

Newark EMA HIV Health Services Planning Council 2005 Needs Assessment Update

EXECUTIVE SUMMARY

Epidemiological Profile

People Living with HIV/AIDS

As of December 31, 2004, surveillance data of the New Jersey Department of Health and Senior Services (NJDHSS), Division of HIV/AIDS Services (DHAS) show that there were 12,569 people living with HIV/AIDS (PLWHA) residing in the Newark EMA. This is an increase of 5.1% or 613 over the 11,956 as of December 31, 2003. Similarly, there were 32,746 PLWHA in New Jersey as of 2004, or a 4.6% increase over the 31,320 in 2003. The Newark EMA accounts for 38.4% of PLWHA in New Jersey.

Within the Newark EMA, most PLWHA (9,287 or 73.9%) reside in Essex County, followed by 2,433 (19.4%) in Union County. A total of 849 or 6.8% reside in the remaining three counties – 619 (4.9%) in Morris, 120 (1.0%) in Sussex, and 110 (0.9%) in Warren County.

The HIV epidemic is further concentrated in the EMA's five largest cities – East Orange, Irvington and Newark in Essex County and Elizabeth and Plainfield in Union County. Over three fourths (76%) of PLWHA reside in these five cities. With 5,865 PLWHA, Newark accounts for 47% of PLWHA in the EMA and 18% of PLWHA in New Jersey.

Of the total PLWHA, 60% or 7,537 are male and 40% or 5,032 are female. This reflects the same distribution as 2003. Within the Newark EMA, the highest percent of female PLWHA (41.7%) reside in Essex County, followed by Union County (36.5%) and Sussex County (34.2%). The lowest percent of female PLWHA reside in Morris County (32.0%) and Warren County (32.7%).

With respect to current age, the highest number (5,119) and percent (40.7%) of PLWHA are age 40-49. The second highest age category is PLWHA age 50 and older (3,561 or 28.3%). The third highest category is individuals age 30-39 at 2,880 or 22.9%. Well over two-thirds (69%) of PLWHA are age 40 and older. The reasons for the older age is that many PLWHA are living longer with HIV disease due to life sustaining medications, many are "aging into" these older age categories following a diagnosis at an earlier age, and more aggressive outreach and HIV testing and counseling efforts have resulted in higher numbers of older adults being diagnosed with HIV.

Nearly three-quarters of PLWHA in the Newark EMA (72% or 9,021) are Black, Not Hispanic. An additional 1,855 (15%) PLWHA are Hispanic and 1,494 (12%) are White, Not Hispanic. The remaining 199 PLWHA (1.6%) are of other races. The racial/ethnic characteristics of the HIV epidemic in the Newark EMA are much different than the rest of New Jersey. Although the Newark EMA accounts for 38% of PLWHA in New Jersey, half of the state's NonHispanic Black PLWHA reside in the Newark EMA and 41% of the state's African American PLWHA reside in Essex County.

Exposure category or mode of transmission is tabulated separately for Adult/Adolescent exposure categories and Pediatric exposure. Within the Newark EMA, Injecting Drug Use (IDU) continues to be the leading exposure category among adult/adolescents, at 31.2% of all diagnoses. Heterosexual transmission is the second leading cause of HIV infection, at 23.2% of PLWHA. Men Having Sex with Men (MSM), is the third leading cause at nearly 14% of PLWHA. MSM/IDU is the fourth exposure category, at 2.4% of all HIV infection. For over one quarter (29%) of adults, their exposure category is unreported or unknown. The leading cause of pediatric HIV is a parent infected with HIV (95%).

The following areas indicate a disproportionate impact of HIV/AIDS in the Newark EMA.

- The entire Newark EMA is disproportionately impacted by the HIV epidemic – with 38% of the state's PLWHA, but only 24% of New Jersey's total residents. Among counties in the EMA, Essex County is most impacted with 74% of the EMA's PLWHA but only 39% of the EMA's general population. All five cities are disproportionately impacted with 76% of PLWHA, but only 28% of the EMA's total residents. However, Newark bears with greatest burden with 47% of the EMA's PLWHA but only 13% of its population, and 18% of New Jersey's PLWHA but only 3% of the state's population.
- Women in the Newark EMA are most affected by HIV, at 40% of PLWHA. As of June 30, 2004, the CDC reported that the Newark EMA contains the highest percent (36.76%) of women, infants, children and youth living with AIDS among the 51 EMAs in the United States.
- HIV disproportionately affects African Americans in the Newark EMA. African Americans account for 22% of the EMA's general population but 72% of its HIV.
- Exposure to HIV via heterosexual contact continues to increase disproportionately in the EMA compared to the rest of New Jersey. The increase is concentrated in the five large cities within the EMA, and from 2003-2004 East Orange and Elizabeth had the highest percentage increases.
- Children in the Newark EMA continue to be disproportionately affected by HIV – the EMA accounts for 46% of New Jersey's PLWHA under age 12 exposed by an HIV-infected parent.

HIV prevalence (PLWHA per 100,000 population) in the Newark EMA is 618 PLWHA per 100,000 population, or nearly twice as high as the rest of New Jersey with a rate of 316 PLWHA per 100,000 population. Within the EMA, HIV prevalence is highest in Essex County, at 1,170 PLWHA per 100,000 population, nearly three times as high as the next county, Union, at 466

PLWHA. The remaining three counties have much lower HIV prevalence rates. The EMA's five cities have high HIV prevalence rates per 100,000 population.

With respect to race/ethnicity in the EMA, HIV prevalence of 1,996 NonHispanic Black PLWHA per 100,000 African American residents is three times greater than the EMA-wide rate for all residents. Hispanics are also disproportionately affected. The EMA's NonHispanic Whites are affected by HIV at the same rates as the rest of New Jersey.

Trends in HIV and AIDS from 1999 to 2004

Surveillance data of the New Jersey Department of Health and Senior Services (NJDHSS), Division of HIV/AIDS Services (DHAS) show the total number of people living with HIV disease and AIDS annually as of December 31, 1999 through 2004. Reporting was changed starting in January 1, 2002 to include only confirmed cases of HIV. Although it appears that there was a reduction in HIV cases thereafter, trends from 2002 and 2004 show continued increased.

Within the Newark EMA, the percent of people living with HIV versus those with AIDS was approximately equal from 1999 to 2001. With the change in HIV reporting in 2002, the relative percent of people living with AIDS increased to 52% versus 48% of people living with HIV from 2002 through 2004. In the rest of New Jersey outside of the EMA, the percent of people living with AIDS was higher, ranging from 52% to 54% from 1999 through 2004. The percent of people living with HIV was lower at 46% by the end of 2004.

Trends in HIV and AIDS vary within the five EMA counties. In Essex County in 1999, slightly more people were living with HIV (51%) than AIDS (49%), which was even by the end of 2004 (50% AIDS and 50% HIV). Since Essex contains three quarters of the EMA's PLWHA, the EMA reflects the Essex distribution of HIV/AIDS. Union County shows a much higher prevalence of AIDS than HIV. In 1999, 55% of PLWHA in Union County were living with AIDS and 45% with HIV, which increased to 58% AIDS and 42% HIV as of the end of 2004. Morris County followed the trends in Union, while Sussex and Warren counties reflect Essex patterns. The EMA's five large cities reflect the HIV/AIDS distribution of their respective counties.

Title I Service Utilization

During FY 2004, the Newark EMA's Title I program funded 17 categories of direct services. A total of 8,061 individuals residing in the Newark EMA received at least one unit of service in one or more of these Title I service categories in FY 2004 (as of 2/28/05). This is a decrease of 987 (11%) over the 9,048 PLWHA who received Title I services in FY 2003. The decline in Title I clients is a direct result of a reduction of over \$2 million in Title I funding to the Newark EMA for FY 2004.

For the second consecutive year since Title I funding began, more clients in the Newark EMA used Title I primary medical care than any other service. The top 5 Title I services used in FY

2004 are primary medical care, case management, nutritional services (food), substance abuse treatment (up from #5 in FY 2003), and transportation.

Top 5 Title I Services Used in Newark EMA By Percent of Title I Clients Using the Service					
FY 2004			FY 2003		
#1	Primary Medical Care	67.4%	#1	Primary Medical Care	65.0%
#2	Case Management	58.6%	#2	Case Management	57.8%
#3	Nutritional Services	26.0%	#3	Nutritional Services	31.3%
#4	Substance Abuse Treatment	19.8%	#4	Transportation	22.8%
#5	Transportation	19.0%	#5	Substance Abuse Treatment	20.9%

Source: Newark DHHS, CHAMP.

Of the total PLWH receiving Title I services, 3,861 (42.7%) were female and 5,187 (57.3%) were male. Male and female PLWHA receive Title I services at the same rates. The only exceptions are the service categories of Direct Emergency Assistance, Health Education/Risk Reduction, Mental Health Services, and Permanency Planning. Females received these services at slightly higher percentages than males.

A total of 5,420 PLWHA residing in the Newark EMA – over two-thirds (67%) of Title I clients - received Title I funded primary medical care services in FY 2004. This reflects a continuously increasing trend, compared to over 65% receiving Title I medical care in FY 2003, 55.2% receiving Title I medical care in FY 2002 and 52.4% receiving such care in FY 2001. By gender, 2,350 (43.4%) were female and 3,070 (56.6%) were male. Receipt of medical care did not vary by gender. However, youth age 13-24 received Title I funded medical care at rates higher than the other age categories – 82% versus 67%.

Part 1: Unmet Need for Primary Medical Care

The CARE Act requires Title I and Title II grantees and planning bodies to estimate, assess, and address the unmet need for HIV-related primary medical care for persons who know their HIV status but are not receiving such care.

The Newark EMA has prepared estimates of unmet need since 2001 for the FY 2002 Title I grant application. For the FY 2005 Title I grant application submitted in November 2004, all EMAs in the United States were required to prepare an estimate of unmet need using the federal **HRSA/HAB Unmet Need Framework**. This estimate and the methodology are set forth in Unmet Need Estimate below. (Estimates for FY 2006 were being prepared at the time the 2005 Needs Assessment Update was finalized and were to be submitted with the FY 2006 Title I grant application.)

Unmet Need Estimate

For the FY 2005 Title I grant application, the Newark EMA estimated unmet need using the “Unmet Need Framework” Option 1 provided by HRSA and HIV/AIDS data for both Calendar Year (CY) and Fiscal Year (FY) 2003 as discussed below and shown in the Table.

HRSA/HAB Unmet Need Framework – Option 1		
Submitted with FY 2005 Title I Grant Application on November 10, 2004		
Input	Value	Data Source
Population Sizes		
A. Number of persons living with AIDS (PLWA), recent time period	6,514	2003 HARS Data from Centers for Disease Control and Prevention (CDC). As of 12/31/03.
B. Number of persons living with HIV (PLWH non-AIDS/aware), recent time period	6,136	2003 HARS Data from Centers for Disease Control and Prevention (CDC). As of 12/31/03.
Care Patterns		
C. Number of PLWA who received the specified HIV primary medical care services in 12-month period	3,859	NJDHSS matched files with HARS, NJ ADAP, Senior Gold, NJPAAD, GA welfare, Medicaid, laboratories. Newark DHHS CHAMP.
D. Number of PLWH (aware, non-AIDS) who received the specified HIV primary medical care services in 12-month period	3,406	NJDHSS matched files with HARS, NJ ADAP, Senior Gold, NJPAAD, GA welfare, Medicaid, laboratories. Newark DHHS CHAMP.
Calculated Results		
E. Number of PLWA who did not receive primary medical services	2,655	6,514 PLWA minus 4,282 PLWA in care
F. Number of PLWH (non-AIDS, aware) who did not receive primary medical services	2,730	6,136 PLWH minus 3,899 PLWH in care
G. Total HIV+/aware not receiving specified primary medical care services (quantified estimate of unmet need)	5,385	Sum of 2,655 and 2,730. Yields unmet need of 42.6% of 12,560.

#1 Population estimates. It is estimated that there are (a) 6,136 people living with HIV/non-AIDS who know their status (PLWH/non-AIDS/aware), and (b) 6,514 people living with AIDS (PLWA) in the Newark EMA as of 12/31/03. This is a total of 12,650 PLWHA.

#2 Estimates of people in care. It is estimated that the number and percent of those in care are: (a) 3,406 (55.5%) PLWH/non-AIDS/aware, and (b) 3,859 (59.2%) PLWA in the Newark EMA who received HIV primary medical care during the 12-month time period of FY 2003, using the Framework definition. This is a total of 7,265 or 57.4% of PLWHA in the Newark EMA who are estimated to be “in care.”

#3 Estimates of unmet need. It is estimated of the number and percent of those not in care or “unmet need” is: (a) 2,730 (44.5%) PLWH/non-AIDS/aware, and (b) 2,655 (40.8%) PLWA in the Newark EMA who did *not* receive HIV primary medical care during FY 2003. The total unmet need is estimated at 5,385 PLWHA or 42.6% of the total population of individuals diagnosed with AIDS and HIV in the Newark EMA.

The table below shows the data sources used to develop the FY 2005 Unmet Need Estimate.

Computations for Unmet Need in Newark EMA FY 2005 Title I Grant Application (November 10, 2004)			
	AIDS	HIV	Total
As of 12/31/03 Persons Living with:	6,514	6,136	12,650
HRSA FY 2003 – Newark EMA			
Newark DHHS CHAMP			
Title I 2003 Medical Care	3,094	2,773	5,867
Medicaid No Title I Medical Care	182	331	513
Medicare No Title I Medical Care	45	66	111
Subtotal	3,321	3,170	6,491
NJDHSS Div HIV/AIDS Services			
Private Insurance – 2002	538	236	774
TOTAL “In Care” – Number	3,859	3,406	7,265
Percent	59.2%	55.5%	57.4%
Unmet Need – Number	2,655	2,730	5,385
Percent	40.8%	44.5%	42.6%

Unmet Need Estimates within the Newark EMA Title I System

Unmet need estimates using only PLWHA receiving Title I medical care can provide an assessment of the responsiveness of the EMA’s Title I system of care to the epidemic. The table below shows these data for PLWHA as of 12/31/04 and Title I CHAMP data for FY 2004 (as of 2/28/05). Because CHAMP data on HIV status (AIDS versus HIV not AIDS) is still being collected, the total PLWHA are reported. The data are presented for the EMA, five counties, and five largest cities.

Unmet Need and the Title I System – PLWHA and Receipt of Title I Medical Care in the Newark EMA - FY 2004					
	PLWHA as of 12/31/04	FY 2004 Title I Medical Care		Not in FY 2004 Title I Medical Care	
		#	%	#	%
Newark EMA	12,569	5,420	43%	7,419	57%
Essex	9,287	4,177	45%	5,110	55%
Morris	619	143	23%	476	77%
Sussex	120	12	10%	108	90%
Union	2,433	808	33%	1,625	67%
Warren	110	10	9%	100	91%
East Orange	1,241	573	46%	668	54%
Elizabeth	1,005	427	42%	578	58%
Irvington	897	311	35%	586	65%
Newark	5,865	3,023	52%	2,842	48%
Plainfield	508	193	38%	315	62%
5 Cities	9,516	4,527	48%	4,989	52%

Source: NJDHSS, DHAS HIV Surveillance Reports 12/31/04.
 Newark DHHS. CHAMP FY 2004 (as of 2/28/05).

Part 2: Connecting To Care and Reducing Unmet Need: Survey Of Title I Medical Providers

The Health Resources and Services Administration/HIV/AIDS Bureau (HRSA/HAB) has placed considerable emphasis on “unmet need” – individuals who know their HIV status but are not “in care” - receiving medical care or HIV medications. The emphasis has shifted from measuring unmet need (PLWHA not in care) to bringing those individuals into care or “connecting them to care”. Consistent with this goal, the Newark EMA HIV Planning Council believes that it is also important to strengthen our existing system of Title I medical care to ensure that PLWHA are not dropping out or not being linked to medical care at available opportunities. Therefore, the Council surveyed existing Title I medical providers to answer the following research questions.

Research Questions:

1. **How do Title I medical providers follow up on current patients to minimize dropouts from medical care?**
2. **For those providers currently conducting or planning to conduct HIV Rapid Test, how are patients who receive a “presumptively positive” test result linked to medical care? (Or how will they be linked to care?)**

Question 1 was to yield baseline information about current follow up and gaps, and to assist the Council and Grantee in developing methods to improve patient follow up so that more patients remain in care. With implementation of the HIV Rapid Test, responses to Question 2 were to yield initial results on the linkages between HIV Rapid Test and start of HIV-specific medical care, and an indication of the expected [increased] demand for Title I medical care.

The fifteen Title I medical providers were asked to complete a brief questionnaire by phone, mail (fax) or online by e-mail. Fourteen providers responded.

Question 1 Current Patient Follow Up

Results – Question 1

All providers take appropriate steps to ensure that PLWH keep medical appointments and receive follow up on missed appointments. These actions include (1) scheduling the next appointment before the patient leaves the current medical visit, (2) providing reminder telephone calls and/or letters, (3) providing follow up contacts for clients who miss appointments, and (4) keeping clients on case rolls for 6 months to one year to continue care when they eventually come in.

On average, 75% of PLWHA EMA-wide keep their scheduled Title I medical appointments and 25% of PLWHA EMA-wide miss these appointments, despite multiple actions taken by all Title I providers to ensure that appointments are kept. With intensive follow, most clients eventually come in such that **only 10%-11% of medical appointments are “missed” and approximately 89%-90% are eventually “kept.”** However, this drop off rate negatively affects patient outcomes, and time spent in follow up increases the overall cost of medical care.

Recommendations – Question 1

The Planning Council and Grantee may want to (1) review the EMA’s standards of primary medical care and determine if the guidelines for **patient follow up** are adequate to ensure that all reasonable efforts are made to maintain PLWHA in HIV medical care; (2) monitor provider **patient follow up procedures** to verify that the above survey results are actually occurring in each agency, and (3) consider **educating consumers** about the effects of not keeping appointments – “overbooking,” long waiting times, etc. – which are common complaints in the EMA’s Needs Assessments. The Council may also encourage peer support or other methods to help patients keep appointments.

Question 2 HIV Rapid Test and Linkage to Medical Care

Results – Question 2

Of the 15 Title I funded medical providers in the Newark EMA, 14 currently conduct HIV testing (except the UMDNJ-Division of Adolescent and Young Adult Medicine). Nine of the 14 are currently performing the HIV Rapid Test – six hospital based clinics and three FQHCs. The HIV Rapid Test is administered at various locations within each agency. The agencies provide geographic access to the HIV Rapid Test throughout the EMA.

Location of HIV Rapid Test in Medical Provider Agencies (July 2005)				
Title I Provider	Emerg Dept.	HIV Clinic	Other	Comments
Hospital-Based Clinics				
6. MMH – Family Health Center	X	X	X	ED (referrals only), C&T clinic, prenatal clinic, labor & delivery
7. Newark Beth Israel Med. Ctr	X	X	X	Separate HIV C&T suite
11. St. Michael’s Med. Center	X		X	C&T Clinic
12. Trinitas Hospital	X	X	X	OraSure at Outreach sites
14. UMDNJ – Infectious Disease Practice	X	X	X	Specific areas of the hospital that request it
15. UMDNJ – FXB	X	X	X	Outpatient Clinics. (Eventually will include inpatient.)
FQHCs				
8. Newark CHC, Inc.		X		
9. Newark DHHS Homeless Health Care HIV Clinic			X	STD Clinic of Newark DHHS.
10. Plainfield Health Center		X		
Total	6	7	7	

C&T = Counseling and Testing

Linkage to medical care. Five of the nine medical providers wait until receiving confirmatory results before linking the patients with HIV medical care (three hospital based clinics and two FQHCs). Once such results are received, medical appointments are scheduled immediately, often on a same day basis. The remaining three hospital based clinics (one respondent did not answer) link patients immediately with medical care following a presumptively positive diagnosis. All providers use Standard Operating Procedures to link newly diagnosed HIV+ individuals to medical care. Methods include a combination of same day appointments, scheduling appointments for the following day or two days, completion of intake, financial screening and blood work pending confirmatory result, and escort to the HIV Clinic for medical care to ensure that patients keep the appointments.

Most (five) providers reported no problems in linking newly diagnosed patients to medical care. Three additional providers reported some problems. One stated that new patients may be reluctant to get medical care at time of their diagnosis. After several phone calls and reminders,

patients are eventually connected to care.¹ Another underscored that some patients need time to accept diagnosis, and if mental health and substance abuse issues are present, this creates additional difficulties in getting newly diagnosed patients into care. The FQHC serving homeless individuals reported that comorbid factors of homelessness, substance abuse, and depression exist in our newly diagnosed HIV positive patients and these problems must be dealt with in addition to HIV. Also, cultural and social barriers prevent some populations from seeking help.

All providers reported that the Rapid Test had resulted in an increase in HIV+ patients in their facilities. One provider estimated an increase of 10-30%. The remaining providers did not quantify the increase. The immediacy of test results associated with the HIV Rapid Test has increased patient retention in care versus the previous system in which 50% of patients never returned for their HIV+ diagnosis. Providers added comments regarding the urgency of getting the increased number of patients into medical care as soon as possible.

Recommendations – Question 2

The overall recommendation was that an initial connection to medical care should be made immediately at time of the HIV test. This linkage can range from education of the patient about the availability of care; discussion of clinic hours, the enrollment process, and the staff available for treating HIV disease; to an immediate or same day medical appointment. This connection can be implemented by strengthening the Memoranda of Understanding (MOU) required by the Title I grantee between all Title I providers and counseling and testing sites to ensure such linkages, and by advocating closer linkages between counseling and testing and HIV medical care, through membership and/or participation in existing regional and statewide committees and forums.

Part 3: Substance Abuse Consumer Survey

HIV/AIDS surveillance data and annual needs assessments of the Newark EMA HIV Health Services Planning Council have continually underscored that substance use and abuse are major factors in the spread of HIV disease in the EMA. The Council's Substance Abuse Committee designed a survey to ask consumers who were homeless and/or living in at risk situation, who might be HIV+, about their HIV medical care and substance use treatment patterns. These individuals are most at risk for dropping out of HIV medical care or not accessing medical care at all due to their transient lifestyles. They have not heretofore provided input to the Planning Council.

¹ These findings are underscored in results of the *2004 Union County HIV Consortium - Focus Group of Long-Term HIV*. Participants had been living with HIV disease for at least 10 years. While over half (53%) of participants came into medical care right away after being diagnosed with HIV, one third (33%) put off medical care for a long time. The remaining individuals put off medical care for a few weeks.

Methodology included surveying individuals in homeless shelters throughout the five-county Newark EMA, in Title I funded substance abuse treatment provider agencies, and those who might be reached by innovative and nontraditional outreach methods. Homeless individuals and substance users (injection and noninjection) are three of the eight populations with “special needs” for Title I care and services. Because the target population is so transient, the Council could not select only those who are HIV+. The approach was to “blanket” survey as many individuals as possible to obtain information about medical care behaviors of those who are HIV+ and about substance abuse treatment patterns of those who are not HIV+.

Research Questions: The research questions to be answered were

- (1) What are the medical care characteristics of HIV+ individuals who are homeless and/or living in high risk situations, and
- (2) What are the substance abuse treatment patterns of individuals who are homeless and at high risk of HIV infection in the Newark EMA?

The results might show if more efforts are needed to target unserved PLWHA living in homeless shelters, and to hone research to be conducted among these “special needs” populations in 2006.

Identifying Information

The survey was administered at three types of sites – homeless shelters, Title I substance abuse providers, and via outreach. Surveys were color coded by site type and Spanish language. Confidentiality of clients and agencies was ensured. Of the 223 surveys received, more than half – 116 or 52% - were received from homeless shelters. Of the remaining respondents, 92 (41%) were from Title I substance abuse providers and 15 (7%) were from outreach efforts. None were identified specifically as Spanish speaking respondents.

Type of Site Surveyed and County of Residence (n=223)						
Site Type	County of Residence				Total	%
	Essex	Union	Morris	Out of EMA*		
Homeless Shelter	83	12	17	4	116	52%
Title I SA Provider	78	8	0	6	92	41%
Outreach	15	0	0	0	15	7%
Total	176	20	17	10	223	100%
	79%	9%	8%	4%	100%	

*Out of EMA includes: Passaic (3), Camden (3), Mercer (2), Cape May (1), Hudson (1)

HIV status of respondents. Two thirds (144) of the 223 respondents reported having HIV disease – 107 (48%) reported HIV not AIDS and 37 (17%) with AIDS. One third (72) did not have HIV disease and seven respondents (3%) did not know their HIV status because they had never been tested.

Demographics of Respondents

Over half of survey respondents (56% or 124) were male and 97 (43%) were female, comparable to the gender breakdown of PLWHA in the EMA. Two individuals (1%) did not list their gender.

The majority (165 or 74%) of respondents were African-American (Black, Not Hispanic) among both men and women. Individuals of Hispanic/Latino ethnicity (30) comprised 14% of respondents (9% of males and 5% of females), and White, Not Hispanic individuals comprised 7% (15) of respondents. Eight individuals did not report race/ethnicity. Respondents were proportionately represented by race/ethnicity regardless of type of survey site.

Over half (54% or 118) of the respondents were age 25-44, followed by 41% (88) who are age 45 and older, with 11 (5%) under age 25 (they resided in homeless shelters).

Most (206) respondents provided sexual identification, and the majority (71%) - 76% of women and 66% of men - identified themselves as heterosexual. Among males, 21% identified themselves as men who have sex with men (MSM) and 10% of females as women who have sex with women (WSW). A total of 10% (8% of males and 13% of females) identified themselves as bisexual. A small number self-identified as transsexual or transgendered.

Most respondents (79% or 175) reported that they resided in Essex County. Only 9% (20) of respondents resided in Union County, and 8% (18) in Morris County. Four percent of respondents reported living outside of the Newark EMA. By municipality, more than half of respondents (133 or 60%) resided in Newark. The cities of East Orange, Elizabeth and Morristown followed with 7% of residents each. Five percent of respondents were from Irvington. The remaining cities accounted for lower numbers. However, respondents from outside the EMA lived as far away as Trenton, Camden, and Cape May City. With respect to HIV status, 70% of HIV+ respondents live in Newark, followed by East Orange (8%), Irvington (4%) and Elizabeth (4%). These four cities account for 86% of the HIV+ survey respondents.

HIV Status and Medical Care

Gender. Of the 144 individuals who reported that they were HIV positive, 142 identified their gender. Distribution of HIV and AIDS was equal among male and female respondents. Among both males and females, 26% have AIDS and 74% have HIV not AIDS. Within both AIDS and HIV, 54% were males and 46% were females.

Year of diagnosis. Respondents have been living with HIV disease a long time. Over one third (52) were diagnosed 11 or more years ago – 18% (26) at 11-15 years ago and 18% (26) at more than 15 years ago. Another one third of respondents (48) had been diagnosed 5 to 10 years ago. One quarter were diagnosed within the past 2-4 years and 5% were diagnosed within the past year. The highest percentage of those with AIDS were diagnosed 2 to 4 years ago, in contrast to the most respondents with HIV who were diagnosed 5-10 years ago.

Receipt of HIV Medical Care. Of the 144 HIV+ respondents, 132 (92%) reported receipt of medical care for their HIV. Nearly all (97% or 36) of individuals with AIDS receive medical care,

but a lower percent (90% or 107) of respondents with HIV not AIDS receive medical care for HIV. This high percentage may be attributable to participants' engagement in the Title I system via their shelter or substance abuse provider.

Nearly all PLWHA received HIV medical care in the county in which they reside. The majority utilized hospital based clinics, followed by community clinics and finally private physicians or substance abuse treatment centers. There was little difference in the type of facility used for people with AIDS versus people with HIV not AIDS.

Type of Health Insurance. Nearly all respondents (98%) reported whether they had health insurance and the type of insurance. When aggregated, over half (75 or 53%) had Medicaid, 8% (11) had Medicare, 9% (12) were "dual eligibles" with both Medicaid and Medicare, 4% (5) reported having private insurance, and 27% (37) were uninsured (including those reporting Charity Care as a source of health insurance). When tabulated by type of facility in which respondents resided, results were different. With respect to homeless PLWHA, nearly 40% had no health insurance, followed by 33% with Medicaid, and 12% who were dual eligibles. In substance abuse agencies, nearly two thirds (64%) reported having Medicaid, and 21% had no insurance.

Time between diagnosis and start of medical care. Nearly half (48%) of PLWHA reported that they entered medical care immediately following HIV diagnosis. One in five (20%) waited for 6 months up to one year before starting medical care. One third waited for one year or longer - 17% for one to two years, and 15% for more than three years (including 7% who waited 8 years or longer). Delays in start of treatment include factors such as denial, disbelief, or depression.

Linkage to HIV medical care. It is important for Title I planning to determine which entities or venues have the most success in linking to medical care PLWHA who are newly-diagnosed or have been out of care or untreated. From time of HIV diagnosis up to 6 months later, the HIV testing site (18%) and a physician (HIV specific or other physician – 17%) and case manager (15%) are equally important in linking the person to medical care. After about one to two years after diagnosis (and later), clients came into medical care only when they felt sick (and HIV disease had progressed), or upon recommendation of a physician, who becomes the most important entity in linking the person to medical care.

Last time received medical care. When asked, "When was the last time you saw a physician?" most respondents (117 or 85%) reported that they saw their doctor within the past three months. Responses varied by AIDS versus HIV; 95% (35) of respondents with AIDS versus only 81% (82) of those with HIV only saw their physician within the past three months. Seven persons with HIV (7%) last saw their doctor over one year ago, and one person had never seen a physician for HIV.

Notwithstanding that many consumers had a medical visit within the past three months, over half (54% or 78) reported reasons for not accessing medical care in the past. The chief reason for not accessing medical care was the individual's substance use (24%), followed closely by lack of transportation (23%). The next three items mentioned were cannot afford to pay, no available child care and [long] waiting times at the clinic/physician office. Other reasons, such

as housing situation, and communications with the physician, were mentioned less often. No one cited religious beliefs as a reason for not accessing medical care.

Antiretroviral medications. Most individuals (95% or 137) reported whether they took antiretroviral medications (highly active antiretroviral therapy - HAART). Although the overall total was 79%, responses varied by HIV status, with 95% (35) of those with AIDS but only 73% (73) with HIV taking HAART. Eleven (8%) did not take medications despite the physician's advice, and 16 (12%) were not taking HAART because their physician did not feel it was time to start HAART yet.

Of the 30 individuals who did not take antiretroviral medications, half reported that the primary reason was that they did not like the side effects. Another five individuals (17%) felt that there were too many pills to take. The remaining individuals reported other reasons, or a combination of the two chief reasons.

Three quarters (76% or 110) of individuals answered the question regarding adherence to medications. Of those responding, 69% (76) reported that they rarely missed a dose, and 23% (25) reported that they sometimes miss a dose. Fewer than ten (8%) reported that do not regularly take medications. When tabulated by HIV status, persons living with AIDS reported that they "sometimes miss a dose" more often than those with HIV not AIDS.

Substance Use and Abuse

Current substance use. Of the 216 who answered the question regarding current substance use, over one third (37% or 80) said "yes" and the remaining two thirds (136) said no. By type of site, 41% in homeless shelters reported current substance use, as did 73% of those contacted by outreach. Most surprising, 26% (23) of respondents at Title I substance abuse provider agencies reported current substance use.

A cross tabulation between current substance use and HIV exposure was completed to determine the extent to which PLWHA exposed by IDU were continuing to use or abuse substances. The conclusion is that IDUs, MSM/IDUs and IDUs + Heterosexual/Other exposure did not currently use substances more than any other exposure category.

The questionnaire asked about the types of substances currently, listing three types – alcohol, heroin, cocaine – and "other." Of the 73 individuals who answered this question, half (36) reported use/abuse of a single substance and the remaining 37 reported using more than one substance (poly substance use). Most surprisingly, alcohol was used in combination with other drugs.

The overwhelming majority (84%) responded that they took drugs by "non-injection" (regardless of HIV status) versus 16% who reported injecting drugs. This is surprising since Injection Drug Use remains the leading exposure category for HIV disease. However, the federal Drug Enforcement Agency (DEA), in its *2005 New Jersey Fact Sheet* (www.usdoj.dea.gov), reported on the increasing purity of heroin in the Newark region. Because of the purity of heroin, modes of use have changed from injection to sniffing, snorting and other non-injection methods.

A majority of respondents (77%) and HIV+ respondents (83%) reported using prescription medications (other than HIV medications). Approximately 55% were using these medications according to their doctor's specifications, and 22% were not. Rates were slightly better for PLWHA. This use of prescription medications not in accordance with physician instructions indicates another potential source of substance abuse and risk for HIV infection or transmission.

Type of Substances Currently Used and HIV Status (n = 73)					
Types of substances	HIV Status			Distribution	
	HIV+	Not HIV+	Total	HIV+	Total
Alcohol	11	3	14		
Heroin	4	2	6		
Cocaine	12	3	15		
Other	0	1	1		
Total - 1 Substance	27	9	36	59%	49%
Alcohol + heroin	1	0	1		
Alcohol + cocaine	3	3	6		
Heroin + cocaine	7	3	10		
Total - 2 Substances	11	6	17	24%	23%
Alcohol, heroin + cocaine	7	9	16		
Alcohol + cocaine + marijuana	1	1	2		
Total - 3 Substances	8	10	18	17%	25%
Alcohol+heroin+cocaine+marijuana	0	2	2		
Total - 4 Substances	0	2	2	0%	3%
Total – All Respondents	46	27	73	100%	100%
Distribution by HIV Status	63%	37%	100%		

How Substances Are Taken (n = 69)			
	HIV Status		
	HIV+	Not HIV+	Total
Injection	7	4	11
Non-injection			
Method not specified	28	11	39
Method specified (sniffing, smoking, oral, drinking, combination)	8	11	19
Total non-injection	36	22	58
Total	43	26	69
Injection	16%	15%	16%
Non-injection	84%	85%	84%

Ever received drug or alcohol treatment. Of both the total and HIV+ respondents, over two thirds (68%) had received drug or alcohol treatment at some time in their lives. With respect to the types of drug/alcohol treatment received, short-term inpatient care was received most often (33% or 21 respondents), followed by long-term inpatient treatment (16% or 10) and methadone maintenance (14% or 9). Responses varied slightly for PLWHA.

“Drop outs” from substance abuse treatment. Regardless of HIV status, nearly half (48%) of individuals who had received drug/alcohol treatment had dropped out such treatment at some time. When asked about the number of times they had dropped out of treatment, over three fourths of individuals dropped out three or fewer times, regardless of HIV status. Several respondents reported dropping out 10 times. Drop out rates were proportionate to the various types of treatment programs they had entered. (There was no tendency to drop out of one type of program more than any other.)

The principal reason for dropping out of treatment – cited by half (50%) – was that they started using drugs again. The second reason was (19%) that they did not like the treatment program, or that the program was not appropriate for them (8%). Respondents additionally reported that they were unwilling to comply with program requirements or that they were not ready to stop using drugs (4% each). Additional reasons included that participants had no time, did not give themselves a chance, did not like program staff, lack of money, need for long term inpatient care, other problems, and being sent to prison.

Currently in drug treatment. Of the 140 individuals who had a prior history of drug treatment, 136 responded, and nearly half (65 or 48%) were currently in treatment, including 35 PLWHA. Of the 83 who had no history of drug treatment (no acknowledged addiction problem), only 6% (four) were currently in drug treatment. Adding both sets of responses, 34% (69) of total respondents are currently in drug treatment, including 30% (40) of PLWHA.

Conclusions

Substance use and abuse remains a major problem in the Newark EMA among individuals with HIV disease and those at risk for HIV, living in homeless shelters and frequenting high drug use areas. Current substance abuse prevails regardless of HIV exposure category. In other words, PLWHA who were exposed by drug-related activity (IDU, etc.) were no more likely than others (heterosexuals) to use drugs now. Substance use interferes with HIV medical care and treatment – causing drop outs, relapses, and lack of adherence to medication regimens and medical care. There is significant self-reported compliance with standards of medical care, but there is need to strengthen the linkage between HIV diagnosis and start of medical care. Patterns of current and past substance use provided by survey respondents raise questions about the efficacy of treatment programs.

Recommendations

All components of the Newark EMA HIV continuum of care must address the issue of substance use among PLWHA, and to assist in removing this barrier to medical care. There needs to be a rigorous review of current treatment programs, particularly those funded by Title I, to determine their effectiveness, the current substance use of participants, and interrelationship between

treatment programs and participation in medical care and medical outcomes. Screening for all types of substance abuse should be incorporated into routine history taking with questions about what prescriptions and over-the-counter medicines the patient is taking and why.

As the second gateway into Title I services, case management agencies should be screening all patients for substance abuse (and mental health issues) and referring them for further testing and/or appropriate treatment.

Title I substance abuse provider agencies should review their HIV clients for current substance use. The Planning Council may want to review substance abuse treatment programs that are not funded by Title I, their standards, and their interrelationship with Title I medical care for HIV+ clients.

The Council's Substance Abuse Committee should review this study and determine future directions and items warranting further study. Such study can include consumer input regarding injection versus noninjection substance use, and strategies to improve adherence to treatment programs and compliance with HIV medical care and medication regimens.

Recommendations of the Housing Committee

Final Report to the City of Newark

July 11, 2005

Introduction

In recent years, the escalating cost of housing in New Jersey has become a significant concern, particularly for low income PLWHA. When considering the amount paid by disability and other benefits for those low-income consumers living with HIV/AIDS, the ability to secure safe housing becomes limited, without the assistance of some form of subsidized housing. As housing costs continue to rise for both homeowners and those who rent, a significant portion of the community is at risk for homelessness.

This is especially true in the HIV/AIDS population, where it is difficult for many to maintain full-time employment as a result of their illness. Consumers rely on housing subsidies, such as Housing Opportunities for People With AIDS (HOPWA) funded by the U.S. Department of Housing and Urban Development (HUD), to assist with monthly rental costs. Other consumers rely on Section 8 housing vouchers; however, many counties and towns have waiting lists spanning years before eligibility for Section 8 can be considered. HUD has cut funding for HOPWA in the past several years.

In the Newark EMA, the HOPWA program has experienced significant decreases in the past two years, totaling \$2 million. This is especially significant when considering the program was funded at \$6 million. In response to these funding decreases, the City of Newark – which is the grantee for HOPWA – changed what is payable under HOPWA through coordination with Ryan

White CARE Act Title I services. Because payment for many support services for PLWHA is available through Title I, the City of Newark removed payment for these support services from HOPWA, which freed up HOPWA funds to become the main source for rental assistance. Although this realignment has kept more PLWHA on HOPWA assistance, it has not removed the financial burdens still facing this program. There are not enough HOPWA funds to meet the housing needs of PLWHA, and the trend appears to be worsening with a projected further decline in federal HOPWA funding. As a result, otherwise eligible PLWHA may have to be disenrolled from HOPWA.

In response to these housing concerns, the City of Newark, Department of Health and Human Services (DHHS) asked the Newark EMA HIV Health Services Planning Council at its meeting of February 18, 2004 to convene an ad hoc [housing] committee to look at the housing issue for the Newark EMA and make recommendations regarding HOPWA. An important aspect, consistent with the Council's role in HIV needs assessments and comprehensive planning, was to secure input from PLWHA and larger community of those affected by HIV/AIDS regarding their housing issues.

Participants for the Housing Committee were recruited from many sources, including existing Planning Council members, Ryan White and HOPWA funded agencies, consumers, and representatives from housing coalitions.

Housing Committee Work

After identifying potential committee members, the Ad Hoc Housing Committee of the Planning Council decided upon the following goal which included four issues to be addressed. "In light of projected HOPWA cuts ...

- #1 What criteria should be used to evaluate an individual's eligibility for HOPWA rental assistance?
- #2 What criteria should be used to evaluate an individual's continuation of HOPWA rental assistance?
- #3 What mechanism should be established to objectively, equitably and compassionately evaluate an individual's elimination from HOPWA assistance?
- #4 What mechanism should be established to work with individuals eliminated from HOPWA to continue to have safe and affordable housing?"

Committee members contacted other EMA's throughout the country to determine how such issues were addressed in these regions, reviewed the existing HUD criteria, and spoke with a representative from AIDS Housing of Washington, a well respected housing agency in Washington State.

Consumer Survey

Committee members recognized the importance of securing consumer input on the HOPWA recommendations, particularly those who access and utilize the services. A survey was developed and in November 2004 supplies were sent to all agencies in the EMA providing HOPWA assistance (attention of the HOPWA administrator) for distribution to consumers

currently receiving HOPWA assistance, and return the completed surveys in self addressed, stamped envelope by December 15, 2004. Six the 13 agencies returned completed surveys. The surveys were also distributed at the town hall forums (see below).

A total of 168 individuals responded to the consumer survey; 54% were male and 46% were female. No clients self-identified as transsexual or transgendered. Of the 158 respondents who indicated their age range, 3% were under 24, 46% were between 25 and 44, and 50% indicated they were over 50 years of age. The majority of the respondents were Black (58%) and Hispanic (27%). A smaller percentage were White (12%) and American Indian (1%). The majority of the 154 respondents who provided their HIV status indicated an HIV diagnosis (75%) while a smaller percentage indicated an AIDS diagnosis (25%). Respondents were also asked to identify the number of persons living in their household. 54% of respondents indicated they live alone, 20% live with one other person, 14% live in a three-person household, and 12% live with 4 or more persons.

Respondents were asked to rate the following criteria (suggested by the Housing Committee) and determine if the criteria should or should not be used to determine HOPWA eligibility.

Results of Consumers' Rating of Possible HOPWA Eligibility Criteria

Criteria	Should be used (%)	Should not be used (%)
Timely payment of client portion of rent	94%	6%
Income eligibility twice each year	86%	14%
Visit Primary Care Physician at least once a year and provide proof	95%	5%
Monthly contact with social services	83%	17%
Urine screens	82%	18%
Feedback from landlord	71%	29%
Inspection of the residence twice each year.	88%	12%

Clients suggested additional eligibility criteria they felt would be appropriate for HOPWA. With respect to an increase in their monthly contribution towards their rent, the majority (53%) indicated they could not afford to increase their contribution, 21% reported they would be willing to increase it by \$10 - \$45, 14% would be willing to increase it by \$50, and 12% reported willingness to increase their monthly contribution by more than \$50 (even as much as \$150 or \$185). Respondents provided specific suggestions regarding HOPWA assistance or the HOPWA program, including training to clear credit/assist with home ownership, courses on budgeting and financial conservation, cap on monthly allotment, standardized qualifications across all agencies, and more landlords willing to accept HOPWA

Town Hall Forums

Town hall forums were hosted in each of the three regions of the EMA (Essex County, Union County and the Tri-County Region). Letters from the Council were sent to all agencies providing HOPWA assistance (and non-HOPWA housing agencies) along with a supply of flyers for distribution and recruitment of consumers for the forums. Results of the forums are

discussed briefly below. Additional findings are discussed above in responses to the questionnaires and are detailed in the full report.

Essex County. The first town hall forum was hosted at St. Bridget's on January 12, 2005, with approximately 45 participants. Those in attendance were primarily consumers, many of whom stated they are currently receiving HOPWA assistance. A limited number of providers also participated in the discussion. Participants overwhelmingly agreed on standard eligibility criteria throughout the EMA for initial HOPWA assistance and continuation, income eligibility criteria, priority for families with children, in particular single parents with children, as well as to consumers with disabilities in addition to HIV/AIDS, and priority of funding for consumers with an AIDS diagnosis, as opposed to an HIV diagnosis.

Tri-County Region (Morris, Sussex and Warren Counties). The second town hall forum was hosted at Hope House on January 14, 2005, with approximately 20 participants. As with the forum in Essex County, the participants were primarily consumers, with only 2 provider agencies participating in the discussion. Participants noted the housing situation in the Tri-County region differs slightly from the other counties in the EMA, because Morris County is one of the wealthiest counties in the State and U.S. Participants discussed eligibility criteria for HOPWA assistance, including priority funding for single parents. Participants made recommendations regarding fairly stringent criteria for continuation of HOPWA assistance, including home visits, ability to work, low priority to employed PLWHA, but higher priority should be given to those consumers with children, and those whose health status is poor.

Union County. The last town hall forum was hosted at Trinitas Hospital on January 26, 2005. Approximately 30 community members, including consumers and providers participated in the discussion. Attendees agreed that HOPWA eligibility criteria must be standardized across all agencies providing HOPWA assistance, recommended use of a quasi "treatment plan" when an individual initially receives HOPWA assistance, to include goals and a proposed time limit on HOPWA assistance, and suggested a six-month probationary period whereby case workers make a determination of whether HOPWA assistance will be continued beyond six months. As opposed to the other town hall forums, some participants in this forum did not agree that priority should be given to single parents with children, citing that individuals without children need housing as well. Participants had mixed opinions of whether consumers should be given multiple chances to change behavior before HOPWA assistance is removed.

Initial Recommendations of the Housing Committee

Based on discussion of committee, survey results and town hall meetings, the Housing Committee made a series of initial recommendations for each of the four items listed in the first goal. Explanation or clarification of the criteria was included where appropriate. The Committee presented its final report to the Newark EMA HIV Health Services Planning Council at the Council's regularly scheduled meeting of May 18, 2005. The Council accepted the report and members were instructed to review the document for purposes of discussion and vote on acceptance of the recommendations at the next Council meeting.

Final Recommendations of the Planning Council

At its regularly scheduled meeting of June 15, 2005, the Newark EMA HIV Health Services Planning Council reviewed the complete report and each of the Initial Recommendations. There was discussion on each criterion and each was voted on individually in accordance with Roberts Rules of Order. The proceedings were recorded in the Council minutes. The following are the final recommendations of the Newark EMA HIV Health Services Planning Council.

#1 Eligibility: (1) Priority for HOPWA services should be given to those consumers with an AIDS diagnosis, or with advanced illness; (2) priority for HOPWA services should be given to those consumers (a) who have children, or (b) who are at immediate risk for homelessness; (3) individuals must be low income, as defined by HUD or other criteria; (4) documented residence in the Newark EMA; (5) consideration of past rental assistance and performance; (6) documentation of HOPWA as the funding of last resort; (7) inspection of dwelling for safety and health concerns; and (8) evidence of willingness to improve job feasibility, if physically/mentally appropriate.

#2-#3 Continuation and Removal: (1) Proof of timely payment of client's portion of rent; (2) documented case management (including HOPWA case management); (3) income eligibility review annually; (4) successful inspection of residence annually; and (5) failure to pay client portion of rent on time (removal after a defined number of infractions).

All recommendations are subject to the review by the City of Newark, who is the HOPWA grant. All final decisions regarding eligibility for HOPWA will be made by the City of Newark in accordance with its HOPWA grant from HUD.

The Council also approved the following language in its acceptance and approval of the rest of the report.

#4 Mechanism for housing alternatives: Establishing a mechanism to work with individuals eliminated from HOPWA to help ensure they continue to have safe and affordable housing – such as an entity to network/advocate for housing – is a future direction of the committee.

The Housing Committee also recommends that regardless of what criteria the Newark Department of Health and Human Services chooses to adopt, these criteria be standardized across all agencies. The Committee recommends that the City of Newark review legal issues related to criteria for eligibility, continuation and removal.

Future Directions

The Housing Committee recognizes that people whose HOPWA assistance is terminated may still need affordable housing and housing assistance, and thus recommends continued work on the committee's other two goals. These goals are: Goal 1: Develop a continuum of care that includes permanent and special needs housing; Goal 2: Educate power brokers in the process as to the issues of permanent housing and special needs housing for PLWHA (City, State Legislature, Federal Government). The outcomes are to increase the number of affordable housing units, and to prevent current HIV+ clients from becoming homeless.