

# **Newark EMA HIV Health Services Planning Council 2004 Needs Assessment**

## **Executive Summary**

### **Epidemiological Profile**

#### **People Living with HIV/AIDS**

As of December 31, 2003, surveillance data of the New Jersey Department of Health and Senior Services (NJDHSS), Division of HIV/AIDS Services (DHAS) show that there were 11,956 people living with HIV/AIDS (PLWHA) residing in the Newark EMA. This is an increase of 3% or 333 over the 11,623 as of December 31, 2002. Similarly, there were 31,320 PLWHA in New Jersey as of 2003, or a 4% increase over the 30,073 in 2002. The Newark EMA accounts for 38.2% of PLWHA in New Jersey.

Within the Newark EMA, most PLWHA (8,822 or 73.8%) reside in Essex County, followed by 2,235 (19.4%) in Union County. A total of 809 or 6.8% reside in the remaining three counties – 595 (5.0%) in Morris, 117 (1.0%) in Sussex, and 97 (0.8%) 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 5,603 PLWHA, Newark accounts for 47% of PLWHA in the EMA and 18% of PLWHA in New Jersey.

Of the total PLWHA, 60% or 7,207 are male and 40% or 4,749 are female. This reflects a change from the distribution in 2002, in which 61% were male and 39% were female. Within the Newark EMA, the highest percent of female PLWHA (41.4%) reside in Essex County, followed by Union County (36.2%) and Sussex County (35.0%). The lowest percent of female PLWHA reside in Morris County (31.6%) and Warren County (29.9%).

With respect to current age, the highest number (4,924) and percent (41.2%) of PLWHA are age 40-49. The second highest age category is PLWHA age 50 and older (3,100 or 25.9%). The third highest category is individuals age 30-39 at 2,981 or 24.9%. Two-thirds 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 8,608) are Black, Not Hispanic. An additional 1,746 (14.5%) PLWHA are Hispanic and 1,432 (12%) are White, Not Hispanic. The remaining 170 PLWHA (1.4%) 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 39% of PLWHA in New Jersey, half (50%) of the state's NonHispanic Black PLWHA reside in the Newark EMA and 40% 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 one third of all diagnoses. Heterosexual transmission is the second leading cause of HIV infection, at 23% 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 3% of all HIV infection. For over one quarter (26%) of adults, their exposure category is unreported or unknown. The leading cause of pediatric HIV is a parent infected with HIV (94%).

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, 2003, the CDC reported that the Newark EMA contains the highest percent (36.31%) 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 Irvington has the highest percent.
- Children in the Newark EMA continue to be disproportionately affected by HIV – the EMA accounts for 47% 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 588 PLWHA per 100,000 population, or nearly twice as high as the rest of New Jersey with a rate of 303 PLWHA per 100,000 population. Within the EMA, HIV prevalence is highest in Essex County, at 1,112

PLWHA per 100,000 population, nearly three times as high as the next county, Union, at 445 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 1,904 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 2003**

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 2003. 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 between 2002 and 2003 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 in both 2002 and 2003. 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 2003. The percent of people living with HIV was lower at 46% to 48% by the end of 2003.

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 reversed by the end of 2003 (51% AIDS and 49% 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 2003. 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 2003, the Newark EMA's Title I program funded 17 categories of direct services. A total of 9,048 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 2003 YTD (as of 2/24/04).

For the first time 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 2002 and FY 2003 are primary medical care, case management, nutritional services (food), transportation, and substance abuse treatment.

**Top 5 Title I Services Used in Newark EMA  
 By Percent of Title I Clients Using the Service**

YTD FY 2003			FY 2002		
#1	Primary Medical Care	65.0%	#1	Case Management	55.3%
#2	Case Management	57.8%	#2	Primary Medical Care	54.2%
#3	Nutritional Services	31.3%	#3	Nutritional Services	33.6%
#4	Transportation	22.8%	#4	Transportation	27.4%
#5	Substance Abuse Treatment	20.9%	#5	Substance Abuse Treatment	18.1%

Source: Newark DHHS, CHAMP 2/24/03. Newark EMA FY 2004 Title I Grant Application.

Of the total PLWHA receiving Title I services, 3,861 (42%) were female and 5,187 (57%) were male. Male and female PLWHA receive Title I services at the same rates, and in relative proportion to their representation in the epidemic. As of 12/31/03, 40% of NEMA PLWHAs were females, roughly equal to the 43% of Title I clients who were females.

A total of 5,879 PLWHA residing in the Newark EMA – nearly two-thirds (65%) of Title I clients - received Title I funded primary medical care services in YTD FY 2003. This is a significant increase over the 55% receiving Title I medical care in FY 2002 and 52% receiving such care in FY 2001. By gender, 2,538 (43%) were female and 3,341 (57%) were male. Receipt of medical care did not vary significantly by age. However, youth age 13-24 received Title I funded medical care at rates higher than the other age categories – 80% versus 65%.

**2004 Needs Assessment - Part 1:  
 Unmet Need for Primary Medical Care  
 within the Newark EMA Title I System**

To assess the extent to which the Newark EMA is addressing the primary purpose of the Title I Emergency CARE Act - which is to ensure that PLWHA have access to primary medical care at standards that meet or exceed guidelines of the U.S. Public Health Service (PHS) - The purpose of this part of the needs assessment was to determine (1) the [unmet] need for primary medical care among the Newark EMA's own Title I clients, and (2) the services needed to get Title I clients into medical care and to keep them in care. The primary research question to be addressed was “**Why is an HIV-positive person in the Newark EMA not receiving primary medical care?**” For the purposes of this research plan, HIV-positive persons were grouped into four categories (1) Undiagnosed; (2) Diagnosed, not receiving any Title I services; (3) Diagnosed, receiving some Title I service, and reporting a source of health insurance - private health insurance, Medicaid or Medicare; and (4) Diagnosed, receiving some Title I service, and reporting no source of health insurance or no payor for medical care (other than Title I). This last group of PLWHA was studied in Part 1.

The purpose of Part 1 was to describe the population in Category 4 – PLWHA who reported no health insurance (“uninsured PLWHA”) and who are receiving Title I services - to identify

barriers to medical care and to explore the services they would need when they do come into care.

## **Part 1A: Comparison of Title I Clients Receiving Title I Medical Care and Those Not Receiving Title I Medical Care**

The purpose of Part 1A was to determine if there were differences in the characteristics of uninsured Title I clients who were receiving Title I funded medical care, versus those not receiving such care. It was presumed that if such differences existed, these characteristics could help identify PLWHA more likely not to be in medical care. Using this information, service providers in the EMA could better target case management and outreach efforts to enroll PLWHA into medical care.

Methods included a review of CHAMP Title I data on service utilization and client demographics to determine if common characteristics existed among PLWHA not receiving Title I medical care. Existing CHAMP data showing Title I services provided during Calendar Year (CY) 2003 (not HRSA Fiscal Year 2003) was used to explore connections between clients' characteristics (gender, age, race/ethnicity, and county/municipality of residence) and whether or not they received primary medical care. A total of 3,081 HIV+ active uninsured<sup>1</sup> Title I clients were studied – 2,124 (69%) who had received Title I medical care at some point during CY 2003 and 957 (31%) who did not receive such care. The 957 individuals not receiving Title I medical care were compared with the 2,124 individuals who received Title I medical care to determine any differences.

### **Findings**

The findings of Part 1A were consistent with results of prior Needs Assessments, Comprehensive Health Plans, and analyses of data on Title I service utilization. In general, there were few differences in the characteristics of uninsured Title I clients who received Title I medical care and those who did not.

**Gender.** Among uninsured Title I clients, men and women received Title I medical care in the same proportions. There were no differences in receipt of Title I medical care by gender. Of the 1,163 women who reported no health insurance in 2003, 70% (815) received Title I medical care and 30% (348) did not. Likewise, of the 1,918 males who reported no health insurance in 2003, 68% (1,309) received Title I medical care and 32% (609) did not. Thus, among Title I clients with no health insurance, men are just as likely as women to receive Title I medical care.

Male and female PLWHA without health insurance had access to Title I medical care in proportion to their representation in the HIV epidemic. Of the 2,124 uninsured PLWHA who received Title I medical care, 38% were female and 62% were male. Of the 957 uninsured

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<sup>1</sup> "Uninsured" clients reported the following entries in CHAMP "Source of Health Insurance" field: None, missing, charity care, self-pay.

PLWHA who did not receive Title I medical care, 36% were female and 64% were male. These percentages are nearly equal to the distribution of total PLWHA in the Newark EMA as of 12/31/03 - 40% female and 60% male.

**Current Age.** When categorized by age, uninsured Title I clients received or did not receive Title I medical care in relatively the same proportions. There were only small differences in receipt of Title I medical care among three age groups. Of the 114 PLWHA under age 13 who reported no health insurance in 2003, 63% (72) received Title I medical care and 37% (42) did not. Of the 1,477 PLWHA ages 25-44 who reported no health insurance in 2003, 69% (1,109) received Title I medical care and 31% (458) did not. Of the 1,295 PLWHA age 45 and older who reported no health insurance in 2003, 67% (866) received Title I medical care and 33% (429) did not. Among the 194 uninsured youth age 13-24, however, a higher proportion received Title I medical care in 2003 – 86% (167) – versus the 14% (27) who did not. In other words, age is not a factor in determining whether or not PLWHA will utilize medical care.

Within the age categories, uninsured PLWHA had access to Title I medical care in proportion to their representation in the HIV epidemic.

When adolescents reach age 18 they are no longer eligible for government insurance such as Medicaid or NJFamilyCare as single individuals. Lack of health insurance among PLWHA age 18-24 can be a barrier to care. Providers in the Newark EMA have sought to enroll these PLWHA in Title I medical care, which accounts for the relatively higher percentage of youth receiving Title I medical care versus their proportion in the HIV epidemic.

**Race/Ethnicity.** There were some differences in receipt of Title I medical care among uninsured PLWHA when categorized by race/ethnicity. Some differences are genuine, and one may be due to error in coding race/ethnicity. Of the 188 NonHispanic White PLWHA who reported no health insurance in 2003, 50% (94) received Title I medical care and 50% (94) did not. The rate of 50% uninsured whites receiving Title I medical care is less than the 69% EMA-wide rate of all PLWHA reporting no health insurance. Of the 1,724 NonHispanic Black PLWHA who reported no health insurance in 2003, 63% (1,090) received Title I medical care and 37% (634) did not. The rate of 63% uninsured African-Americans receiving Title I medical care is also lower than the EMA-wide rate of 69%. However, of the 952 Hispanic PLWHA who reported no health insurance in 2003, 87% (825) received Title I medical care and 13% (127) did not. Based on a review of CHAMP coding options and internal reports, it is believed that Hispanic ethnicity may be “overcoded”. That is, a number of Title I clients are being coded as “Hispanic” without exploring their true race/ethnicity, which is most likely not Hispanic or Latino.

To overcome this coding error, the total number of NonHispanic Blacks and Hispanics were added together to determine overall participation in Title I medical care. The results more accurately reflect medical participation as reported by Title I medical providers. Of the 2,767 Black and Hispanic PLWHA reporting no health insurance in 2003, 72% (1,915) received Title I medical care and 28% (761) did not.

With respect to individuals of other races or ethnic origins and those for whom the information was not reported or was missing, of the 217 PLWHA in this category, 53% (115) received Title I medical care and 47% (102) did not.

When categorized by race/ethnicity, PLWHA with no health insurance received Title I medical care in varying proportions to their representation in the HIV epidemic. NonHispanic Whites comprised only 4% of uninsured Title I medical clients but 12% of PLWHA. Individuals of other/unknown/missing race/ethnicity comprised 6% of Title I clients with no health insurance but 1% of total PLWHA. The combined total of NonHispanic Blacks and Hispanics comprised 90% of Title I clients with no health insurance who received Title I medical care, slightly higher than their combined representation in the epidemic at 87% of PLWHA.

In May 2004 CHAMP began to address the coding issue related to Hispanic ethnicity with implementation of two mandatory coding fields for each client – one for Hispanic/Latino ethnicity and the second for race. This change is consistent with federal coding requirements and protocols which are being implemented nationwide for all federal programs including Title I. All Title I clients will be recoded according to these protocols.

**Geography (County of Residence).** There were differences in receipt of Title I medical care in 2003 by county of residence. Uninsured PLWHA residing in urban counties received Title I medical care at higher rates than those in the three suburban/rural counties. Of the 2,477 PLWHA residing in Essex County who reported no health insurance, 71% (1,753) received Title I medical care and 29% (724) did not. This rate is slightly higher than the EMA-wide rate of 69% of all uninsured Title I clients who receive Title I medical care. Of the 469 PLWHA residing in Union County who reported no health insurance, 64% (302) received Title I medical care and 36% (167) did not. The Union County rate of 64% is slightly lower than the EMA-wide rate of 69%.

Differences are greater in the remaining counties, where only half or fewer of Title I clients without health insurance received Title I funded medical care in 2003. In Morris County, 53% (61) of PLWHA with no health insurance received Title I medical care in 2003 and 47% (54) did not. In Sussex County, 33% of PLWHA with no health insurance received Title I medical care in 2003 (three individuals), and 67% did not (six individuals). Likewise, in Warren County 45% of PLWHA with no health insurance received Title I medical care in 2003 (five individuals), and 55% did not (six individuals).

Title I clients with no health insurance who reside in Essex County received Title I medical care in greater proportion than their representation in the HIV epidemic, and uninsured clients in the remaining counties received proportionately less.

### **Conclusions Regarding Gender, Age, Race/Ethnicity, Geography**

Gender and age are not strong predictors of receipt of Title I medical care by Title I clients with no reported source of health insurance. As shown above, clients participate in Title I medical care in proportion to their gender and age within the EMA's HIV epidemic. Race/ethnicity has some predictive value in that NonHispanic Whites without a reported source of health insurance are less likely to access Title I medical care. It is difficult to determine whether NonHispanic Black PLWHA and Hispanic PLWHA as individual racial/ethnic groups can predict access to Title I medical care due to CHAMP coding issues. When both categories are combined, however, they receive Title I medical care at a slightly higher proportion than their representation in the HIV epidemic.

Geography – county/municipality of residence – as a client characteristic cannot be used to predict receipt of Title I medical care because a client can change county of residence but continue to receive medical care with the same provider and at the same location. This is particularly true within the densely-populated urban counties. For example, a client can move from Newark (Essex County) to neighboring Elizabeth (Union County) and continue to receive Title I medical care in Essex County. However, geography may play an important role in predicting access to care when combined with other variables, such as poverty.

### **Poverty and Utilization of Title I Medical Care.**

There appears to be a strong correlation between geographical areas with high levels of poverty and utilization of Title I medical care by those with no health insurance.

For municipality and ZIP code areas within the EMA, a comparison was made between the percent distribution of uninsured Title I clients who received Title I medical care in 2003 and the distribution of residents living below the Federal Poverty Level as reported in the 2000 Census. “Poverty” is computed based the “ratio of income to poverty” data element as reported by the U.S. Census. (The total number of individuals whose ratio of income to poverty is less than 1.0 are considered to be living below poverty.) This data element is commonly used by EMAs to estimate the total number of residents living below 300% of the Federal Poverty Level for the annual Title I grant applications.

The results showed that the percent of uninsured PLWHA receiving Title I medical care was nearly equal to the percent of residents living below poverty within municipalities and ZIP areas in larger cities (e.g., Newark). With the exception of one ZIP area in Newark (07104) and the city of Elizabeth, there is a strong correlation between poverty – the percent of EMA residents living below poverty – and uninsured Title I clients who received Title I medical care.

Newark ZIP area 07104 contains a large long-term care facility which houses many uninsured PLWHA, which may account for the high portion of NEMA uninsured Title I clients. The city of Elizabeth has a high percent of NEMA residents living below poverty versus uninsured PLWHA in Title I medical care and a large population of Hispanics/Latinos and immigrant groups who do not appear to be using Title I medical care. This disparity may be the subject of future research.

It appears that the most accurate predictor of receipt of Title I medical care by PLWHA with no reported health insurance is relative poverty within the specific geographical area. The higher the percent or concentration of individuals living below poverty, the greater the utilization of Title I medical care by PLWHA with no source of health insurance. Since the purpose of Title I is to provide access as “payor of last resort” to medical care for PLWHA living below 300% of poverty, these data show that the Newark EMA is fulfilling this mandate, particularly for those under 100% of poverty most in need of assistance.

## **Part 1B: Study of a Sample of Title I Clients Not Receiving Title I Medical Care to Determine Barriers to Care**

The purpose of Part 1B was to collect additional data from clients who have not received primary medical care to learn about their health-care beliefs and their health care behavior. Part 1B was to consist of a survey of a sample of PLWHA who did not appear to have any source of health insurance and who did not receive Title I medical care. The survey would ascertain whether they are receiving medical care for their HIV, and if not, the services needed to bring them into care. It was presumed that these individuals would be more likely than others to be brought into medical care because they have an existing connection to the Title I system through receipt of some service(s) from at least one Ryan White Title I provider.

### **Methods**

The target population was the 957 Active HIV+ Title I clients who reported no health insurance and received a Title I service in CY 2003 but not Title I medical care. The results of Part 1A, particularly characteristics which were predictive of Title I medical care utilization, were to have helped determine what types of clients might be of particular interest for Part 1B. Stratified random sampling was to be used to select a representative subgroup. The initial sample size was 180 clients - 10% representative sample (97), with an additional 10% selected to allow for client nonresponse and replacement.

The study was designed initially as a written questionnaire mail survey to the sample of clients, to be supplemented by oral interviews (face-to-face or by telephone) by the client's case manager for those who did not respond to the mailing. The method was later revised so that the case manager would contact the client, who would then telephone the Newark EMA Planning Council office for a telephone interview by Council staff. A \$10 voucher incentive was to be offered to increase participation.

The questionnaire would ascertain whether the client had had any HIV-related primary medical care during the time period, and whether he or she had any source of health insurance (other than Ryan White Title I) for medical care. It would assess the client's service needs = services required to connect or re-connect the person into HIV medical care, barriers to remaining in HIV medical care, and the additional core services needed.

Due to reduction in FY 2004 Title I funding, in March 2004 the scope and methodology of the Part 1B research were scaled back. The Council decided to proceed with selection of a 10% representative sample, but to utilize focus group research instead of a mailed questionnaire. This approach was less labor intensive, would require less staff time and travel time to complete, and could allow consumers to participate anonymously. Incentives such as food and food vouchers could more easily be implemented in a focus group setting.

To recruit focus group participants, a 10% sample of (97) uninsured Title I clients was randomly selected from the CY 2003 CHAMP data file utilized in Part 1A. (Stratified random sampling

was unnecessary because the four client characteristics of gender, age, race/ethnicity, and geography did not yield measurable differences warranting more in-depth study.) The sample was representative of the EMA in terms of gender, age, race/ethnicity, and geographical area including municipality and ZIP code level. Clients were selected for the sample by CHAMP unique coding only; no information was available which could identify any individual consumer.

Clients were invited to the focus group via mailing. To ensure client confidentiality, the Planning Council recommended that the mailing come from the Title I agencies which had provided one or more services to the 97 clients, and not from the Planning Council or staff. It took approximately one month to complete all work for the focus group mailing, reflecting the many steps taken by the Council and grantee to ensure client confidentiality. A special CHAMP program identified the Ryan White Title I funded agencies where the 97 consumers received support services. Excel was then used to cross-check all 61 providers and clients and yield a consolidated list of 23 provider agencies who had provided services most recently. Council staff completed all draft letters, certificates, envelopes and labels for the mailing to be sent to the provider agencies for mailing on their letterhead to their selected Title I clients. Each agency received a cover letter from the grantee stating the purpose of the research and individual packets for each client containing an invitation to the focus group from the Council Executive Director, certificate to redeem for a \$10 supermarket gift card, and directions to the Council offices for the June 17, 2004 group which included lunch. Providers were instructed to identify the client addresses and mail packets to them.

Approximately one week after the mailing, some of the agencies telephoned the Planning Council. They advised that the consumers listed would be unable to attend the focus group, for reasons such as incarceration, health concerns including hospitalization, inability to locate a current address for the consumer, and unwillingness on the part of the consumer to participate. It is unknown if these providers ever sent the mailing to the clients despite their concerns. Although the mailing had asked consumers to contact the Council before the focus group date, no client phone calls had been received. As of June 16, 2004, Council staff did not know if anyone would show up for the focus group on the following day.

## **Results of the Focus Group**

The focus group was held at the offices of the Newark EMA HIV Health Services Planning Council on Thursday, June 17, 2004 from 10:30 a.m. to 12 noon. The group was facilitated by Deloris Dockrey, MPH, Executive Director of the Planning Council.

**Demographics.** Two consumers participated in the focus group, one male and one female. The demographic questionnaire used in Part 2 focus groups was administered. Both reside in Essex County, both speak English primarily, both identified as Black/African American, and one was age 25-44 and the other over age 45. However, both receive primary medical care for their HIV and visit their primary care physician on a regular basis. One receives primary medical care in Monmouth County, visits the doctor once a month, and reported Medicaid as source of health insurance. The other receives medical care in Essex County, sees the doctor every three months, and reported charity care (and Ryan White Title I) as source of health insurance.

**Risk Factors.** Both participants agreed that risk factors do not vary by age, noting anyone is vulnerable to HIV if they engage in risky behavior. While youth are at risk because they explore

and engage in unprotected sex with multiple partners, seniors are also at a great risk because they are often “settled in their ways” and are not as accepting of the need to change their behaviors, i.e., practice safe sex.

Both participants agreed that risk factors do not vary geographically, commenting that as long as there “is a drug infested area, all the risk factors will be there”. The group was split on whether risk factors vary by culture – one commenting that risk factors do not vary by culture and that anyone can contract the virus, but the other participant noted that there may be a variation, specifically for those cultures who do not openly discuss HIV or other sexually transmitted diseases. The participants agreed that risk factors may vary by education and culture, noting that many people are in denial.

**Medical Care.** Both participants agreed that the medical care they receive is not appropriate. One participant commented on feeling rushed when seeing the doctor and wanted to spend [more] time with the physician (care received in Monmouth County). The other commented that it often takes a long time to see the doctor, specifically in the waiting room, and once she is with the doctor, the physician spends a very short amount of time with her and she feels rushed out the door.

It is unknown if **medical services are “culturally and linguistically appropriate”** but they commented that the language used by physicians may be difficult to understand, specifically for the newly diagnosed. When they are unable to understand what their physician is explaining to them, they rely on their case managers, psychiatrists and social workers for clarification.

**Support Services.** Both participants agreed that transportation is “one of, if not the most important” service to help HIV+ individuals access medical care. One participant commented on the importance of mental health services, psychiatric services, support groups and nutritional counseling. Both participants agreed that education is also important to help consumers maintain medical care.

**Factors preventing HIV+ consumers from accessing medical services.** Participants cited numerous factors. Persons who are actively using drugs will not seek primary medical care, stating they “don’t care because of their drug use”. Substance use helps to alleviate the pain of diagnosis, and helps the individual “not face reality”. For some HIV-positive consumers, an HIV diagnosis may be so devastating that individual may have a death wish; many consumers do not seek medical care because they “claim they are going to die anyway”. Lack of income or health insurance can significantly impact an individual’s ability to seek primary medical care, and consumers “can’t get help if they don’t have any money”. Stigma associated with sites providing medical services causes reluctance to visit medical providers known primarily known for treating HIV+ patients, because by going to these facilities their status is often “broadcast” openly to others. A variety of mental health issues affects willingness to seek medical care. Many HIV+ individuals are not emotionally prepared to disclose their status, which prevents them from obtaining medical care. The mental turmoil of living with HIV can impact a person’s willingness to access medical care. The need to be able to trust others when disclosing status is as important as the stigma of HIV. Fear of rejection is also a reason consumers do not access medical services.

Non-compliance with anti-retroviral medications negatively affects medical care. Many HIV+ consumers do not regularly take their antiretroviral medications, or do not follow the instructions. As a result, blood tests indicate that the medications are not working, which frustrates consumers, causing them to conclude that the medications do not help with their health, and leading to selling the medications on the streets.

**Actions to motivate HIV-positive consumers to access primary medical services.** Outreach is essential, but it “needs to be done from the heart” by meeting people where they are, and not imposing beliefs. Outreach could be more effective if done by individuals who are themselves HIV+, because “they can better understand where the people are coming from”.

**Participant Suggestions.** One participant suggested training for providers that specifically details the needs of HIV-positive patients is essential. Participants must be assured of confidentiality, because there are many individuals who do not want others to disclose their HIV status. If an individual was met with resistance when they disclosed in the past, they may be reluctant to disclose in the future, which may impact their willingness to access services, including primary medical care.

## **Final Notes**

Participants in this focus group provided detailed and important information, but they were not the target population because they receive medical care for their HIV regularly. This suggests that provider agency staff should ensure correct information is entered into the CHAMP database, and that there should be a means on CHAMP to record medical care received from non-Ryan White sources and from outside of the EMA. It is possible that a larger portion of consumers may be receiving medical care than CHAMP data suggest.

While it was important to maintain confidentiality of consumers, this may have significantly impacted the outcome of the focus group. Of the 97 individuals recruited for the focus group, only two participated. For future EMA client surveys, the Council and grantee should investigate methods that will result in higher levels of participation.

Future research is necessary regarding uninsured Title I clients and all HIV+ -positive consumers who do not receive primary medical care, to understand their specific reasons for not seeking medical care.

## **2004 Needs Assessment - Part 2: Assessment of Populations with Special Needs**

The Health Resources and Services Administration (HRSA) has identified a minimum of six populations of HIV infected individuals with special needs who must be included in each EMA's community based needs assessment. These are:

- (1) Youth (age 13-24),
- (2) Injection Drug Users (IDUs),
- (3) Substance Users who are not IDUs,
- (4) Men Of Color Who Have Sex With Men (MSM),
- (5) White/Anglo MSM, and
- (6) Women of child-bearing age (13-44).

EMAs can identify additional HIV-infected special populations with special needs residing within their region. The Newark EMA has identified two such populations:

- (7) Older Adults (age 45+) and
- (8) Homeless.

An updated assessment of the needs of these populations must be included in the annual Title I grant application. The following five questions must be completed for each population. Answers to Questions 1 and 3 are obtained from the EMA's Epidemiological Profile and from the HIV Planning Council during its deliberations for setting of service priorities and allocating resources for FY 2005. Answers to Questions 2, 4, and 5 were obtained as part of the Newark EMA's 2004 Needs Assessment.

1. Briefly describe this population group, including geographic distribution, income level, any language/cultural barriers, and other relevant characteristics.
2. Describe the HIV infection and risk trends in this population.
3. Discuss how the special needs of this population were determined in the Need Assessment and how the Planning Council addressed these specific needs in their priority setting and allocation decisions.
4. Describe the HIV/AIDS service needs of individuals in this population who know their status and who are in HIV/AIDS primary medical care.
5. Describe the extent to which members of this population group are not in a system of HIV/AIDS primary care and the barriers to care for those individuals.

The purpose of Part 2 of the needs assessment is to gather current information on the needs for medical care and other services of PLWHA who are receiving Title I medical care and those who are not receiving such care. Results would also be used as baseline on which future EMA studies could be based.

## **Methods**

The Planning Council utilized focus groups to complete this section of the needs assessment. A total of eight focus groups were conducted with 108 individuals to assess the needs of the eight populations. To ensure geographical and demographic representation, six groups were conducted in Essex County and two were conducted in Morris County. Attempts were made to have PLWHA from all five counties in the Newark EMA participate. The dates of the groups are shown below.

<b>Dates of Focus Groups for Populations with Special Needs – Newark EMA 2004 Needs Assessment</b>			
<b>Populations with Special Needs</b>		<b>Focus Group</b>	
		<b>Date</b>	<b>#</b>
<b><u>HRSA required populations (minimum)</u></b>			
<b>#1</b>	Youth (Age 13-24)	4/7/04	10
<b>#2</b>	Injection Drug Users (IDU)		
<b>#3</b>	Substance Abusers other than IDUs		
<b><u>Substance Users (IDU + NIDU)</u></b>			
	Essex County	4/28/04	8
	Morris, Sussex, Warren counties	4/14/04	9
<b>#4</b>	Men of Color who have Sex with Men (MSM)	3/16/04	11
<b>#5</b>	White/Anglo MSM	4/7/04	4
<b>#6</b>	Women of Childbearing Age (13-44)	4/22/04	28
<b><u>NEMA specific populations (additional)</u></b>			
<b>#7</b>	Older Adults (Age 45+)	5/26/04	14
<b>#8</b>	Homeless Individuals	5/26/04	24

The Council's extensive Committee structure was utilized to assist in the community needs assessment in order to involve as many PLWHA as possible. Committees helped select moderators and venues for each focus group that they thought would support optimal results. Letters were sent out to over 20 HIV/AIDS service agencies across the Newark EMA inviting participants to each focus group. The target audience for each group was consumers, but providers also took part in the discussions.

Council staff and other appropriate individuals served as moderators for the focus groups. All participants were assured that their contribution would remain anonymous, that they were not required to provide personal information, and that the information was being tape recorded for note taking purposes only, and that their names would not be used in the final report. At the beginning of each focus group, a brief demographic questionnaire was distributed to obtain demographic data on the participants. Council staff were always present at the focus groups to help manage the discussion and to take notes.

A focus group Discussion Guide was developed to help the moderator guide each discussion and ensure needed information was obtained. Participants in each focus group were prompted to discuss the following topics related to their experience with HIV:

1. HIV infection risk factors and risk groups;
2. HIV service needs of people who know their status and are in primary medical care;
3. Extent to which people are not in a system of HIV/AIDS primary medical care and barriers to care; and
4. Recommendations.

At the end of each focus group, people were thanked for their participation and were given the opportunity to ask questions of Planning Council staff. Although the purpose was to obtain information from consumers, Council staff answered questions and provided clarification about Title I services and other issues raised in the groups.

The demographic questionnaires were tabulated and used to prepare the Demographic Analysis section (Appendix D). Modified transcripts and detailed summaries of each group highlighting salient points were used to prepare the Summary Analysis narrative for each special population. Reports were prepared for each of the eight populations as well as a summary report comparing results of all groups.

**Limitations of the Focus Groups.** Use of HIV/AIDS service agencies, support groups, and Council Committees gave access to a broad and varied sample of PLWHA throughout the EMA, but also had certain limitations. Most HIV+ focus group participants were either in medical care or connected to the HIV system of care through support services. Although they provided valuable information on medical care, support services, and barriers to care, the voice of PLWHA not in care was not really heard. Furthermore, HIV service providers were present in most focus groups. They contributed valuable input but also stifled participation of consumers on several occasions when they displayed their professional knowledge and dominated conversations. Future research should attempt to involve more unserved PLWHA and to involve providers as key informants or in all-provider focus groups and surveys.

## **Comparison of All Focus Groups**

This Executive Summary compares and contrasts the results of all eight groups. See the full Needs Assessment narrative for an analysis of each group. The tables below provide snapshot views of the discussions that occurred across the focus groups. The tables are divided into the following topics: (1) HIV Infection Risk Factors and Risk Groups, (2) HIV/AIDS Service Needs of Individuals in HIV/AIDS Primary Medical Care, (3) Barriers to Care for PLWHA not receiving medical care, and 4) Recommendations. The results throughout this section were reported by participants.

**HIV Infection Risk Factors and Risk Groups**

All focus group participants identified a lack of information as a risk factor for contracting HIV. Many people are misinformed about the modes of transmission, progression of the disease, and services that are available. People who have limited education or whose primary language is not English are particularly vulnerable, because it is difficult for them to access the information that is available. Information must be tailored to the target audiences to be effective.

**Table 2-2: Populations in Newark EMA Identified by Eight Focus Groups as “High Risk”**

	Youth	Subst. Abuse (IDU + NIDU)		MSM		Women	Older Adults	Home- less	Total
		Essex	MSW	Essex (Color)	MSW (White)				
Young Women	√					√			<b>2</b>
Youth (general)	√	√	√			√		√	<b>5</b>
Young MSM	√			√	√				<b>3</b>
Transgendered Youth	√			√					<b>2</b>
Older Adult Women						√	√		<b>2</b>
Gay Men/ MSM				√	√		√		<b>3</b>
Older Adult MSM				√	√		√		<b>3</b>
Older Adults (general)		√					√	√	<b>2</b>
Formerly Incarcerated				√		√		√	<b>3</b>
Men on the “DL”				√			√		<b>2</b>
Partners of Men on the “DL”				√		√	√		<b>3</b>
Children born HIV-positive		√				√			<b>2</b>
Sex Workers			√			√		√	<b>3</b>
Lesbians						√	√		<b>2</b>
IDU	√	√	√			√	√	√	<b>6</b>
Non-IDU	√	√	√			√	√	√	<b>6</b>
Illiterate								√	<b>1</b>

With respect to exposure category or modes of transmission, participants noted that the two major risk factors are injection drug use and unprotected sex. Substance abuse is prevalent among all populations such as teenagers, older adults, men, women, and the homeless. The main source of infection among substance users is the sharing of needles and cookers. Non-

injected substance use, including alcohol, is also a risk factor because people lose their inhibitions when they are under the influence and will engage in risky behavior such as unprotected sex with multiple partners. People will get involved in sex work to pay for their drugs. Women will turn to sex work to pay for basic necessities and to feed their families. Inconsistent condom use among sex workers places them at high risk for infection.

MSM participants identified meeting places (clubs, bars, etc.) as places where men interact and engage in risky sexual behaviors. There are more meeting places in urban areas such as Essex County compared to the more rural counties of Morris, Sussex, and Warren. Gay men tend to travel to cities outside of their community in search of meeting places which results in the virus spreading beyond city borders. Risk factors vary by age. Young MSM and transgendered are high risk groups and are more likely to engage in risky sexual behavior. Older MSM are also at high risk because they are not as well informed about HIV.

The following is a list of all the high-risk subgroups that the participants of all eight focus groups identified. The table identifies the subgroups and the focus groups that discussed them.

**Youth.** Participants are witnessing an increase in risky behavior among the young people in their community - experimenting with injecting and non-injecting drugs and engaging in sexual relationships at very young ages. Drug choices vary between rural and urban areas, but many young people travel between the areas in search of different drugs.

Young Women. Young women engage in risky behavior such as unprotected anal sex. Women are willing to practice unsafe sex in an attempt to hold on to their partner. Many young women who come from broken homes are looking for love outside of the home and are confusing sex with love.

Young MSM and Transgendered Youth. Young men are experimenting with their sexuality and are engaging in unprotected sex. Over the last few years, HIV rates have been rising in this population and it is important to reach out to these young men. Many of these young men do not identify as gay or MSM and will therefore not respond to programs tailored to these groups. Many transgendered youth have been kicked out of their homes and are living on the streets.

Children Born HIV-Positive. Children born HIV-positive in the eighties and nineties are now teenagers and young adults. Many are now experimenting with sex and drugs. Many of these young people do not disclose their status, and as a result are placing their partners and peers at risk for infection.

**Older Adults.** One of the biggest risk factors for older adults is the fact that they are not as well informed about HIV and modes of transmission as their younger counterparts. Older adults are not very open to talking about sex. There are older adults who abuse injected and non-injected substances. Seniors resist being labeled as a high-risk group.

Older Women. Older women are not well informed about HIV. Many older women do not use protective barriers because they no longer need the contraceptive function of these devices. Society tends to deny that women over age 50 have sex, which is far from reality.

Older MSM. Many older MSM are not as aware of the benefits of using condoms.

**Men on the “Down-Low”.** The “down low” phenomenon describes men who lead double lives. They identify as heterosexual and often have wives or steady female partners, but are engaging in same-sex relationships. Men on the “down low” and their female partners are both at risk for HIV infection.

Men on the “down low”. These men live double lives and put themselves at high risk because they do not take the proper precautions when they engage in same sex activities.

Partners of men on the “down-low”. The impact of the “down-low” culture on women is serious. These men are partaking in unsafe sexual practices outside the home and are, in turn, infecting their female partners. Women do not have enough power in their sexual relationships to demand the use of a condom.

**Substance Users.** Substance users are an important risk group in their community. Several factors contribute to their risk: (1) Injecting drug users share needles and other drug paraphernalia; (2) both injecting and non-injecting drug users lose their inhibitions while they are high and will engage in unsafe sexual activities; and (3) many substance users will trade sex for drugs or money to pay for drugs.

**Sex Workers.** Participants commented that people in their communities trade sex when they are searching to get high. They do not take proper precautions in these commercial sex transactions, putting themselves at high risk for infection. Women engage in commercial sex to pay for basic necessities and to feed themselves and their families. In most cases prostitutes do not have the power to negotiate safe sex.

**Formerly Incarcerated/Recently Released.** Many people are released from jail or prison both HIV-positive and substance addicted. These individuals are contributing to the spread of the disease because they are engaging in unprotected sex with their partners and are still abusing substances.

## **HIV/AIDS Service Needs of Individuals in this Population Who Know Their Status and who are in HIV/AIDS Primary Medical Care**

**Primary Medical Care.** The following two tables reflect focus groups participants’ discussions on primary medical care.

Only participants of three focus groups agreed that they were satisfied with the care that they receive. They know that not all people in their community share these views and many participants also added that they were not always satisfied with their care.

**Reported Satisfaction with HIV Medical Care among Participants in Eight Focus Groups**

	Youth	Subst. Abuse (IDU + NIDU)		MSM		Women	Older Adults	Home- less	Total
		Essex	MSW	Essex (Color)	MSW (White)				
Satisfied with medical care			√		√		√		<b>3</b>
Not satisfied with medical care	√								<b>1</b>
Members split on satisfaction with medical care		√		√	√			√	<b>4</b>

Focus groups participants listed several factors that affected the quality of medical care. The most common factors were self-advocacy, provider attitude/respect for clients, and insurance. Other factors included doctor-patient communication, continuity of care, coordination of services, wait time/hours of operation, and cultural and linguistic competency.

**Reported Factors Contributing to Quality of HIV Medical Care among Participants in Eight Focus Groups**

	Youth	Subst. Abuse (IDU + NIDU)		MSM		Women	Older Adults	Home- less	Total
		Essex	MSW	Essex (Color)	MSW (White)				
Insurance		√	√	√	√		√		<b>5</b>
Doctor-Patient Communication			√	√					<b>2</b>
Respect for Clients/Provider Attitude	√	√		√	√		√		<b>5</b>
Self-Advocacy			√	√	√	√	√	√	<b>6</b>
Continuity of Care					√				<b>1</b>
Wait times/hours of operation	√				√				<b>2</b>
Cultural & Linguistic Competency					√			√	<b>2</b>

Insurance. Participants stated that insurance is the best way to guarantee access to good quality medical care, and provided testimonials of their own experiences and those of their peers that compared the medical encounters of HIV-positive individuals with and without medical insurance. All agreed that medical care with insurance was of much higher quality. A few participants noted good experience in the clinic setting, but only because they have worked hard to establish a rapport with the clinicians and have advocated for themselves.

Doctor-Patient Communication. Doctor-patient communication is important; and people will be more satisfied with their care if the doctor or support staff takes the time to explain diagnoses, treatments, and medications. Many medical providers do not take the effort to initiate this communication, and the client will not be well informed of his/her medical regimen if specific questions are not asked.

Respect for Clients/Provider Attitude. Provider attitudes influence the perception of the quality medical care. Medical and support staff in various agencies are disrespectful of their HIV clients and often stigmatize and treat them in a condescending manner. The manner in which a person is treated is often more important than the physicians demonstrating their high level of medical expertise.

Self-Advocacy. Self-advocacy was the most common factor that participants identified as affecting the quality of medical care. Although it is the provider's responsibility to ensure that the client understands all information conveyed, it is essential for HIV+ people to be empowered so that they can serve as self-advocates and be an active participant in their care regimen. Unfortunately, many people living with HIV/AIDS have low self esteem and are therefore unable to advocate for themselves.

Continuity of care. Continuity of care as an important factor for quality medical care. Clinic patients do not see the same clinician at every visit, and therefore they feel that they have to start over again with each group.

Wait Times/Hours of Operation. Participants in some Youth and Women's groups were not satisfied with the medical care services in their community because of the hours of operation. It is hard for working women and youth to access care between the hours of 9:00 a.m. and 5:00 p.m. People who are in school cannot access services during regular business hours. There are long waiting times at the clinics and they do not have the time to spend the entire day waiting for services.

Cultural and Linguistic Competency. Cultural and linguistic competency is a determinant of good quality health care. Many services are not offered by culturally or linguistically competent providers and this leads to a breakdown in communication between provider and client.

**Support Services.** The table below lists of all support services identified by participants as vital to help maintain HIV-positive individuals in medical care. The table identifies the services and the focus group that discussed them.

Case Management. Case management as an essential service to keep PLWHA in medical care, and is the key service to help coordinate all services relied upon by PLWHA. Case

management services are especially important for the newly diagnosed or for people who are just entering the system of care. Most participants are satisfied with the case management services they receive, but some case managers have been rude and condescending. These attitudes can cause people to drop out of care.

Complementary Services. Only participants in the Women's focus group listed complementary services as an essential support service. The women who identified this service are already well-established in a system of primary medical care.

**Support Services Needed to Help PLWHA Remain in Care, as Identified by Participants in Eight Focus Groups**

	Youth	Subst. Abuse (IDU + NIDU)		MSM		Women	Older Adults	Home- less	Total
		Essex	MSW	Essex (Color)	MSW (White)				
Case Management			√		√	√	√	√	<b>5</b>
Complementary Services					√				<b>1</b>
Dental Care					√				<b>1</b>
Housing			√	√	√	√	√	√	<b>5</b>
Legal Services	√								<b>1</b>
Mental Health	√	√			√	√	√	√	<b>6</b>
Nutritional Counseling				√	√	√	√	√	<b>5</b>
Programs for recently incarcerated,		√		√					<b>2</b>
Substance Abuse Service		√	√			√		√	<b>4</b>
Transportation	√	√			√	√	√	√	<b>6</b>

Dental Services. Participants in the Women's focus group noted that dental health is very important for PLWHA, but they are not satisfied with the dental services they have accessed and described the dentist and staff as discriminatory and rude.

Housing. Housing is an important support service, which makes accessing medical care easier and offers PLWHA stability in their lives. People who are homeless will not seek primary medical care because they are more concerned with finding shelter or their next meal. Homeless youth are of particular concern.

Legal Services. Legal services are an essential for PLWHA but legal concerns can be quite different. E.g., older MSM (over age 45). The primary concern of older MSM (age 45+) was

advice on Social Security and other benefit packages, and how to prepare in the event that they got sick. Youth focus are primarily concerned with access to HIV testing and care and treatment. Parental consent is needed to access these services, and legal services would help minors navigate the system and/or file for emancipation.

Mental Health. Mental health services in the form of one-on-one counseling or support groups helps HIV-positive individuals manage the emotions such as depression and anxiety that accompany HIV. It is important to links mental health and substance abuse services.

Nutritional Services. Nutritional Services is an important support service because HIV+ individuals have particular nutritional needs. Nutritional counseling can help people manage their HIV. Proper nutrition helps stabilize PLWHA. Nutritional service in the form of distribution of food is very important to homeless individuals because people will not worry about going to the doctor when their primary concern is finding their next meal.

Programs for the Formerly Incarcerated. Many people are HIV-positive when discharged from jail or prison. Programs for the formerly incarcerated can help link these individuals into medical care and other support services.

Substance Abuse Services. Injection drug use is one of the primary modes of transmission in their communities. Most people must address their addiction first in order to access primary medical care and other services to manage their HIV. There is a need to condense Substance Abuse and Mental Health Services.

Transportation. Transportation services are essential to link people into and maintain them in medical care. Many HIV services exist but people cannot access reasonable and reliable transportation. Transportation is a major barrier to care for people living in Morris, Sussex, and Warren Counties where public transportation systems like those in Essex and Union Counties do not exist.

**Extent to which members of this population group are not in a system of HIV/AIDS primary care and the barriers to care for those individuals**

The following table lists the major services identified by the eight focus groups, which, if not available to PLWHA, act as barriers to care.

**Barriers to Care Identified by Participants in Eight Focus Groups**

Service Category	Youth	Subst. Abuse (IDU + NIDU)		MSM		Women	Older Adults	Home-less	Total
		Essex	MSW	Essex (Color)	MSW (White)				
Child Care		√				√			2
Coordination of services						√	√	√	3
Cultural and Language Barriers					√	√			2
Fear/Denial	√		√	√	√	√		√	6
Hours of operation/time	√	√				√			3
Housing		√		√	√	√	√	√	6
Immigration Status		√							1
Insurance			√	√	√	√	√	√	6
Lack of Education/Information	√	√	√	√	√	√	√	√	8
Legal Barriers	√								1
Medications		√	√		√		√	√	5
Mental Health		√							1
Nutrition							√	√	2
Stigma/Discrimination	√	√	√	√	√	√	√	√	8
Substance Abuse		√	√					√	3
Transportation	√	√	√	√	√		√	√	7

Child Care. Women who do not have access to child care services are unable to seek medical care. Women tend to be the primary care taker of partners, parents, children, and other family members. Many women work and need help with their care taking responsibilities so that they have the time to go to the doctor.

Coordination of Services. Coordination of services is important, particularly the coordination of mental health and substance abuse services, which can eventually help get HIV-positive people into medical care. Women can get lost in the system of care and coordination of services can help them remain in medical care.

Cultural and language barriers. Most services for people living with HIV/AIDS are offered in English, and people who do not speak this language often fall through the cracks. Also, adjustments are not made in programs and agencies to approach sensitive issues such as drugs and sexuality in different cultural groups.

Fear/Denial. Fear and denial are major barriers to care. Many people fall into denial after they receive an HIV-positive diagnosis and refuse to seek medical care. Some people think that since they do not look or feel sick, it is not really serious. Many people keep their HIV-status a secret because they fear the repercussions of disclosing to friend, families, and coworkers. People who do not disclose their status tend to have a support system to help them access medical care and other services.

Hours of Operation/Time. Hours of operation and/or lack of time may be a barrier to care. It is difficult for people to take time off of work or school during the day to go to a medical appointment and most services are offered between 9:00 a.m. and 5:00 p.m. Long wait periods are a barrier. People do not have time to wait all day and many clients get frustrated and leave before they are seen by a doctor.

Housing. Housing is a major barrier to care (all except Youth and MSM in Morris County). There is a lack of affordable housing especially in Morris County. Housing brings a certain level of stability to a life – particularly for the homeless - and allows people to deal with essentials such as food and eventually prepares them to access medical services.

Immigration Status. Undocumented individuals do not seek medical care because the fear deportation.

Insurance. Lack of insurance as a major barrier to medical care. People with private insurance have access to higher quality medical care. HIV-positive individuals who do not have insurance usually visit clinics for their medical care but for various reasons such as long wait times and discrimination, they refuse to seek treatment.

Lack of Education/Information. All focus groups identified lack of education and information as a barrier to care. People in their community are not aware of available HIV services. Lack of information prevents people from advocating for themselves. Lack of information leads people to distrust medications and the medical establishment. Providers are not always well enough informed to offer appropriate services to the communities they serve.

Legal Barriers. The Youth focus group identified legal barriers to accessing care. These barriers are unique to minors (under age 18) because many youth do not want to disclose their status to their families and minors need parental consent to access certain HIV services.

Medications. Participants stated that many HIV medications have bad side effects. Some people get frustrated trying to manage these medications and become non-compliant and eventually drop out of care.

Mental Health and/or Substance Use. Many PLWHA are dealing with substance abuse and mental disorders or distress. Participants focused more on the barrier that current substance use creates. People need help addressing these issues before they can properly medically manage their HIV.

Nutrition. Lack of adequate nutrition hampers a person's ability to access medical care. Older adults and homeless individuals are particularly at high risk for malnutrition.

Stigma/Discrimination. All groups identified stigma and discrimination as major barriers to care. Stigma associated with HIV/AIDS still exists. People refuse to seek services in buildings that are associated with AIDS because they are afraid of being labeled by people in their community and the repercussions of that label. Staff and clinicians sometimes discriminate against HIV-positive individuals and frequently look down on them.

Transportation. Nearly all focus groups identified transportation as a major barrier to care. Many HIV services exist but people cannot access them because they do not have access to reliable transportation. Residents of Morris County emphasized that a public transportation system like those in urban areas does not exist in their communities. In addition, services are far away from each other and from their residences.

**Recommendations**

The table below lists of the major recommendations made to respond to the barriers to care participants of all eight focus groups identified.

Recommendations for Services to Help PLWHA Remain in Care Identified by Participants in Eight Focus Groups									
Service Category	Youth	Subst. Abuse (IDU + NIDU)		MSM		Women	Older Adults	Home-less	Total
		Essex	MSW	Essex (Color)	MSW (White)				
Colocation of Services						√			1
Education programs for providers		√				√			2
Empowerment & Educational workshops for PLWHA	√			√	√	√	√	√	6
Establish real role models	√								1
Holistic treatment					√				1
Improve communication				√					1
Improve coordination of services		√						√	2
Improve housing services				√			√	√	3
Incentives			√			√			2

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Increase advocacy	√	√		√	√	4	
Internet discussion forums			√	√		2	
Intervention programs to show realities of HIV	√					1	
Legal help	√			√		2	
More interpreters					√	1	
More night services	√	√		√		3	
More reliable, safe transportation					√	1	
More support groups					√	1	
Needle Exchange					√	1	
Peer navigation programs	√			√		2	
Targeted outreach programs	√	√	√		√	√	5

Co-location of services. A variety of service should be offered in one location to minimize the time and travel people need to invest in their care. More people would access services in such a setting.

Educational Programs for providers. There is a need for the community and people living with HIV/AIDS to be more educated regarding HIV/AIDS and available services. Providers should be more educated on HIV and how it affects the people in the communities they serve. Educational programs should be developed for providers, and can help providers understand the needs of the clients they serve and treat HIV-positive individuals with more respect. These programs will prepare providers to communicate better with their clients.

Empowerment and educational workshops for PLWHA. A common theme across the focus groups was the importance of self-advocacy to ensure quality care. They recommended the development of empowerment and educational workshops for people living with HIV/AIDS. Education is power and through these workshops you can inspire HIV-positive individuals to advocate for themselves. These programs will help clients communicate with their service providers.

Establish real role models. Groups discussed the image of Magic Johnson as a face of HIV/AIDS, and the effect of this type of “role model” on PLWHA and people who are at high risk. Youth noted that for them, Magic Johnson is not a good model because they do not consider him a reflection of their community. People from the community should serve as role models and spokespersons regarding sensitive issues such as HIV. A real role model would have more success encouraging people to get tested and/or getting people into medical care.

Improve Coordination of Services. Services for people living with HIV/AIDS should be better coordinated. Many people drop out of care because there is not a strong link between agencies to keep people in care. These linkages are especially important for people dealing with mental health issues, substance abuse, and/or are homeless.

Improve Housing Services. Housing provides PLWHA with the necessary level of stability to access medical services, and participants recommended an increase in housing services for PLWHA. There is a need for housing services for youth who are currently living on the streets, and PLWHA should have priority on lists for housing services.

Incentives. More HIV/AIDS service agencies should offer incentives to encourage people living with the virus to access care.

Increase Advocacy. More advocacy would help people connect into medical care. Advocacy at a community level is important to help maintain services in the community and help people access these services.

Internet Discussion Forums. The two MSM focus groups discussed the need for forums for HIV-positive individuals to collaborate and share information on living with HIV/AIDS, and suggested the development of Internet forums or chat rooms where gay men or MSM could communicate.

Intervention Programs to show realities of HIV/AIDS. The Youth focus group suggested the creation of intervention programs to show young people the realities of living with HIV/AIDS. They recommended taking high-risk and newly diagnosed individuals to visit centers such as Broadway House for continuing an HIV test and seeking care for HIV.

Linguistic Competence – More Interpreters. Services should be more linguistically competent. Agencies providing HIV services should not only have interpreters for people who do not speak English but for people who have limited reading abilities as well. However, interpreters would make clients feel very uncomfortable and suggested that agencies find alternatives to help people communicate with physicians and other staff.

More Night Services. HIV service providers should offer services after regular business hours. People who work or go to school cannot access services that are offered between the hours of 9:00 a.m. and 5:00 p.m.

More reliable safe transportation. Almost all groups noted that transportation as a major barrier to medical care, and one group made a specific recommendation to increase safe and reliable transportation options for people living with HIV/AIDS to access medical and support services.

More Support Groups. More support groups should be developed. However, most support groups are arranged by mode of transmission, and support groups should be implemented that serve populations such as older adults.

Needle Exchange. The group that discussed needle exchange programs did not all agree on a position in favor of needle exchange programs, but many participants argued that the distribution of clean needles would help control the epidemic and recommended the development of needle exchange programs.

Peer navigation programs. Peer navigation programs would link people living with HIV/AIDS who have experience navigating the system of care and services with newly diagnosed individuals and people who are trying to enter the care system.

Targeted outreach programs. Outreach programs should be individually designed to reach out to the target populations, specifically to groups such as young MSM, older adults, and substance users. The outreach programs should strive to get HIV-positive individuals into care but the programs should be offered to both HIV-positive and HIV-negative individuals to avoid labeling people.

Location of Services. Several groups noted that many people do not access services because certain buildings are associated with HIV/AIDS. Youth recommended that service should be offered in anonymous locations that have no particular association with HIV/AIDS.

## **Needs Assessment 2004 - Part 3:**

# **Reduced Health Disparities in the Veterans' Administration System of HIV Health Care and Applicability to Access to Care in the Newark EMA**

### **Introduction**

During the Planning Council's Research Committee meetings regarding access to medical care, members discussed research which showed that patients in the Veterans' Administration (VA) health system were purported to experience fewer racial/ethnic disparities in access to and utilization of health care than other systems. This might be true for HIV as well as for other health problems. The Newark EMA grantee (Newark Department of Health and Human Services - DHHS) has a contract with the East Orange VA Hospital to provide supportive services of nurse case management, transportation and other services to the **VA HIV Health Clinic**. It is estimated that the clinic serves 500+ PLWHA who are veterans residing in the Northern New Jersey region.

Because access to quality HIV care is a major goal of Title I, the 2004 Needs Assessment included a goal to determine whether the Veterans' Administration system of HIV medical care reduces health disparities and improves access to care, particularly among racial/ethnic minorities, and whether this system can serve as a model for other HIV medical care in the EMA. The specific objectives were to determine (1) whether fewer health disparities exist in access to [HIV] care, and if so, (2) the reasons, and (3) whether the lessons for delivery of health care services can be transferred to non-VA systems as "best practices." The Council was to utilize the contractual relationship between the grantee and East Orange VA Hospital to obtain information.

### **Methods**

Health disparity issues were reviewed with the Newark DHHS epidemiologist (member of the Council's Research Committee), particularly with respect to information regarding the VA Health Care system. Secondary research was also completed, including extensive online research with the VA, Centers for Medicaid and Medicare, USDHHS, and other sources regarding access to care and health disparities, focusing on access to HIV care. Background information about the Title I services provided at the VA clinic was obtained from the assigned Newark DHHS Ryan White Title I Monitor and from CHAMP. A questionnaire guide was developed to elicit specific information from the VA. Staff interviewed key informant Robert H.K. Eng, M.D., who is an infectious disease specialist and Director of the VA HIV Clinic. Dr. Eng provided considerable information about the VA HIV Clinic, how this clinic functions within the larger hospital system, and possible "best practices." Results were compiled and a report prepared and presented to the Council.

## **Results**

**Overview of the VA System of Health Care.** The Department of Veterans' Affairs is a branch of federal government that provides services to veterans who were honorably discharged from duty and who require medical services. Numerous facilities are located throughout New Jersey, including two hospitals, ten outpatient clinics, four community based outpatient clinics, four veterans' centers, two cemeteries, and one regional administration office. The hospitals are located in East Orange in Essex County and Lyons in Somerset County. The outpatient clinics are located throughout the state, from Hackensack to Cape May.

The Veteran's Affairs New Jersey Health Care System located in East Orange provides a wide range of healthcare services to veterans residing primarily in Northern New Jersey. Services which are applicable to HIV+ patients include pain management, treatment for Post Traumatic Stress Disorder (PTSD), substance abuse treatment and medical care for treatment of HIV/AIDS. The VA HIV Clinic serves approximately 550 HIV+ veterans annually. The Clinic provides primary medical care services to PLWHA and receives Ryan White Title-I funding to provide supportive services, including case management, transportation and nutritional services. These services are not otherwise available through the VA Health Care system.

**Eligibility for Services.** The primary factor in determining a veteran's eligibility to receive VA health care benefits is 'veteran status.' Veteran status is established by active duty service in the military, naval, or air service and a discharge or release from active military service under other than dishonorable conditions" Once a veteran applies for enrollment, eligibility is verified and a priority group assigned. The eight Priority Groups are: (1) service-connected disabilities rated 50% or more disabling, (2) service-connected disabilities rated 30% or 40% disabling, (3) former POWs, those awarded the Purple Heart, discharge for disability incurred or aggravated in the line of duty, service-connected disabilities rated 10% or 20% disabling, (4) receiving aid and attendance or housing benefits, catastrophically disabled, (5) nonservice-connected veterans 0% disabled whose annual income and net worth are below VA Means Test thresholds, those receiving VA pension benefits or eligible for Medicaid, (6) compensable 0% service-connected veterans, veterans of World War I and other specific wars/conflicts, (7)-(8) veterans who agree to pay specified co-payments with income and/or net worth above VA Means Test threshold and income below the HUD geographic index, plus other factors.

While a great number of veterans qualify for cost-free health care services, veterans whose income and net worth exceed the VA Means Test threshold must pay required co-payments to become eligible for VA health care services and to receive outpatient and inpatient services, medications and long-term care services. VA provides an extensive array of preventive care services, outpatient and inpatient diagnostic and treatment services (such as medical, mental health & substance abuse services), inpatient diagnostic and treatment services, and prescription drugs. The VA does not pay for drugs not approved by the FDA, and provides limited coverage for dental care, durable medical equipment, and rehabilitative services. Medical services are not provided for family members. Limited counseling services are provided to family members, in the context of the veteran's counseling, e.g., for mental health or substance abuse. A complete listing of services is available on the VA website [www1.va.gov](http://www1.va.gov).

**Outreach and referral.** The VA does not actively reach out to or recruit consumers for HIV medical care and support services. Most patients of the HIV Clinic are referred from other

departments within the VA, e.g., treatment for physical problems or mental health/substance abuse. A nationwide medical records and data base system immediately notifies the HIV Clinic when a patient has been diagnosed with HIV. The clinic can then reach out to that patient to help link them to medical care.

### **HIV/AIDS Services Provided by the VA New Jersey Health Care System, East Orange**

**Primary Medical Care.** Through the HIV Clinic, the VA provides outpatient and inpatient health care services for eligible veterans living with HIV/AIDS, and access to treatment for substance abuse and mental illness within other sections of the VA hospital, but not most of the support services necessary to help consumers stay in medical care. As reported by the key informant, "The mission of the VA is medical care." Nor does the VA fund services for HIV-affected family members, unless the services are directly related to service-related injuries of the veteran (e.g., family counseling and mental health services for a service-connected mental health disorder). This is a significant gap in services for HIV+ veterans, which is filled by Ryan White Title-I wrap-around services. These services include case management, transportation, and food vouchers.

**Services other than Primary Medical Care.** Case managers assist patients with health care planning, spiritual, cultural, dietary and social needs. Transportation services assist where VA transportation services are not available. To be eligible for VA transportation services, a patient must be service connected. A patient who lives miles away from the facility, but has the ability to walk is not eligible for VA transportation services. Wrap-around services provided by Ryan White Title-I assist with transporting patients for medical appointments through bus vouchers. Food vouchers enable patients to have breakfast or lunch at the VA cafeteria while waiting to see the doctor. Thus patients are able to maintain their nutritional needs while taking antiretroviral medications. The VA has a working relationship with the Dental Clinic at UMDNJ to provide dental services to veterans not eligible for dental services with the VA (VA dental services are only for those veterans whose oral health concerns are service connected).

**Medical Appointment Scheduling.** A number of appointment scheduling methods have been tried over the years but the following treat patients most equitably. Scheduled clinic appointments on Tuesday and Thursday mornings and Thursday evenings. Approximately 25 patients are seen each morning, and 10 patients are seen each evening. The HIV Clinic has a walk-in clinic, where patients can come for health care services without an appointment any time during business hours. An estimated 10 walk-in patients are seen each day. Scheduled appointments are encouraged, because "walk-in" care is primarily for PLWHA with more immediate health concerns. Appointments are scheduled for 8am in the morning, and patients are then seen on a first-come, first-served basis. Patients who "walk-in" are seen within an hour of their arrival at the clinic.

**Pharmacy Services.** The VA Hospital has a pharmacy on site, and prescriptions written at the VA Hospital can only be filled at this pharmacy. The VA attempts to have medications delivered to patients' homes. However this requires the patients to navigate the VA's phone system, where prescriptions can be refilled over the phone. The VA Health System is a large purchaser of antiretroviral medications and provides these medications to HIV+ veterans.

## **Demographics of HIV+ Veterans Receiving Services at the VA HIV Clinic**

Of the approximately 550 HIV+ veterans, 97% are male and 3% are female. The majority (80%) are African American, 11% are White Non-Hispanic, 5% are Hispanic, 1% are Asian/Pacific Islander, and the remaining 3% are not specified. Nearly all (95%) HIV+ patients reside in the Newark EMA. Over half (60%) of patients reside in Essex County - 35% in Newark, 15% in East Orange/Orange, and 10% in Irvington. One fifth (20%) reside in Union County, 10% reside in Morris County, and the smallest percentage resides in Sussex County (5%). The remaining 5% live in other areas of Northern New Jersey.

Approximately 43% or 235 of the 550 patients received Title I funded wrap-around services in FY 2003. Of the 235 patients, 99% are male, while 3% are female. With respect to race/ethnicity, 89% are African American, 3% are Hispanic, 7% are Non Hispanic White, and less than 1% are unknown or Puerto Rican.

## **Benefits of the VA Model of Health Care**

The benefits of the Veteran's Affairs New Jersey Health Care System with respect to access to care are related primarily to the fact that it is a system of care. The major feature is that care of patients is monitored through a nationwide electronic medical records system. All VA medical sites across the U.S. are connected by one central computer system of patient medical records. Physicians have the ability to contact other physicians who have previously seen patients. All testing and blood work is done by the VA, and is entered directly into the VA's computer system and stored, which provides immediate access to a patient's medical history and current status. The computer system is also equipped with clinical reminders, e.g., which remind staff when to obtain CD4 counts or other necessary blood work or procedures. The clinical reminders are especially appropriate for providers who do not treat patients with HIV on a daily basis. The system also ensures that if a patient is diagnosed with HIV in another department of the hospital or another VA medical site in the state, the HIV Clinic is immediately notified. As a result, patients can be brought into medical care almost immediately upon diagnosis, which reduces the likelihood of patients being "lost" once they leave the hospital.

The VA also keeps extensive records on contacts for patients, which enable staff to communicate with patients if they have dropped out of care. For example, patients' records include next of kin, addresses and phone numbers, for patients and for family members. This enables staff to contact patients to determine why they have dropped out of care, and to attempt to bring the patient back into the system of care.

Quality of HIV medical care is ensured because when HIV-positive patients present for medical care at the VA Hospital, they must be seen by the Infectious Disease physicians in the HIV clinic. This helps to ensure continuity of care to all patients receiving HIV services. It also helps the hospital identify and track down noncompliant patients.

The VA HIV Clinic in East Orange is the only outpatient clinic that provides primary medical care specific to HIV disease to HIV+ veterans. The Clinic has a high compliance rate with primary medical care appointments, which may be attributed to the convenience of receiving these services in the context of other veteran's services.

Because it operates within a system of care, the VA HIV Clinic has been able to coordinate non-HIV health services with HIV medical care on behalf of its patients. Many HIV+ veterans also have substance abuse problems for which they are receiving treatment, and substance abuse patients may not be aware of their HIV status. The HIV clinic has established a working relationship with the VA substance abuse department, through which patients newly diagnosed with HIV or substance abuse problems are made. HIV medical care and substance abuse treatment are coordinated between the two departments on behalf of patients.

The VA has recently begun using telemedicine to provide access to healthcare to individuals in remote areas. If a patient is unable to travel to a VA hospital for health care services or to the VA HIV Clinic, they can be seen at a local VA outpatient center, and physicians from the larger hospitals can manage their health needs, particularly with respect to HIV.

### **Limitations of the VA Model of Health Care**

Public perception suggests that all veterans are provided free healthcare through the VA, which is accurate only for veterans with lower incomes in top priority eligibility groups. Veterans who fall within lower priority eligibility categories or have income which exceeds the VA Means Test Thresholds must contribute toward the cost of care, and may be faced with extensive medical bills.

While patients can receive a majority of their services “under one roof”, the VA model of care does not ensure supportive services such as housing and nutritional needs. Many supportive services are provided by Ryan White Title-I, however, without the Ryan White funding, these patients cannot access “one-stop shopping”.

As with other non-VA providers, the HIV Clinic must establish relationship for coordination of care through interpersonal contact, not relying only on the system-wide medical records system. This has been effective for substance abuse treatment but the HIV Clinic admittedly does not have a strong relationship with the VA mental health department. Recognizing the numerous mental health diagnoses which accompany many HIV+ veterans, including PTSD and depression, a working relationship with mental health services is essential and will be established.

The current scheduling system for the clinic means that patients may be required to wait for long periods of time before they are seen by a physician. All patients are given 8 am appointments on a given day, and they are seen first-come, first-served. While this eliminates disagreements among patients and frustration in the waiting room, it may result in less compliance for medical appointments. For example, if 10 patients all arrive at 9 am, it may take all morning for them to be seen by the physician.

### **Recommendations**

The Veteran’s Affairs New Jersey Health Care System has components that other primary medical care providers in the Newark EMA can learn from. The current system allows VA patients to access “one-stop shopping” where they can receive most, if not all, services at the

same location. The requirement that all HIV+ patients see an Infectious Disease patient helps to ensure that patients are receiving the same standard and quality of care. In many health care settings, patients see family practitioners and other physicians, and do not have their care managed by an Infectious Disease specialist. This is something all providers of HIV primary medical care should consider.

The electronic medical records system utilized by the VA ensures that patients' records follow them throughout a hospital system. For large hospitals, a similar medical records system would help ensure continuity and quality of care. The software used by the VA is available for free through the Freedom of Information Act and is reportedly extremely user friendly. The clinical reminders are especially important and helpful for physicians managing the health care needs of a large number of patients as well as patients with co-morbid diseases, such as diabetes or Hepatitis C. The immediate computer notification of HIV diagnosis appears to help bring the patients into medical care at the HIV Clinic, as opposed to a verbal referral to an Infectious Disease physician. In addition, the VA's efforts to bring the newly diagnosed into medical care and provide consistent follow-up with their patients also is an example of how other primary medical care providers could increase the compliance of their patients.

As previously noted, public perception suggests that all veterans are eligible for free health care services through the Veteran's Administration. While the services offered by the VA are often extensive, veterans must be extremely low income or service connected to qualify for these services at no cost. Other veterans can still receive the services, but must contribute financially. As such, this system is similar to many other health benefits programs, where income determines the fiscal responsibility of the patient. Therefore, while the system does not drastically reduce disparities for patients living with HIV, the providers at this facility employ measures to ensure the quality of care provided to those living with HIV/AIDS.