

Meeting the Legal Needs of People Living with HIV

Effort, Impact, and Emerging Trends

April 2016

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the
Williams
INSTITUTE

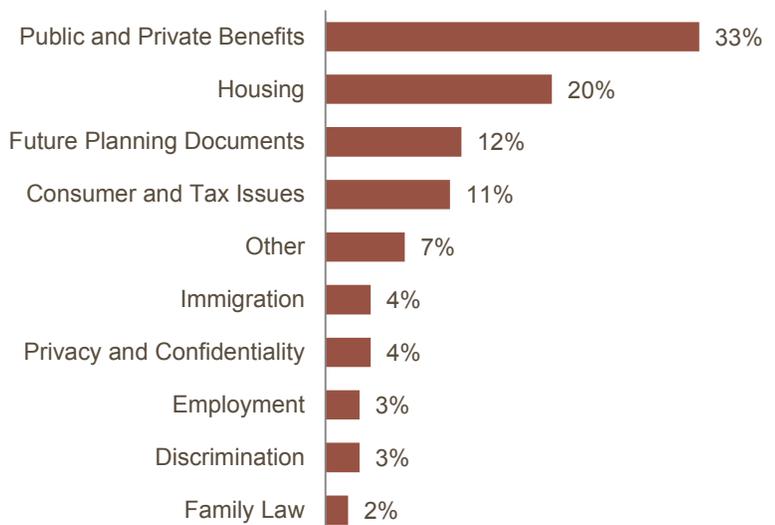
EXECUTIVE SUMMARY

An estimated 1.2 million people in the United States are living with HIV. Legal services providers can often address the impact of destabilizing forces that may create barriers to accessing and maintaining regular health care for people living with HIV (“PLWH”). In this study, we sought to understand more broadly the efforts of legal service organizations dedicated to serving PLWH, the impact of their work, and emerging trends observed by such organizations. In 2013, the Williams Institute sought access to archival client services data from legal services providers dedicated to serving PLWH in the ten Metropolitan Statistical Areas with the largest number of HIV-positive residents. Fourteen agencies were surveyed.

Key findings from the survey include:

- Eight agencies reported their total number of cases serving PLWH. Together, they fielded 22,682 cases from 2010 to 2012.
- Almost all of the agencies reported that the majority of their clients were people of color.
 - Agencies reported that the percent of clients living with HIV identifying as Black ranged from 15% to 80% with a median of 43%, and the percentage identifying as Latino/a ranged from .02% to 46% with a median of 18%. The median numbers largely reflected the racial/ethnic breakdown of individuals recently diagnosed with HIV in the United States.
- The median figures for clients’ gender identity were similar to the gender representation of individuals recently diagnosed with HIV in the United States.
 - Among those who reported specifically on their HIV-positive clientele, the median percentage of clients identified as cisgender men was 73%, cisgender women was 26%, and transgender was 2%. By comparison, 80% of those newly diagnosed with HIV in 2010 were men, and 20% were women (no figures are available to separate out transgender people).
- Three agencies reported specifically reaching out to intravenous drug users as a target client population, and three agencies reported targeting incarcerated populations, including individuals held in immigration detention.
- Agencies offered a broad range of legal assistance in a variety of issue areas. However, among those reporting on legal services provided to HIV-positive clients, 33% of the cases involved public and private benefits (e.g. public or private health insurance, income assistance, life and disability insurance), 20% of cases were in housing, 12%

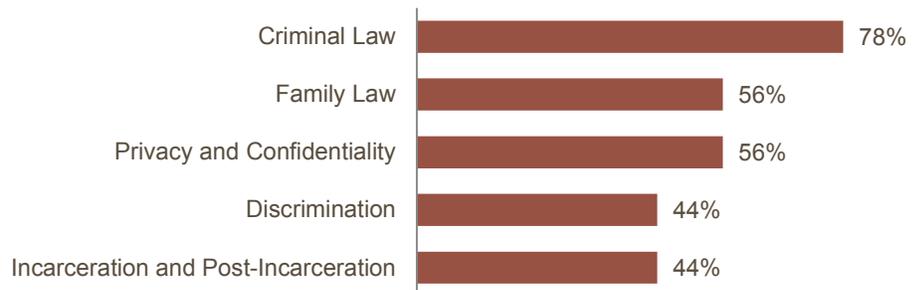
Percent of Caseloads across Agencies for Clients Living with HIV, by Legal Issue Area



provided assistance with future planning documents (e.g. wills and advance health care directives), and 11% involved consumer and tax issues. Fewer than 5% of cases were in each of the following legal issue areas: immigration, privacy and confidentiality, employment, discrimination, and family law.

- The majority of agencies (77%) reported encountering a client’s legal need that the agency could not address by either providing services or referring the client to another agency. Of those agencies, 50% reported that this happened sometimes, and 20% reported that this happened very often.
- Among the agencies that reported having clients with unmet legal needs, criminal law issues were the most likely to be reported as a legal issue area where the agency was unable to provide or refer assistance, followed by family law issues, privacy and confidentiality, and then discrimination, and incarceration and post-incarceration issues.

Percent of Agencies Reporting Being Unable to Meet Specific Legal Issue Areas among Agencies that Reported Unmet Legal Needs



- Not surprisingly, almost all of the legal issues that were the largest parts of the caseloads for respondents were only reported as unmet legal needs by two or fewer agencies. Conversely, many of the legal issue areas that took up less than 5% of the agencies’ total caseloads (criminal law, family law, privacy and confidentiality, discrimination, incarceration and post-incarceration, domestic violence, employment, and immigration) were reported as unmet legal needs by three or more agencies.
- When asked about trends in the legal needs of their clients, a few agencies reported an increase in legal needs around housing, some of which was attributed to gentrification.
- Eight agencies (67%) reported specifically planning for the Affordable Care Act (ACA). Such preparations included legal education and counseling on benefits, training navigators, community education and outreach, hiring new staff, and consulting with states and the federal government on LGBT nondiscrimination requirements in the law.

The survey highlighted a few areas for further exploration. Over 20,000 individuals living with HIV were confined in state and federal prisons as of 2010, making the rate of diagnosed HIV infection among inmates more than five times greater than the rate among people not incarcerated. While three agencies specifically reached out to these populations, further research is necessary to determine to what degree these populations’ needs are being served, especially given the unmet needs in the areas of criminal law and incarceration and post-incarceration services. Additionally, more research is needed to understand possibly emerging trends related to unmet legal matters in family law, privacy and confidentiality, and discrimination.

I. INTRODUCTION

An estimated 1.2 million people in the United States are living with HIV.¹ For individuals who are diagnosed and treated early, living with HIV may no longer serve as a significant barrier to surviving and thriving in the United States. Much of this, however, relies upon continued access to life-saving medication, care and treatment.

Previous research indicates a kaleidoscope of reasons that individuals or specific subgroups struggle to access or maintain access to HIV care and treatment. Among these reasons are overlapping social and economic conditions (e.g. poverty, stigma, discrimination) which impact HIV prevention and treatment.² Additionally, significant disparities have been noted among specific subgroups including trends regarding which communities are vulnerable to acquiring HIV to begin with (e.g. communities living in poverty, men who have sex with men “MSM,” and injection drug users).³ Other trends include data on communities that struggle most to achieve and maintain optimal health, including but not limited to viral load suppression (e.g. racial/ethnic minorities, sexual and gender minorities, and formerly incarcerated populations).⁴

Meeting unmet legal needs through the provision of legal services is one strategy to address disparities among people living with HIV/AIDS (“PLWH”) on an individual level. Legal services providers can often address the impact of destabilizing forces in the individual lives of PLWH. In this study, we sought to understand more broadly the efforts of legal service organizations dedicated to serving people living with HIV, the impact of their work with regard to extending the reach of legal representation to those who would not otherwise have it, and emerging trends observed by such organizations.

II. NATIONAL HIV LEGAL SERVICES PROVIDER SURVEY

In 2013, the Williams Institute sought access to archival client services data from legal services providers dedicated to serving people living with HIV/AIDS. Organizations were targeted based on the geographic areas they served. Primary focus was on the ten Metropolitan Statistical Areas with the largest number of HIV-positive residents. These jurisdictions included the following: New York, New York, Miami, Florida, Los Angeles, California, Washington, D.C., Chicago, Illinois, Philadelphia, Pennsylvania, San Francisco, California, Atlanta, Georgia, Houston, Texas, and Dallas, Texas.

Fourteen different legal services providers serving PLWH responded to the request for data.⁵ Respondents were

¹ CENTERS FOR DISEASE CONTROL & PREVENTION (CDC), HIV/AIDS—LIVING WITH HIV (2015), <http://www.cdc.gov/hiv/basics/livingwithhiv/>.

² See Hazel D. Dean, & Kevin A. Fenton, *Integrating a Social Determinants of Health Approach into Public Health Practice: A Five-Year Perspective of Actions Implemented by CDC’s National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention*, 128 PUBLIC HEALTH REP. 5 *passim* (2013).

³ See Paul Denning & Elizabeth DiNenno, Ctr. for Disease Control & Prevention, *Communities in Crisis: Is There a Generalized HIV Epidemic in Impoverished Urban Areas of the United States?*, HIV/AIDS BY GROUP, <http://www.cdc.gov/hiv/group/poverty.html> (last updated June 23, 2015).

⁴ See Ctr. for Disease Control & Prevention, *Risk by Racial/Ethnic Groups*, HIV/AIDS BY GROUP, <http://www.cdc.gov/hiv/group/raciaethnic/index.html> (last updated Apr. 15, 2015); Ctr. for Disease Control & Prevention, *HIV Among Gay and Bisexual Men*, HIV/AIDS BY GROUP, <http://www.cdc.gov/hiv/group/msm/> (last updated Sept. 29, 2015); Ctr. for Disease Control & Prevention, *HIV Among Transgender People*, HIV/AIDS BY GROUP, <http://www.cdc.gov/hiv/group/gender/transgender/index.html> (last updated Dec. 17, 2015); Ctr. for Disease Control & Prevention, *HIV and Injection Drug Use in the United States*, HIV/AIDS RISK AND PREVENTION, <http://www.cdc.gov/hiv/risk/idu.html> (last updated Oct. 27, 2015); Ctr. for Disease Control & Prevention, *HIV Among Incarcerated Populations*, HIV/AIDS BY GROUP, <http://www.cdc.gov/hiv/group/correctional.html> (last updated July 22, 2015).

⁵ Brooklyn Legal Services (New York, NY); Gay Men’s Health Crisis (New York, NY); Queens Legal Services (New York, NY); Legal Services of Greater Miami (Miami, FL); Inner City Law Center (Los Angeles, CA); Lambda Legal (Los Angeles, CA); Los Angeles HIV Law & Policy Project (Los Angeles, CA); Public Counsel (Los Angeles, CA); Whitman-Walker Health (Washington, D.C.); AIDS Legal Council of Chicago (Chicago, IL); AIDS Law Project of Pennsylvania (Philadelphia, PA); AIDS Legal Referral Panel (San Francisco, CA); Atlanta Legal Aid Society (Atlanta, GA); and Legal Hospice of Texas (Dallas, TX).

requested to report intake and case data documenting legal matters addressed by each agency from 2010 through 2012. Other questions on the survey included inquiries into the following areas: eligibility criteria, funding, client demographics, target populations, and emerging trends in practice.

III. FINDINGS

A. Eligibility Criteria and Funding Sources

Ten of the agencies (71%) had residency requirements for client eligibility, and eight (57%) specifically served low income individuals. Five of the agencies (36%) had some other eligibility requirement tied to outside funders (e.g. Ryan White Care Act, Housing Opportunities for People with AIDS “HOPWA,” or

Table 1: Client Eligibility Requirements among Agencies

Eligibility Requirements for Clients	Number of Agencies Reporting	Number of Agencies Reporting Having That Eligibility Requirement	Percent of Agencies Reporting Having That Eligibility Requirement
Residency	14	10	71%
Low Income	14	8	57%
Ryan White Eligible	14	4	29%
HOPWA Eligible	14	2	14%
IOLTA Eligible	14	2	14%

Interest on Lawyer Trust Accounts “IOLTA” funds). The majority (79%) of the agencies received a mix of both public and private funding, one agency received only public funding, and two received only private funding.

B. Client Demographics

1. Race/Ethnicity

Almost all of the agencies reported that the majority of their clients were people of color. Agencies reported that the percent of clients living with HIV identifying as Black ranged from 15% to 80% with a median of 43%. The percent of clients living with HIV identifying as Latino/a ranged from .02% to 46% with a median of 18%, and the percentage identifying as White ranged from 6% to 51% with a median of 28%. Asian/Pacific Islanders, Native Americans and those categorized as “Other” made up 12% or less of any agency’s clientele. Median data provided on the race/ethnicity of clients served by respondents mirror closely recent demographic data on new HIV infections in the United States.

⁶ It is unclear if demographic data were collected based on clients’ self-identification or by other means.

Table 2: Race/Ethnicity of Clients and Among Newly Diagnosed PLWH in the United States

Race/Ethnicity	Number of Agencies Reporting	Number of Agencies Reporting Specifically on Clients Living with HIV	Range Among Agencies Reporting Specifically on Clients Living with HIV	Median Among Agencies Reporting Specifically on Clients Living with HIV	Proportion of Estimated New Infections in the United States (2010) ⁷
Black	13	8	15% - 80%	43%	44%
White	13	8	6% - 51%	28%	31%
Latino/a	13	8	.02% - 46%	18%	21%
Asian/Pacific Islander	13	8	0% - 4%	1%	2%
Other	13	8	0% - 6%	1%	1%
Native American	13	8	0% - 4%	<1% ⁸	<1%
Unknown	13	8	0% - 14%	0%	0%

2. Sexual Orientation and Gender Identity

Three agencies reported on the percentage of their HIV-positive clients who were identified as MSM;⁹ these percentages ranged from 40% to 72% with a median of 57%. Because only three agencies reported collecting client data on sexual orientation, it is difficult to ascertain the degree to which respondents are currently serving one of the most impacted subgroups of PLWH. Given that 69% of newly diagnosed individuals are MSM, legal service organizations may want to consider collecting data to better evaluate the extent to which they may be serving this particular subgroup.

Thirteen out of 14 agencies reported on the gender breakdown of their clients. Eight reported exclusively on the gender breakdown of their HIV-positive clients, while five agencies reported on their clients overall without regard to HIV status. Among those who reported specifically on their HIV-positive clientele, the percentage of clients identified as cisgender men ranged from 61% to 86% with a median of 73%. The percentage of clients identified as cisgender women ranged from 10% to 35% with a median of 26%. The percent of HIV-positive clients identified as transgender people¹⁰ ranged from 0.01% to 7% with a median of 2%. The median figures are similar to the gender representation of individuals recently diagnosed with HIV in the United States.

⁷ CTR. FOR DISEASE CONTROL AND PREVENTION, ESTIMATED HIV INCIDENCE IN THE UNITED STATES, 2007–2010, 17 HIV SURVEILLANCE SUPPLEMENTAL REPORT 1, 15 (2012), available at <http://www.cdc.gov/hiv/topics/surveillance/resources/reports/#supplemental>.

⁸ This is not an exact number because a few agencies wrote “<1%”.

⁹ It is unclear whether this category is based on past sexual behaviors or based on whether clients self-identified as “gay,” “bisexual” or being a man who engaged in sex with another man.

¹⁰ The inquiry did not distinguish between individuals identified as transgender men and transgender women.

Table 3: Sexual Orientation/Sexual Activity and Gender Identity of Clients and Among Newly Diagnosed PLWH in the United States

Sexual Orientation/ Activity and Gender Identity	Number of Agencies Reporting	Number of Agencies Reporting Specifically on Clients Living with HIV	Range Among Agencies Reporting Specifically on Clients Living with HIV	Median Among Agencies Reporting Specifically on Clients Living with HIV	Proportion of Estimated New Infections in the United States (2010) ¹¹
Men who Have Sex with Men	7	3	40% - 72%	57%	63%
Cisgender Men	13	8	61% - 86%	73%	80%
Cisgender Women	13	8	10% - 35%	26%	20%
Transgender People	12	8	0.01% - 7%	2%	Unknown ¹²

3. Youth

Five (41%) of the 12 agencies that reported on whether they served youth reported not serving clients younger than age 18. Among those who did serve youth, the percent of HIV-positive clients under 18 ranged from less than 1% to 19% with a median of 1%.

C. Target Populations

The survey asked whether respondents targeted specific populations or subgroups in the course of their service provision. Of 14 agencies, five (36%) specifically reached out to members of a racial or ethnic group, three (21%) specifically targeted intravenous drug users, two (14%) targeted individuals incarcerated in jails, prisons or youth detention facilities, and one (7%) focused on individuals held in immigration detention. All three agencies that targeted intravenous drug users were located in the Northeastern United States.

Table 4: Populations of People Specifically Targeted by Agencies

Target Populations	Number of Agencies Reporting	Number of Agencies Reporting Targeting that Population	Percent of Agencies Reporting Targeting that Population
Members of a Racial/Ethnic Group	14	5	36%
Intravenous Drug Users	14	3	21%
Individuals Incarcerated in Jails, Prisons or Youth Detention Facilities	14	2	14%
Individuals in Immigration Detention Facilities	14	1	7%

¹¹ CTR. FOR DISEASE CONTROL AND PREVENTION, *supra* note 7 at 6, 15.

¹² Figures on the prevalence of HIV among transgender people is difficult to ascertain given the lack of specific demographic data capturing accurate gender identity for this population overall. However, the CDC reported that in 2010, the highest rate of new infections was among transgender people (2.1%) as compared to cisgender men (1.2%) and cisgender women (0.4%). Ctr. for Disease Control & Prevention, *HIV Among Transgender People*, HIV/AIDS BY GROUP, <http://www.cdc.gov/hiv/group/gender/transgender/index.html> (last updated Dec. 17, 2015).

D. Client Services

Respondents were asked to share administrative data detailing services they provided in the years 2010, 2011 and 2012. Eight agencies reported the number of HIV-positive clients that they served in those years. Agencies' annual average number of HIV-positive clients ranged from just under 100 to nearly 1,700, with a median of 750. The eight agencies that reported their total number of cases serving PLWH fielded 22,682 cases from 2010 to 2012.

Table 5: Number of Clients Living with HIV Served by Responding Agencies, 2010-2012

Year	Number of Agencies Reporting	Total Number of HIV-Positive Clients Served ¹³
2010	8	6,725
2011	9	7,044
2012	10 ¹⁴	6,739

1. Scope of Services

While assistance short of full scope representation can be a more cost-effective strategy to serving a greater number of individuals, 13 agencies reported providing full scope representation to their clients.¹⁵ Most agencies also engaged in limited scope representation (77%), utilized legal clinics (62%) and assisted clients to move forward pro se (54%). Seven agencies (54%) reported engaging in impact litigation.

Table 6: Types of Legal Services Offered by Responding Agencies

Services Offered	Number of Agencies Reporting	Number of Agencies Reporting Offering that Service	Percent of Agencies Reporting Offering that Service
Full Scope Representation	13	13	100%
Limited Scope Representation	13	10	77%
Legal Clinics	13	8	62%
Pro Se Assistance	13	7	54%
Impact Litigation	13	7	54%

Results indicate that in addition to legal representation of clients, agencies offered activities including the provision of community education (86%), outreach (36%), research (21%), housing (14%), support groups (7%) and HIV testing (7%).

2. Legal Issue Areas Addressed by Respondents

Assistance with public benefits was the most common legal issue area addressed by agencies, with all responding agencies¹⁶ reporting that they provided legal assistance in that area. This was followed by services for consumer legal assistance, discrimination, and employment issues which were addressed by all reporting agencies except for one. Only one agency reported providing legal assistance in cases of hate crimes or incarceration or post-

¹³ It is possible that there may be people who received services from these agencies more than once in the three-year span recorded above, so these numbers cannot be conclusively added together to determine the number of clients who were served in sum over that time period. Additionally, there is a small possibility that some of the clients included in each year's total may have received services at more than one of the agencies that reported, as some are in the same metropolitan area, so there is a small possibility of some duplication in those numbers.

¹⁴ Two agencies began serving HIV-positive clients proactively in 2012 and served an additional 239 clients in that year.

¹⁵ Some agencies were reporting on the services offered to their entire clientele and not specifically to those services offered to clients living with HIV. Here, we report on the responses of all agencies, working under the assumption that there is a not a more limited scope of services or legal issue areas for clients living with HIV than for any other client the agencies serve.

¹⁶ One agency did not provide any information on the types of legal services that it offers or the number of cases it has addressed. Agencies were counted as providing services in a specific legal issue area if they either checked a box reporting that they provided services in that area or reported having completed a number of cases in the previous three years in that legal issue area.

incarceration work. See Figure 1 and Table 7 for a detailed description of the legal issue areas and the proportion of agencies that provided services in those areas.

Six agencies (50%) reported providing legal services in other areas not otherwise listed, including: HIV criminalization, conservatorships, contracts, torts, workers compensation, assistance working with veterans, return to work counseling, education, non-insurance-related health issues, and juvenile work.

Fig. 1: Percent of Agencies Reporting Providing Legal Services, by Issue Area

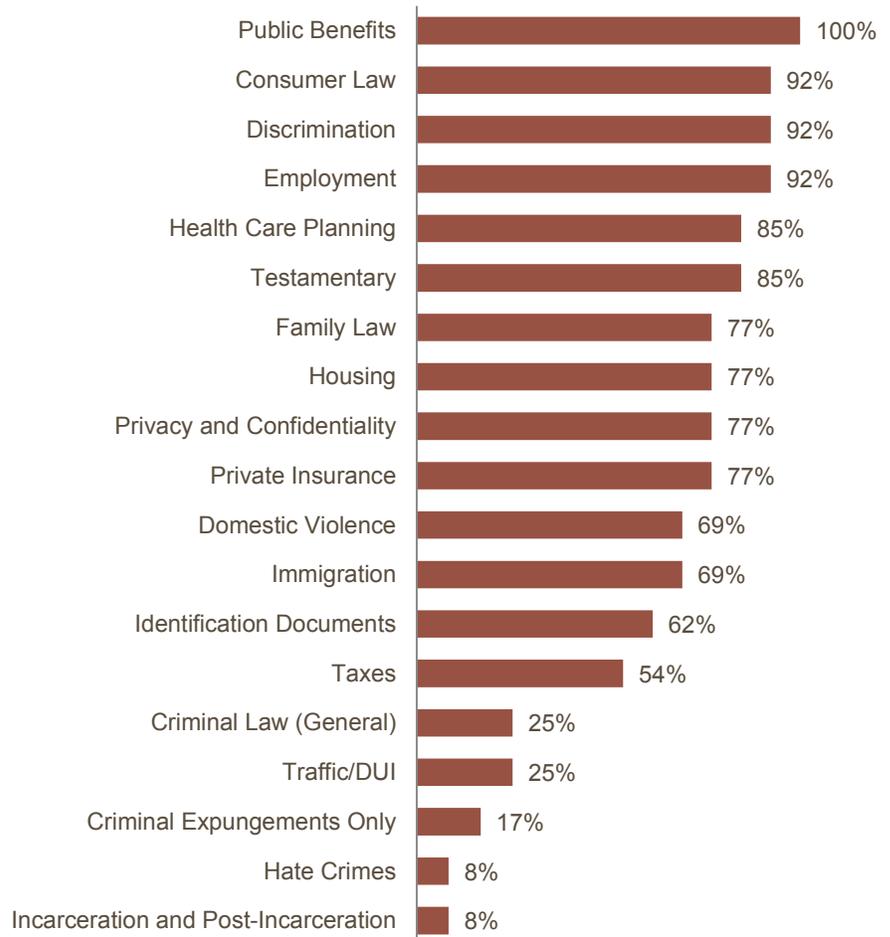


Table 7: Legal Issue Areas with Explanations Provided in the Survey

Legal Issue Area	Examples of Legal Issue Area Provided in the Survey
Public Benefits	Health care, income, housing
Consumer Law	Debts, student loans, credit reports, bankruptcy
Discrimination¹⁷	Health care, employment, housing
Employment¹⁷	Discrimination, privacy, reasonable accommodations, return to work
Testamentary	Wills, financial power of attorney
Health Care Planning	Health care power of attorney, advanced directive, hospital visitation authorization
Family Law	Adoption, joint guardianship, child support, DP and marriage advice, divorce, etc.
Privacy and Confidentiality¹⁷	Medical, work, housing, community
Housing	Eviction, HOPWA, Section 8, repairs, security deposit
Private Insurance	Health, life, disability
Immigration	Green card, citizenship, asylum
Identification	Social security, tax ID numbers, gender changes
Taxes	Filing, owe taxes, offers and compromise
Criminal Law	Defense, expungement, etc.

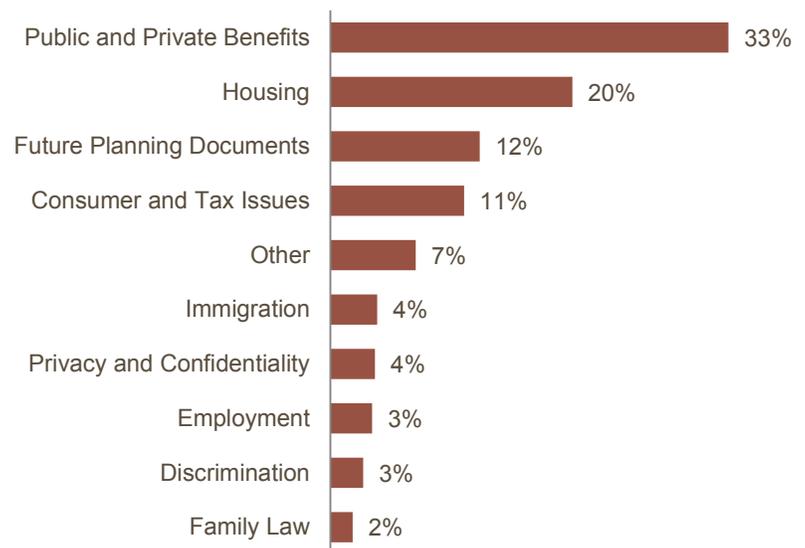
¹⁷ There may have been some overlap between responses to the employment questions, responses to discrimination questions, and privacy and confidentiality questions.

3. Legal Needs Met by Legal Issue Area

The survey also requested information on the number of cases respondents addressed from 2010 to 2012 and what legal issue areas were addressed as part of this service. Eight agencies reported the number of cases they fielded within each legal issue area for people living with HIV from 2010 to 2012. When those cases were aggregated across agencies, and over the three years of reporting, cases involving public and private benefits¹⁸ were the most likely to receive assistance, composing one third (33%) of the caseload for those eight agencies. Twenty percent of the cases dealt with housing, 12% provided assistance with future planning documents,¹⁹ 11% involved consumer and tax issues,²⁰ and 7% were in other miscellaneous legal issue areas.

Fewer than 5% of cases were in each of the following legal issue areas: immigration, privacy and confidentiality, employment, discrimination, and family law. Criminal law, identity documents, domestic violence, incarceration and post-incarceration, traffic, and driving under the influence all added together made up less than 1% of all of the cases that these eight agencies fielded over three years. None of the agencies reported working on addressing hate crimes for people living with HIV.

Fig. 2: Percent of Caseloads across Agencies for Clients Living with HIV, by Legal Issue Area



E. Limitations to Services

Despite the incredible workload responding agencies undertook, there were still times when they were not able to meet all of the legal needs of their clients. Five agencies reported on the percent of HIV-positive clients who were referred to other agencies, either entirely or for services in addition to what the agency provided. The referral rates ranged from 5% to 80% with a median of 49%. Five agencies reported having been forced to refuse services or waitlist an applicant who otherwise met eligibility criteria because they were overburdened with client work in the six month period prior to the survey. The majority of agencies (77%) reported encountering a client's legal need that the agency could not address by either providing services or referring the client to another agency. Of those agencies, 50% reported that this happened sometimes, and 20% reported that this happened very often.

¹⁸ Some agencies only track their private insurance and public benefits cases together under the category of public and private benefits, so this analysis followed that categorization.

¹⁹ This included both testamentary documents and health care planning documents, which some agencies tracked jointly.

²⁰ Again, some agencies tracked these two issue areas together, so this analysis followed that.

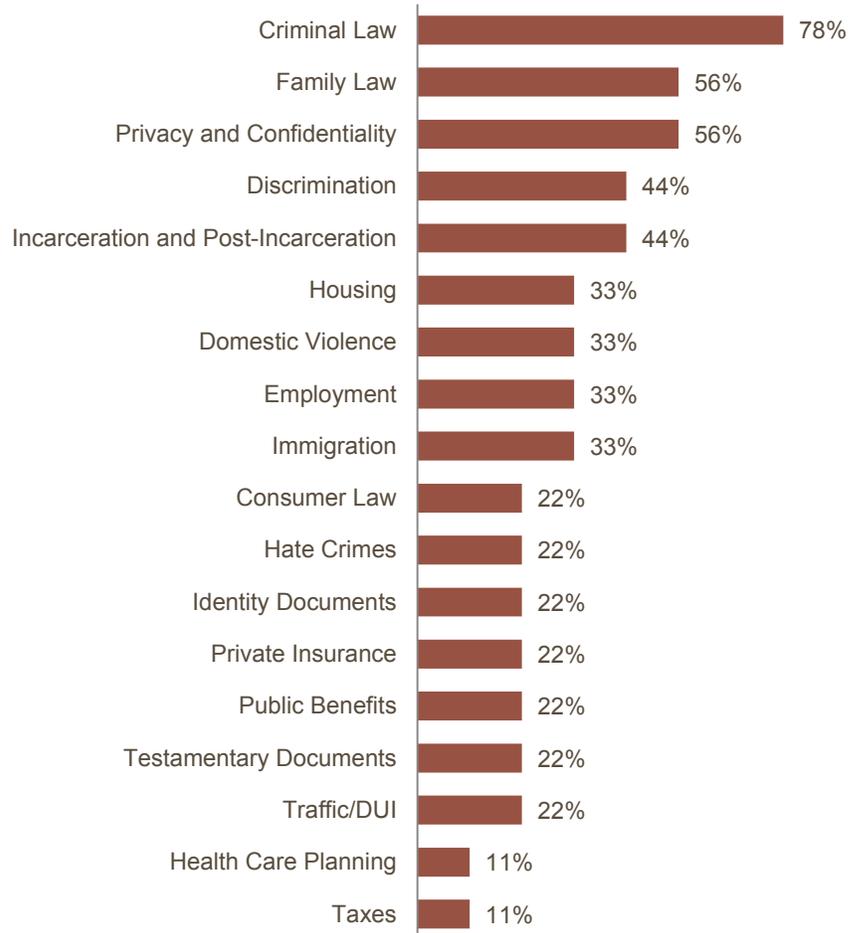
1. Unmet Legal Needs

Among the agencies that reported having clients with unmet legal needs, criminal law issues were the most likely to be reported as a legal issue area where the agency was unable to provide or refer assistance, with seven agencies (78%) reporting clients with unmet criminal legal needs.

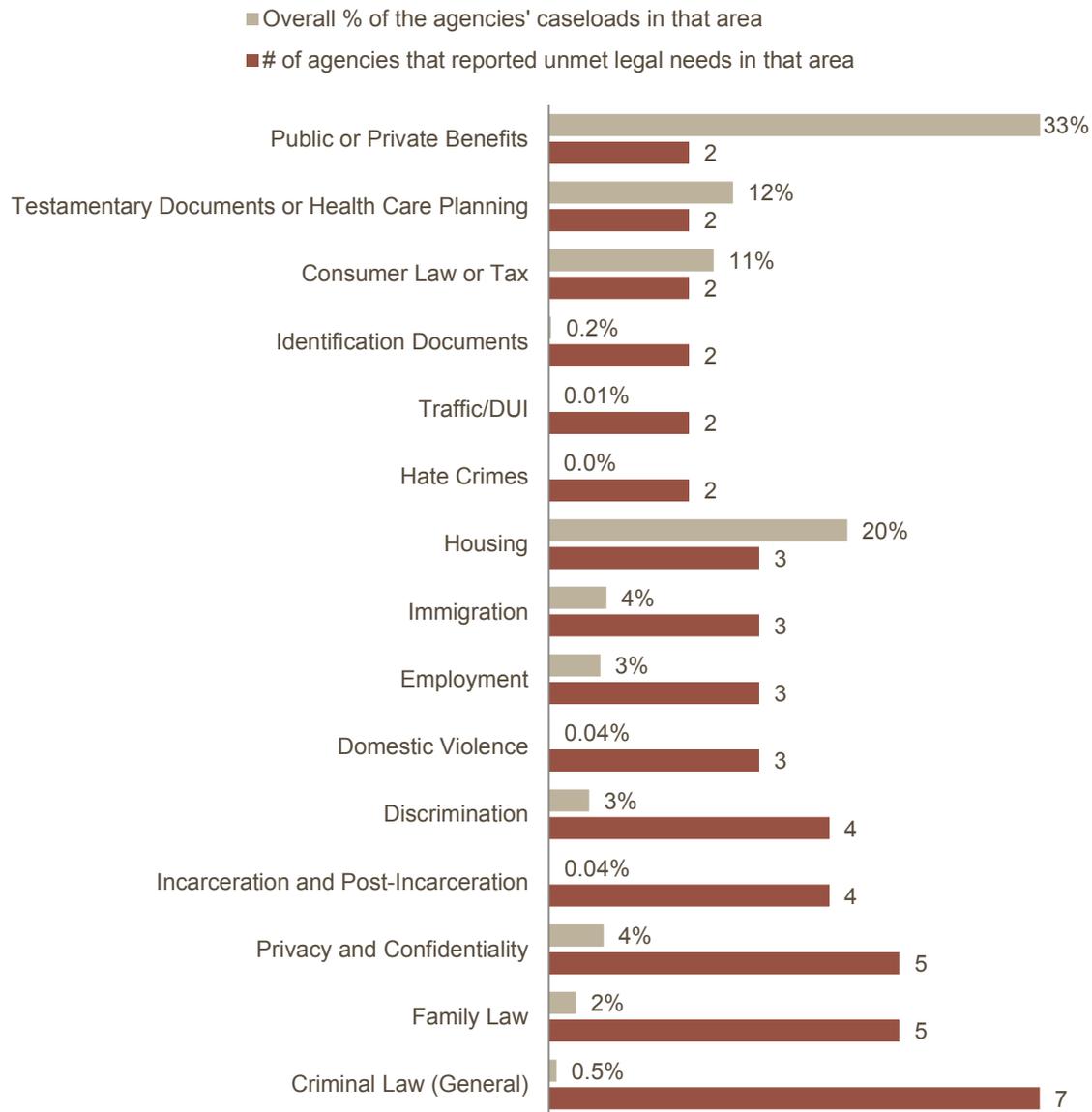
Family law and privacy and confidentiality issues were the second greatest unmet need with five agencies (56%) reporting being unable to serve clients with those needs. Four agencies (44%) reported having clients with unmet legal needs in the areas of discrimination and incarceration and post-incarceration.

The other categories for unmet needs included matters involving domestic violence, employment, housing, and immigration, which were each reported by three agencies (33%). Two agencies (22%) reported unmet needs in consumer law, hate crimes, identity documents, private insurance, public benefits, testamentary documents, and traffic and driving under the influence issues. Other unmet needs reported included needs for child support arrears issues, medical malpractice claims, and private disputes (11%).

Fig. 3: Percent of Agencies Reporting Being Unable to Meet Specific Legal Issue Areas among Agencies that Reported Unmet Legal Needs



Not surprisingly, almost all of the legal issues that were the largest parts of the caseloads for respondents (e.g. public benefits, private insurance, testamentary documents, health care planning, consumer issues, and taxes) were only reported as unmet legal needs by two or fewer agencies. Conversely, many of the legal issue areas that took up less than 5% of the agencies' total caseloads (criminal law, family law, privacy and confidentiality, discrimination, incarceration and post-incarceration, domestic violence, employment, and immigration) were reported as unmet legal needs by three or more agencies.

Fig. 4: Comparison of Legal Services Provided and Unmet Legal Needs

F. Emerging Trends

Respondents were asked to identify any trends or shifts in the types of cases they were seeing. Nine agencies noted various and varying trends leading to few consistent responses across the board. Agencies in the most rapidly gentrifying metropolitan areas in the country (New York and the San Francisco Bay Area) reported dealing with more evictions and housing-related legal problems recently. One agency reported an increase in helping clients plan for the future, including employment, education and debt, while a different agency reported a much lower demand for estate planning, which might reflect an overall trend among PLWH to anticipate having longer lifespans to plan for rather than limiting future planning to legal issues that are dealt with upon death.

Other trends went in opposite directions for different agencies: one reported an increase in HIV-based discrimination cases and another reported a decrease; one reported skyrocketing immigration needs, while another reported many fewer immigration matters; two agencies reported an increase in public benefits cases, while one agency reported

a reduction in SSDI/SSI cases involving HIV-related disabilities. Other increasing needs reported by only one agency without dispute from others included: insurance, consumer issues and transgender legal needs, including name and gender marker changes and discrimination. A few agencies reported dealing with shifts in legal needs based on recent law and policy changes, such as the Affordable Care Act and Deferred Action for Childhood Arrivals. Eight agencies (67%) reported specifically planning for the ACA when asked about it directly. Such preparations included legal education and counseling on benefits, training navigators, community education and outreach, hiring new staff, and consulting with states and the federal government on LGBT nondiscrimination requirements in the law.”

IV. DISCUSSION

Generally in the United States, people tend to face tough odds in accessing justice and achieving success through legal action.²¹ Some studies indicate that most low-income Americans would rather choose to avoid seeking legal assistance than resolve disputes through the court system.²² A recent legal needs assessment found this trend to be true among many people living with HIV in Los Angeles County, California.²³ In the study, 71% of overall respondents did not seek help for their most recent legal need.²⁴ Regardless of whether a person does or does not seek legal assistance, however, failing to receive legal assistance is a problem which can have significant consequences, most especially for people living with HIV. Being low-income, coming from a racial or ethnic minority, and/or identifying as a sexual or gender minority can also complicate access to justice issues and may increase the need for legal intervention.²⁵

As previous studies have documented, legal services play a vital role in the lives of people living with HIV. This is primarily due to the fact that legal services help to facilitate continued access to basic needs (e.g. food, income, and housing) and appropriate and continued access to health care.²⁶ In a multitude of jurisdictions, needs assessments focused on the health and basic needs of people living with HIV almost always find legal services as

²¹ *SRL Experience “the same” both sides of the border: Preliminary Results preliminary findings from the US study*, THE NATIONAL SELF-REPRESENTED LITIGANTS PROJECT, (Sept. 8, 2015), <http://representingyourselfcanada.com/2015/09/08/srl-experience-the-same-both-sides-of-the-border-preliminary-results-from-the-us-srl-study/> (finding that the impact of self-representation is often severe and multifaceted, including emotional trauma, health issues and financial consequences, such as personal debt, employment difficulties, etc.).

²² Mark David Agrast, Juan Carlos Botero, Joel Martinez, Alejandro Ponce & Christine S. Pratt, *Rule of Law Index 2012-2013*, WORLD JUSTICE PROJECT (2013), http://worldjusticeproject.org/sites/default/files/WJP_Index_Report_2012.pdf (finding that low income people in the United States act very differently than higher income individuals because only a few use the court system, while many take no action to resolve their disputes).

²³ 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), <http://williamsinstitute.law.ucla.edu/wp-content/uploads/Legal-Needs-People-Living-with-HIV-Los-Angeles-County-April-2015.pdf>.

²⁴ *Id.*

²⁵ See John-Manuel Andriote & R. Bradley Sears, *Ensuring Access to Health Care for People with HIV/AIDS: The Role of Legal Services*, RYAN WHITE CARE ACT POLICY STUDY (2000), http://www.bc.edu/content/dam/files/schools/law_sites/library/pdf/content/tremblay_schulman/2000-00-00.Andriote_Sears.Report.Full.pdf; CENTER 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>; LEGAL SERVICES NYC, POVERTY IS AN LGBT ISSUE: AN ASSESSMENT OF THE LEGAL NEEDS OF LOW-INCOME LGBT PEOPLE (2015), <http://www.legalservicesnyc.org/storage/PDFs/lgbt%20report.pdf>; Sara Sternberg Greene, *Race, Class, and Access to Civil Justice*, DUKE L. SCHOLARSHIP REPOSITORY (April 8, 2015), http://scholarship.law.duke.edu/faculty_scholarship/3450.

²⁶ *Id.*

an area with continued unmet need.²⁷

A. Client Demographics and Target Populations

Client data provided by respondents suggest that organizations are serving a representative group of people living with HIV in the United States. With regard to race/ethnicity, sexual orientation, and gender identity, providers appear to be serving a significant number of minorities who are particularly impacted by HIV infection. These data, however, raise further questions regarding service provision to other subgroups which represent traditionally underserved communities, including youth, intravenous drug users, and incarcerated individuals (including those held in immigration detention facilities). Overall, a minority of respondents reported targeting services to these specific impacted communities.

While some respondents serve people under the age of 18, the survey failed to capture what percentage of agencies' client populations are between the ages of 18 and 24. This is significant given that nationally, approximately 26% of newly diagnosed individuals are between the ages of 18 and 24.²⁸ Further research is necessary to determine whether young adults are currently underserved.

Eight percent of new infections are attributed to injection drug use.²⁹ The high level of stigma, discrimination and criminalization of people who use injection drugs, coupled with HIV-related stigma, makes this subgroup particularly vulnerable.³⁰ While this study ascertained that 21% of respondents reported targeting injection drug users in their service provision, the survey failed to capture what percentage of these agencies' clientele identify as using intravenous drugs. Again, further research is necessary to determine whether individuals who are using injections drugs are underserved.

Over 20,000 individuals living with HIV were confined in state and federal prisons as of 2010, making the rate of diagnosed HIV infection among inmates more than five times greater than the rate among people not incarcerated.³¹ In fact, as many as one in six people living with HIV has been found to be involved with the criminal justice system at one time or another.³² Thus, the transition from being incarcerated to being back in one's home community is yet

²⁷ See CITY OF W. HOLLYWOOD, CITY OF W. HOLLYWOOD 2013 COMMUNITY STUDY (2013), <http://www.who.org/home/showdocument?id=19876> (finding that legal services was ranked among the top 5 social service needs across demographic categories and second in preference among social services for residents with special needs); LA. DEP'T OF PUBLIC HEALTH AND HOSPITALS, PEOPLE LIVING WITH HIV NEEDS ASSESSMENT (2013), http://new.dhh.louisiana.gov/assets/oph/HIVSTD/RFI/PLWHA_Statewide_Report_DRAFT.pdf (finding legal services to be among the top 5 most utilized supportive service and a continued unmet need among 14% of respondents); FLA. DEP'T OF HEALTH, 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 (finding that legal services is one of the services areas with the greatest need); JSI RESEARCH & TRAINING INST., MASS. AND S. N.H. HIV/AIDS CONSUMER STUDY (2011), <http://www.mass.gov/eohhs/docs/dph/aids/consumer-study-june-2011.pdf> (finding that 25% of people living with HIV surveyed need and use legal services, and 15% of those surveyed indicated they needed legal services within the last 6 months but did not receive it.); HOUSTON RYAN WHITE PLANNING COUNCIL, 2011 HOUSTON AREA HIV/AIDS NEEDS ASSESSMENT (2011), https://www.houstontx.gov/health/HIV-STD/RWPC_2011_Houston_HIV_Needs_Assessment.pdf (finding that legal services was ranked among the top 5 categories of supportive services by 23% of respondents who believed it was important and useful).

²⁸ See Ctr. for Disease Control & Prevention, *HIV Among Youth*, HIV/AIDS BY GROUP, <http://www.cdc.gov/hiv/group/age/youth/index.html> (last updated June 30, 2015).

²⁹ Ctr. for Disease Control & Prevention, *HIV and Injection Drug Use in the United States*, HIV/AIDS RISK AND PREVENTION, <http://www.cdc.gov/hiv/risk/idu.html> (last updated Oct. 27, 2015).

³⁰ Lianping Ti & Thomas Kerr, *Task shifting redefined: removing social and structural barriers to improve delivery of HIV services for people who inject drugs*, 10 HARM REDUCTION JOURNAL 1 (2013).

³¹ Ctr. for Disease Control & Prevention, *HIV Among Incarcerated Populations*, HIV/AIDS BY GROUP, <http://www.cdc.gov/hiv/group/correctional.html> (last updated July 22, 2015).

³² Anne C. Spaulding, Ryan M. Seals, Matthew J., Amanda K. Brzozowski, William Rhodes, & Theodore M. Hammett, *HIV/AIDS Among Inmates of and Releasees from US Correctional Facilities, 2006: Declining Share of Epidemic but Persistent Public Health Opportunity*, 4 PLoS ONE, e7558 (2009).

another challenge with regard to maintaining HIV care for incarcerated PLWH.³³ Targeted focus to serve incarcerated or previously incarcerated individuals is, therefore, especially important. In this survey, three organizations (21%) reported targeting incarcerated populations, including individuals held in immigration detention. More research into services provided to this subgroup is warranted given their unique legal circumstances.

What remains unclear is to what degree agencies' caseloads represent matters stemming from individuals who can be identified from these subgroups. Thus, further inquiry is necessary to determine to what degree services provided to individuals within these subgroups are different or the same as the services provided to others.

B. Legal Issue Areas Addressed by Respondents

In a national survey of legal services providers serving people living with HIV administered in 2000, researchers identified two primary ways that legal services can help people living with HIV to access health care services.³⁴ This included deeper examination into health-related legal issues such as discrimination by health care providers, breaches of confidentiality and testing rights by health care providers, problems with accessing/using public medical benefits, problems with accessing and using private health insurance, barriers to employment-based health coverage, advance planning documents such as advance directives, and barriers to healthcare for specific subgroups (children, foreign-born, incarcerated).³⁵ The other legal needs which impact access to healthcare included "subsistence needs" such as legal matters related to housing and landlord/tenant, public and income-related benefits, life and disability insurance, debtor/creditor, bankruptcy, and tax assistance.³⁶

Since that time, much has changed with regard to the treatment and prevention of HIV. Legal protections have long been established to ensure that all people living with HIV are eligible to receive some form of health care and access to public services and public accommodations free from HIV-based discrimination.³⁷ Additionally, private health insurance providers are no longer permitted to deny coverage on the basis that a person living with HIV has a pre-existing condition disqualifying them from coverage.³⁸ Given these shifts and changes, we expected to see some shift with regard to legal issue areas addressed by respondents. As it turns out, nearly all providers (92%-100%) indicated that they continue to provide services in many of the legal issue areas identified in the study completed over 15 years prior. These include public benefits, consumer law, discrimination, and employment.

C. Legal Needs Met by Legal Issue Area

Shifts in legal services provision were slightly more noticeable when reviewing the caseload of responding agencies by legal issue area. Rather than focus on what services these agencies offered, these data provide a snapshot of what types of matters were actually being addressed by respondents. Here, the top categories for services provided included public and private benefits, housing, future planning documents, and consumer and tax issues. While there continues to be a focus on health-related legal needs and subsistence needs, including an increase in housing-related matters, there seems to be a reduction in the number of discrimination cases. This study found that only 3% of legal matters addressed by respondents were in this area of law.

³³ Julia Rozanova, Shan-Estelle Brown, Ambika Bhushan, Ruthanne Marcus & Frederick L. Altice, *Effect of Social Relationships on Antiretroviral Medication Adherence for People Living with HIV and Substance Use Disorders and Transitioning from Prison*, 3 HEALTH AND JUSTICE 1 (2015).

³⁴ Andriote & Sears, *supra* note 37.

³⁵ *Id.*

³⁶ *Id.*

³⁷ See *Bragdon v. Abbott*, 524 U.S. 624 (1998).

³⁸ 45 C.F.R. §§144, 146, 147; See U.S. DEPT OF HEALTH AND HUMAN SVS., HHS.GOV—HEALTH CARE (2014), <http://www.hhs.gov/healthcare/about-the-law/pre-existing-conditions/index.html>.

D. Unmet Legal Needs

While there appears to be some consensus around unmet legal needs in criminal law, family law and privacy and confidentiality issues, it should be noted that many of the legal issue areas that were minimally addressed by respondents, representing less than 5% of the agencies' total caseloads, happen to also be the legal issue areas reported as unmet legal needs. This seems to indicate that providers are continuously challenged to meet the needs of clients, wherever those needs may be. In the case of criminal law matters, legal services providers who tend to focus solely on civil legal matters are, understandably, unable to address criminal law matters more broadly. However, the same rationale would not apply in the context of family law and privacy and confidentiality matters. Further exploration is needed to understand why these areas of law continue to represent areas of need.

A few legal issue areas that did not take up substantial numbers of cases and also did not appear to be high areas of unmet need seem to suggest that these areas may be well covered by most (but not all) legal services agencies. These include matters related to identity documents, hate crimes, and traffic/driving under the influence. Given the nature of this study, however, it is possible that a smaller minority of subgroups are in need of these specific services as compared to the overall population of PLWH served by these agencies (e.g. gender and other minorities and individuals who own vehicles).

E. Emerging Trends

While there remain three main legal issue areas representing unmet legal needs, the mixed responses with regard to trends are worth exploring further. Reports of increased need for housing assistance in both in New York City and in the San Francisco Bay Area may indicate a need for further exploration about the impact of gentrification on low-income PLWH.

V. CONCLUSION

Recent research reveals that individuals living with HIV who are not retained in care are most likely to transmit HIV to others.³⁹ This revelation further underscores the importance of addressing conditions which influence individuals' ability to achieve optimal health once diagnosed with HIV infection. Because legal services interventions focus on the ability to access care, and to create better conditions that make such possible, legal services have the potential to broadly impact HIV transmission moving forward.

This study captures a portion of the efforts and impact made by legal services providers dedicated to serving people living with HIV, particularly providers serving the largest communities of people living with HIV in the United States. Findings indicate that respondents are making great efforts in meeting the diverse needs of a very diverse population of people living with HIV. Many agencies are serving historically underserved subgroups and some are targeting particular subgroups that remain disparately impacted by HIV. More research is needed to understand the complicated nature of identifying unmet legal needs, and whether some of the identified unmet legal needs warrant further attention. This is especially true of possibly emerging trends related to unmet legal matters in criminal law, family law, privacy and confidentiality, discrimination, and incarceration and post-incarceration.

³⁹ Jacek Skarbinski, Eli Rosenberg, Gabriela Paz-Bailey, H. Irene Hall, Charles E. Rose, Abigail H. Viall, Jennifer L. Fagan, Amy Lansky, & Jonathan H. Mermin, *Human Immunodeficiency Virus Transmission at Each Step of the Care Continuum in the United States*, 175 JAMA INTERN MED. 588 (2015) (finding that persons who are HIV diagnosed but not retained in medical care (45.2% of the population) were responsible for 91.5% of the estimated 45,000 HIV transmissions in 2009 as opposed to previous research finding that as a group, undiagnosed individuals transmitted HIV to others the most).

V. ACKNOWLEDGEMENTS

We would like to thank the respondents who participated in the study: AIDS Law Project of Pennsylvania, AIDS Legal Council of Chicago, AIDS Legal Referral Panel, Atlanta Legal Aid Society, Brooklyn Legal Services, Gay Men's Health Crisis, Inner City Law Center, Lambda Legal, Legal Hospice of Texas, Legal Services of Greater Miami, Los Angeles HIV Law & Policy Project, Public Counsel, Queens Legal Services, and Whitman-Walker Health. Without their assistance, this study would not have been possible.

We thank our Research Associate Hussain Turk for his assistance with this report. Thank you to our colleagues Soonie Choi, for analytical assistance, and Lauren Jow, for design assistance.

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CITATION

AYAKO MIYASHITA & AMIRA HASENBUSH, THE WILLIAMS INST. UNIV. OF CAL. L.A. SCH. OF LAW, MEETING THE LEGAL NEEDS OF PEOPLE LIVING WITH HIV: EFFORT, IMPACT, AND EMERGING TRENDS (2016), <http://williamsinstitute.law.ucla.edu/wp-content/uploads/Meeting-the-Legal-Needs-of-People-Living-with-HIV-April-2016.pdf>.

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