48%	41%	49%
Health care access <sup>20</sup>	48%	49%	44%	47%
Housing <sup>21</sup>	46%	39%	29%	42%
Public benefits <sup>22</sup>	31%	28%	21%	30%
Criminal <sup>23</sup>	28%	23%	41%	28%
Discrimination <sup>24</sup>	22%	18%	24%	21%
Immigration <sup>25</sup>	19%	10%	50%	19%
Taxes <sup>26</sup>	17%	12%	9%	14%
Private insurance <sup>27</sup>	10%	9%	21%	12%
Tort (Injury) <sup>28</sup>	10%	11%	9%	11%
Family <sup>29</sup>	4%	11%	3%	6%
Improper disclosure of HIV status <sup>30</sup>	4%	4%	3%	4%

<sup>17</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>18</sup> Includes responses indicating respondents did not have a will or an advanced health care directive in place.

<sup>19</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>20</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>21</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>22</sup> Includes responses indicating respondents were denied disability, general income or health care benefits and/or were informed of a benefits overpayment.

<sup>23</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.

<sup>24</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>25</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>26</sup> Includes responses indicating respondents owed or had been told they owe money for taxes for past years.

<sup>27</sup> Includes responses indicating difficulty in getting private insurance or termination of private insurance due to HIV status.

<sup>28</sup> Includes responses indicating experiences of being badly injured due to someone else's fault including bad medical treatment.

<sup>29</sup> Includes responses indicating needing help with a divorce, separation, child custody or adoption.

<sup>30</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.

The study showed that PLWH in LAC have a diverse array of legal needs. Among respondents surveyed, 98% identified experiencing a legal need in the year prior to taking the survey. Respondents reported experiencing a mean of six (median = five) distinct legal needs in four (median = three) legal issue areas. Table 5.1 describes the legal needs respondents faced in the year prior to the interview, arranged according to legal issue area. The table provides further breakdown of the data across GBM, cisgender women, and transgender women.

A large percentage of respondents (85%) 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. Even after removing respondents who identified this issue area as their sole legal need, results indicated that 91% of all respondents reported experiencing a legal need in at least one other remaining legal issue area. Legal issue areas, other than not having a testamentary will and/or an advanced health care directive, most frequently identified by respondents included the following:

- consumer law (e.g. debt collection, bankruptcy, and/or overdue bills);
- health care access (e.g. not getting medical care or medication when needed, not having health coverage at the time of the survey or in the five-year period prior to the survey, and/or not seeking routine HIV care because of lack of money or health insurance); and
- housing (e.g. experiences of homelessness or unstable housing, landlord refusal to fix habitability issues, receipt of a notice to leave the home such as an 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).

## A. Consumer Law

Almost half of respondents (49%) reported experiencing a legal issue having to do with consumer law in the past year. Among those with consumer/debt issues, 64% reported receiving harassing phone calls or letters demanding payment from creditors, and 29% reported that a government agency had taken money from their public benefits due to debt. Over 60% of respondents with consumer/debt issues reported being three or more months behind on payments for student loans, medical bills, credit cards, child support or car loans.

## B. Health Care Access

Measures in the survey regarding access to medical care, medication, health insurance or health coverage indicated that 47% of respondents, regardless of gender, sexual orientation and race/ethnicity, experienced some challenges accessing health care in the year prior to the survey. Of those respondents, 55% reported they did not get medical care when they needed it, and 62% did not get medication when they needed it in the year prior to the survey. Over 16% reported having no health insurance or health coverage at the time of the survey, and over 32% experienced a lapse in health insurance/health coverage in the five-year period prior to the survey.

## C. Housing

Nineteen percent of respondents reported unstable housing (being homeless, in a shelter or staying somewhere temporarily sometime in the year prior to the survey). Forty-two percent of all respondents reported a legal need in housing, including being unstably housed. Among respondents who reported having a legal housing need who were renters in the past year, 66% reported a habitability problem (e.g. lack of heat or mold) that a landlord refused to address, 20% reported being three or more months behind on paying rent or a mortgage, and 34% reported receiving some type of notice of eviction.

## D. 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. Table 5.2 describes respondents' reported experiences with HIV-related discrimination in housing, employment and health care settings. The table provides further breakdown of the data across GBM, cisgender women, and transgender women.<sup>31323334</sup>

Five percent of respondents reported experiencing discrimination in health care settings related to their HIV status in the year prior to the interview and ten percent in a five-year period. Among those respondents who reported health care discrimination in the past five years, 43% reported being denied dental care, 25% reported being denied care by a

**Table 5.2: Experiences of HIV-Related Discrimination in Housing, Employment and Health Care Settings**

		GBM	Cisgender women	Transgender women	All respondents
Housing	<b>One year</b> <sup>31</sup>	10%	11%	3%	10%
	<b>Five years</b> <sup>32</sup>	12%	12%	9%	12%
Health care <sup>33</sup>	<b>One year</b>	5%	4%	9%	5%
	<b>Five years</b>	11%	6%	12%	10%
Employment <sup>34</sup>	<b>One year</b>	9%	6%	9%	8%
	<b>Five years</b>	17%	12%	15%	16%

doctor, nurse or medical specialist, and 73% reported being treated differently by a doctor or dentist on the basis of their HIV status.

Thirty-nine percent reported currently working or reported working sometime in the five years prior to the study. Among those individuals, 21% reported experiencing some form of workplace discrimination in the five-year period prior to the survey. Five percent of all respondents reported being denied a job because of their HIV

<sup>31</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>32</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>33</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>34</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.

status in the five years prior to the survey. Some of those respondents reported not finding work at all in the five years prior to the survey. Among those who reported specific experiences of workplace discrimination based on HIV status in the previous five years, 37% were harassed by a co-worker, 26% were fired, 26% were asked inappropriate questions about their HIV or AIDS status, 21% reported being refused a reasonable accommodation (e.g. adjustable workstation, rest breaks for fatigue, or modification of work schedule), 18% were refused time off from work to attend a medical appointment, 16% were removed from direct contact with other people, 13% were denied a promotion, and 3% were attacked with violence while at work.

## **E. Attacked, Harassed, or Subjected to Crime**

Apart from the figures in Table 5.1 indicating respondents' recent experiences with criminal law matters, the study also asked respondents about experiences of being attacked with violence, harassed and/or subjected to another crime in year prior to the taking the survey. Thirty-five percent of all respondents reported being attacked with violence, harassed, and/or subjected to another crime. Within that group, 49% reported a violent attack, 70% reported harassment, and 51% reported victimization from some other crime.

## **VI. TRENDS IN LEGAL NEEDS AMONG SUBPOPULATIONS OF PLWH**

In some legal issue areas, trends with regard to legal needs varied between and among specific subpopulations. A few issues should be highlighted based on reported gender identity, sexual orientation, and race/ethnicity.

### **A. Latinos and Immigration**

Of respondents who reported immigration issues as a legal need, 93% identified as Hispanic, Latino or of Spanish origin. Approximately 41% of Latino respondents reported an immigration need, compared to 1.5% of White respondents and 2% of Black respondents. Among all respondents who identified an immigration need, 49% stated they needed assistance to obtain a green card, 22% reported needing assistance with citizenship, and 22% indicated some contact with the Immigration and Customs Enforcement in the past year.

### **B. GBM, Transgender Women and Harassment and Violence**

Gay and bisexual men as well as transgender women reported high levels of harassment, violent attack and victimization from some other crime(s). Gay and bisexual men were significantly more likely to report such victimization (41%) as compared to cisgender women (24%) and straight cisgender (17%) men. Transgender women were particularly vulnerable to violent attacks (29%) and were significantly more likely to report being violently attacked than straight cisgender men (7%).

### **C. Transgender Women and the Criminal Justice System**

Forty-one percent of all transgender women reported an interaction with the criminal justice system, which was a significantly higher rate than cisgender women (23%). This included having a sex partner threaten to contact the



police, being accused of committing a crime, being arrested, being criminally prosecuted, receiving a sentence/probation, and/or reporting incarceration for a week or more. Among incarcerated transgender women, 56% reported experiencing problems<sup>35</sup> related to their HIV during that time.

## D. Incarcerated Individuals

Sixteen percent of respondents reported being incarcerated for a week or more in the five years prior to the interview. When asked about their experiences while confined, 56% of those respondents reported experiencing problems associated with their HIV status. Among those who were incarcerated, 32% reported problems accessing HIV medications, 41% reported being separated from others due to their HIV status, and 15% reported being denied access to services in the jail or prison as a result of their HIV status.

## VII. BARRIERS TO ACCESSING ASSISTANCE FOR LEGAL NEEDS

Seventy-one percent of respondents who answered follow up questions regarding their most recent legal need reported not looking for a lawyer or legal advisor for help.<sup>36</sup> As a result, among respondents who identified a legal need, only 16% reported receiving legal assistance.<sup>37</sup>

**Table 7.1: Barriers to Accessing Legal Assistance for Most Recent Legal Need**

	GBM	Cisgender women	Transgender women	All respondents
<b>For those who looked for help (n=89)</b>				
Could not find help	27%	40%	0%	26%
...because provider did not handle that area of law	27%	33%	0%	26%
...because provider was insensitive to my needs as HIV-positive person	27%	17%	0%	22%
<b>For those who did not look for help (n=223)</b>				
I could not afford legal services	26%	24%	26%	26%
I did not know if a lawyer could help me	23%	14%	16%	19%
I did not know who or where to call	17%	16%	11%	15%
I was afraid of being treated badly because of my HIV status	7%	6%	5%	6%

Some of the information provided by respondents regarding their most recent legal need may explain common barriers for accessing assistance for a legal need. For example, among respondents who looked for assistance and reported not finding help, 22% reported feeling that the provider was insensitive to respondents' needs as a PLWH, and 26% of respondents were told by a legal services provider that the provider did not handle that particular area of law. Among respondents who did not look for assistance, 26% of respondents indicated they did not seek help because they could not afford legal services. Table 7.1 describes respondents' experiences with regard to barriers to accessing legal assistance. The table provides further breakdown of the data across GBM, cisgender women, and transgender women.

<sup>35</sup> See section VI(D).

<sup>36</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>37</sup> Indicates that respondent reported that the person assisting them was a lawyer.

One pattern that emerged in findings was that among the different subpopulations, transgender women who looked for legal help reported no barriers in accessing assistance. This was not the case for the other subgroups. Yet, a similar proportion of transgender women as all other respondents who did not seek help experienced barriers to receiving help.

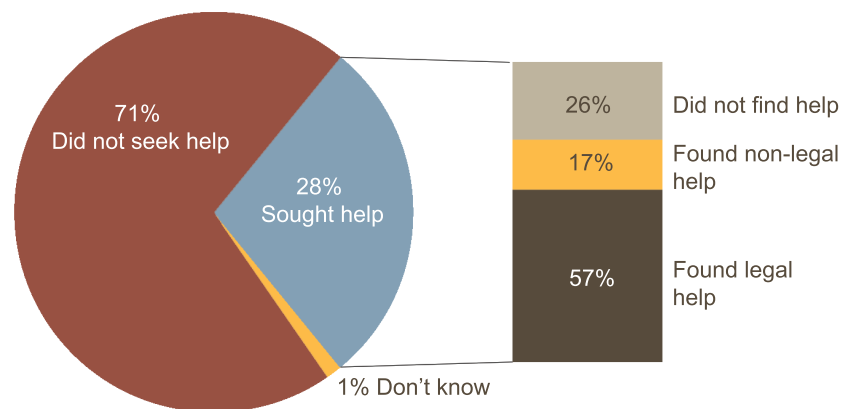
## VIII. ACCESSING ASSISTANCE FOR LEGAL NEEDS

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.<sup>38</sup>

Of the 28% of respondents who sought help, 26% did not find help, 57% found legal help,<sup>39</sup> and 17% found non-legal help.<sup>40</sup> Among respondents who reported that they received any assistance, 76% found the assistance was helpful,<sup>41</sup> 14% found the assistance was not helpful, and 11% did not know if the assistance was helpful.

**Figure 8.1: Assistance Received Among Those who Sought Help**

How many looked for a lawyer or legal advisor to help with their most recent legal issue?



At the time of survey, 30% of respondents indicated the identified problem was resolved. Seventy percent of respondents indicated that they still had the problem, regardless of whether they had received assistance. Among those who had sought assistance, those who received assistance were significantly more likely to report having resolved the problem at the time of the survey (35%) than those who did not find assistance (9%). Among respondents who still had the problem, 20% felt the situation had gotten worse, 16% felt the situation had gotten better, and 65% felt there was no change with the problem. Overall, 16% of all respondents indicated they either helped themselves or solved the identified problem on their own.

## IX. IMPACT OF LEGAL NEEDS

The impact of legal needs on the lives of respondents was explored in follow up questions to the legal needs evaluation. Seventy percent of respondents reported difficulty in carrying on their normal life as a result of their most recent legal need. Eighty-eight percent indicated that resolving the problem was important, and 59% reported experiencing a stress-related illness as a result of dealing with their legal need. Twenty-five percent of

<sup>38</sup> See Figure 1.2.

<sup>39</sup> Indicates that respondent reported that the person assisting them was a lawyer.

<sup>40</sup> Indicates that the respondent reported that the person assisting them was not a lawyer or they did not know if the person assisting them was a lawyer or not.

<sup>41</sup> Includes responses indicating assistance was "somewhat helpful" or "very helpful."



respondents reported suffering physical ill health, 19% reported difficulty keeping medical appointments, and 17% reported difficulty taking medications. Finally, 19% of respondents reported experiencing loss of income or financial difficulty as a result of dealing with their most recent legal need.

## X. DISCUSSION

The LeAN study is the first client-level study since 1998 to capture the depth and breadth of the legal needs of PLWH in LAC.<sup>42</sup> The study sample focused on a particularly vulnerable population of PLWH in LAC, and, therefore, our results are not representative of all

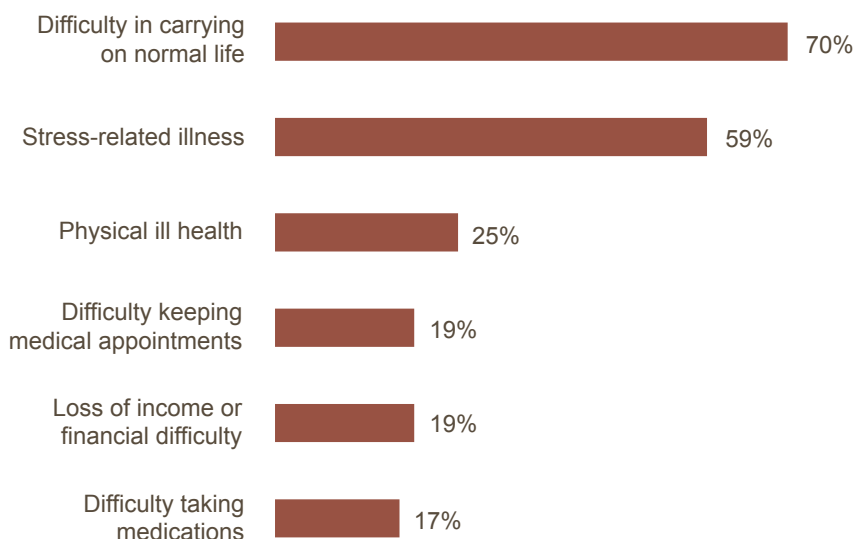
PLWH in LAC. Respondents were low-income individuals and included a greater number of cisgender women, transgender women, Black-identified individuals, and heterosexual or straight-identified individuals than the general population of PLWH in LAC. Table 10.1 describes the demographics of the LeAN Survey respondents as compared to all PLWH in LAC.

Legal service providers may find the specific focus on vulnerable populations to be relevant to their practice of the law. For example, individuals with higher incomes than those represented in our study are more likely to access legal assistance from private counsel, which lower income individuals cannot afford. Most HIV legal services providers are funded by government sources that limit client eligibility by income, thus, understanding the particular legal needs of lower income PLWH who are also likely to be accessing other types of safety net programs is useful in designing targeted interventions.

Results of the study indicate that almost all individuals reported the likely presence of a legal need (98%), and respondents reported experiencing an average of six distinct legal needs in four legal issue areas in the year prior to taking the survey. Legal issue areas of highest need included testamentary documents and directives (85%), consumer law (49%), health care access (47%), and housing (42%).

Almost all respondents indicated not having testamentary documents and/or directives, such as an advance health care directive. Testamentary documents, such as wills or trusts, provide power of attorney over financial affairs. Low-income individuals may not feel a need to have such documents in place for their personal property. Advance health care directives, on the other hand, provide power of attorney over health decisions. All individuals, regardless of income, may need assistance from another person in making health decisions in the future. This document is particularly important for individuals living with a chronic condition such as HIV.

**Figure 9.1: Reported Impacts of Most Recent Legal Need**



<sup>42</sup> HIV & AIDS LEGAL SERV. ALLIANCE, *supra* note 2.

Health care access was also identified as a high need legal issue area. Almost half of all respondents reported problems accessing health care, including problems accessing medical care, medication, health insurance or health coverage. Ongoing access to these resources is central to ensuring that PLWH stay in care and continue to be compliant with treatment. Not every problem accessing health care requires legal assistance. However, tackling barriers to these resources can often be aided by legal assistance. Maintaining good health also supports a person's ability to work and maintain a regular income. Given that many legal problems stem from a lack of financial resources, experiencing ill health as a result of difficulties accessing health care may contribute to greater legal needs especially among vulnerable low-income individuals.<sup>43444546</sup>

Many respondents faced challenges related to housing. Nearly one in five respondents reported being unstably housed sometime in the year prior to the survey, meaning that they had lived in a shelter, stayed with friends or family temporarily, or were homeless. Among respondents who were renters reporting a legal need in housing, two out of three respondents indicated likely problems with substandard housing. GBM-identified respondents reported the highest housing-related needs. Stable housing is associated with better health outcomes among PLWH,<sup>47</sup> which highlights the need to get these issues addressed by qualified legal staff.

**Table 10.1: LeAN Survey Sample Compared to PLWH in Los Angeles County**

	LeAN survey respondents	PLWH in LAC <sup>43</sup>
<b>Sex</b>		
Cis-male	69%	89%
Cis-female	21%	10%
Transgender <sup>44</sup>	9%	1%
<b>Age</b>		
40-49	29%	32%
40 or older	82%	75%
<b>Geographic Residence</b>		
Metro	43%	38%
South Los Angeles	21%	11%
South Bay	16%	17%
San Fernando	11%	14%
<b>Race/ethnicity</b>		
Latino	44%	41%
Black	37%	20%
White	17%	33%
American Indian/Alaska Native	6%	<1%
Asian/Pacific Islander	1.6%	3%
<b>Sexual Orientation/Mode of Transmission<sup>45</sup></b>		
Straight/Heterosexual	35%	10%
GBM/MSM	55% <sup>46</sup>	77%
<b>Living with AIDS diagnosis</b>		
	48%	58%

When asked about perceptions and experiences of HIV-based discrimination in the year and five-year period prior to the interview, respondents indicated experiencing discrimination in housing, employment, and health care settings. Among respondents who indicated experiencing HIV-related discrimination in the five years prior to the survey, one out of two experienced discrimination in health care settings, more than one out of three experienced discrimination in housing, and one out of three experienced discrimination in employment. Among all respondents that reported currently working or having worked sometime in the five-year period prior to the survey, one out of five reported experiencing some form of workplace discrimination on the basis of their HIV status. It is notable that these experiences with discrimination were reported despite the existence of federal and

<sup>43</sup> DIV. OF HIV & STD PROGRAMS, L.A. CNTY. DEP'T OF PUB. HEALTH, *supra* note 1.

<sup>44</sup> All transgender respondents were transgender women.

<sup>45</sup> Transmission categories indicate the type of contact that led to acquiring HIV. While inaccurate, we use this figure as a proxy to estimate the percentage of HIV-positive men who have sex with men in LAC. This is for the limited purpose of providing a general comparison between the study sample and the broader HIV-positive community in LAC.

<sup>46</sup> Includes respondents that reported male sex at birth, male current gender identity and sexual orientation as gay or bisexual.

<sup>47</sup> Chad A. Leaver, Gordon Bargh, James R. Dunn & Stephen W. Hwang, *The Effects of Housing Status on Health-Related Outcomes in People Living with HIV: A Systematic Review of the Literature*, 11 AIDS & BEHAVIOR S85 (2007).

state laws that theoretically protect PLWH against discrimination because of their HIV status.

Traditional legal service providers typically do not address legal needs in criminal law and are not always available to address discriminatory and unsafe conditions of confinement. Results of the survey, however, indicate that a fair number of respondents faced problems with these legal issue areas. More than a third of respondents were attacked, harassed, or subjected to some other crime in the year prior to the survey. The majority of individuals reporting incarceration for a week or more in the five years prior to the survey also reported problems associated with their HIV status while confined.

Among the subgroups of GBM, cisgender women and transgender women, the legal needs of GBM and transgender women were most distinct when compared to the legal needs of other respondents. GBM reported more experiences of being harassed, attacked with violence and/or subjected to another crime in the year prior to the survey, and transgender women had especially high rates of violent attack. Transgender women also had significantly more interactions with the criminal justice system than cisgender women. These differences between subgroups of PLWH appear to mirror previously documented vulnerabilities among LGBT people compared to cisgender and heterosexual people.<sup>48</sup>

Respondents were surveyed regarding their experiences with their most recent legal need. More than one out of four respondents reported looking for a lawyer or legal advisor for help. The top three reasons why the remaining nearly three-quarters of respondents reported not looking for help from a lawyer or legal advisor were that they could not afford legal services, they did not know if a lawyer could help, and they did not know who or where to call.

Finally, respondents reported experiencing impacts on their health related to their most recent legal need. Though this study was not designed to test the influence of legal need-related stress on health, the data do indicate a relationship between legal needs and reported overall health of PLWH. This should be explored in further research.

## **XI. IMPLICATIONS**

The following are implications of the study for policymakers and legal services providers serving PLWH. These implications reflect potential next steps for policy, practice and research.

- It appears that low-income PLWH have numerous legal needs and in a broad range of legal issue areas. Thus, addressing all legal needs of PLWH would require 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 serving PLWH to prioritize areas of legal practice (e.g. testamentary documents and directives, consumer law, health care access, and housing).
- Despite general trends toward legal specialization, study findings indicate that legal service providers must be prepared to address the breadth of legal needs PLWH currently face. This may be achieved through greater collaboration among legal organizations and HIV/AIDS organizations that provide non-legal services.
- HIV legal service providers must develop strategies to address the legal needs of PLWH such as those

<sup>48</sup> Gary W. Harper & Margaret Schneider, *Oppression and Discrimination among Lesbian, Gay, Bisexual, and Transgendered People and Communities: A Challenge for Community Psychology*, 31 AM. J. CMTY. PSYCHOL. 243 (2003).

captured among the low-income PLWH we studied. Given that immigration law is an area of high need among Latinos in LAC, legal services providers may consider prioritizing legal resources for immigration law. While serving undocumented individuals may not be possible for some federally-funded legal service providers, HIV legal service providers must pursue strategies, such as private funding or outside collaborations, which allow their Latino clients to be fully served.

- Study findings also indicate that incarcerated individuals experienced high levels of separation, denial of services and lack of access to medications during confinement. This was particularly 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 may be unmet by current assistance structures. Doing so may require HIV legal service providers to explore broadening the scope of legal services and shifting legal service delivery methods.
- One in five respondents faced HIV-related stigma and discrimination in different aspects of daily life. Additionally, it appears that some PLWH continue to experience, and fear, HIV-based discrimination when accessing legal assistance. To bolster existing HIV non-discrimination law, steps taken to reduce stigma and discrimination may include providing continuing education on HIV/AIDS issues and law to service providers who serve PLWH in these contexts (e.g. health care providers, housing providers, employers, corrections, legal services providers, and law enforcement officers). Further, research on best practices for delivering culturally competent legal services would be a useful next step for the field.
- Study findings indicate that 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, and/or they felt that they could not afford such services. Vulnerable PLWH in LAC need more information on the availability of legal resources that are low to no cost. Educating PLWH about how to identify a legal need and the availability of legal resources would address this particular gap in knowledge and could influence the help-seeking behavior among low-income PLWH with legal needs.
- The self-reported impacts resulting from legal needs indicate more research is necessary to explore the relationship between the presence of legal needs and its impact on the health of PLWH. Given that this study was not designed to directly test the effects of experiencing legal needs on health among the HIV-positive population in general or among low-income PLWH specifically, further research is needed to systematically assess the differences in experienced health outcomes between those with and without legal needs, and between those with varying responses from the legal system.

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