

# Send Lawyers, Guides and Money

Legal Services Needs of  
People Living with HIV  
in the Southern United States





**Send Lawyers, Guides and Money:  
The Legal Services Needs of People Living  
with HIV in the Southern United States**

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## MISSION STATEMENT

The Center for HIV Law and Policy is a national legal and policy resource and strategy center for people with HIV and their advocates. CHLP works to reduce the impact of HIV on vulnerable and marginalized communities and to secure the human rights of people affected by HIV.

We support and increase the advocacy power and HIV expertise of attorneys, community members and service providers, and advance policy initiatives that are grounded in and uphold social justice, science, and the public health.

We do this by providing high-quality legal and policy materials through an accessible web-based resource bank; cultivating interdisciplinary support networks of experts, activists, and professionals; and coordinating a strategic leadership hub to track and advance advocacy on critical HIV legal, health, and human rights issues.

To learn more about our organization and access the Resource Bank,  
visit our website at [www.hivlawandpolicy.org](http://www.hivlawandpolicy.org).

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## INTRODUCTION

This report describes the state of legal services for people with HIV based on responses from eleven Southern states. The information was gathered in a survey which was designed to gain a detailed picture of the current need for HIV-related legal services in this region, and to determine whether adequate services exist to meet these HIV-related legal needs. The responses to the survey provide a telling snapshot of the type of resources and services needed by people with HIV and by providers who represent or advocate for people with HIV. This report is intended for use by legal and social services organizations and funders to inform program planning and resource allocation for HIV related services in the coming months and years. As organizations and service providers struggle with limited resources, we hope that this data can help to clarify and direct priorities.

Legal services are an essential component of creating and protecting quality of life for those living with HIV. Advocates and researchers have helped identify how legal services help people living with HIV to “access care, use entitlement programs, and meet subsistence needs by overcoming immediate barriers to underserved populations.”<sup>1</sup> The legal needs of those with HIV can be “typical of those seen in poverty law practices—including advocacy for public entitlement programs such as welfare, SSI, and Medicaid; landlord/tenant law; family law; and consumer law, particularly for debt relief.”<sup>2</sup>

However, all of these needs are compounded by the stresses of living with HIV and the stigma it still carries. More than one-third of people living with HIV studied in a 2000 HRSA report went without, or postponed, their medical care because they had to “pay for food, clothing, or housing, lacked transportation, could not leave work, or were too sick.”<sup>3</sup> Because competing needs and practical barriers frequently mean not receiving antiretroviral therapy, people living with HIV require legal help aimed at alleviating their subsistence needs in addition to procuring medical services.

This report discusses the survey results by state, and then by the statistically significant results of the specific questions. Graphs and charts are used wherever possible to make the data more useable. We include information about our methodology and sampling at the end of the report, and conclude with recommendations based on the data. The appendix contains, for reference, the survey questions in their entirety, and the complete responses for a survey question about recent barriers to accessing legal help.

Eighty-five percent of the respondents to this survey identified HIV-related needs that required legal help for themselves or the clients they serve. Of these people, *almost 50% were not able to receive legal help the last time they needed it.* These needs are among the most basic rights -- housing, employment, family security -- and contribute substantially to the quality of life of those with HIV. Accessing affordable housing was persistently identified as the most pressing legal need, though it was also the need most often met. The most identified unmet need was legal help in immigration matters. The full report seeks to tease out the demographic and geographic differences in identified priorities, resources, and met and unmet needs.

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<sup>1</sup> John-Manuel Andriote, R. Bradley Sears, *The Role of Legal Services in Ensuring Access to Care for People with HIV/AIDS*, HRSA Policy Brief 4, (2000).

<sup>2</sup> Id.

<sup>3</sup> Id.

We targeted our survey's data collection specifically to respondents in Alabama, Arkansas, Georgia, Louisiana, Mississippi, North Carolina, South Carolina, and Tennessee.<sup>4</sup> However, because the survey was circulated through coalitions and lists whose reach extends beyond these eight states, we also received significant responses from additional Southern states, including 34 respondents from Florida, 32 from Kentucky and 29 from Texas. Because these states were not targeted for individual analysis, their responses were all grouped together as "other" in our survey data. Thus, because of the survey design, separate summaries of specific priorities and needs of Florida, Kentucky and Texas were not completed.

We close the report with recommendations for how advocates and policy makers might begin to address the gaping holes in the essential legal services coverage available to HIV-positive people in the South.

## DISCUSSION OF RESULTS<sup>5</sup>

### A. Met and Unmet Needs By State

Breaking the information out by state helps give some sense of reoccurring needs and can assist community activists, program directors and decision makers identify strengths and needs in their state as opposed to the whole region. Access to housing remained a consistent legal need across all jurisdictions.

#### *Alabama*

The top identified issue, regardless of whether legal help was received, was **access to affordable housing**, with 46% of respondents identifying it as an issue. **Landlord/tenant issues, access to job training, access to benefits, and family law** matters were all identified with 37.5% needing legal help. Only 52.4% of the respondents were able to access legal services the last time they needed it, with the needs met ranging fairly evenly across the spectrum. **Family law** services were cited most as the legal need that was most recently not met.

#### *Arkansas*

**Access to affordable housing** and **access to benefits** were the most identified issues that respondents needed legal help with - 75% of respondents identified each as an issue. This was followed by 62.5% of respondents identifying **access to jobs/job training** as an issue with which they required help. Fifty percent of the respondents were able to access legal services the last time

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<sup>4</sup> These states are based on those prioritized by the Ford Foundation and National AIDS Fund in an initiative to address the human rights of people with HIV living in the South. This initiative also included portions of Northern Florida and the District of Columbia, which were not specifically included in our survey. Press Release regarding Ford Foundation Initiative available at: <http://www.fordfoundation.org/issues/human-rights/reducing-hiv-aids-discrimination-and-exclusion/news?id=380>

<sup>5</sup>A note about the statistical significance of the data throughout the document. In order to test the significance of the data, we selected a few tables to analyze. In the case of the identity question being cross-tabbed with geography, we tested the data using the chi square test for statistical significance and goodness of fit test. Statistical significance is used to determine whether the sample drawn from a population is actually from the population or if the sample results were based on chance. The level of significance commonly used is 5%. For this particular table, the results were as follows: chi square = 54.2, degrees of freedom = 32, and probability (p) = .008. Since  $p < .05$  we can say that the sample meets the good of fit requirement and the sample is representative of the population.

they needed it, particularly if they needed help with **access to benefits**. **Access to affordable housing** was cited most as the need that was most recently not met.

### *Georgia*

The top identified issue in Georgia, regardless of whether help was received, was **access to affordable housing**, with 66.7% of respondents identifying it as an issue. **Access to benefits** was identified by 51.7% of respondents as something for which they had needed legal help. Fifty-two point one percent of respondents were able to access legal services the last time they needed it, most often if they were trying to **access benefits** (21.7%), dealing with **wills or power of attorney** (17.4%) or **employment discrimination** (17.4%). **Immigration** was cited most often (in 22.7% of the respondents) as the need that was most recently not met. Georgia had some of the highest response rates at 66 respondents, and produced some of the most statistically significant results.

### *Louisiana*

**Access to affordable housing** was also the top identified issue in Louisiana, with 77.3% of the respondents identifying it as an issue with which they required legal help. Considering that the survey was conducted in 2009, it is safe to assume this data includes the challenges presented by the aftermath of Hurricane Katrina. **Access to jobs or job training** (54.5%) and **family law matters** (50%) were also identified as major issues that required help. Seventy-eight point nine percent of respondents were able to access legal services the last time they needed them, particularly when it required help with **access to benefits** (20%) or help with **wills/power of attorney** (20%). **Access to affordable housing** was cited most as the need that was recently not met.

### *Mississippi*

**Access to affordable housing** was the top identified issue in Mississippi, with 66.7% of the respondents identifying it as an issue with which they required legal help. **Employment discrimination** (53.3%) was also identified as a significant issue. Sixty percent of respondents were able to access legal services the last time they needed them, particularly when it required help with **access to benefits** (33.3%) or help with **employment discrimination** (33.3%). However, **employment discrimination** was prevalent enough as an issue that it was also cited as the need that was most recently not met with legal services.

### *North Carolina*

The top identified issue in North Carolina, regardless of whether help was received, was **access to affordable housing**, with 77.8% of respondents identifying it as an issue. **Access to benefits** was also identified by 72.2% of respondents as something they or their client had needed legal help with. Sixty-two point seven percent of respondents were able to access legal services the last time they needed it, most often if they were trying to **access benefits** (34.6%). **Employment discrimination** (18.8%) and **access to benefits** (18.8%) were cited most often as the legal need that was recently unmet.

### *South Carolina*

The top identified issue, regardless of whether help was received, was **access to affordable housing**, with 78.4% of respondents identifying it as an issue. **Access to jobs/job training** were identified by 59.5% of respondents, **wills/power of attorney** were identified by 56.8%, and over all the categories there was a high level of need for legal services. Only 55.9% of the respondents were able to access legal services the last time they needed it, with **access to benefits** (25%) and

**landlord/tenant issues** (15%) services most likely received. **Landlord/tenant issues** and **employment discrimination** (both 26.7%) were cited as the need that was most recently not met.

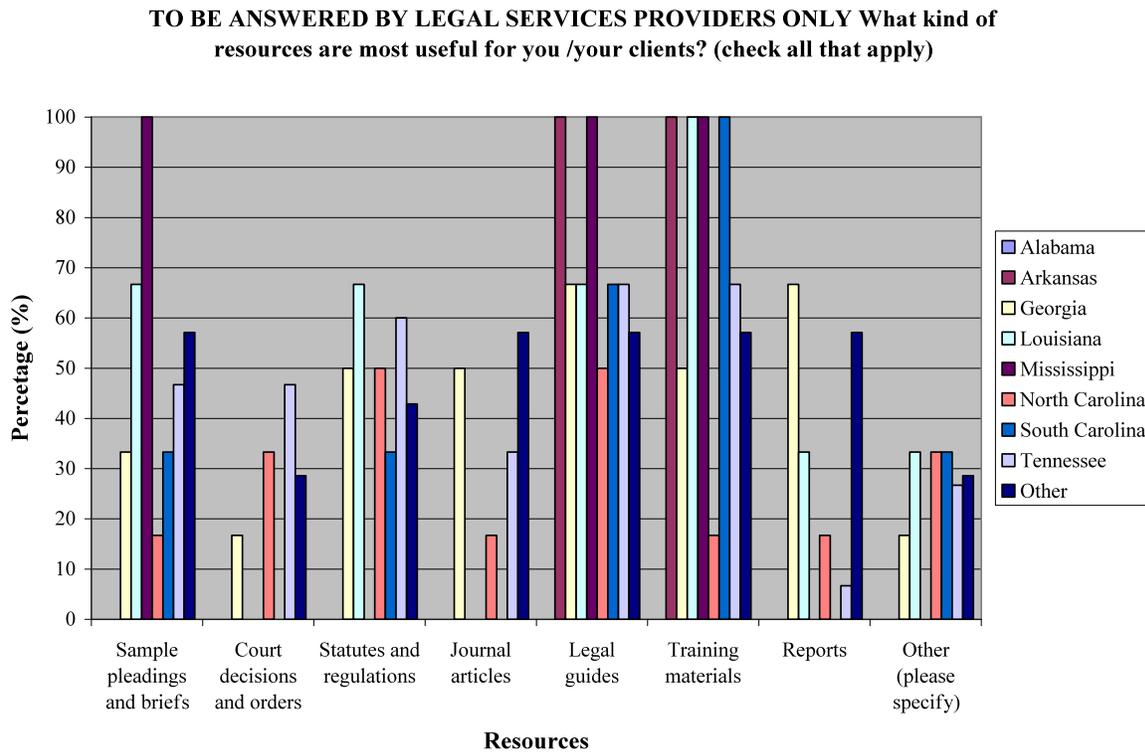
*Tennessee*

**Access to affordable housing** was also the top identified issue in Tennessee, with 46.2% of the respondents identifying it as an issue that they required legal help with, regardless of whether help had been received. **Landlord/tenant issues** and **access to benefits** were each identified by 36.5% of respondents as an issue. Fifty-seven point eight percent of respondents were able to access legal services the last time they needed it, most often if they were dealing with **landlord/tenant issues** (28%) or **wills/power of attorney** (24%). **Employment discrimination** (38.5%) was disproportionately cited most often as the legal need that was recently unmet.

**B. Resources Found Most Useful**

In addition to identifying the needs for HIV legal services by state, it is useful to look at what resources legal service providers in specific states find most useful to themselves or their clients. The bar graph below in Figure 1 illustrates the perceived usefulness of these resources by state.

**Figure 1:**

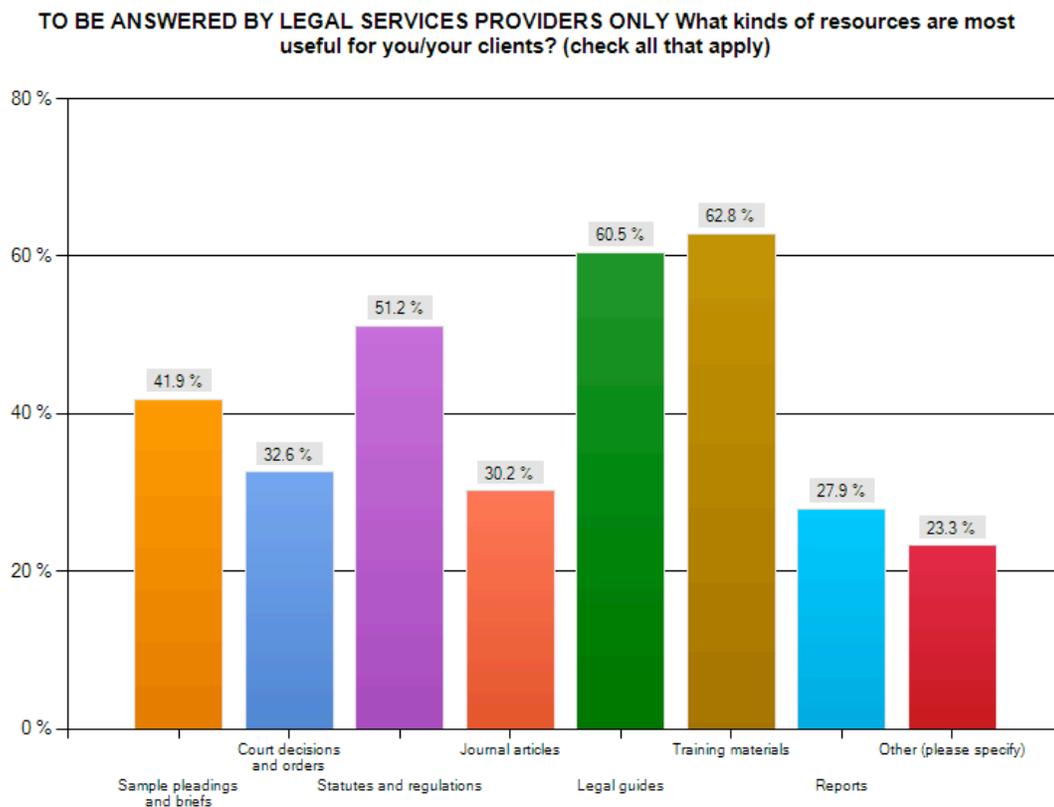


<sup>6</sup> “Other” useful resources cited included “networking”, “access to medical experts” and “educational materials for communities”.

As the graph illustrates, legal guides and training materials were the resources found most useful across the majority of the states, with a universally positive response in Arkansas and Mississippi. Sample pleadings and briefs, and relevant statutes and regulations, were rated next highest in usefulness. Legal service providers in Georgia, North Carolina, and Tennessee found all seven resources useful along with additional resources identified in the “other” category.

Figure 2 provides an overall view of the perceived usefulness of legal resources by legal service providers.

**Figure 2:**



Legal guides and training materials are clearly identified as the most useful resources, again followed by statutes and regulations, and sample pleadings and briefs. This is information particularly useful for funders and national organizations looking for clarity in project priorities.

### C. Results by Identity of Respondent

#### *Community Advocates*

- 69.4% cited access to affordable housing as the issue regardless of whether or not legal services were received.

- 15.6% of those respondents identified access to/eligibility for benefits as the issue for which they were able to receive services.
- 52.6% indicated that they/their client were not able to access legal services the last time an issue arose.
- On the question of what the issue was the last time services were not received, out of all the community advocate respondents, 13.9% identified immigration as the issue.

#### *Female person living with HIV*

- 42.4% reported that regardless of whether or not legal services were received, the issue they needed help with most was access to affordable housing.
- 56% said that they were not able to access legal services the last time they had an issue.
- 16.7% said that the last time they had a legal issue and got services, the issue had been access to affordable housing, landlord/tenant issues, or employment discrimination.
- Of females with HIV who were not able to access services, 27.3% identified access to/eligibility for benefits as their primary issue.

#### *Government HIV program staff*

- 78.6% said that the most prevalent issue for them, regardless of whether or not services were received, was access to affordable housing.
- 65% said that their client was not able to access legal services the last time a client had an issue.
- 28.6% identified affordable housing as the issue when legal services were received.
- When services were not received, 25% of the respondents stated that immigration was the issue.

#### *Health care providers*

- 66.7% of health care providers cited access to affordable housing as an issue regardless of whether or not services were received.
- More than 66% of health care providers indicated that a client was able to access services the last time an issue arose.
- 26.7% said that the last time they/their client had an issue and received services, the issue was access to/eligibility for benefits.
- 42.9% of the health care providers cited access to affordable housing as the issue last time their patient was not able to receive services.

#### *HIV case managers*

- 88% cited access to affordable housing as a key issue regardless of whether or not services were received.
- 48.6% said that the last time they received services, the issue was access to/eligibility for benefits.
- 17.9% said that landlord/tenant issues were the problem the last time their client was not able to access legal services.

*Lawyers*

- 64.3% identified access to benefits as a key issue regardless of whether or not services were received.
- 53.6% of lawyers identified landlord/tenant issues, access to affordable housing, access to health care, and will/power of attorney as key issues.
- 88% of the lawyers said that they were able to access legal services. Although perhaps obvious, it is still important to state the assumption that lawyers are the respondents, out of all the other groups classified by identity, with the easiest means and most resources to access legal services. This is confirmed by the analysis. When asked what issues existed when not able to receive services, 50% of the lawyers said access to/eligibility for benefits and the other 50% said access to healthcare.
- 76.2% of the lawyers who identified themselves as HIV legal service providers said that training materials were the most useful resource.

*Male person living with HIV*

- 48.6% identified access to affordable housing as an issue regardless of whether or not legal services were received.
- 59.7% said they were unable to access legal services the last time they needed assistance.
- For males with HIV who were able to access legal services, 21.7% said that they received services related to accessing HIV medications and treatment.
- 19.4% said they were not able to get services for employment discrimination.

*Social Workers*

- 75.5% stated that access to affordable housing was the key issue regardless of whether or not services were received.
- For the question asking what the issue was the last time a client was able to get services, 18.5% of the social workers said it was access to/eligibility for benefits.
- 26.7% said the last time a client was not able to access services, the issue was immigration.

*Transgender with HIV*

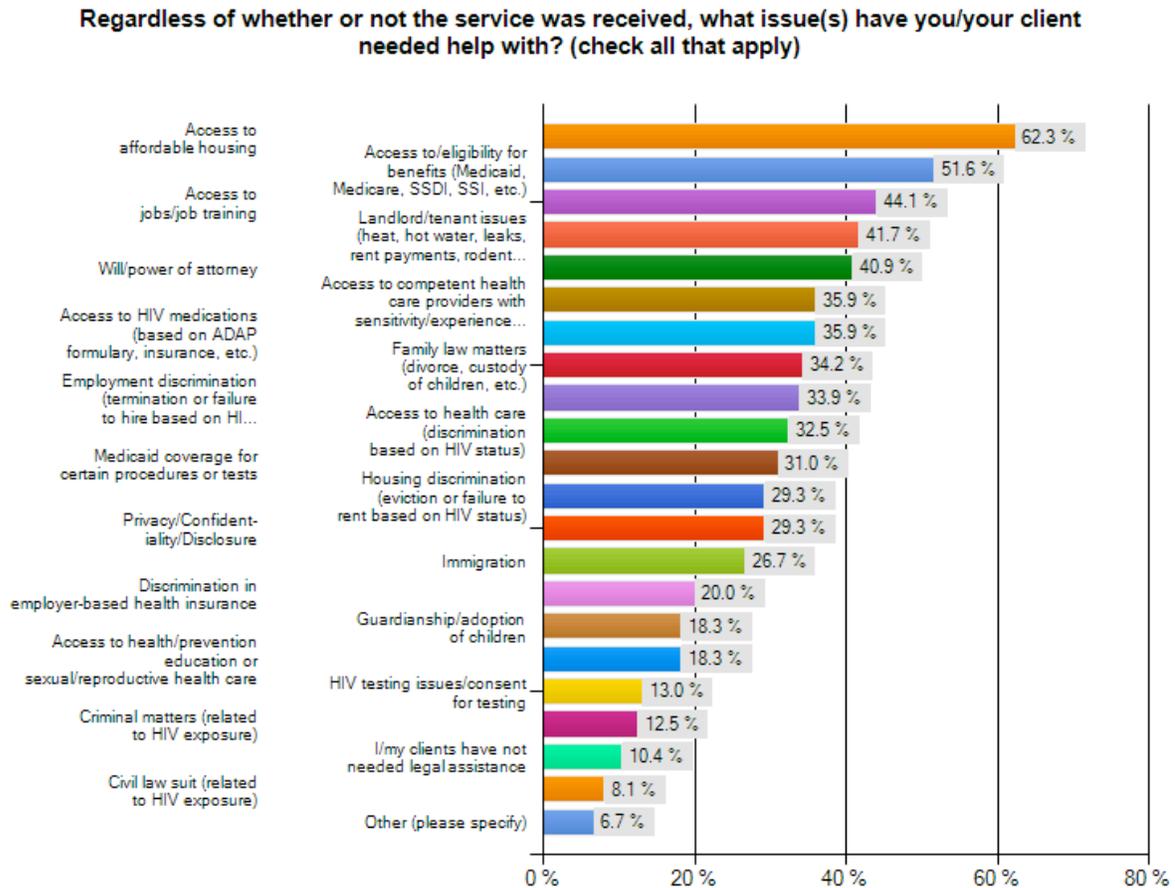
- Only three respondents identified as transgender with HIV, and all either live or work in Georgia.
- Regardless of whether or not legal services were received, all identified housing discrimination, landlord/tenant issues, access to affordable housing, employment discrimination, access to jobs/job training, access to health care, and discrimination in employer-based health insurance as issues they needed help with.

**D. Utilization of legal services and issues identified**

Data was collected about issues that required HIV-related services, who provided the services, which services could or could not be accessed, and satisfaction with those services. Legal services were needed for most issues asked about in the survey, but the most prevalent issues that need attention included (1) access to affordable housing (identified by 62.3% of the respondents), (2) access

to/eligibility for benefits (Medicaid, Medicare, SSDI, SSI, etc.) (identified by 51.6%), (3) access to jobs/job training (identified by 44.1%), (4) landlord/tenant issues (identified by 41.7%), and (5) will/power of attorney (identified by 40.9%).

**Figure 3:**



The most striking finding in relation to the top five issues is that of people identifying those issues, just 55% reported that they were able to access legal services the last time they needed services.

Out of the respondents who identified the top five issues, between 20 and 30% said that the last time they were able to get services, the issue was access to/eligibility for benefits.

### **E. Legal Services Accessibility**

Thirty-one point five percent of the people who were not able to access legal services the last time they or their client had a legal issue identified as community advocates.

Out of the people who said “yes” to being able to access legal services the last time they or their client had an issue, 21.6% identified as HIV case managers.

HIV case managers are more likely than any other group to know where and how services can be obtained along with having adequate resources at their disposal to find them. Of the same group, 66.3% cited access to affordable housing as an issue they have needed help with. Similarly, out of those who said “no” to the question of being able to access legal services, 70.5% cited access to affordable housing as a main issue of concern. We can confidently say that access to affordable housing is an issue that needs attention regardless of whether or not legal services are available.

Out of those who said “yes” to accessing legal services, 56% said that the last time they received a service, a legal services organization provided the service. An even higher percentage (79%) of those same respondents said that their provider was familiar with HIV related issues.

Out of the respondents who said “no” to being able to access legal services, 13% said that the last time they were not able to get services, the issue was immigration.

## F. Legal Issues When Services Were Unavailable

The top five issues identified when respondents were NOT able to access legal services were immigration, access to affordable housing, employment discrimination, family law matters, and access to benefits (in that order). Figure 4 below illustrates the exact breakdown.

**Figure 4:**

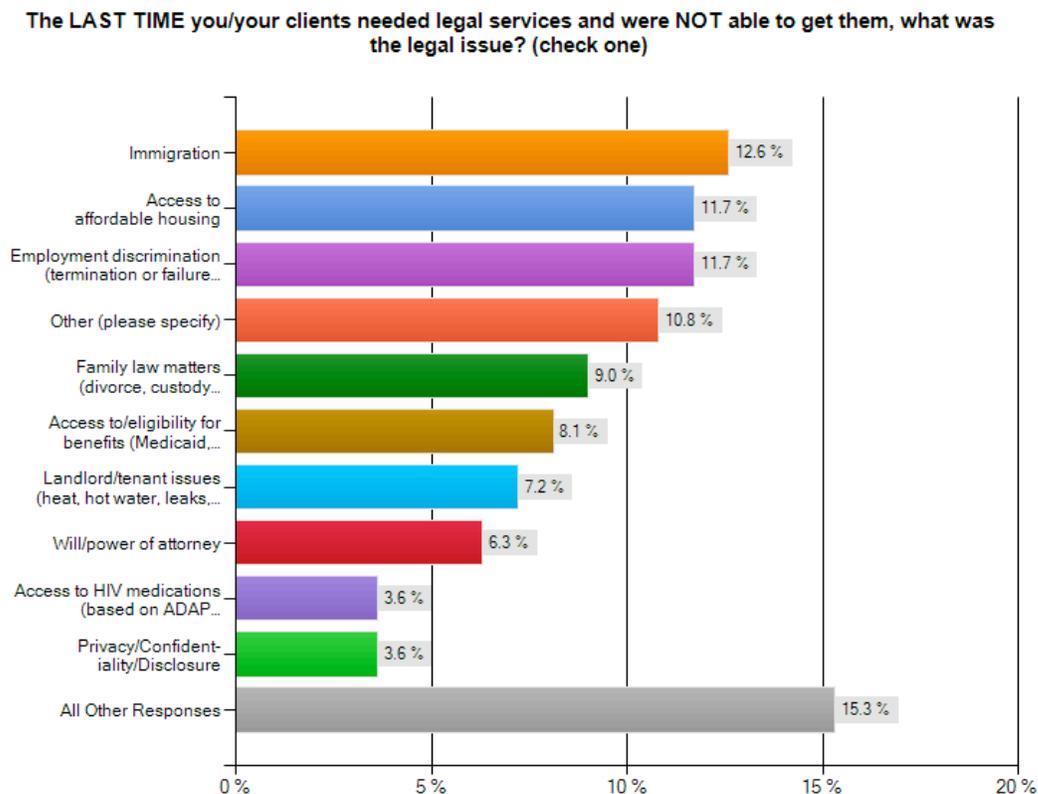
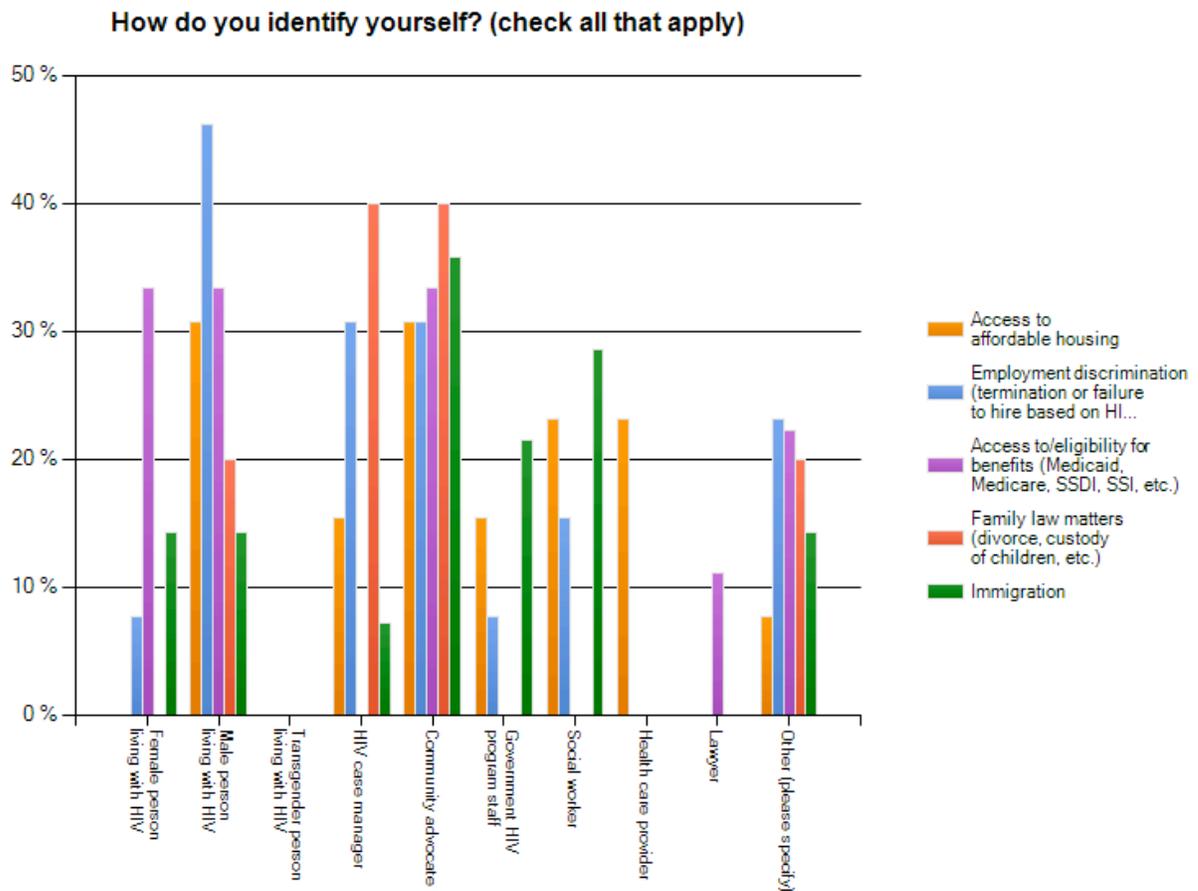


Figure 5 below breaks down unmet legal needs of the respondent or the respondent's client by the respondents' self-identification.

**Figure 5:**



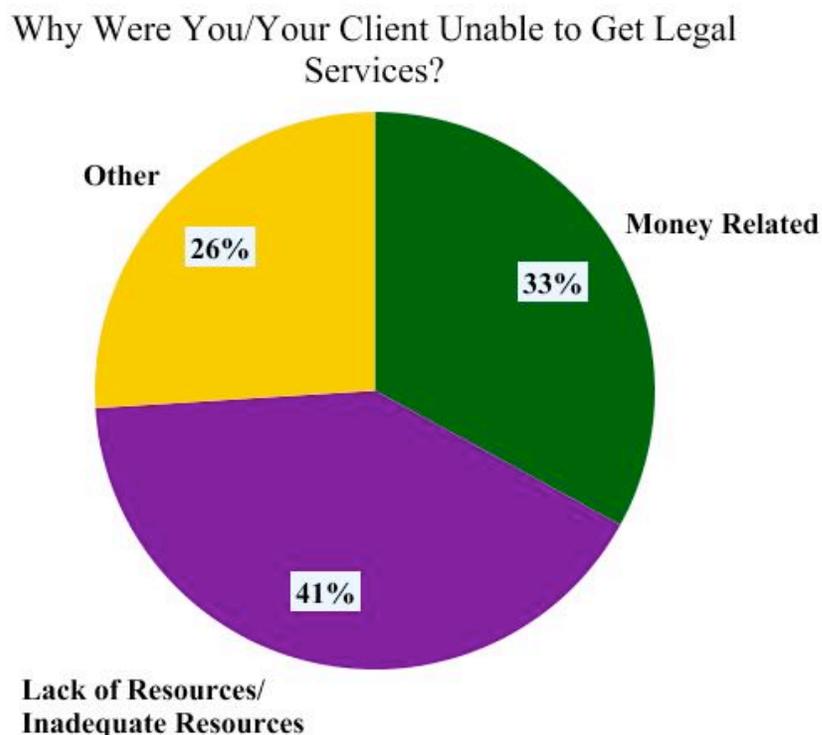
Immigration, while identified by nearly all respondents as an unmet legal need, was identified as an issue most often by community advocates (35.7%). Access to affordable housing was identified most often as a legal issue by both community advocates and males living with HIV (30.8%). Employment discrimination was an issue most often identified by males with HIV (46.2%), while family law matters were an issue most often for community advocates and HIV case managers (40%). In this category, access to benefits was cited equally as often by males living with HIV, females living with HIV, and community advocates (33%). It is important to note here that many people who identified as community advocates also identified as another category of respondent, sometimes including male or female with HIV. This may account for the large number of responses from people who identified as community advocates.

## G. Barriers to Accessing HIV legal services

Responses were collected about the barriers that persons with HIV, or persons representing people with HIV, encountered in Southern states when attempting to access legal services. Based on content analysis of the answers, the barriers that surfaced can be grouped into two broad categories: (1) financial limitations and (2) lack of services.

The financial limitations responses were all fairly similar, but there are some interesting variations in the “lack of service” category.<sup>7</sup> Some of these answers include: “long wait list with Texas Rio Grande Legal Aid, and their prioritization of cases often excludes eligibility on HIV related matters”; “the funded agency does not provide legal services for these issues”; “was told the agency did not assist with custody issues”; and “did not know of a gay friendly attorney and was told that this town is so homophobic that it would not be worth my time pursuing”. The full list of responses to “Why were you/your client unable to get legal services?” can be found in Appendix B.

**Figure 6:**



The “other” category most often included reasons such as “Legal services contacted said that client’s case would be too difficult”, “immigration status”, language barriers, “demand greater than the supply of section 8 housing”, and “Lack of awareness. The client did not know about the services available”.

<sup>7</sup> Please see Appendix B for the complete narrative responses given.

## METHODOLOGY

The survey on which this report was based took place over a four-week span, from June 9 to July 10, 2009. The Center for HIV Law and Policy (CHLP) distributed a link to an online survey to persons living with HIV, HIV service providers, and anyone whose work may involve people with HIV, regardless of whether the work is HIV-specific. Respondents included people who work or live in Southern U.S. states, including Alabama, Arkansas, Georgia, Louisiana, Mississippi, North Carolina, South Carolina, Tennessee, Texas, Kentucky, and Florida. The last three states listed were not choices on the survey, but were identified through responses in the “other” category. Because they were not individually identified answers, it is not possible for us to analyze their answers independently. Respondents were able to write in any other state of work or residence.

The survey was designed as a questionnaire for ease of completion with a split in the direction of questions half way through the questionnaire based on the response to Question 4 (The last time you/your clients had a legal issue, were you able to access legal services for that issue?). This means that not all respondents answered each of the 11 questions. (See Appendix A for the complete list of survey questions)<sup>8</sup>.

## SAMPLING

A total of 377 people responded to the survey. The overall population demographic for this survey is nearly impossible to estimate because the population consists of people with HIV, HIV service providers, and anyone whose work may be linked to people with HIV in any way. Nonetheless, the total number of people known to be HIV positive in the surveyed Southern states, which is 92,289, serves as a useful baseline for the analysis. The given sample and population size yielded a sampling error of 5.4%, meaning that we can say with 95% certainty that the results of this survey have a statistical precision of plus or minus 5.4 percentage points of what they would be if the entire HIV positive population in Southern states had been surveyed.

Other than sampling, there are several other possible sources for error in surveys such as this one. They include the non-response rate (the number of people offered the survey who refused to participate), wording or order of the questions, and the existing relationship between response choices for a given question. It is difficult to calculate errors that may result from these factors.

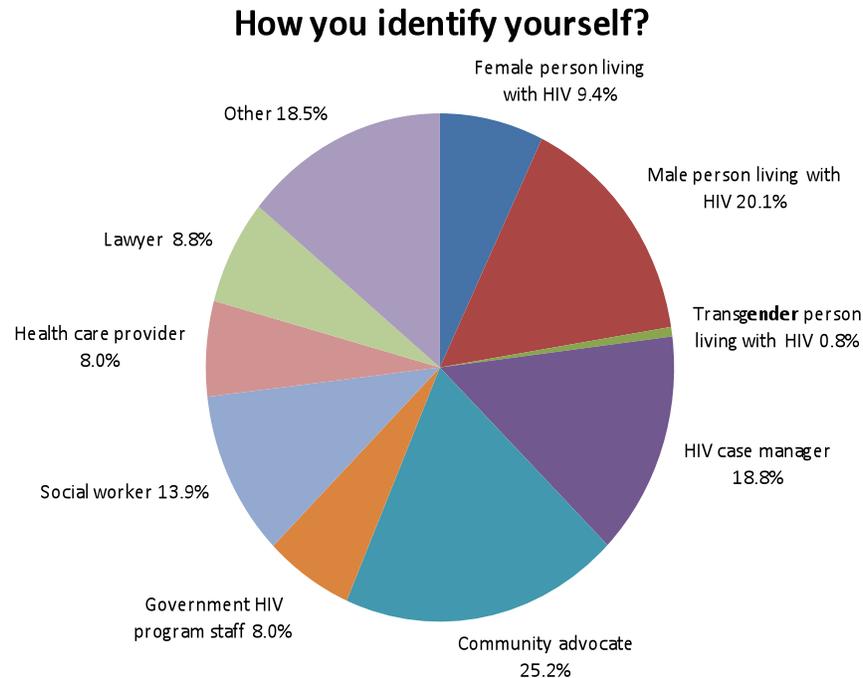
To reduce the non-response bias rate in Alabama, the state with the lowest response rate, the survey was opened up to Alabama for an additional two weeks.

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<sup>8</sup> The method used for collecting the data was a combination of random and convenience sampling techniques that yielded both qualitative and quantitative analysis. The data were entered and analyzed in Survey Monkey, which allowed for descriptive analysis. For the analysis, output from cross-tab tables was interpreted. Cross-tabs display the joint distribution of two or more variables in a single display table and allow for analysis which examines the relationship between two variables at a time. The variable defining the group is presented in the column heading and the variable for which the results are displayed, is presented in the rows of the table. The output allowed for the comparison of subsets of data by creating a table view of the cross-tab question with the cross-tabbed results. Due to limitations with the Survey Monkey software, we were not able to select more than five responses from the cross-tab question.

The distribution of the sample responses was as follows:

**Figure 7:**



Most of the people who identified as “other” work in HIV-related jobs that do not fall under one of the other headings. Examples would include an HIV Educator, Policy Specialist or supervisor of HIV/AIDS Programs at a government agency, AIDS service organization or community based organization.

## RECOMMENDATIONS AND CONCLUSIONS

Access to legal services is an essential part of guaranteeing protection from discrimination and meeting basic needs for HIV positive persons. Yet in all of the Southern states surveyed, such services either do not exist or are insufficiently resourced. Legal services for those with HIV have too often been focused exclusively on end of life planning and accessing public benefits programs. While those are legitimate needs, and while medical benefits are indisputably central to maintaining health, the increased life spans of those infected, coupled with more understated discrimination and stigma, have considerably broadened and deepened what should be considered the legal needs of those with HIV/AIDS.

The data show that there are huge gaps in access to legal services in a part of the country where nearly half of those affected by HIV reside.<sup>9</sup> As illustrated in the responses in Appendix B, there may be underlying cultural and social issues that act as barriers to services. Homophobia and HIV-

<sup>9</sup>According to the Southern AIDS Coalition, over 40% of Americans living with HIV/AIDS reside in the South. [http://www.southernaidscoalition.org/policy/southern\\_states\\_manifesto\\_2008.pdf](http://www.southernaidscoalition.org/policy/southern_states_manifesto_2008.pdf).

related stigma may discourage some people from accessing help. Immigration status and language barriers were also identified as obstacles to receiving legal services.

Barring the creation of new legal services organizations in the South, existing agencies and individuals must fill the gaps in access to HIV-related legal services. At the outset, organizations currently providing HIV related services need a detailed, current directory of available legal resources in the South. Private firms in each state should be recruited and trained to make HIV-specific legal services a *pro bono* program priority. Law school clinics should also be encouraged to address the dearth of low cost legal options for those with HIV/AIDS.

Organizations with experience in social security and medical benefits should not temper these services, but should look for creative ways to recruit volunteer attorneys with experience in underserved areas of need such as employment discrimination, housing discrimination, family law, and immigration. Volunteer attorneys with relevant substantive experience can and should be introduced to some of the additional factors for clients with HIV, such as the ways stigma can affect custody decisions.

Well-crafted legal resources such as manuals and primers are needed throughout the Southern states surveyed, and could considerably strengthen and expand the availability of services. Primers and training manuals on the more pressing needs of people with HIV in the South would help to increase the range of services offered by existing legal service providers and by private firms' pro bono programs. These types of resources also expand the ability of service providers to make meaningful referrals to affordable and HIV-familiar legal services. Training manuals can greatly enhance the number of lawyers able to provide basic services in an area. Legal manuals and primers, which provide information tailored to HIV related issues, were identified as extremely important and useful resources by the majority of our respondents. Summaries of state laws and model pleadings and briefs tailored to specific issue areas also would have widespread use in identifying relevant laws and recourse and streamlining legal assistance. There is a real need for written legal guides that are also state-specific on family law and immigration law as it relates to HIV status. The Center for HIV Law and Policy has worked to fill identified gaps through creation of primers and resources on housing, employment and other areas of importance to affected populations in the South, but much more needs to be done.

The scope of this survey did not include the need for legal help in the defense of criminal prosecutions based on HIV status, but it should be included in any comprehensive provision of legal resources. Custody, access to services and counseling, and other civil legal issues can all be compounded and complicated by the risk and reality of criminal prosecution based on HIV positive status. Human Rights Watch has described it as "an environment of risk" for those with HIV in the South<sup>10</sup>. Advocates and persons with HIV/AIDS need resources that can help all parties understand the overlaps in criminal prosecution vulnerability and the civil legal issues addressed here. CHLP has taken a first step by publishing a comprehensive manual on state HIV-specific criminal laws and prosecutions, but advocates need more primers, resource packets, and training

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<sup>10</sup> Human Rights Watch, *Southern Exposure: Human Rights and HIV in the Southern United States*, (Nov. 2010), <http://www.hrw.org/node/94476>

manuals to understand and address the overlap between civil legal needs and criminal prosecution vulnerabilities.<sup>11</sup>

In short, there is a pressing need for 1) coordination and sharing of existing legal resources, 2) creation of basic primers and training materials that can be used across the Southern region, 3) increased access to summaries and catalogs of applicable state and federal laws and model pleadings, and 4) a significant increase in the number of attorneys and paralegals providing direct services to people living with HIV in the South.

In providing funding and resources, it is vital to listen to the needs identified by people living with HIV and the providers who represent or advocate for them, and respond accordingly. Communities affected by HIV throughout the South have articulated clear priorities for addressing barriers they confront when accessing essential services, from housing to health care. As this survey and report demonstrate, legal services are a central bridge across those barriers.

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<sup>11</sup> Center for HIV Law and Policy, *Ending and Defending Against HIV Criminalization, A Manual for Advocates: Volume 1: State and Federal Laws and Prosecutions*, (2010), <http://www.hivlawandpolicy.org/resources/view/564>

## Appendix A: Survey of Legal Services for People with HIV in the Southern U.S.

### Survey of Legal Services for People with HIV in the Southern U.S.

The Center for HIV Law & Policy provides legal resources for people with HIV and their advocates. Your answers to this short survey will help us better serve people living with HIV in the Southern states of Alabama, Arkansas, Georgia, Louisiana, Mississippi, North Carolina, South Carolina, and Tennessee.

#### 1. How do you identify yourself? (check all that apply)

- Female person living with HIV
- Male person living with HIV
- Transgender person living with HIV
- HIV case manager
- Community advocate
- Government HIV program staff
- Social worker
- Health care provider
- Lawyer
- Other (please specify)

#### 2. In what state(s) do you live or work? (check all that apply)

- Alabama
- Arkansas
- Georgia
- Louisiana
- Mississippi
- North Carolina
- South Carolina
- Tennessee
- Other (please specify)

**Survey of Legal Services for People with HIV in the Southern U.S.****3. Regardless of whether or not the service was received, what issue(s) have you/your client needed help with? (check all that apply)**

- Housing discrimination (eviction or failure to rent based on HIV status)
- Landlord/tenant issues (heat, hot water, leaks, rent payments, rodents/bugs)
- Access to affordable housing
- Employment discrimination (termination or failure to hire based on HIV status)
- Access to jobs/job training
- Access to health care (discrimination based on HIV status)
- Discrimination in employer-based health insurance
- Access to competent health care providers with sensitivity/experience in HIV
- Access to HIV medications (based on ADAP formulary, insurance, etc.)
- Access to/eligibility for benefits (Medicaid, Medicare, SSDI, SSI, etc.)
- Medicaid coverage for certain procedures or tests
- Family law matters (divorce, custody of children, etc.)
- Guardianship/adoption of children
- Will/power of attorney
- Criminal matters (related to HIV exposure)
- Civil law suit (related to HIV exposure)
- Immigration
- Privacy/Confidentiality/Disclosure
- HIV testing issues/consent for testing
- Access to health/prevention education or sexual/reproductive health care
- I/my clients have not needed legal assistance
- Other (please specify)

**4. The LAST TIME you/your clients had a legal issue, were you able to access legal services for that issue?**

- Yes
- No

**Survey of Legal Services for People with HIV in the Southern U.S.****5. The LAST TIME you/your client needed legal services AND GOT THEM, what was the issue? (check one)**

- Housing discrimination (eviction or failure to rent based on HIV status)
- Landlord/tenant issues (heat, hot water, leaks, rent payments, rodents/bugs)
- Access to affordable housing
- Employment discrimination (termination or failure to hire based on HIV status)
- Access to jobs/job training
- Access to health care (discrimination based on HIV status)
- Discrimination in employer-based health insurance
- Access to competent health care providers with sensitivity/experience in HIV
- Access to HIV medications (based on ADAP formulary, insurance, etc.)
- Access to/eligibility for benefits (Medicaid, Medicare, SSDI, SSI, etc.)
- Medicaid coverage for certain procedures or tests
- Family law matters (divorce, custody of children, etc.)
- Guardianship/adoption of children
- Will/power of attorney
- Criminal matters (related to HIV exposure)
- Civil law suit (related to HIV exposure)
- Immigration
- Privacy/Confidentiality/Disclosure
- HIV testing issues/consent for testing
- Access to health/prevention education or sexual/reproductive health care
- Other (please specify)

**6. The LAST TIME you/your client needed legal services AND GOT THEM, who provided the services? (check one)**

- Legal services organization that provides only services related to legal issues
- Community based organization that provides general support services but also has a legal services department
- Private lawyer
- Other (please specify)

**Survey of Legal Services for People with HIV in the Southern U.S.****7. Was the legal services provider familiar with HIV-related issues?**

- Yes
- No

**8. The LAST TIME you/your clients needed legal services and were NOT able to get them, what was the legal issue? (check one)**

- Housing discrimination (eviction or failure to rent based on HIV status)
- Landlord/tenant issues (heat, hot water, leaks, rent payments, rodents/bugs)
- Access to affordable housing
- Employment discrimination (termination or failure to hire based on HIV status)
- Access to jobs/job training
- Access to health care (discrimination based on HIV status)
- Discrimination in employer-based health insurance
- Access to competent health care providers with sensitivity/experience in HIV
- Access to HIV medications (based on ADAP formulary, insurance, etc.)
- Access to/eligibility for benefits (Medicaid, Medicare, SSDI, SSI, etc.)
- Medicaid coverage for certain procedures or tests
- Family law matters (divorce, custody of children, etc.)
- Guardianship/adoption of children
- Will/power of attorney
- Criminal matters (related to HIV exposure)
- Civil law suit (related to HIV exposure)
- Immigration
- Privacy/Confidentiality/Disclosure
- HIV testing issues/consent for testing
- Access to health/prevention education or sexual/reproductive health care
- Other (please specify)

**9. Why were you/your client unable to get legal services?**

**Survey of Legal Services for People with HIV in the Southern U.S.**

**10. If you/your client were NOT able to get legal services LAST TIME, what was the outcome of the issue?**

**11. TO BE ANSWERED BY LEGAL SERVICES PROVIDERS ONLY**

**What kinds of resources are most useful for you/your clients? (check all that apply)**

- Sample pleadings and briefs
- Court decisions and orders
- Statutes and regulations
- Journal articles
- Legal guides
- Training materials
- Reports
- Other (please specify)

Thank you for lending your voice to this important issue. The people most vulnerable to HIV are the same people who are most often in need of legal services to help them secure the basic necessities in life, including safe housing, employment free of discrimination, and equal access to health care. Access to affordable legal services is therefore a key component of the overall service needs of people with HIV. Unfortunately, access to legal services is not guaranteed and, in some parts of the country, is not even available. This is especially true in the South where a few dedicated providers have shouldered the legal services load for people with HIV.

The Center for HIV Law & Policy intends to help bridge this gap in necessary services by making available resources for legal and community advocates assisting people with HIV. In order to do this effectively, it is critical that we hear from people with HIV in the South, as well as their advocates, to inform us about which needs are most critical and how those needs might be met. Your answers to the questions in this survey will help us reach that goal. Thank you for your time.

## Appendix B: Complete Answers to Question Regarding Barriers to Accessing HIV Legal Services

### Why were you/your client unable to get legal services?

*answered question 90*

*skipped question 287*

#### Response Text

- 1 There was no one that would help me that didn't want a big fee & I couldn't afford it
- 2 There is no one in our services that is familiar on how to proceed with immigration issues and the client/agency has no money to pay the lawyer.
- 3 No money
- 4 no access to specific type of legal aid
- 5 The agency I contacted stated they do not provide that type of service.
- 6 I called the legal services' phone number and had to leave a message and no one ever returned my call.
- 7 I was not aware of any services that could do what I tried to do myself any quicker than I could do it. My client needed to complete his SSI paperwork in order to Medicaid, in order to get a procedure done on his foot.
- 8 well it's been my experience that legal aid will gladly help drawn up a will but when I need an attorney for divorce court the only thing I got was a dear John letter, you know the one Dear Ms. Williams we regret...and that has happened to me on more than one occasion with Legal Aid.
- 9 cost of legal services
- 10 My clients are not legal aliens in the USA
- 11 Lack of financial ability
- 12 There are not laws to prevent Doctors for not seeing Pt. based on HIV status. There're too many ways to get around it.
- 13 Did not know of a gay friendly attorney. Or was told that this town is so homophobic that it would not be worth my time pursuing.
- 14 Because The Tennessee State Law Protecting The Employer and Not The Employee...
- 15 When the client complained, he and his wife were given an eviction notice and then moved out of state, but never got satisfaction here.
- 16 not sure if legal was what we needed.
- 17 lack of direction
- 18 They could not afford services
- 19 N/A
- 20 Was told that you couldn't get citizenship?
- 21 lack of providers
- 22 The director of "Nancy's House" in Cleveland, TN was incompetent and really didn't care.
- 23 Case management/follow up
- 24 Each person we spoke with didn't want to take the case.
- 25 facilities that are given are very often rat infested, nasty and unsafe
- 26 he decided to move to another area
- 27 Couldn't afford
- 28 The client was told that the case was not worth taking to court.
- 29 Money issues
- 30 could not afford services, too many on wait list
- 31 There were no pro-bono services.
- 32 Client was told the agency did not assist with custody issues
- 33 Cost of care...lack of transportation to the office.
- 34 The client was unable to afford them.
- 35 not available
- 36 The funded agency does not provide legal services for these issues...
- 37 The client had to wait for the processes over 6 months. He decided to go back to his country.
- 38 They were over the income limits for services
- 39 unable to obtain services for the specific need
- 40 There is a long waiting list.
- 41 financial
- 42 No services could help him, it was a legal issue.

- 43 unable to afford attorney fees
- 44 long wait list with Texas Rio Grande Legal Aid, and their prioritization of cases often excludes eligibility on HIV related matters
- 45 agencies are overbooked and could not take on new clients
- 46 Lack of employment attorneys who have any experience with HIV issues.
- 47 Lack of awareness. The client did not know about the services available.
- 48 did not know of any one to help
- 49 Cost
- 50 They couldn't find an attorney to represent them and they had no way to pay for it.
- 51 none available for free
- 52 Agency had no housing available in area
- 53 limited finances.
- 54 No money.
- 55 Lack of resources and attorneys versed in matters of HIV and immigration
- 56 client had no funds and no attorney would assist
- 57 Employment constraints
- 58 The client is Haitian and speaks French and his broken English is hard to understand, I think that is why legal aide never returned our calls.
- 59 No reliable representation
- 60 Cost.
- 61 demand greater than the supply of section 8 housing
- 62 Attorney told the client that due to landlord laws in Kentucky, there was no legal action they could take.
- 63 Client was not able to afford legal services; free services were not available to the client.
- 64 not sure
- 65 No money to file against insurance company.
- 66 no money for a lawyer
- 67 legal services agency does not currently address because of the status of HIV Travel & Immigration ban and the "shelving" of this issue by HHS since PEPFAR reauthorization.
- 68 Residence denied due to HIV status. As a foreigner with HIV, I cannot reside in the U.S. legally
- 69 Multiple barriers including money, lack of support or will from the legal services, time constraints with work and family circumstances-etc.
- 70 Unavailable in client's community
- 71 South Carolina Legal AIDS Services did not accept his case.
- 72 It was too expensive.
- 73 Lack of affordable legal representation; HIV/AIDS stigma
- 74 Because of the legal status
- 75 Inability to afford services
- 76 No providers in area at reasonable fees.
- 77 The client had just arrived to our area from the northern states and they did not have a provider here in Georgia. If it were a national database for example then we could have gotten her medications issues resolved quicker
- 79 make too much money
- 78 Unsure. Legal services contacted said that client's case would be too difficult. Client low income.
- 80 Legal Aid is way too backed up with helping folks to keep their homes and I do not have the money to pay a lawyer to file for me.
- 81 none serving my area
- 82 lack of money
- 83 I wasn't really sure where to go or what to do in order to resolve the situation.
- 84 finances
- 85 Did not know where to turn.
- 86 didn't know where to go
- 87 Waiting list
- 88 Finances to pay for immigrations services
- 89 Could not afford the cost
- 90 no assistance or support available to facilitate utilization of the non-existent housing system.