

VOLUSIA AND FLAGLER COUNTIES (AREA 12)
RYAN WHITE HIV/AIDS TREATMENT EXTENSION ACT OF 2009

FY2009-2010 HIV/AIDS PATIENT CARE NEEDS ASSESSMENT UPDATE

Introduction

In the fall of 2009, the Florida Department of Health, Bureau of HIV/AIDS, Epidemiology Section published and disseminated data reflecting the estimated number and percentage of HIV-positive individuals believed to be “*not in care*” in each of Florida’s HIV/AIDS planning districts. The counts were based on actual client-level data available through 2006.

The Area 12 Partnership for Comprehensive HIV/AIDS Planning (PCHAP) quickly recognized that it’s region ranked with the highest percentage in the state of HIV-positive persons who were reported as not receiving any type of routine HIV/AIDS Primary Care (as determined through laboratory and program reporting) – with an estimated 35% overall showing as “*not in care*” in the report. In comparison, the statewide average for this indicator was 17%.

The timeliness of this information allowed the planning body to adopt a primary goal in the region’s 2009-2012 HIV/AIDS Patient Care Comprehensive Plan to reduce the number/percent of Area 12 residents who are known to be HIV-positive but are not accessing routine medical care from 35% to the statewide average of 17% over the 3-year period. Entering FY2009-2010, the PCHAP members determined that seeking additional information about this population was a necessary first step in attempting to develop strategies to address the disparity; and subsequently created action steps for each of the two standing PCHAP subcommittees to assist in the assessment during this first goal-year.

The Problem

It is well known that persons who are living with HIV infection should receive early and ongoing routine primary medical care services in order optimize their health status and quality of life; and to prevent opportunistic illness. National guidelines from the US Centers for Disease Control and Prevention (CDC) state that “*Persons with a diagnosis of HIV infection need a thorough evaluation of their clinical status and immune function to determine their need for antiretroviral treatment or other therapy... HIV-infected persons should receive or be referred for clinical care promptly, consistent with USPHS guidelines for management of HIV-infected persons.*”¹

Routine primary care serves to identify and evaluate HIV-related complaints that may require immediate intervention; to establish a strong provider-patient relationship; to assess and improve the patient’s knowledge of their disease status and necessary care; to identify and treat concurrent medical problems; to establish baseline clinical measures for comparison when attempting to diagnose and treat future problems; and to provide needed education and information to clients regarding transmission and high-risk behaviors.²

¹ MMWR: “Revised Recommendations for HIV Testing of Adults, Adolescents, and Pregnant Women Healthcare Settings,” Sept. 2006

² US Health Resources and Services Administration (HRSA): *Guide to Primary Care for People with HIV/AIDS*, 2004.

Persons living with HIV disease who do not access routine primary care are therefore known to be at higher risk of developing complications from concurrent illnesses; because they often miss opportunities for the prevention, early detection, and intervention of these types of threats. Immediate and/or early initiation of routine primary care after a positive HIV diagnosis can greatly improve the patient's quality and length of life; as well as significantly reduce overall costs of care by appropriately providing less intensive preventative and wellness care on an outpatient basis as opposed to more expensive emergency room and in-patient hospital services later on. Primary medical care providers also often serve as the leading entry point for HIV-positive individuals to access other needed services such as mental health and social support services, housing assistance, case management, and ongoing education. Decreasing the number/percent of Area 12 residents who are known to be HIV-positive but who are not accessing routine primary medical care will ultimately improve the length and quality of life for the individuals served; as well as reduce the long-term costs of providing care and treatment for this population.

Methodology

The members of the PCHAP Needs and Resources Committee assisted Lead Agency staff in the development of a general methodology to further examine and address the issue of HIV-positive persons "*not in care*" in Volusia and Flagler Counties, via a two-pronged approach:

1. Survey all existing HIV counseling and testing sites in the region to identify and assess referral and linkage protocols for persons who are newly diagnosed with HIV; and
2. Conduct community-based research with HIV-positive individuals (both in and out of care) to identify common barriers to accessing primary medical care services.

Additionally, the planning body's contracted Lead Agency, The Health Planning Council of Northeast Florida (HPCNEF) requested technical assistance from the Bureau of HIV/AIDS to identify and rank the specific populations most impacted by this issue. The Bureau's epidemiology section, in turn, provided a detailed report of the estimated demographics for the not-in-care population. The detailed population data was then utilized by the committee members to develop assessment strategies that would most effectively engage the highest priority population(s).

The Needs and Resources Committee also determined early on that the expertise of the members in the PCHAP Standards and Quality Committee would be required for the development of truly effective engagement strategies for this group. It was decided that this second committee would subsequently take the lead during the strategy development phase, nearing the end of the assessment cycle.

With the objectives and action plan established, the Lead Agency (HPCNEF) secured the services of an intern from University of South Florida's College of Public Health to assist in a direct survey of all existing HIV testing centers in Volusia and Flagler Counties. A current list of certified testing sites was provided by the Area 12 AIDS Program Office at the Volusia County Health Department. A survey tool was developed by the Lead Agency staff, with input from the PCHAP Needs and Resources Committee members, to solicit detailed information about the sites' existing protocols to link persons who are found to be HIV-positive into needed health

and community-based services. The intern then contacted each site by telephone to establish a primary contact person, and to obtain a direct fax number. The survey instrument was then faxed to the sites to be completed independently and returned (via fax). Telephone follow-up was conducted with any sites that did not return the survey right away. The survey results were then compiled and presented to the Needs and Resources Committee members for discussion and consideration; along with a full report of testing data from the region as provided by the Bureau of HIV/AIDS.

The committee members also sought to learn from the community directly what the primary and common barriers are to HIV-positive persons initiating and staying in primary medical care and related services. To accomplish this, the members first examined the estimated demographic data for this population, as provided by the Bureau of HIV/AIDS. Based on the findings of this data, the group then selected an information gathering approach that they felt would be the best fit for the highest priority population groups.

The members elected to employ qualitative data collection techniques (as opposed to more structured quantitative methods) in order to draw out any obscure or otherwise unknown barriers that may exist in the community, but that may otherwise not make it onto a multiple choice survey. The members also found significant value in being able to gain more detailed information from the community including contributing and underlying factors that are also not easily determined from multiple choice/limited response surveys. In this way, the committee hoped to gain a more complete understanding of the issues faced by this population.

With assistance provided by Lead Agency staff, the committee chose to host open community discussions utilizing the nationally recognized “World Café” model. This model was selected because it utilizes a more community-based and participatory approach than traditional focus groups; and has been found to be most successful in settings where the study leaders may not be as recognized or trusted as members of the community itself. The model empowers the community participants to elect their own discussion leaders (i.e. table leaders); and to answer important questions freely among themselves without the often unwelcomed influence of academic “outsiders.” It was agreed among all of the committee members and lead agency staff that this approach would be much more effective than the traditional “didactic” methodologies among the communities we needed to reach.

Findings

As stated earlier, a breakdown of the estimated population of HIV-positive persons in Area 12 “not in care” by major demographic determinants was provided by the Bureau of HIV/AIDS Epidemiology Section. The report indicated that the *not-in-care* population was at least equally diverse as the population already served under the Ryan White program in Area 12; and that no single population was significantly affected more than any other. There were subtle elevations, however, in the percentages of Hispanic persons, Men who have Sex with Men (MSM), and Injecting Drug Users (IDU) who are believed to be not in care when compared to the remaining population groups.

Additionally, the HIV Counseling and Testing Site survey revealed that there were a total of eleven (11) active and licensed testing sites (including at least 1 mobile testing unit) at the time in Volusia and Flagler Counties (combined). Virtually all of the sites provided information about how clients are directly linked into eligibility and case management services if/when they are found to be HIV-positive. The committee members were unable to identify any referral/linkage gaps among the site protocols.

The members did note, however, that there appeared to be a lack of evening and/or weekend hours during which HIV tests were offered in the community. It was later determined that this was due to a misunderstanding around the wording of the question in the survey instrument itself, rather than an actual deficiency. The question stated: *“What days and hours does your agency regularly operate?”* It was found that most organizations understood the question to mean only their main-office hours – and therefore they did not account for after-hours outreach and testing. Supplemental information from Counseling and Testing providers who are also committee members clarified that there is indeed a great deal of testing that occurs in Area 12 both during evenings and on weekends.

Finding that an effective and coordinated system was in place to provide Counseling, Testing, and Linkage/Referral services throughout the region, the PCHAP committee members then looked to the community to find more answers. The Committee initially worked to begin planning 2 separate World Café events – one in the primary service area of Daytona Beach, where more than a third of the HIV-positive individuals in Area 12 reside and receive services; and a second in western/north-western Volusia County, where there are emerging numbers of HIV/AIDS cases and where other community feedback indicates that services are not as frequently available.

The first of these events was scheduled to occur in early November of 2009. (The second would be scheduled after the winter holidays, incorporating lessons learned from the first.) A suitable and appropriate venue was secured; as well as sponsorship from a pharmaceutical company that serves HIV/AIDS clients. A flyer was created to inform community members about the event, and to encourage them to attend and participate. The flyer was widely disseminated through PCHAP, case managers, eligibility workers, the Area’s ADAP coordinator, and others. RSVP contact information was provided and clearly marked on the flyer. Unfortunately, with only 3 days left before the event, it was reported that not a single participant had registered; and so this first event had to be cancelled.

The Needs and Resources Committee members met again in January to regroup, and to discuss alternative options and solutions for the discussion group(s). It was decided that a second attempt would be planned during February. Based on feedback from the committee members, the event flyer was completely redesigned and redistributed. It was also decided that personal invitations would be more effective in reaching the target population(s); and so committee members volunteered to make telephone calls and/or otherwise directly contact enrolled clients as well as others known to be HIV-positive but not in care. A new community-based location was also chosen.

The World Café discussion, called “*Chit, Chat, and Chew*” was successfully conducted on February 23rd by Lead Agency staff, with more than 16 active community participants (consumers). As suggested in the model, participants were divided into table groups of 3-4 participants each; and each table was asked to address 1 of 5 separate questions. The tables discussed the information freely among themselves, with an elected table leader taking notes from the proceedings. Each table was also pre-covered with large sheets of blank paper, and participants were given markers and encouraged to jot down random notes, thoughts, and pictures during their discussion. After a pre-determined length of time (10-12 min.), the participants (all except for the table leader) moved on to the next question/table. This process was repeated until all participants had an opportunity to address all five questions.

The questions themselves were presented to the group as a primary question, with suggested probing/follow-up questions intended to help give more depth to the discussion. The questions were presented on large table-tents as follows:

What are the five most important things that someone who is HIV-positive needs in order to stay as physically and mentally healthy as possible?

- *Is there any one thing that stands apart as the MOST important?*
- *How much do these needs differ from person to person, and why?*

What do you think prevents some people from going to a doctor or other health provider when they first find out that they are HIV-positive?

- *What helped you/your loved one decide to visit a doctor after testing HIV-positive?*
- *How long did it take to decide?*
- *What might have helped you/your loved one go to the doctor sooner (if you waited)?*

Do you think it would be more helpful for people who are living with HIV/AIDS to have emergency help that pays large or unexpected household bills only once in a while; OR, to have a little bit of help with their household bills every month?

- *What household bills do you think that people need the most help with?*
- *How do you think that having steady and secure housing helps people stay healthy?*

Do you think that there is a relationship between illegal drug use and HIV/AIDS in our community?

- *How does illegal drug use affect people’s physical and mental health, especially if they’re already dealing with being HIV-positive?*
- *What types of services do you think would be most helpful for someone who might be using illegal drugs and who is also HIV-positive?*

Why do you think people who are living with HIV sometimes stop going to regular medical appointments and/or stop taking prescribed medicines?

- *What can service providers do to help?*
- *Where else might someone who is HIV-positive go to get information about how to stay healthy if they do not attend regular medical appointments (for any reason)?*
- *What types of information do you think that someone who is HIV-positive might want to have most?*

Once all of the questions had been discussed by all participants; the table leaders were asked to summarize the main points that they heard throughout the discussion. Those summary points were then entered onto a large chart by lead agency staff, for further participant input. Lead agency staff also collected the paper table covers after all of the discussions were complete, in order to compile the community comments listed on those. Example community comments from the tables and summary discussion are listed below (in random order, by question).

Community Comments

Service Priorities: *“What are the five most important things that someone who is HIV-positive needs in order to stay as physically and mentally healthy as possible?”*

- Jobs!
- Financial Assistance (*i.e.* money)
- Healthy Lifestyle / Healthy Food / Exercise
- Doctors and Medical Care
- Medications
- Transportation
- Support / Communication with others / “Love”
- Stable Housing

Delayed entry into care: *“What do you think prevents some people from going to a doctor or other health provider when they first find out that they are HIV-positive?”*

- “Fear” (stated multiple times), and a “lack of coping skills” to overcome it
- “Denial”
- “Giving up” (*i.e.* hopelessness)
- “Depression”
- Lack of family or other emotional support

- Not knowing where/how to initiate services
- Religious views
- “Partners” (*it is unclear from this comment alone if it relates to fear of disclosure to partners, or direct discouragement from partners.*)
- Going through an “emotional 360”
- A client who was diagnosed during pregnancy stated: “1. cost 2. denial 3. fear”
- Alcoholism and drug abuse
- “Location”

Housing Needs: *“Do you think it would be more helpful for people who are living with HIV/AIDS to have emergency help that pays large or unexpected household bills only once in a while; OR, to have a little bit of help with their household bills every month?”*

- HELP EVERY MONTH! (Unanimous)
- Less paperwork
- Need help with:
 - Rent
 - Utilities (especially Electric)
 - Gas
 - Food

Impacts of Substance Abuse: *“Do you think that there is a relationship between illegal drug use and HIV/AIDS in our community?”*

- Yes!
- Some initiate substance use before HIV diagnosis, some after
- Drugs “make life worse” for everyone
- Drugs “increase risky behaviors” / decrease inhibitions
- Drugs cause people to “make bad decisions”
- Have a negative impact on both physical and mental health
- Make people lose needed sleep and nutrition
- “Drug addicts want shelter, not rehab.”
- Drugs distance users from their family and friends, causing a breakdown in their support structure
- “Drugs affect the user, but not the community at-large.”
- “Put them in jail.”

- “There is no difference between how drugs affect HIV-negative people and how they affect HIV-positive people.” “We are all the same.”
- Drug testing should be required in jail
- “No testing, No status, No support.”
- Support groups should be offered in jails
- There is no linkage into services when someone gets out of jail
- There are no rehab. facilities available.

Discontinuing Care/Treatment: *“Why do you think people who are living with HIV sometimes stop going to regular medical appointments and/or stop taking prescribed medicines?”*

- Lack of transportation
- “Don’t want to” and “Bad time”
- Depression
- “Lack of doctor options”
- “Frustration... There are no good reports from the community about the available doctors.”
- Lack of bedside manners from doctors
- FEAR of available doctors bedside manner
- Lack of compassion from doctors
- Side effects from medications
 - Nightmares
 - Diarrhea
- HIV Medications are not given in jail
 - *(even though supposed to be dispensed within 48 hrs)*
- PLWHA’s get information from:
 - POZ magazine
 - The internet
 - Friends
 - Support meetings
- To help, providers should:
 - Call patients when they go missing
 - Give prescriptions (for depression)
 - Offer more education and teach people how to live healthy
 - Offer support groups

Summary and Conclusions

Based on the comments and discussion from the community members, there were some reoccurring themes that clearly emerged as common across all population groups and geographies. These community-wide concerns and recommendations should be considered among the top priorities of program planners and service providers for future program development, as they have the potential to benefit the greatest number of affected individuals in the region. The most dominant themes that surfaced from this community exercise are summarized in more detail below.

Fear and Stigma as significant barriers to initiating and maintaining care. Veiled within a wide variety of terms, the core concept of fear of disclosure of HIV-positive status clearly remains the strongest determinant of treatment and service access among persons who are HIV-positive in the region. Often self-reported as “*fear*” and “*not wanting people to know,*” this finding has been by far the most frequent response from both HIV-positive persons and their loved ones when asked why PLWHA either delay entry into HIV medical care services and/or they discontinue treatment after they have started – consistently for at least five years and among all population groups.

The community participants offered recommendations for providers to help ease the transition into services for PLWHA. Suggestions included increasing community education and awareness about HIV in order to help address public stigma/fears, and inform people where they can go for help. It was also recommended that the community messages incorporate “*hope*” for persons who are newly diagnosed and having difficulty coping with the news. Participants also advocated strongly for support groups for persons living with HIV, especially newly diagnosed.

Mental Health / Emotional Support. Regardless of the question or topic at hand (*service priorities vs. housing vs. drug abuse vs. getting into care*) – a cross-cutting request from consumers throughout the discussion was for ongoing community support groups where people who are living with HIV can meet, discuss concerns, gain emotional support, and share information. Notes from at least two separate table-groups show a clear deviation from the question at hand (one was addressing housing assistance, the other was addressing substance abuse) into a detailed explanation of why support groups are needed and how they should be structured. Participants even identified potential sites, sponsors, and topic matter. One event participant even asked others to offer their names and telephone numbers on a sign-up sheet to start a group among the community members present. A list was quickly formed. The frequency and consistency of this request, coupled with the willingness of participants to join a group “*on-the-spot,*” even among strangers, and without hesitation, is a strong testament to the perceived need for this option among our HIV-infected population.

Further supporting the direct requests/recommendations from the table-groups for an improved emotional support structure were repetitive individual written and spoken comments related to fear, depression, and hopelessness among PLWHA’s regarding their HIV-positive status. Again, these responses appeared repetitively on the table notes regardless of the

topics discussed. The findings appear to contradict Ryan White service utilization data in the region that show a steady and sharp decline in the use of mental health services among enrolled clients – and it could be considered evident from these findings and requests for more emotional support that the actual needs for this service have not decreased proportionately, if at all. It is evident, however, between the data and the discussion that consumers are more willing to access and attend support groups than to visit an individual mental health counselor.

Lack of Transportation. Transportation barriers were another recurring theme across the discussion tables; as also similarly reported in previous assessments. Many clients report not having any mode of personal transportation; and many who do report that they often cannot afford fuel. While limited public transportation routes are available in central/eastern Volusia County, clients have historically reported that ride and wait times are excessively long; and also that even getting to the nearest bus stop can create a significant challenge for some. Additionally, there is virtually no bus or other public transportation service to most areas in west Volusia and all of Flagler County.

Other Common Barriers that Interrupt Care. The most prominent issues reported that would potentially cause a person living with HIV who has already initiated HIV primary medical care to discontinue treatment included significant side effects from medications, substance use/abuse, and depression. It was also reported from former inmates that HIV medications are not available to persons who are incarcerated, despite a known protocol that the meds should be dispensed within 48 hours of entry into the jail.

Varying perceptions related to substance use/abuse in the community. Consistently, the region's most difficult known access barrier to measure has been the issue of recreational and habitual drug use among some HIV-positive persons. Providers repeatedly report this as a common and priority issue in the community; yet a majority of PLWHA in the region repeatedly report that it isn't a problem at all. Subsequently, a long standing question remains regarding the possibility of a cause and affect relationship (or any relationship) between the two. (*i.e. Does drug use increase the possibility of HIV infection; or does a positive HIV diagnosis increase the potential for drug abuse?*) The answers obtained from this community discussion only further illustrate the wide variety and complexity of perspectives among community members on this topic.

One group of participants responded to the question of *"is there a relationship between HIV disease and illegal drug use in our community"* with a resounding YES! Based on their notes and comments, these participants appeared to be fairly well-informed regarding both the negative physical and psychological impacts of illicit drugs. They also seemed to offer the strongest opinions in regards to how to address this issue in the community, with responses such as "put them in jail"; "require drug testing as a condition to receive services"; and "drug addicts want shelter, not rehab." This group clearly appears to advocate for more screening/testing and stricter penalties for users.

A second tier of participants had a milder but still somewhat negative response regarding drug use and positive HIV status – stating that using drugs affects the individual, “but not the community at-large.” This group suggested that case managers and medical providers should take a more active role in screening and identifying substance abuse issues – and then linking clients into needed services. It could be inferred, then, that this group recommends more individual-level identification and intervention over community-wide programs.

Finally, a third group did not recognize a relationship between HIV status and drug use/abuse at all. Participant notes stated that “there is no difference between how drugs affect an HIV negative person and an HIV positive person,” and “we are all the same.”

This wide variety in community perceptions and awareness regarding the proven significant impact of drug use and abuse among persons living with HIV is concerning. While a small group among the discussion participants did seem to be fairly well informed about most or all consequences of illicit drug use (and had subsequently formed strong opinions against it); it appears that a larger segment of the HIV-positive population in Volusia/Flagler is at least partially, if not fully unaware of the increased health risks associated with co-occurring HIV disease and illicit drug use, or the “ripple effects” that can impact entire families and communities. This finding is also consistent with findings from previous assessments in the region. (The PCHAP standards and quality committee subsequently developed a substance abuse and HIV “fact sheet” in 2007 to address the issue.)

A final finding under this topic, again consistent with historical assessments, is a lack of substance abuse treatments facilities (i.e. “beds”) in Volusia and Flagler Counties. Participants reported more than once during this discussion that “there are no rehab. facilities available.”

In conclusion, it is clear that personal/internal beliefs and barriers are still the strongest influencers in Area 12 of whether individuals seek and maintain treatment and care after they are diagnosed as HIV-positive. These barriers reportedly affect individuals of all genders, races, ages, and risk categories in very similar ways – although their origins may differ slightly between various cultures. Community feedback describes how feelings of fear, denial, and hopelessness can be emotionally paralyzing to many individuals who are just starting to learn to cope with the diagnosis; and that multiple levels of emotional support (individual/family, group, and community) are needed to help those persons regain the strength and confidence they need to ask for help (i.e. seek medical care and/or support services). Another recommendation may be for immediate licensed/professional intervention at the time (or within 24-48 hours) of the first HIV-positive diagnosis.

Additionally, despite a sharp decline in the utilization of mental health counseling services among HIV-positive consumers who are enrolled in the Ryan White program in Area 12; a strong need was expressed among consumers for more options to access “emotional support.” Consumers appear to believe strongly that this needed emotional support can and should be provided through organized peer-support groups around the community; as opposed to traditional professional counseling. Recommendations for support-group structure included that groups should not be segregated by population type (i.e. a men’s group separate from a women’s group; or African-Americans separated from Hispanics and Whites) because people

living with HIV often experience the same feelings and issues regardless. Participants also appeared to be empowered by meeting others who also advocated for groups; and subsequently even initiated the formation of a consumer-driven group among themselves.

Based on current and historical findings – all emotional support for newly diagnosed individuals, those who know they are HIV-positive but are not-in-care, those who have initiated but then discontinued care, and even those who are regularly accessing care should have a strong emphasis on providing the skills and techniques needed to appropriately disclose their HIV-positive status to healthcare professionals and other trusted individuals. Additionally, consumers recommend that community-wide messages be developed that work to reduce the stigma and negative perceptions surrounding HIV infection; and that offer hope and guidance to persons who may be trying to cope with a new HIV diagnosis.

One final finding involves the importance given by participants in the community discussion group of jobs for HIV-positive individuals. This was cited as a priority need among consumers. A possible recommendation might be for stronger linkage/referral relationships between existing HIV/AIDS services providers and agencies that specialize in job training and placement.

These recommendations will be shared with the members of PCHAP for consideration as they develop goals and implement programs moving forward. The findings from this assessment will also be integrated into the region's upcoming 3-year full needs assessment beginning in April of 2010.