

2013 Anonymous Needs Assessment Survey Narrative

Introduction

The Florida Department of Health, Bureau of HIV/AIDS, now referred to as the HIV/AIDS and Hepatitis Section, (HAHS) recognized the need for consistent reporting within the state and collaborated with the Institute for Health, Policy & Evaluation Research in 2004, to create a standardized data collection protocol and needs assessment survey for people living with HIV/AIDS (PLWHA). After an initial revision in 2007 and a subsequent update in 2010, the survey and implementation guide were updated by section staff and members of the Patient Care Planning Group Needs Assessment workgroup again in 2013. The primary focus of the needs assessment survey is to determine met and unmet service needs in Florida for PLWHA, whether the person was in care or currently not in care. As such, this survey was not limited to individuals currently served by the Ryan White Program.

The needs assessment is an interconnected part of other Ryan White Treatment Modernization Act planning tasks. Results from the needs assessment are used in setting priorities for the allocation of funds, developing the comprehensive plan, and creating the annual implementation plan. Needs assessment results can also provide baseline data for evaluation and help providers improve services. The survey of PLWHAs, which is only one component of the Needs Assessment process, examines the service needs, gaps in service, and barriers from a consumer perspective.

Methods

The anonymous needs assessment survey was administered in a variety of different ways, with some counties using multiple strategies. It was not possible to compute response rates. However, with more than 6,700 completed surveys, coverage was adequate for a straightforward descriptive analysis of the data to convey useful information, without applying tests of statistical significance. Major issues that emerged were cautiously assumed to be approximations of trends among the general PLWHA population in the state.

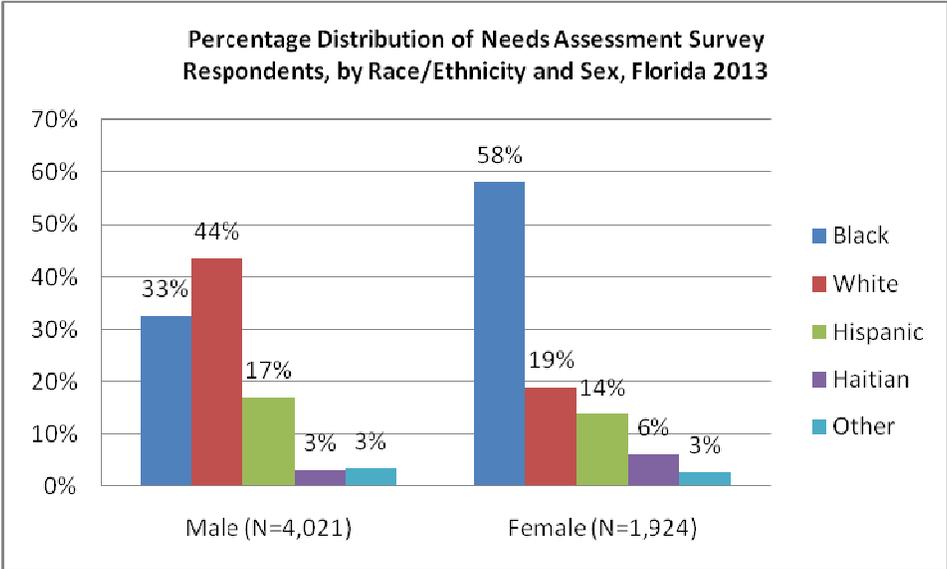
Examples of implementation approaches include the following: clients were given paper copies of the survey (if they had not already answered the survey) as they entered the agency. Case managers completed the survey with clients during appointments or clients completed them while waiting to see the case manager. Case managers called clients in outlying counties and asked if they would complete a survey- if clients agreed a survey was mailed to them, sometimes with postage included. Staff personnel (not an individual's own case manager) also called clients in outlying areas to complete surveys over the phone. Other personnel were used so that clients would feel free to answer the questions honestly. The same staff would meet with a client in an office to help complete the survey if the client needed assistance. Links to the survey were posted on social media sites with a brief description of the targeted population, its purpose and beginning and ending dates. Throughout the state, the Internet was used to reach at-large PLWHAs.

A standardized survey tool consisting of 45 items and multiple-choice responses was developed to assess service and other gaps in the HIV/AIDS patient care systems across the state. The tool was largely administered via the Internet and available in three languages (English, Spanish, Creole). Paper surveys were also available. Local areas were allowed to customize the standardized tool by

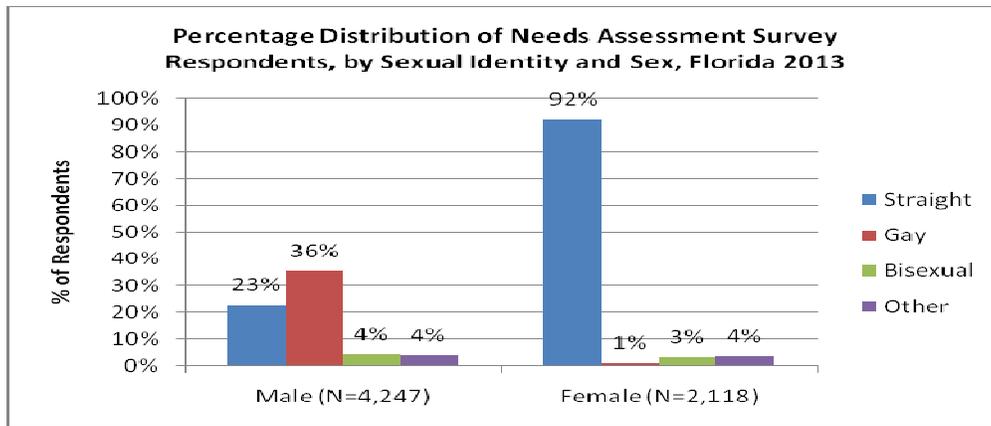
reordering or locally branding the survey, but were not allowed to modify the questions or question choices. Selected survey items were analyzed and discussed here, primarily those considered essential for individual well-being. Demographic, behavioral, and situational characteristics were then described. No tests of statistical significance were applied to the data.

Results

Among 4,021 male survey respondents, non-Hispanic whites predominated with 44% of the completed surveys, followed by non-Hispanic blacks (33%) and Hispanics (17%) (Figure 1). Six percent were of Haitian or other race/ethnicity. This is not dissimilar from statewide racial/ethnic surveillance data on all PLWHAs among males through 2009 (N = 60,992), where 38% are white, 38% are black, 23% are Hispanic, and 2% are of other race/ethnicity. Among 1,924 female respondents (and among 27,691 women living with HIV/AIDS), the percentage responding (versus the percentage PLWHAs) was 19% (19%) for whites, 59% (58%) for blacks, 14% (13%) for Hispanics and 9% (2%) for those of other race/ethnicity.



The distributions of self-reported sexual identification were very different for males and females (Figure 2). While gays (36%) predominate among males, “straight” (heterosexual) females (92%) account for virtually all respondents. There were 60 male-to-female transgendered persons and 8 female-to-male transgendered persons in the sample. Questions regarding injection drug use were not included in the survey.



According to age (N=5,901 respondents), 57% were 45-64, 35% were 25-44, 3% were 13-24, 5% were older than 64, and <1% were younger than 13. Of 6,359 clients responding to employment questions, 55% were not working, 20% were working full-time, 11% part-time, 8% “off and on” and 5% were self-employed.

During the past 12 months, virtually all respondents (92%) were receiving some form of care, including but not limited to having had a CD4 count or viral load test. Among the 8% who did not receive care, multiple reasons for not receiving care were offered by 502 respondents. A variety of reasons were offered, some of which could lend themselves to intervention, such as “I could not pay for services”, “I did not know where to go”, and “I could not get transportation” (Table 1). However, some barriers were less directly or readily amenable to corrective action on the part of the public health system. Examples of these include, “I did not feel sick” (though better education about taking meds could help overcome this barrier), “I did not want people to know I have HIV”, and “I could not get time off work”. Differences according to race/ethnicity were unremarkable (data not shown).

Table 1 - Reasons for not receiving medical care in the past 12 months, Florida, 2013

Reason	Rate	N
This does not apply to me. I did get the services I needed.	21%	191
I did not want people to know that I have HIV	11%	99
I was depressed	11%	96
I did not feel sick	10%	92
I could not get transportation	9%	80
I could not pay for services	8%	71
I was not ready to deal with having HIV	7%	65
I did not know where to get services	6%	57
I could not get an appointment	4%	37
Other	4%	35
I had a bad experience with the medical	4%	35
I could not get time off work	2%	19
I could not get childcare	2%	17
I did not qualify for services	1%	13
Services were not in my language	1%	5
Total		912

Of the 5,485 respondents who indicated they received care, 35% received care through a public or health department clinic, 30% through a doctor’s office, and 28% through an HIV specialty clinic. The remaining 8% received care at a walk-in/emergency clinic, the Veterans Affairs Health Care or by other provider.

Table 2 - Services received and service gaps for services needed, Florida, 2013

Services	Service Gap	Received Needed Service	N	N Gap
Hospice Services	70%	30%	953	670
Rehabilitation	62%	38%	1,590	986
Home Health Care	57%	43%	1,335	761
Housing	55%	45%	2,830	1545
Outreach	54%	46%	1,659	900
Peer Mentoring	50%	50%	2,044	1030
Transportation	46%	54%	2,604	1208
Substance Abuse Treatment	45%	55%	1,469	657
Food Bank or Food Vouchers	43%	57%	3,481	1511
Nutritional Counseling	41%	59%	2,851	1160
Legal Support	39%	61%	2,406	945
Mental Health Services	33%	67%	3,009	987
Dental/Oral Health	33%	67%	5,247	1714
Health Insurance	33%	67%	4,253	1388
Health Education/Risk Reduction	26%	74%	2,719	712
Early Intervention Services	23%	77%	2,885	670
Treatment Adherence	17%	83%	3,047	533
Case Management	10%	90%	5,686	580
Outpatient Medical Care	4%	96%	5,916	262
Medications	3%	95%	5,982	184

Excluding those who did not need a specific service, the majority of respondents received needed specific services (except for hospice services, rehabilitation, home health care, housing and outreach where 50% or fewer received the needed service). There were numerous specific gaps (Table 2). The difference between the total number of survey respondents and the totals shown in the table represent those who did not need the particular service. Of 20 services listed, six specific services were needed by more than half of respondents (service gaps in parentheses): food bank or food vouchers (43%), dental/oral health (33%), health insurance (33%), case management (10%), outpatient medical care (4%) and medications (3%). The latter two services are considered vital, and fortunately these needs are met for more than 95% of respondents. Differences in service gaps according to race/ethnicity were unremarkable (data not shown).

3,648 respondents (72%) reported no barrier to services. Of the 2,810 who indicated they experienced one or more barriers, 18% did not know where to receive services (Table 3). This could probably be addressed by public health authorities via education and social marketing. Social

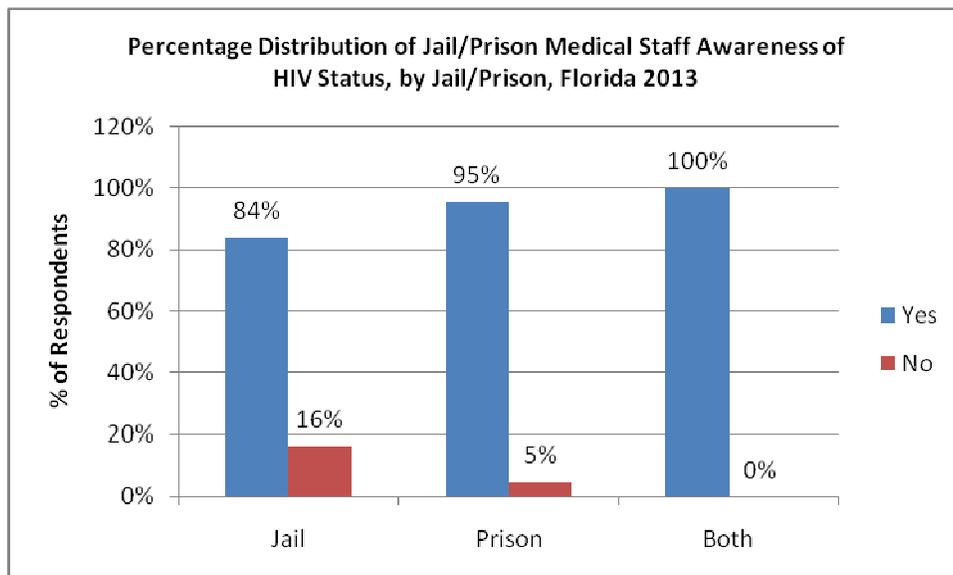
marketing could also be effective in reducing stigma, which underlies not wanting others to know the respondent was HIV-positive (8% of those expressing barriers).

Table 3 - Service Barriers, Florida, 2013

I did not know where to get services	18%	565
I could not pay for services	14%	438
I was depressed	13%	396
I could not get transportation	11%	333
I did not qualify for services	8%	260
I did not want people to know I had HIV	8%	257
I could not get an appointment	5%	157
I had a bad experience with the staff	5%	145
I could not get time off work	4%	131
I could not get childcare	3%	81
Services were not in my language	1%	38
Total:		2,810

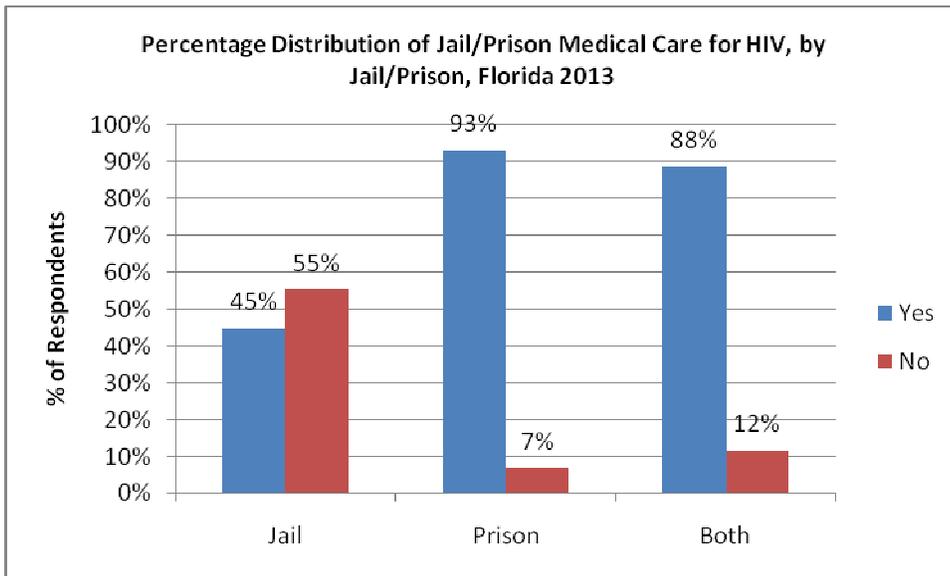
13% indicated depression as a barrier, and a sizeable proportion of those needing mental health services did not receive them (27%; Table 2). However, the degree of clinical or sub-clinical depression was not determined. Depression was more common among racial/ethnic minorities than among whites.

Among those respondents who indicated they were in jail and/or prison, more than 80% indicated that the medical staff was aware of the respondent’s HIV status.



Among those respondents who indicated they were in jail and/or prison, more than half indicated they received medical care while in custody. Those respondents who had been in prison only

reported the highest rate (90%) of HIV care; those who were only in jail reported the lowest (60%) although the low number of respondents (N=31) in both jail and prison makes this result unstable.



Discussion

Although many reasons were offered for not receiving medical care in the past six months (Table 1), a relatively small proportion had need in this regard. Only 7% (N=502) of respondents in the sample gave one or more reasons why they had trouble obtaining medical care. Of these, 13% were depressed. While the extent of clinical or sub-clinical depression was not ascertained, a shortage of mental health services could be addressed and resources committed to this need. Roughly 32% of respondents in need of medical services did not get them because they either did not know where to get services or could not pay for services. In these cases, improved communication of service locations and the availability of programs to pay for services may be made through education efforts. Almost 10% of respondents in need of medical services avoided them because they did not want people to know that they had HIV. Addressing underlying stigma and reality-checking in this group may require effective social marketing, which could address other unmet needs as well, including where to find transportation. In-service cultural sensitivity training could have an impact on reducing bad experiences with staff.

Those respondents in need of a particular service were most numerous for case management (5,686), outpatient medical care (5,916), and medications (5,982) (Table 2). A relatively small proportion of respondents indicated an unmet need for delivery and receipt of these services (respectively, 10%, 4%, and 3%), which is encouraging as the most needed services were also the most often received. Alternatively, service gaps (measured as number of persons experiencing the service gap) were greatest in dental/oral health (1,714), housing (1,545) and food bank/vouchers (1,511). All the above unmet need categories can be addressed to some extent by public health and community-based organizations. The general absence of differences across the racial/ethnic spectrum suggests all demographic groups require similar levels of additional professional attention and intervention.

Limitations of the Data

The demographic profiles of the sample and all PLWHAs differed enough – especially among females – to suggest a non-representative sample of clients had been achieved. Clients were self-selected for survey participation. Next time, efforts will be made to more systematically sample eligible individuals to produce a more representative sample, whose characteristics, knowledge, attitudes, and behaviors could then be reliably compared from one survey cycle to the next. Responses were subjective and subject to respondent biases, including recall and social desirability of answers to sensitive questions. However, this would be the case even if a randomized survey had been conducted. To enable better generalization to the overall PLWHA population will require a different study design and consume more resources, but the cost-effective benefits in achieving the survey goals and objectives should outweigh the drawbacks. Finally, the survey period was April 1, 2013 through May 31, 2013. This was a shortened period of time and thus spanned with a smaller number of respondents than previous surveys. The timeframe was shortened because most planning areas needed the completed survey analysis processed prior to the submission of grant applications.

Conclusion

This survey provided a snapshot of a cross-section of needs and reasons that some of those needs went unmet. The number of a self-selected group of PLWHAs with actual unmet need is what we obtained, which may be regarded as a minimum estimate. However, the proportions of the sample in need of services likely differ from the proportion of all persons in need, due to the non-representative nature of the sample. Resources could be assigned to improve the situations where the most PLWHAs had specific service needs and where these services were amenable to change. Future surveys will deploy more uniform sampling methodology to achieve a sample from which generalizations can be made, statistical tests of comparison can be conducted, and comparisons over time can be made.