

## Part 2: Assessment of Populations with Special Needs

### Introduction

HRSA requires EMA's to conduct a community based needs assessment as a condition of receiving Title I funds. HRSA has identified a minimum of six populations of HIV infected individuals with special needs who must be included in this needs assessment. These are: youth (age 13-24); injection drug users (IDUs), substance users who are not IDUs, men of color who have sex with men (MSM), white/Anglo MSM, and women of child-bearing age (13-44). An assessment of their needs must be reported annually to HRSA via "Table 7." EMAs can identify additional HIV-infected "special" populations within their region. The Newark EMA has identified two such populations - older adults (age 45+) and the homeless.

HRSA/HAB asks EMA's to complete the following five questions for each population with special needs. 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.

### Methodology

The Newark EMA HIV Health Services Planning Council utilized focus groups to complete this section of the Needs Assessment in 2004. A total of eight focus groups were conducted 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. The results will be utilized to complete Table 7 for the FY 2005 application. The dates of the groups are shown in Table 2-1 below.

<b>Table 2-1: 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 conducting the community needs assessment in order to involve as many PLWHA as possible. The Council and staff involved the Council's committees in the planning and execution of the focus groups. 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. At the beginning of each focus group, Council staff provided an introduction explaining the purpose of the session. A brief demographic questionnaire was distributed to obtain demographic data on the participants (Appendix C-1). Moderators informed participants that their contributions in the discussion would remain anonymous. Participants were informed that they were not obligated to provide any personal information, that the session was being recorded for note taking purposes, and that their names would not be used in the final report. Participants were

given the option to request that the tape be turned off. Council staff was always present at the focus groups to help manage the discussion and to take notes.

A focus group Discussion Guide had been developed to help the moderator guide each discussion and ensure needed information was obtained (**Appendix C-2**). 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, participants were thanked for their contribution and were given the opportunity to ask questions of Planning Council staff.

Following each focus group, results of the demographic questionnaires were tabulated and used to prepare the Demographic Analysis section of Part 2. Also, Council staff and interns used the tapes and notes to create modified transcripts of the discussion. Modified transcripts are detailed summaries of each group highlighting salient points made by the participants, and were used to prepare the Summary Analysis narrative for each special population.

The results of the focus groups are listed in the order that HRSA presents the populations, not in order that the groups were conducted. The results address HRSA questions 2, 4 and 5. The timing of the focus groups was based on the data(s) that were most convenient to consumers throughout the EMA. The assessment of populations with special needs is divided into the following sections: (1) demographic analysis, (2) summary and analysis, and (3) comparative analysis, interpretations and recommendations. At the end of Part 2 is a summary of EMA-wide findings and recommendations which reflect common themes expressed by participants throughout the eight focus groups.

### **Limitations of the Focus Groups**

To recruit participants, the Council tapped into HIV/AIDS service agencies, support groups, and the Planning Council committees. We were thus able to work with a broad and varied sample of PLWHA throughout the EMA. However, this methodology also resulted in certain limitations to results obtained from the focus groups. Most HIV-positive focus group participants were either in medical care or connected to the HIV system of care through support services. Although valuable information was gathered on medical care, support services, and barriers to care, the voice of PLWHA not in care was not really heard. Furthermore, providers of HIV services were present in most focus groups. Although provider input is valuable on the various topics of discussion, on several occasions their input stifled participation of consumers. Providers usually mentioned that they are not HIV-positive, but understand the struggles. Nevertheless, they talked about HIV services from a professional point of view, which was quite different from that of consumers. This created an unacknowledged but real hierarchy among participants. On several occasions, once providers started making comments, they dominated the conversation and consumers were silenced.

## **DEMOGRAPHIC ANALYSIS**

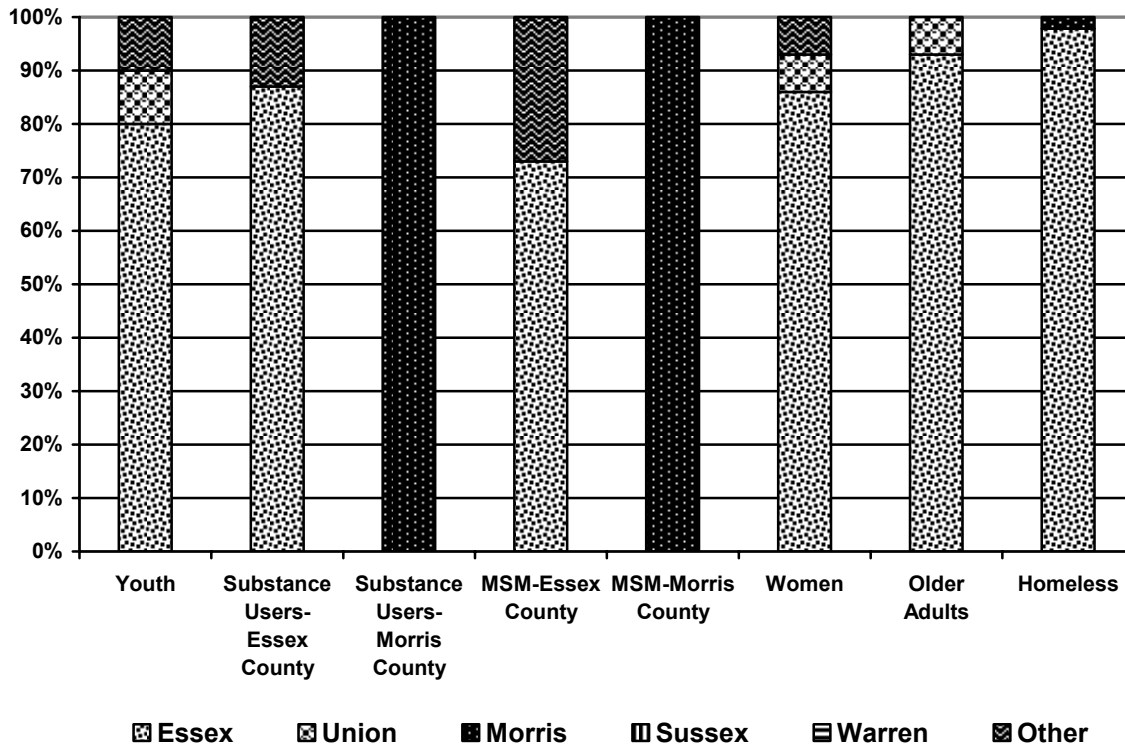
### **Comparison of all Focus Groups**

A total of eight “special population” focus groups were conducted. At the beginning of each focus group session, participants were given a demographic questionnaire to fill out (see Appendix C for questionnaire). The purpose of the demographic questionnaire was to analyze the population sample represented at the focus groups.

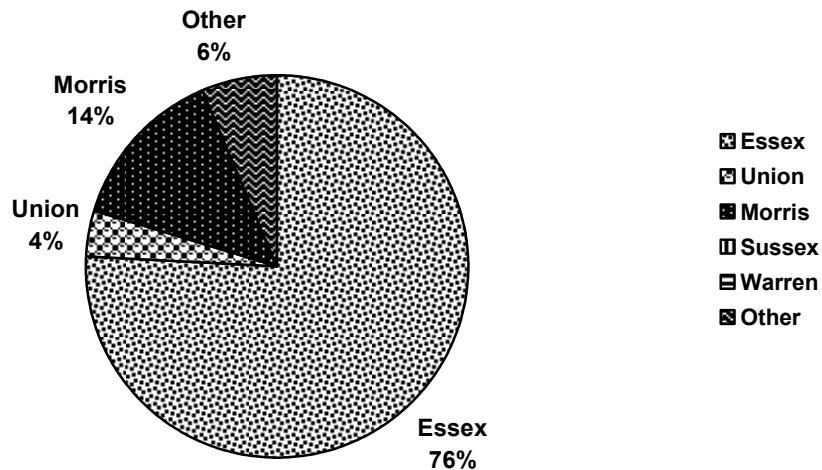
The questions on the questionnaire were divided into four sections: (1) residence, (2) personal information, (3) HIV status and medical care, and (4) employment. The questionnaires varied slightly from group to group as they were tailored to best fit the population being surveyed. For example, questions on child care were added to the Women’s Focus Group, and more detailed questions on the history of substance use were added to the two Substance Use Focus Groups.

The pages which follow compare the demographic data collected in each focus group. Bar graphs are used to compare each question on the questionnaire and pie graphs are used to show cumulative data. There were a total of 108 participants. (Demographic data for each individual focus group is included in Appendix D)

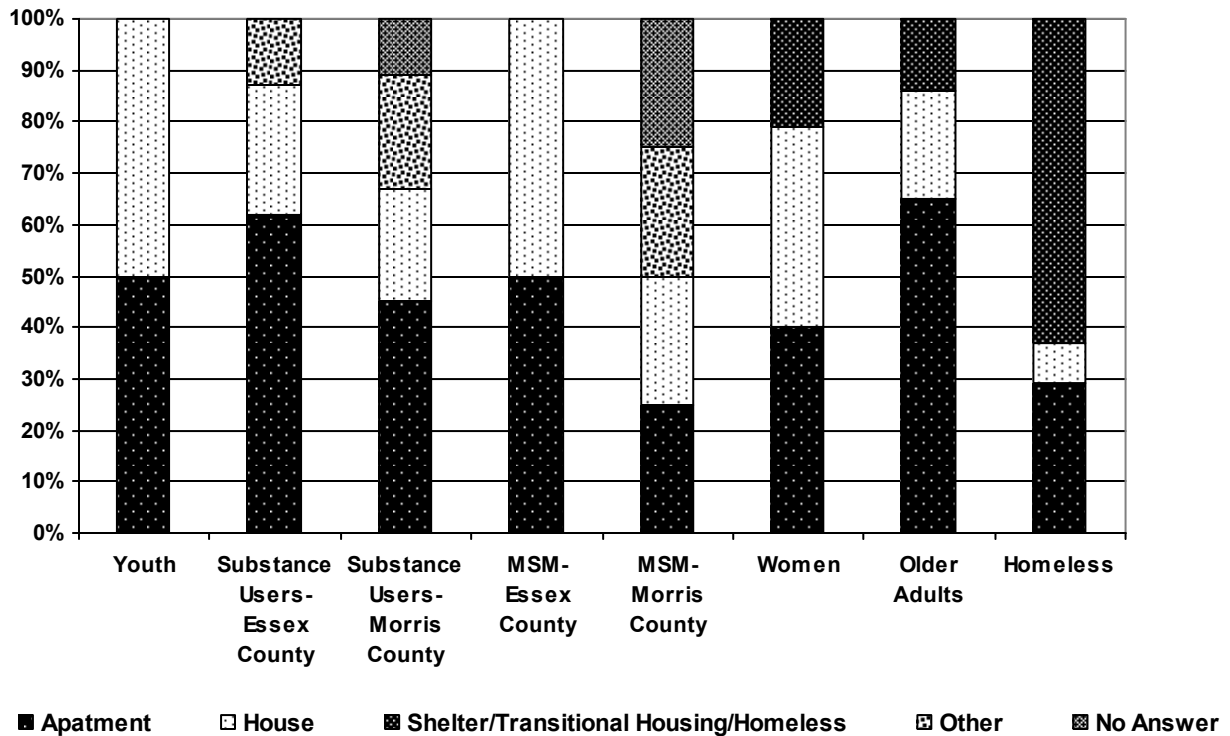
Residence:



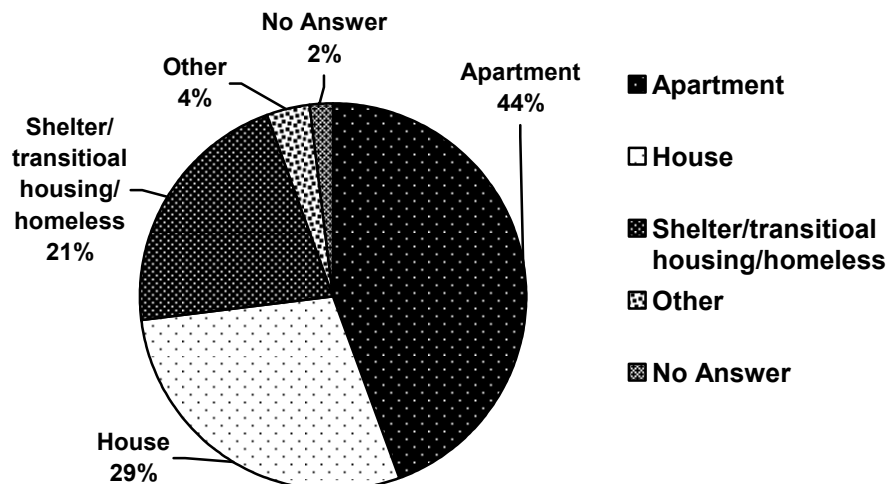
The bar graph above is a side-by-side comparison of the percent distribution of county residence by focus group. Below is a pie-chart which details the County of residence for all focus group participants.



76% of the participants in the 8 focus groups live in Essex County. 4% live in Union County and 14% live in Morris County. The remaining 6% live outside the Newark EMA.

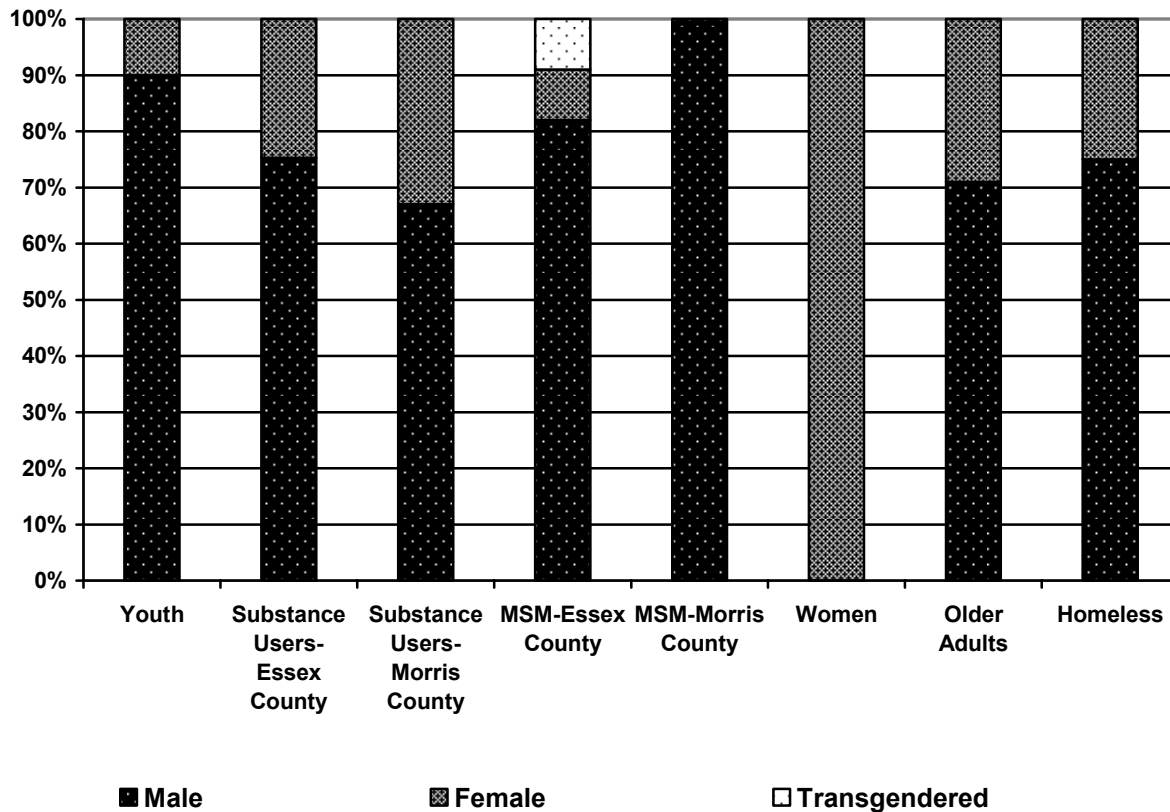


The bar graph above is a side-by-side comparison of the percent distribution of type of residence by focus group. Note that in the MSM focus group in Essex County, participants did not differentiate between apartment and house and therefore a 50-50 distribution is represented. Below is a pie-chart which details the type of residence identified for all focus group participants.

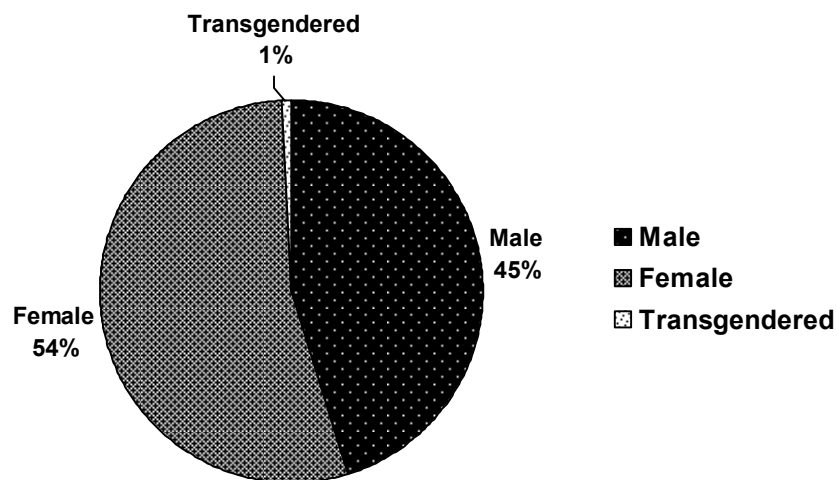


44% of the participants in the 8 focus groups indicated that they live in apartments. 29% indicated that they lived in houses and 21% noted indicated that they live in a shelter/transitional housing, or are homeless. 2% of the participants did not answer the question and 4% marked other.

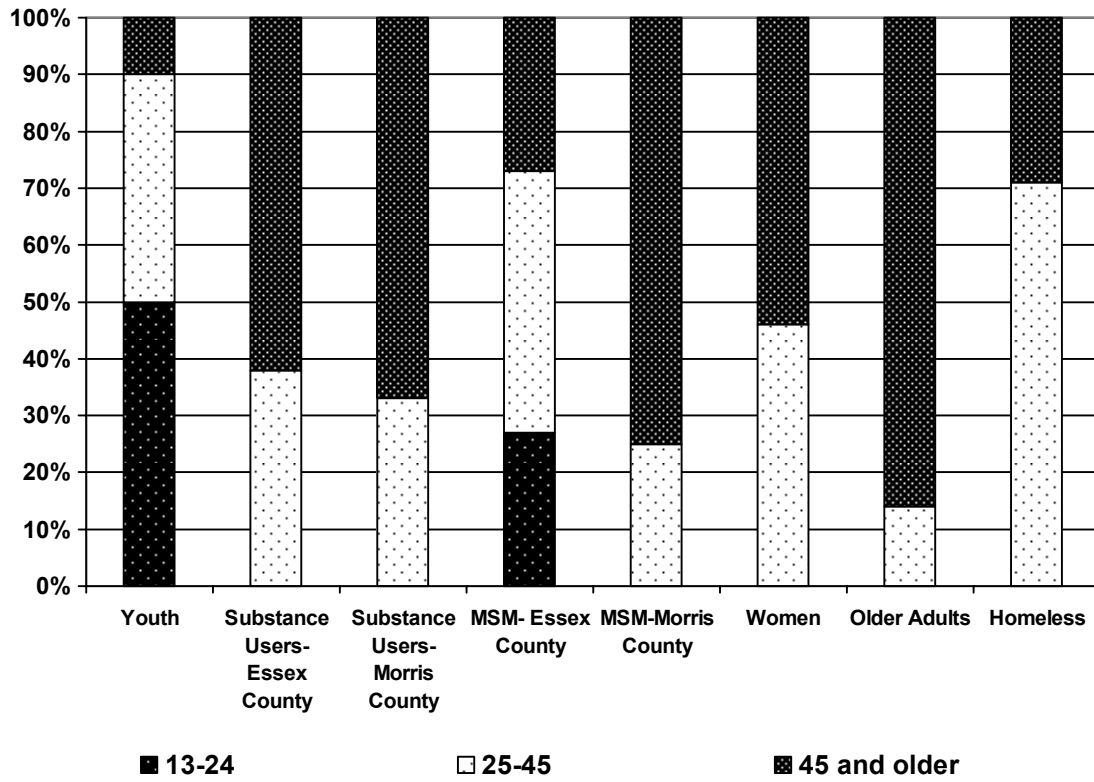
Personal Information:



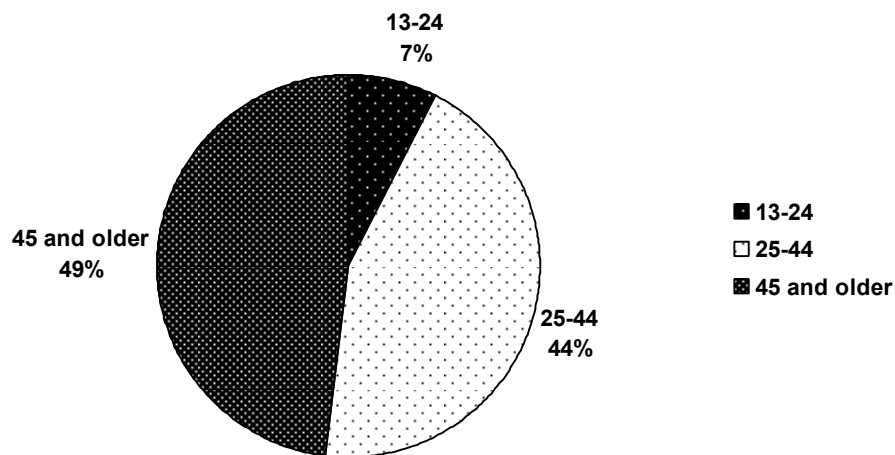
The bar graph above is a side-by-side comparison of the percent distribution of sex/gender by focus group. Below is a pie-chart comparison of sex/gender for all focus group participants.



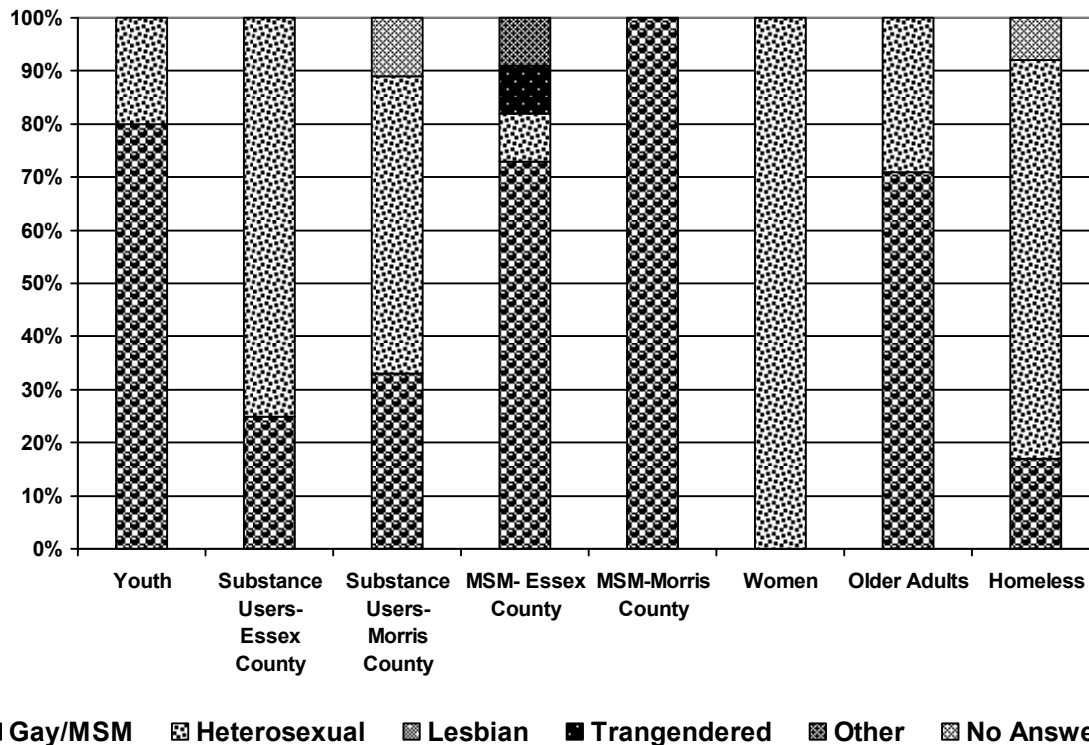
54% of all participants were female and 45% were male. 1% of the participants indicated that they are transgendered.



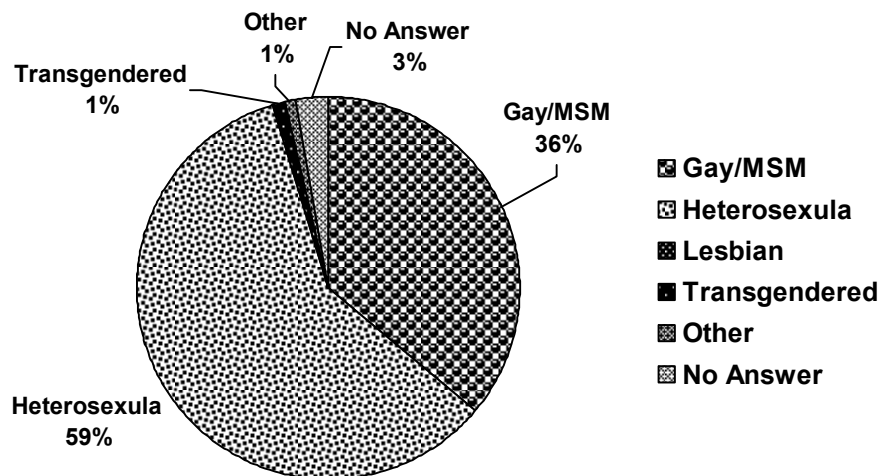
The bar graph above is a side-by-side comparison of the percent distribution of age by focus group. Below is a pie-chart describing age for all focus group participants.



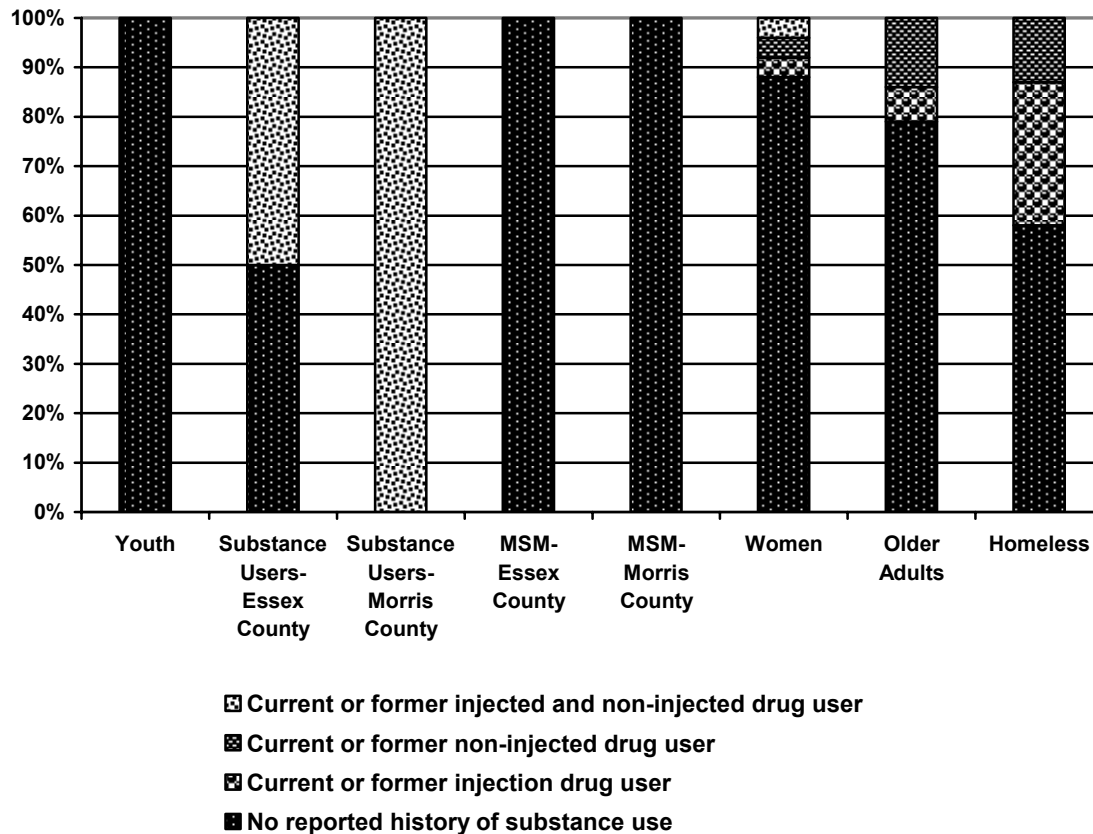
7% of all participants were between the ages of 13 and 24. 49% were between the ages of 25 and 44 and the remaining 44% were 45 and older.



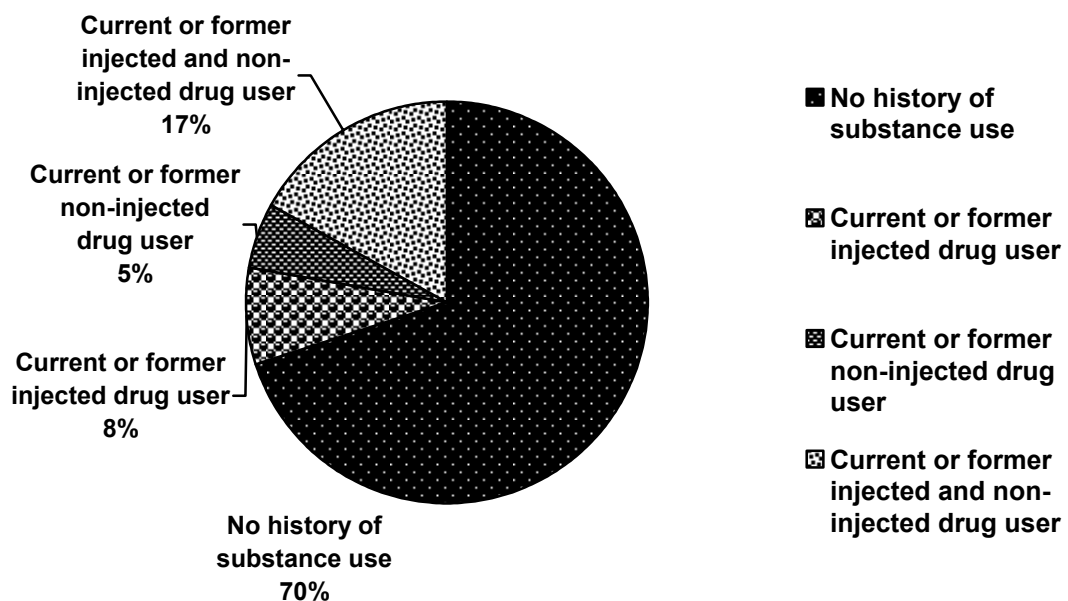
The bar graph above is a side-by-side comparison of the percent distribution of sexual lifestyle by focus group. Below is a pie-chart which describes sexual preferences for all focus group participants.



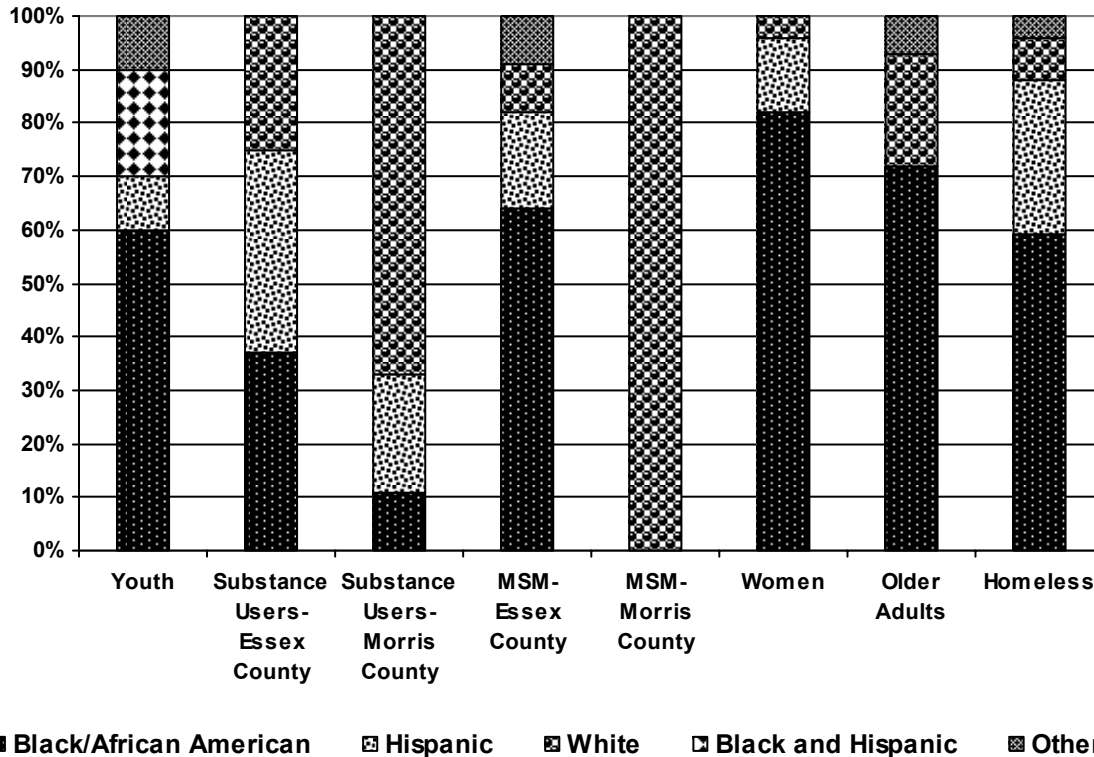
59% of all the focus group participants identified as heterosexual, 36% identified as Gay/MSM and 1% identified as transgendered. Of the remaining 4%, 1% marked other and 3% did not answer the question. No one identified as lesbian.



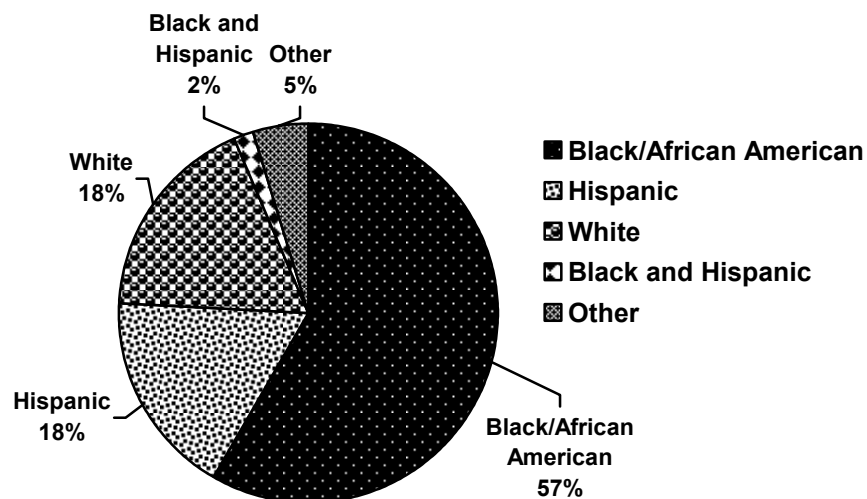
The bar graph above is a side-by-side comparison of the percent distribution of substance use history by focus group. The pie-chart below describes reported substance use history for all focus group participants.



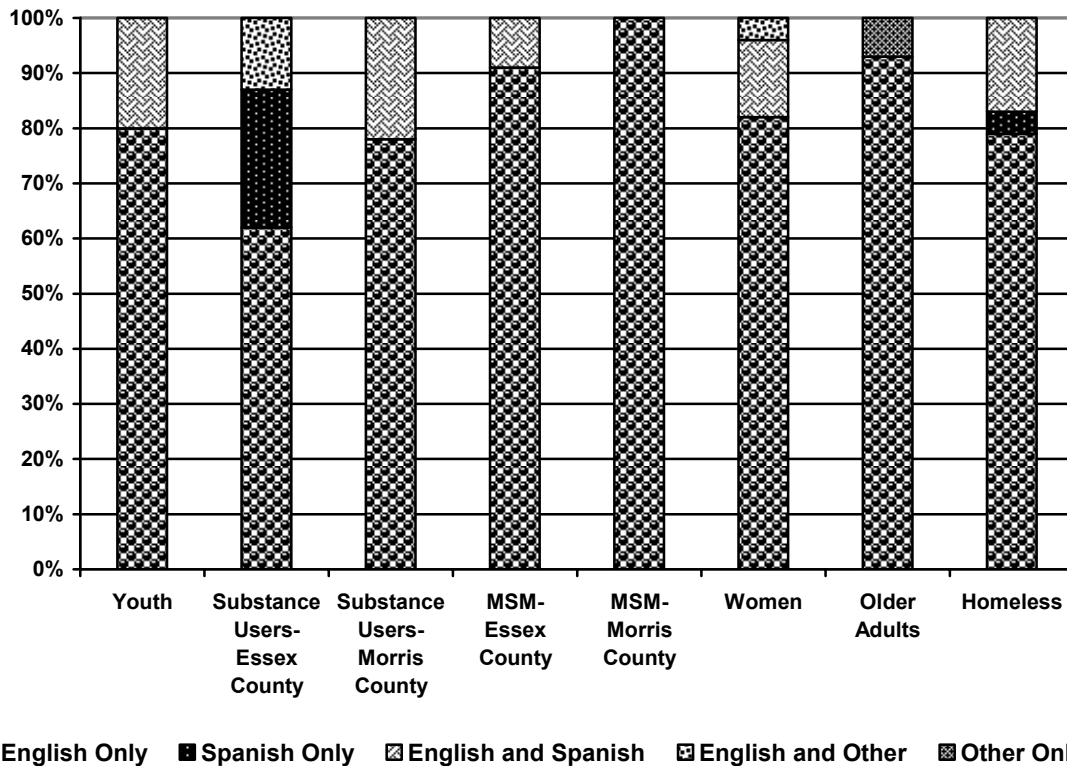
70% of all focus group participants reported no history of substance use. 8% reported current or former injected drug use and 5% reported current or former non-injected drug use. 17% reported current or former injected and non-injected drug use.



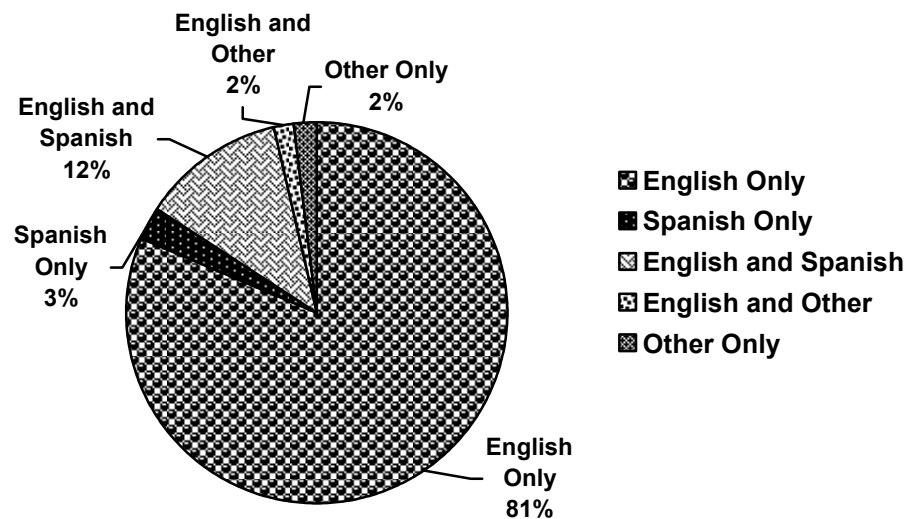
The bar graph above is a side-by-side comparison of the percent distribution of ethnicity/race by focus group. Below is the reported ethnicity/race for all focus group participants.



57% of all focus group participants identified as Black/African American. 18% identified as White and an additional 18% identified as Hispanic. 2% identified as Hispanic and Black. 5% indicated other ethnicities/races including Asian Pacific Islander and Haitian.

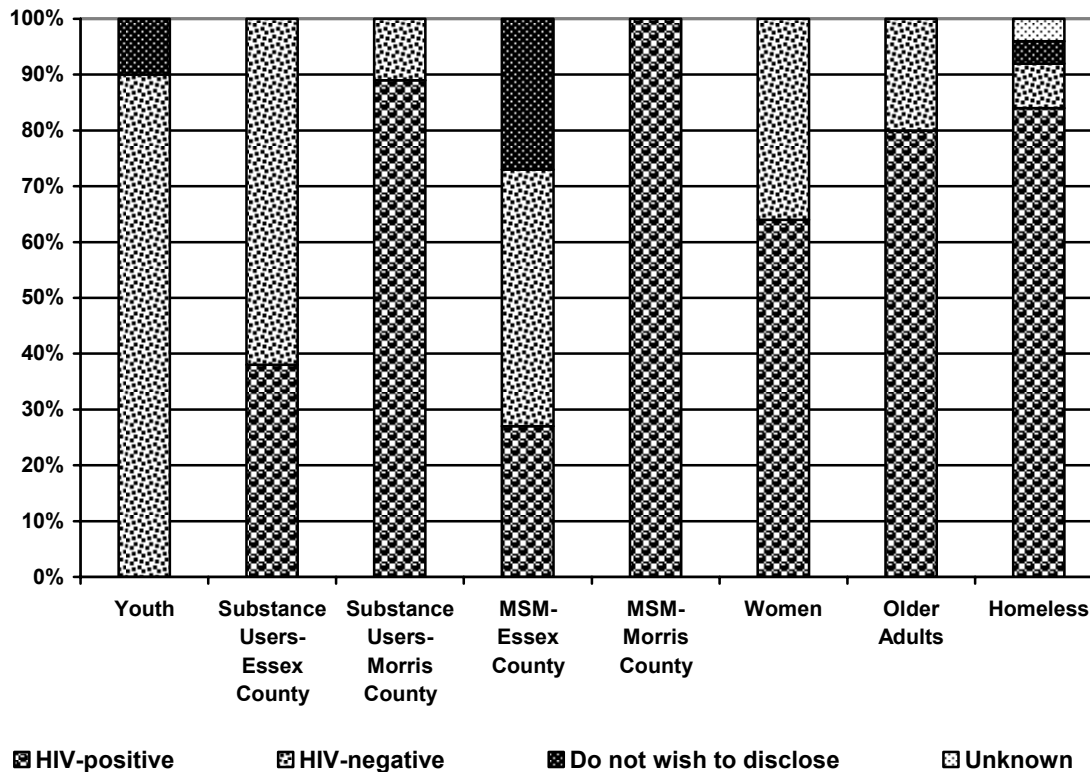


The bar graph above is a side-by-side comparison of the percent distribution of primary language by focus group. Below is the percent distribution of primary language for all focus group participants.

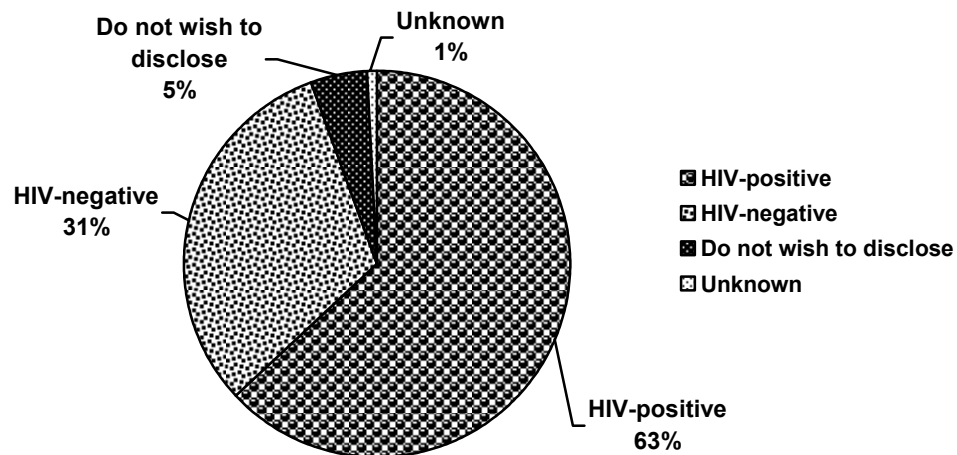


81% of all focus group participants identified English as their primary language and 3% identified Spanish as their primary language. 12% identified English and Spanish as primary languages and 2% identified English and Other as primary languages. 2% identified other as their primary language. "Other" languages include Arabic and Haitian Creole.

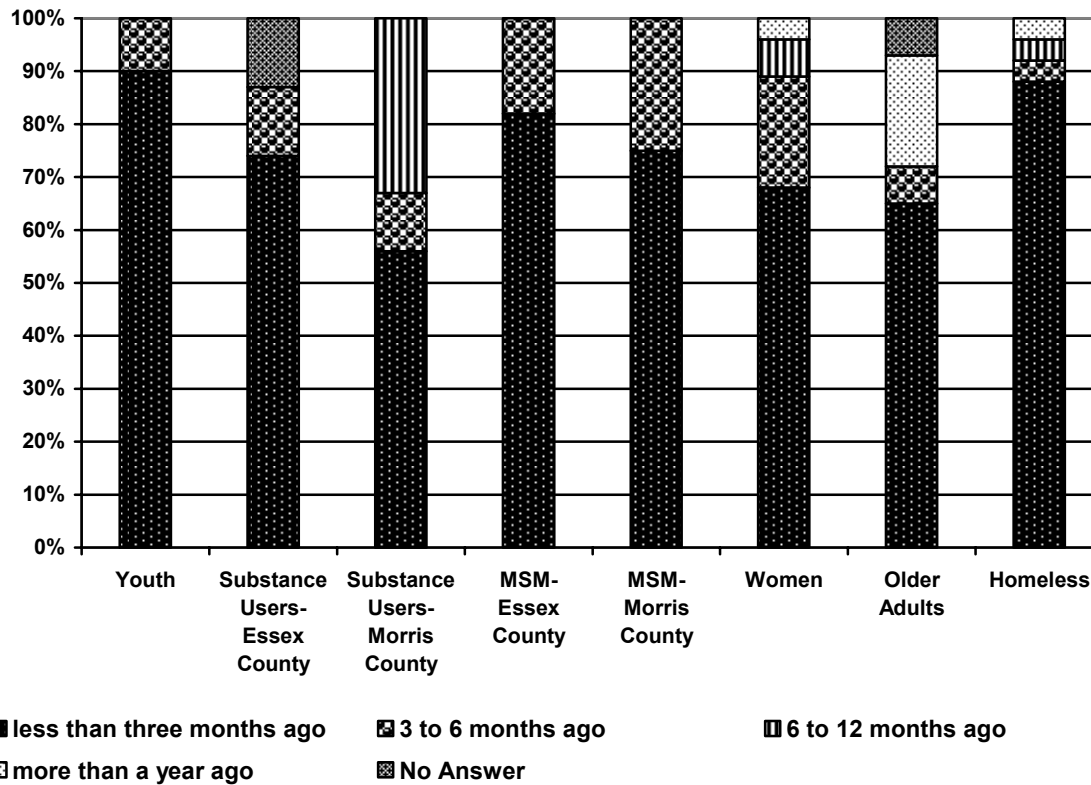
HIV Status and Medical Care:



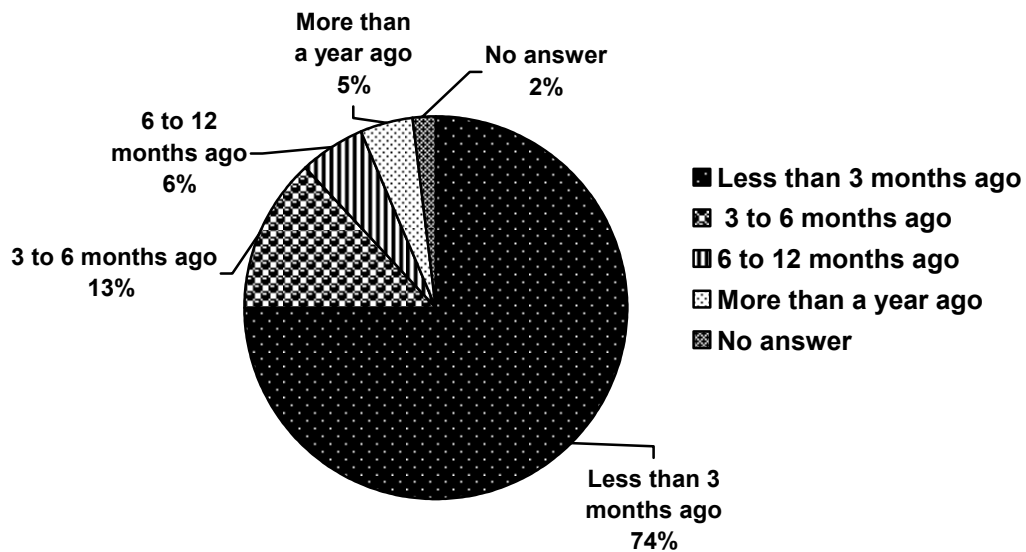
The bar graph above is a side-by-side comparison of the percent distribution of HIV status by focus group. Below is the reported HIV status for all focus group participants.



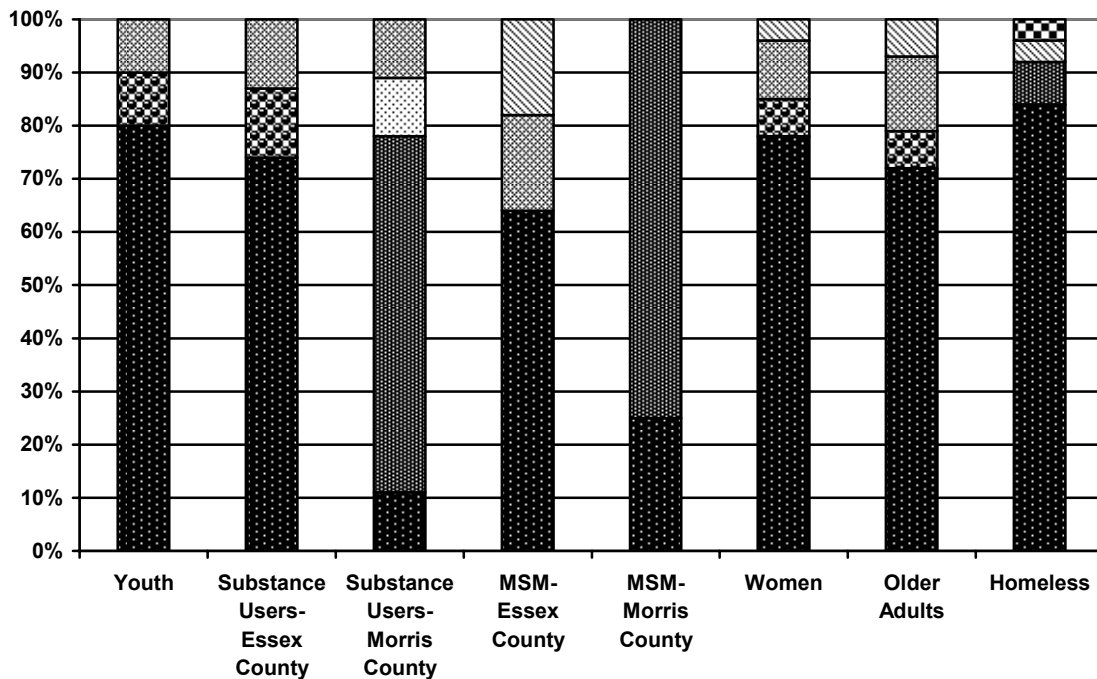
63% of all focus group participants reported that they are HIV-positive and 31% reported that they are HIV-negative. 5% did not wish to disclose their status and 1% did not know their status.



The bar graph above is a side-by-side comparison of the percent distribution of last medical visit by focus group. Below is the response for all focus group participants.

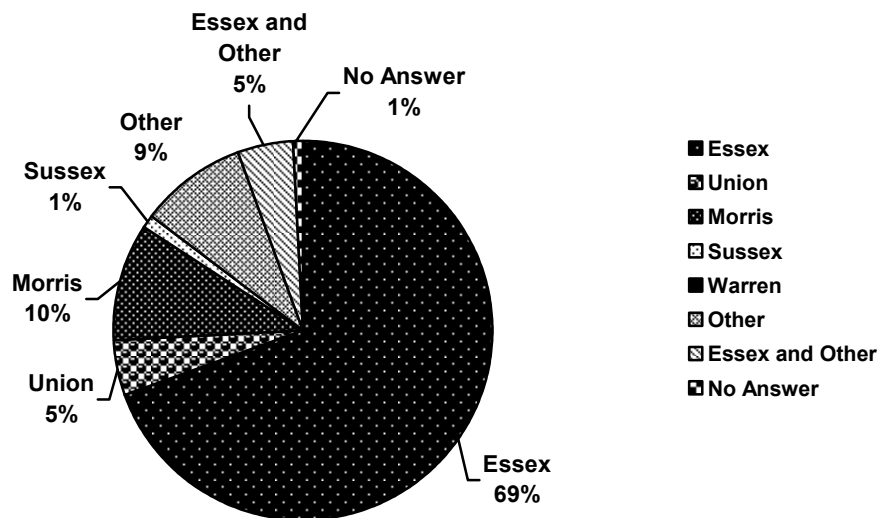


74% of all participants visited their primary care provider less than 3 months ago; 13% visited their primary care provider 3 to 6 months ago and 6% visited their primary care provider 6 to 12 months ago. 5% visited their primary care provider more than a year ago. 2% did not answer the question.



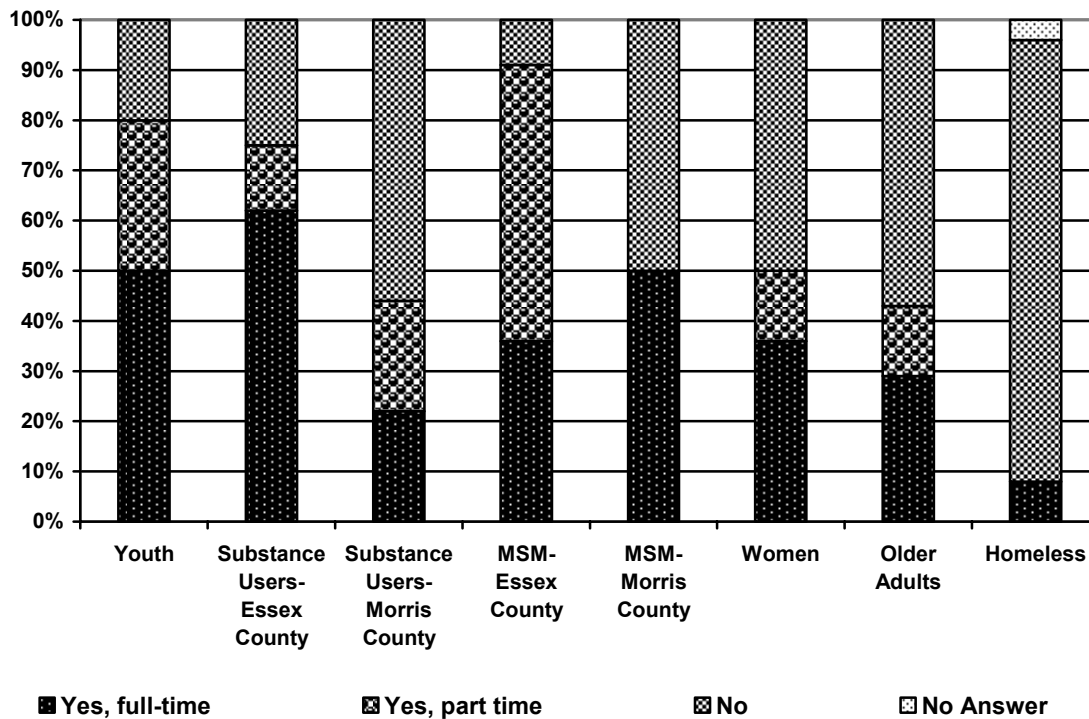
■ Essex ■ Union ■ Morris ■ Sussex ■ Warren ■ Other ■ Essex and Other ■ No Answer

The bar graph above is a side-by-side comparison of the percent distribution of county of medical care by focus group. Below is the distribution of county where medical care is received for all focus group participants.

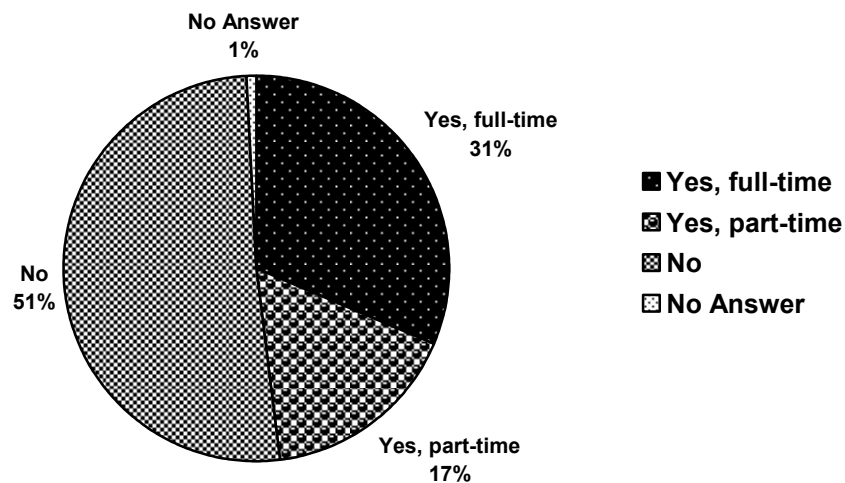


69% of all participants seek medical care in Essex County and 5% seek medical care in Essex and other counties. 10% seek medical care in Morris County, 5% in Union County, and 1% in Sussex County. 9% seek medical care outside the Newark EMA and 1% did not answer the question.

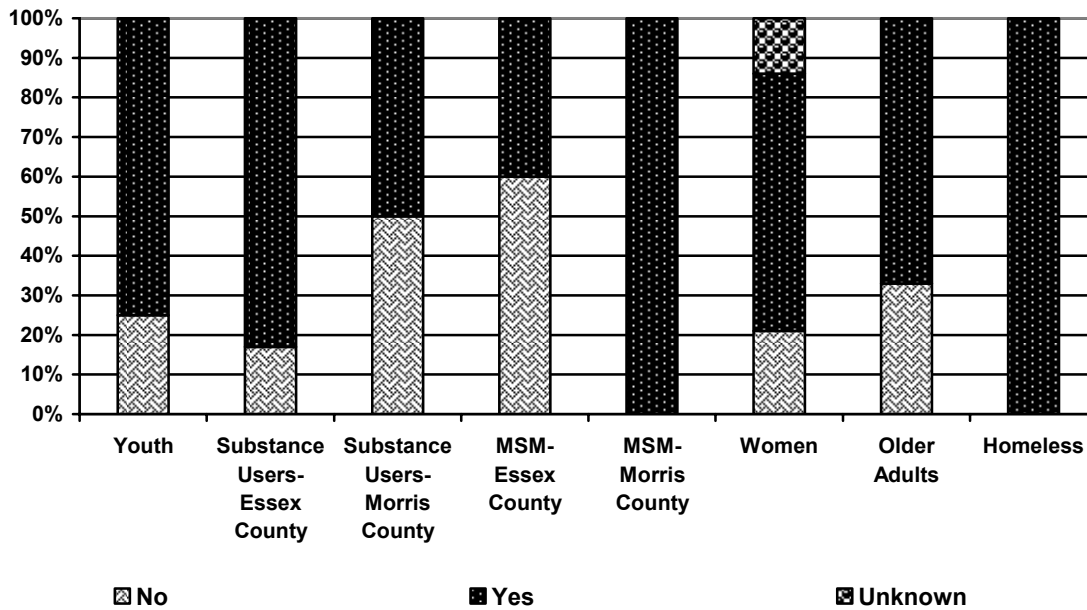
Employment:



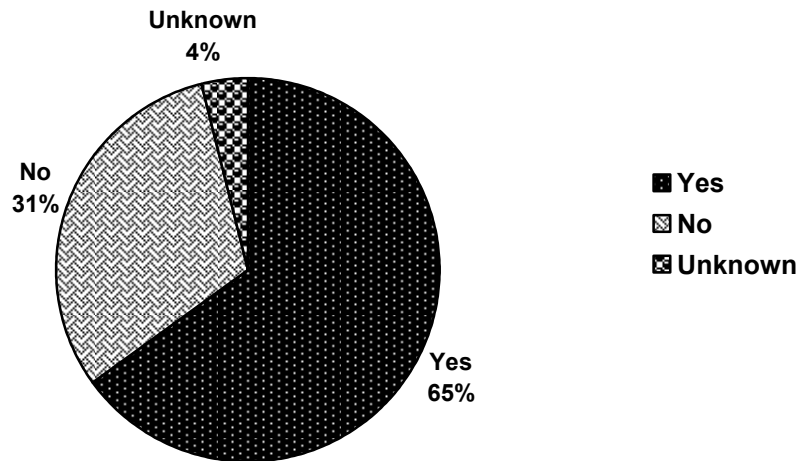
The bar graph above is a side-by-side comparison of the percent distribution of employment by focus group. Below is the distribution of employment for all focus group participants.



48% of all focus group participants are employed. More specifically, 31% are employed full-time and 17% part-time. 51% are not currently employed and 1% did not answer the question.



The bar graph above is a side-by-side comparison of the percent distribution of employment benefits by focus group. This graph only measures those who are employed (N = 49). Below is the response for all focus group participants.



65% of all employed participants reported that they receive health benefits from their employer. 31% reported that they do not receive benefits and 4% did not know if their employer offered benefits.

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## SUMMARY AND ANALYSIS

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### Population with Special Needs #1 Youth (Ages 13-24)

#### Introduction

The Youth Focus Group (ages 13-24) was conducted on April 7, 2004 at North Jersey Community Research Initiative's (**NJCRI**) Project WOW! (Web Outreach Works) in Newark. The purpose of the focus group was to gather information on the HIV care and treatment needs of teenagers and young adults living in the Newark EMA.

There were a total of ten participants in this focus group, which was facilitated by Shonali Choudhury, Planning Council staff. Invitations were sent out to numerous agencies providing medical and non-medical service throughout the Newark EMA as well as to members of the Youth Caucus. Both youth and providers of youth services were present in the focus group.

#### HIV Infection Risk Factors and Risk Groups

Participants noted that drug use is one of the biggest risk factors for this population. They specified that both injecting and non-injecting drugs (including alcohol) were prevalent among teenagers and young adults. Participants commented that the sharing of used needles is common among injecting drug users and people will engage in risky sexual behavior under the influence of these drugs.

Participants identified nightclubs as a risk factor for teenagers and young adults. They noted that in the urban areas there are no curfews and therefore people from other areas come to urban centers to enjoy the nightlife. They commented that this allows the virus to spread from community to community.

Participants commented there are differences between suburban/rural areas and urban regions. They noted that people in the suburban and rural areas have more money and therefore access to more expensive drugs such as Ecstasy and Special K. However, some participants commented that teenagers and young adults from the suburban and rural areas travel to urban centers in search of drugs such as heroin and crack. They noted the use of Ecstasy and Special K is not very common in urban areas but they predict that it will be soon.

Participants identified some differences in risk factors among groups with different cultural orientations, pointing out that West Indian and Latina women are more submissive and therefore less able to negotiate safer sex. Participants stated the men in relationships "own" their female partners.

Participants commented that many girls in their community come from broken homes and are searching for love elsewhere. They noted that these young women equate love with sex and

are willing to practice unsafe sex in order to hold on to their partners. Participants commented that young men do not use condoms because they claim it does not feel natural or that the condoms are too small.

One participant stated young women are at high risk because they are under the impression that they are in a monogamous relationship. The reality is that only the young woman is monogamous, her partner is not.

Participants also identified transgendered and MSM youth as a population at high risk for infection. They noted many of these young men are living on the streets and are frequently taken advantage of by older men.

Participants agreed many young adults and teenagers do not take proper precautions to protect themselves because they have a perceived invincibility and do not believe they need to worry about things such as HIV.

### **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.** Participants described the medical care services available for youth living with HIV/AIDS as poor, mainly because the physicians do not know how to communicate with the clients they serve. They noted the physicians do not explain enough or talk in a language that young adults understand. Medical services at some clinics were described as terrible, and it was noted that many people do not return because clinic staff are condescending and disrespectful.

Participants commented it is difficult for many HIV-positive teenagers to seek medical care if they have not disclosed their status to their parents because they need parental consent for treatment. Moreover, it is difficult for children under age 18 to get tested without parental consent; therefore many teenagers are living with the virus and do not know it. They noted that while the University of Medicine and Dentistry of New Jersey (UMDNJ) provides good medical services for adolescents, many adolescents cannot get connected into the program. Participants applauded support services and prevention programs such as Project WOW! that helps connect people to UMDNJ's medical care program.

**Support Services.** Participants listed mental health, transportation, and legal services as essential to linking youth to primary medical care and maintaining them in care.

It was noted that youth living with HIV/AIDS need a lot of psychosocial support and many are not receiving that support from their families. Mental health services in the form of one-on-one counseling and support groups are important parts of a continuum of care to help them manage their HIV.

Participants commented that transportation services are necessary to help youth physically access medical care and other HIV services. They stated that the number of agencies providing services is insignificant if youth cannot access these services.

The last support service that participants mentioned was legal services. Legal services are necessary for youth under age 18 so that they can better understand their rights in terms of medical decision-making and the process of emancipation (to enable them to provide consent before the age of 18).

**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**

Transportation. Participants identified the lack of dependable transportation as a barrier to care. Participants stated that they are aware of several agencies that offer a range of HIV services but know many people cannot access them because they do not have a mode of transportation.

Lack of education/information. Participants noted most teenagers and young adults are not well informed about HIV and the services available for people living with HIV/AIDS. Some participants stated that many youth are actually misinformed because they “hear too much from the streets.”

One participant noted that it is hard to reach out to youths so that they are better informed. He stated: “Young people do not want to talk about AIDS; they want to talk about partying.”

According to participants, some young adults and teenagers have an apathetic attitude regarding HIV because they are suffering from information burn out. The repetition of health education in schools and community settings results in a mundane attitude towards learning. One participant compared such attitudes to not reacting to hearing gun shots on the streets. Moreover, participants noted that they are tired of being preached to.

Fear/Denial. Participants commented many young people are afraid to get tested for HIV because they fear the repercussions if family and friends know their status. Those who do know their status do not disclose it for fear of being ostracized. Participants also noted many people are in denial of their diagnosis because they do not feel sick and have a perceived invincibility, which leads them to believe they will not get sick.

Stigma and Discrimination. Participants agreed discrimination and the stigma associated with HIV/AIDS still exist. Participants noted many young adults and teenagers do not access services because they are afraid they will be identified as a person with AIDS, particularly if someone recognizes them entering a building that is associated with AIDS.

Participants also noted medical and administrative staff frequently patronize their young clients and treat them in a disrespectful manner. Many people will not return for services after bad experiences.

Hours of operation. Participants noted that the hours of operation of most HIV service agencies is from 9:00 a.m. to 5:00 p.m. and these hours do not correspond to the free time that many teenagers have, since a majority of them are in school.

Lifestyle. Participants noted managing a chronic illness is hard to fit into the active and sometimes chaotic lifestyle of many young adults and teenagers. One participant noted it can be difficult to incorporate a medical regimen that includes complex medications when you are still trying to be a kid.

Legal Barriers. Participants agreed that legal barriers exist for minors (under age 18) living with HIV/AIDS. They noted that there are a limited number of places in New Jersey where someone under age 18 can either get tested for HIV or access medical services without parental consent. They emphasized that a large portion of the HIV-positive youth community in the Newark EMA does not have access to these services. One participant noted that it is particularly difficult for minors who have been kicked out of their house and are now homeless to obtain parental consent. These youngsters are therefore left with no access to medical care for their HIV.

## **Recommendations**

Participants agreed that young people need to be able to access testing and care and treatment services for HIV without parental consent. They also suggested that HIV services should be offered in non-identifiable settings to help remove the stigma and increase participation and retention.

Participants noted that information is essential to helping young adults and teenagers access services. They suggested the development of innovative programs to reach out to HIV-positive young adults and teenagers. Youth should be involved in the development of these programs as they are in tune with the needs and interests of the target population.

One participant suggested implementation of a peer advocate/navigator program. Such programs would link newly diagnosed individuals with people who have more experience living with the virus and managing the system of care.

Participants suggested that HIV service organizations and clinics should alter their hours of operation to accommodate youth who are not available during regular business hours because they are in school or at work. They also noted that best time to outreach to this population is at night. One participant suggested that HIV programs should offer incentives to help attract new clients and to retain existing ones.

One participant suggested the development of an intervention program in which young people visit long-term care facilities for people living with HIV/AIDS. This may increase awareness of the realities of living with the virus.

Participants agreed that youth need role models who encourage them to seek treatment and properly manage their HIV. They also agreed figures such as Magic Johnson do not serve as good role models because he does not represent "the people." To them, he is a rich celebrity and does not reflect the lives of people in their community living with HIV/AIDS. They noted that he can afford his medications and can afford to look healthy. Participants suggested that HIV spokespersons should be people from the community, people who face the same problems as they do, and people they can really look up to.

## **Population with Special Needs #2 - #3**

### **Injection Drug Users (IDUs)**

### **Substance Abusers Other Than IDUs**

### **Substance Users – Essex County**

#### **Introduction**

The Substance Abuse Focus Group in Essex County was one of two groups held for this special needs population. The group was held at the Newark EMA HIV Health Services Planning Council in Newark (Essex County) on April 28, 2004. The purpose of the focus group was to gather information on the care and treatment needs of HIV-positive substance users living throughout the Newark EMA, but especially in the urban areas of Essex and Union Counties.

The focus group, which had a total of eight participants, was facilitated by Gwendolyn Davis, President of Coalition of HOPE and member of the New Jersey HIV Prevention Community Planning Group (NJHPCPG). Invitations were sent out to numerous agencies providing medical and non-medical services throughout the Newark EMA as well as to members of the Substance Abuse Committee. Both consumer and providers were present in the focus group.

#### **HIV Infection Risk Factors and Risk Groups**

Risk factors identified include injected and non-injected substances including alcohol. Participants noted that both injected and non-injected substances put people at high risk for infection. They also commented alcohol use can lead people into engaging in risky sexual behaviors. One participant stated, "Alcohol removes your inhibitions completely, it even places you in dangerous positions when you go for sex." Participants testified that they got infected by sharing needles, and listed the sharing of needles as a significant risk factor. They noted substance users will engage in risky behaviors when they are trying to get high. One participant noted many turn to sex work in order to pay for drugs.

Participants noted risk factors do tend to vary by age, suggesting the youth population seems to think that they are invincible. Participants suggested it is obvious youth are engaging in risky behavior because of the pregnancy rates and increases in HIV-positive diagnoses among them. One participant noted there are children who were born with HIV that are now teenagers experimenting with sex and drugs. It was also mentioned that there is an increase in HIV-positive older adults.

Participants also commented that risk factors also vary by cultural orientation, using the example of many cultures that have strong taboos against the use of condoms, resulting in people not protecting themselves. The group did not discuss any particular risk patterns correlating culture and substance use. Participants noted the major differences in risk factors

between rural, urban, and suburban areas are directly related to the ethnic composition of communities, their level of education, and their income.

According to members of this focus group, there are preconceived notions of the type of person who is a drug addict. They explained that in most people's minds, a substance user is a junkie on the street, but there are also "people in suits" (professionals) who have substance abuse problems. Participants also mentioned those who were formerly incarcerated/ recently released, many of whom are drug addicted and HIV-positive.

### **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.** Participants noted that providers of HIV services tend to have a bad attitude and are not very respectful to their clients. They emphasized that the attitude of the providers worsens when they identify a person as a substance user. One participant stated, "The providers make you feel like they are doing you a favor, you can take it or leave it. A lot of them have bad attitudes especially if you are an IV drug user. They look down on you; they make you feel dirty." Others noted that belittling substance users is so common in society that it is not surprising that physicians and other health care professionals have the same attitude.

One participant noted doctors who are HIV specialists have preconceived notions about the clients they serve. Participants remarked physicians act as if people who are HIV-positive no longer have sex, and sometimes refuse to write a prescription for Viagra.

**Support Services.** Participants commented on the need for more substance abuse treatment programs. In particular, they noted the need for methadone and detox programs.

Participants noted that HIV-positive individuals who are emerging from mental health or substance abuse facilities are not being connected into other services, including medical care, to help them manage their HIV. One participant noted there is a need for better coordination between mental health and substance abuse programs. He maintained that substance use and mental health are intricately connected, but many psychiatrists are reluctant to deal with substance abuse issues. Participants also agreed there is a need for better coordination of substance abuse services and medical care for HIV-positive individuals.

Participants also briefly discussed housing and transportation services, noting they are essential to help connect HIV-positive substance users to medical care. Finally, they noted the importance of having programs to help recently released individuals manage the HIV system of care.

### **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**

Mental Health and Substance Abuse. Participants noted many individuals struggling with mental health issues still currently abusing drugs and are not accessing care. They described

the current substance abuse as a barrier to care. It was pointed out that many people living with HIV/AIDS drop out of care between detox (or other substance abuse treatment programs) and the time in which they start medical care for their HIV.

Transportation. Participants agreed that [lack of] transportation is a major barrier to care. Although many services exist for people living with HIV/AIDS, many people cannot access these services due to the lack of access to reliable transportation. Several participants testified that they have missed scheduled appointments because they had no means to get to them.

Housing. Participants noted the lack of stable and affordable housing is a barrier to medical care, but did not elaborate on how it affects an individual's ability to access medical services.

Medications. Participants listed medications as a barrier to care. They noted that HIV medications have many side effects and some people are not prepared to deal with them. It was also mentioned that medication regimens are very complex and hard to follow. One participant stated, "You forgot to take it [your medication] and now you are afraid to tell the doctor about you not taking the medication because you don't know what he is going to say." Participants agreed that people who are afraid their doctor will reprimand them will drop out of care.

Time and Child Care. Participants noted that balancing work and family life while managing HIV can be very difficult. They commented it is difficult for people to take time off of work to go to a medical appointment. They also remarked that lack of child care is a barrier to care. People, especially women, will drop out of care if they do not have a form of child care. No one in the group testified they had personally dropped out of care because of the lack of child care.

Immigration Status. Participants noted there is a large population of HIV-positive individuals who are undocumented, and the lack of legal status in this country is a barrier to care. One member of this focus group pointed out that many undocumented individuals are afraid they will get caught and deported to their home countries. He explained this fear keeps them out of care.

Lack of education/information. Participants commented that society's lack of knowledge about HIV is a barrier to care. They commented both community members and health care professionals appear ignorant. Everyone needs to be more aware of issues concerning HIV and of the services that are available, in order to make accessing care easier.

Stigma and discrimination. Participants noted the stigma associated with HIV/AIDS still exists, particularly among the Black/African American and Hispanic communities. Moreover, many churches still do not allow open discussions about HIV.

According to members of this group, stigmatization and discrimination are found not only within communities but also in the health care setting. They commented that people who are HIV-positive and substance users have to face the stigmas associated with both. Providers do not respect them and tend to treat them like "low-lives." One participant stated, "Some things like shunning drug users are so embedded in society, it is going to be difficult to change that."

## **Recommendations**

Participants suggested conducting workshops for providers to educate them on how to better address individuals who are current or former substance users. One participant stated, "We need to reeducate the doctors on how to communicate with the substance abuse clients and not look down on them. I know what's going on with my body, so I tell the doctor what I need because he does not know." Others added that each agency should host cultural competency workshops in which the needs of the substance abusing community are discussed.

Participants noted the best way to reach out to the community is in places they already feel comfortable, such as churches. They recommended such institutions should be educated on HIV.

There was general agreement that programs providing substance abuse treatment, mental health services, and medical care need to be better coordinated to manage the needs of addicted HIV-positive individuals. Participants also suggested developing more programs to link the recently released/formerly incarcerated into care.

Participants stated that HIV is not a "9 to 5" disease. They suggested that more services should be available at night. They specifically recommended that medical, support, and outreach services should be available after hours. One participant stated, "Why don't, since there is a church on every corner, the churches stay open one night and make them the basis of operation and you will have food and information to give people."

In light of current cuts in federal and state programs, one participant noted the need for advocacy on behalf of the community. This participant stated, "The community needs to get together and form an advocacy group to protest and write their congressman and fight, or else people are going to be on the street and get sicker, and it's going to get much worse."

## **Population with Special Needs #2 - #3**

### **Injection Drug Users (IDUs)**

### **Substance Abusers Other Than IDUs**

### **Substance Users –**

### **Morris, Sussex and Warren Counties**

#### **Introduction**

On April 14, 2004 the Newark EMA hosted a focus group for substance users in Morris, Sussex and Warren counties. The focus group took place at The AIDS Center at Hope House in Dover during the weekly scheduled Substance Abuse support group for Persons Living with HIV/AIDS. The purpose of the focus group was to identify the care and treatment needs of substance users living in Morris, Sussex and Warren Counties.

The Focus Group was facilitated by Janine Norris, MSW, from the Planning Council staff. A total of nine people participated in the focus group.

#### **HIV Infection Risk Factors and Risk Groups**

Participants noted a major risk factor for substance users in their community is the sharing of dirty needles and cookers. They also noted that addiction to injecting drugs and non-injecting drugs (including alcohol) lower your inhibitions and limits the ability to reason and take proper precautions to protect oneself from HIV infection.

A majority of the participants agreed that risk patterns vary geographically. Within the three counties, residents of Morris County have the easiest access to major urban areas. Participants noted that exchanges with residents of urban areas put Morris County residents at higher risk, since the prevalence of HIV is much more concentrated in big cities. Participants noted certain regions not located near urban areas but with perceived "wealth," such as Sussex and Warren counties, have increased drug use, specifically among the youth population. They noted heroin use, in particular, is on the rise among young people in these areas.

Participants commented that prostitution to obtain money to pay for drugs is not uncommon among substance users in the tri-county region. They stated sex workers put themselves at further risk of infection and put their clients at risk as well.

Participants overwhelmingly agreed risk factors do not vary by education and income level, noting the wealth in the Morris, Sussex and Warren region does not make a difference. They stated the only difference between the tri-county region and urban areas is the number of persons living with the virus. Participants stated that while HIV is not as visible in the tri-county region, it is just as pervasive. However, it may be more hidden.

## **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.** Some participants noted they receive medical care from Morristown Memorial Hospital, and described the care as “great.” Others noted they have sought services at free clinics when they did not have health insurance, and reported receiving good medical care. A few participants noted that when visiting clinics, they have waited long periods of time for appointments, and stated that staff members at the clinics are overworked but described the doctors as “outstanding.”

Participants noted that health insurance helps ensure access to good quality medical care. They discussed the care provided by private physicians versus the care provided at clinics. A majority of the participants were pleased with the care they have received at clinics. One participant noted he sees a private physician, but stated he originally met this physician at a clinic. Participants commented there are long wait times at the clinics, but if one goes to a private physician, the waiting period to see the doctor is relatively short.

Participants were asked to describe their perception of the continuity of care at clinics, specifically the public perception that patients are only seen by residents and frequently are assigned new doctors. Participants commented while this was true in the past, the system has improved. One participant commented that while residents may oversee physical exams, ongoing physicians at the clinic see the patients to manage their medical needs. Another participant commented that when receiving care at a local clinic, they were frequently assigned a different physician and stated that a client has to “start all over again every time.”

One participant commented she has learned the necessity of networking and self advocacy. She commented that many consumers visit a particular medical care site without knowing what the available options are. This participant noted the importance of knowing the staff at primary medical care providers by name, and building a rapport with them to help navigate the system.

Participants agreed the medical services they receive are not culturally and linguistically appropriate. They stated patients are spoken to in a rushed environment, but are never questioned to make sure they comprehend what is being told to them. They noted that many patients will sit quietly and not ask questions, and therefore do not gain any understanding of their medical care. Participants also agreed it is extremely difficult to be a self-advocate if consumers are unable to understand the language of their physician. One participant stated, “providers speak English, but they speak a different version of English.” In sum, physicians do not communicate with their patients in a language they can understand.

**Support Services.** Participants agreed transportation is a vital support service to help connect people living with HIV/AIDS in their community to medical care. They noted while many services may be available, they are useless if people cannot reach them.

Participants agreed that case management is essential to help coordinate the services that HIV-positive consumers depend on. They also discussed the importance of housing services, commenting that having a roof over one’s head helps to keep them in primary medical care.

One participant noted the importance of pharmacies in helping people maintain their medical care.

The importance of all services was noted, and one participant stated that services “work together as a team” to help keep consumers in medical care. Finally, participants agreed that community based organizations are essential to linking consumers to primary medical care services.

### **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**

Insurance. Participants discussed insurance constraints to accessing medical care. One participant noted that even private insurance does not pay for everything. This participant commented he has to pay \$60 each time he visits the doctor, and therefore he requests the maximum amount of refills on his medications to decrease the number of times he is charged for a visit. He stated, “I haven’t gone to the doctor since November because I am still paying off the bills. They sent me a note that said ‘we haven’t seen you.’” Another participant commented that as a result of the cost for his blood work, he has not visited the doctor as frequently as he should. This participant commented his health insurance company refuses to pay for a resistance panel (a lab test to determine resistance to certain antiretroviral medications), which his doctor wants administered every year.

Other participants commented there are significant differences between private insurance and entitlement programs, noting that with private insurance “you pretty much have everything at your disposal.” Participants agreed that with private insurance there is a significantly shorter waiting period to see a physician. One participant commented he has had to leave before seeing his physician, because he waited so long in the waiting room.

Substance use. Participants agreed substance use is a major barrier to accessing medical care. One participant stated, “People are too busy getting high to seek medical care.” Another participant commented the lifestyle which accompanies substance use contributes to many substance users not taking care of their medical needs until they are critical. Participants also noted many substance users are unaware of their HIV status when they are actively using. One participant commented substance use was not a barrier to medical care for everyone. He stated, “I went to the doctor all the time. It was the only normal thing in my life.”

Participants noted the barriers to care do not differ between injecting drug users and non-injecting drug users. One participant stated, “Addiction is addiction. No matter what you are doing, if you are doing it you are not taking care of yourself.”

Transportation. Participants agreed that transportation is a major barrier impacting the ability to access medical care. They remarked that the lack of public transportation in the tri-county region makes it difficult to get to medical appointments and other HIV services.

Medications. Some participants noted when they were diagnosed as HIV-positive; AZT was the only available treatment. They were reluctant to seek treatment because of the horror stories they had heard about the medication.

Some participants agreed that the side effects of the antiretroviral medications have prevented them from visiting the doctor. Others disagreed. One participant stated, "Diarrhea doesn't keep you from getting to the doctor." Participants also noted that people get tired of dealing with the side effects, and as a result many people drop out of care.

Lack of Education/Information. Participants agreed that information should be disseminated to notify people living with HIV/AIDS of the availability of HIV services. Many of them agreed that the lack of information and referrals to medical care upon diagnosis resulted in a reluctance to seek medical care. One participant commented that in 1987, he was sent out the door just after receiving his diagnosis, without any information about connecting to case management or medical care.

Fear and Denial. Participants agreed that fear and denial significantly contribute to an individual's decision to access medical care. One participant stated: "A lot of people have death wishes; I know I did." Another participant commented that although he was diagnosed in 1985, he did not begin medical treatment until 1997. He described his fears of diabetes and other medical conditions as a result of the antiretrovirals. It was not until his CD4 count was below 200 that he made the decision to start medications and engage in primary medical care. Another participant commented that he tested positive in 1986, but did not begin medical care until 1992, noting that it was the same time he entered recovery. He stated, "Before that, I didn't feel I could handle the medical end of it. I told my doctor, if you want to treat me, that's fine, but don't tell me about it. I think there may be other people who are the same way, who can't handle that dose of reality." Lastly, one participant suggested denial is a reason many consumers avoid medical care, because they are not willing to change their lifestyle in order to improve their overall health.

Stigma and discrimination. Participants agreed that discrimination and the stigma associated with HIV still exist. One participant, describing a recent hospital experience, said his food trays were left outside his room, and the nurses did not frequently check on him. He commented that he was treated like he had the plague, his room was not kept clean, and drug paraphernalia surrounded him. Another participant commented that during a recent hospital visit, he did not see the doctors and was not given his HIV medications. Participants relayed stories of their peers, noting they have knowledge of other patients who were hospitalized for five days without receiving their HIV medications.

Most participants agreed they have never experienced discrimination by a primary care physician, but noted they have experienced discrimination when seeing physicians for other procedures and medical concerns who do not regularly treat HIV-positive patients.

One participant has had the same primary care physician for five years, but has only seen this physician twice. When she informed her physician that she was HIV-positive, her physician responded by saying, "Oh my God, I don't have HIV patients." This participant stated, "She gave me a prescription and took care of my cold, and I was out of there really fast. She gave me nine refills at a time; they didn't want to see me."

Participants agreed that stigma impacts access to medical care. They noted that stigma exists in both the health care field and in the community, and agreed that the mode of transmission seems to be more important to people than anything else.

Members noted that coming to an agency is often the first time an individual can say the words "I'm HIV-positive." One participant remarked, "That's my most closely guarded secret, my HIV status. Aside from my family, my sponsor, and maybe a few friends, no one else knows. Maybe I'm a little paranoid, but the last thing I'm going to do is tell people why I need time off from work, or something if I got sick. I'm hoping I'm overreacting, but I fear backlash, that someone will use it against me. So I play it safe. However, if I had cancer or anything else, I'd go to my boss and say 'I need to go see this doctor.'" This participant also commented that he travels to a different region of the state to receive his medical care. Other participants noted that many people refuse to seek treatment for their HIV because they fear that people they know will identify them as a person living with HIV/AIDS.

Participants agreed that the "white coat" image of physicians and the condescending attitudes of health care providers is an intimidating factor in obtaining medical care.

## **Recommendations**

Participants noted the importance of individual advocacy during treatment, recommending more involvement on the part of patients during their medical care. One participant suggested that outreach efforts are not accessing minorities and undocumented consumers.

Participants suggested incentives to motivate consumers to get into medical care. Participants also noted the importance of spreading the word about HIV/AIDS to the community. One participant commented that she recently saw a bus with an ad for AIDS, and commented she was shocked, because she never sees ads like that anymore. She commented, "It's not out there, how is the public going to get used to this if they're not inundated by it. It should be brought to the masses."

Members also discussed concerns about projected cuts in New Jersey's AIDS Drug Distribution Program (ADDP). Many agreed that the provision of ADDP in New Jersey significantly assists people living with HIV/AIDS and work needs to be done to preserve this type of program. One participant commented, "ADDP has saved me, I couldn't do it without that."

One participant suggested legislation that requires HIV testing for certain reasons. Participants expressed concern about the number of HIV-positive people who are not aware of their status. Participants agreed that testing procedures, as well as public ideas about HIV, have to change.

## **Population with Special Needs #4**

### **Men of Color Having Sex with Men (MSM)**

#### **Essex County**

#### **Introduction**

The Men of Color having Sex with Men (MSM) focus group was conducted in Essex County on March 16, 2004 at the Newark EMA HIV Health Services Planning Council offices in Newark. The purpose of the focus group was to gather information on the care and treatment needs of the Gay Men/MSM living throughout the Newark EMA, but especially in the urban areas of Essex and Union counties. The primary focus was MSM of color.

The focus group of 11 participants was facilitated by John Daws, Ph.D. of the Planning Council staff. Invitations were sent out to numerous agencies providing medical and non-medical services throughout the Newark EMA as well as to members of the Gay Men's Ad Hoc Committee. Both consumers and providers were present in the focus group.

#### **HIV Infection Risk Factors and Risk Groups**

Participants stated that condoms are not used consistently in same sex relationships. For example, one participant noted that condoms may be used for anal sex but not during oral sex.

Participants identified several subpopulations within the general category of MSM that are at high risk for HIV infection. Participants noted that they are observing an increase in same-sex sexual activity among young men, coupled with a careless and carefree mindset. Many young men who are engaging in same sex relationships do not identify as MSM or gay, and therefore do not respond to programs or efforts that attempt to educate young gay men. Participants also noted they have been observing an increase in the youth who are transgendered and engaging in unprotected sex.

One participant stated, "It [HIV] is rising among the young population. Between October of last year (2003) and the end of January this year (2004), there were 28 cases with the youngest being 15 years old and the oldest was 21. And that is just the cases that I'm dealing with. And if I'm dealing with that, just think of what is going on out there with the others."

Participants also identified older adults as a significant risk group within MSM. Older men are not as aware of the benefits of using condoms. Participants also noted that seniors are very resistant to being labeled as a risk group for HIV infection.

Participants commented that incarcerated individuals are also an at risk group. Many men are getting infected within prison walls and once released they are spreading the virus.

The final subgroup the participants identified is the men “on the down low” or on the “DL”. Participants commented men on the “DL” are living double lives and are putting themselves and others at high risk for infection. According to participants, the epidemic is spreading because these men are bringing HIV into the home.

Participants did not discuss any major differences in risk factors by ethnicity, culture, income level or education. Participants briefly mentioned that there are more social meeting places in urban areas. Gay men from other areas of the Newark EMA travel to places in Essex County in search of bars and clubs. Participants also noted that people in Essex and Union counties also move around in search of social activity to nearby areas, such as New York City.

### **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.** Participants noted there is a lack of respect for clients in medical care settings and this lack of respect starts at the front door. A participant stated that if the receptionist is not respectful, it is doubtful that the client will return for services. One participant stated he was “tired of people discussing him as if he were a piece of meat.”

A plurality of the participants reported they have private insurance to pay for medical care. Participants agreed the quality of care that one receives depends on the type of insurance one has. Participants commented they are treated more humanely and with more respect when the provider knows the patient has private insurance instead of Charity Care, Medicaid, or is considered a “clinic patient.” Participants agreed that private insurance is the best way to navigate the system and it helps maintain people in medical care.

One participant commented on the different treatment that insured patients and clinic patients receive. He stated: “From a personal experience, I was in St. Michael’s and every day a different doctor would come in and no one would explain anything to me and one doctor even said that I was a clinic patient. I had to correct him and tell him that I had commercial insurance. From that point on they started to explain things to me and treat me like a human being.”

Participants noted that health care professionals appear to have preconceived notions of the population they serve and frequently stigmatize the clients. Clients frequently do not understand their treatment, and it was noted that it is the health care provider’s responsibility to make sure every patient understands. One participant attested that some agencies have staff members who are dedicated to communicating with clients and ensuring that they understand the information the physician relayed to them. Participants noted that miscommunication between client and health care provider causes people to drop out of care.

One participant recalled: “I was in the hospital for four months with encephalitis, CMV (cytomegalovirus), PCP (pneumocystis carinii pneumonia) and something to do with my lungs. I just got tired of people coming in, sticking me, and not saying anything to me. There were teams of people at the foot of my bed discussing me and not saying anything to me, so one day I said, ‘Wait a minute, is somebody going to tell me something?’”

Participants noted it is important for clients to educate themselves about HIV and the services available to them, so they are able to advocate for themselves and be a participatory member in the management of HIV. One participant stated: "There seems to be two sets of problems, one is that the doctors are too busy to explain and take the time with the patient; the other is that sometimes the clients don't care." Other participants agreed and one responded, "Until I started asking, I was never getting any information."

Overall, participants focused on the relationship between the health care provider and the client and how that relationship determines the client's perception of the quality of care. Participants agreed that although some people have positive experiences, there is room for improvement.

**Support Services.** Participants noted that housing and nutritional services are necessary to help stabilize some people living with HIV/AIDS and prepare them to be ready to access medical care. They also cited transportation services as important to help people access other services. Participants commented that there is no free transportation in Essex County. Finally, participants noted the importance of having programs to help recently released individuals manage the HIV system of care.

### **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**

Insurance. Participants agreed that the lack of adequate insurance is a barrier to care. They noted that the benefits from welfare, Social Security and Charity Care are limited. Participants agreed that patients who have private insurance receive better care. According to participants, not having insurance is one of the main reasons why some people are not in care.

One participant commented that many people with private insurance are hesitant to use it because they fear their employers will be informed of their diagnoses. Participants also noted that clients with private insurance are given priority over those who do not have it.

One participant stated: "If you have to go for a CAT-scan or something else, if you have insurance you will get the procedure done in no time, whereas if you don't, you might have to wait months."

Transportation. Participants agreed that transportation is a barrier to accessing medical care. Participants noted that many services exist for people living with HIV/AIDS but that many people still cannot access them because they do not have the means to get to their appointments. They noted that public transportation is relatively easy to access in urban areas, but this is not true for suburban and rural regions.

Participants noted that some agencies in Essex County offer their clients bus tickets to help them attend their appointments. Participants testified however that many people will take these bus tickets and use them for other purposes. It was noted that people prioritize the use of the bus cards. For example, if it is a choice between going to get food and going to a medical appointment, food will win.

Housing. Participants noted that a lack of stable housing is a barrier to medical care for people living with HIV/AIDS. They noted there is a lack of affordable housing and that landlords associated with AIDS programs such as HOPWA can be discriminatory.

Lack of Education/Information. Participants noted there are too many people living with HIV/AIDS who are not well informed about the virus and available services and resources. They explained that this lack of knowledge serves as a barrier, because uninformed clients are unable to advocate for themselves and eventually get frustrated with the providers and drop out of care. It was also noted that some people do not access HIV services because they are not aware of what is available.

Fear and Denial Participants agreed that a major barrier to accessing medical care and other HIV services is fear. People are afraid their lives will change negatively if people know their status. Participants noted that HIV-positive individuals do not access services for HIV because they are afraid people will know their status and they will lose their jobs.

Stigma and Discrimination. Participants agreed discrimination and the stigma associated with HIV/AIDS still exist. They referred to people having preconceived notions about who is at risk and the way in which people get infected. One participant stated "Stigma is still prevalent. If you are gay and you get it, that's O.K. But if you are straight and you get it, it means that you weren't really straight."

Participants commented that many individuals do not access services because they are afraid of being identified as HIV-positive and fear the discrimination that follows that label. For example, participants stated that some HIV-positive individuals refuse to access service at certain agencies because the building is associated with AIDS. Participants noted that people will do whatever it takes, such as seeking services out of state, to avoid being identified as "having AIDS" by others in their community.

Instability. Participants stated that life changes after an HIV diagnosis. People are at risk of losing their jobs and their homes. The loss of a job and/or home causes many people to need assistance with food. Many people react to the diagnosis with depression and anxiety. This instability in their lives makes it difficult for them to access services. According to participants, many of these issues need to be addressed first.

## **Recommendations**

One participant suggested that more Internet based discussion forums would help HIV-positive individuals by allowing them to share their experiences with others. These forums or chat rooms can help educate and empower people. People can learn the basics of HIV and about the different programs in their area.

Participants agreed there is a need for more outreach programs directed toward teenagers and young adults, especially those who are experimenting with their sexuality. Some participants also suggested outreach programs should also be developed for the senior population. All outreach programs should be developed in a way that they reach out to their target audience in an environment in which they are comfortable.

Participants expressed concern that people in the community are not aware of the programs and services that are available to them. They suggested that programs be set up to educate high-risk groups. One participant expressed a particular concern with the young transgendered community because “they think they are invincible.”

In terms of provider-client communication, one participant suggested that agencies should have staff that are solely responsible for helping patients understand the information that has been conveyed to them by the medical professionals.

Participants noted there is a need for improvement in housing services. One participant noted that no one is addressing the needs of homeless youth. He suggested a program that can offer youth a stable housing option that is not a group home can help stabilize their lives and prepare them to access medical care. Another participant agreed and added that if we provide youth with housing assistance, they will not work on the streets.

One participant suggested that people should be connected with agencies and programs in the two weeks between the test and the results. He noted that if the result is negative, people are still engaging in risky behavior and may test positive later. He noted it is good to make the connections as early as possible to prevent people from falling through the cracks once they receive a positive diagnosis.

Another participant suggested there is a need for ongoing workshops to help empower HIV-positive individuals. He noted that life changes after you are diagnosed, and these workshops could help highlight the positive aspects in the lives of people living with HIV/AIDS.

## **Population with Special Needs # 5**

### **White/Anglo Men Having Sex with Men (MSM)**

#### **Morris County**

##### **Introduction**

The White/Anglo Men Having Sex with Men (MSM) focus group was held in Morris County at the AIDS Center at Hope House in Dover on April 7, 2004. The purpose of the focus group was to gather information on the care and treatment needs of Gay Men/MSM living in the counties of Morris, Sussex, and Warren.

The focus group of four participants was facilitated by Shonali Choudhury of the Planning Council staff. This focus group was conducted during a regularly scheduled support group session for HIV-positive Gay Men/MSM. The regular support group facilitator was present but did not participate.

##### **HIV Infection Risk Factors and Risk Groups**

Participants noted that they believe that there are fewer cases of HIV/AIDS among MSM in Morris, Sussex, and Warren counties in comparison to more urban areas, such as Essex County. They believe the reason for this is that there are fewer meeting places in this region. Participants described bars and other meeting places as locations to engage in promiscuous and unsafe sexual behavior. One participant noted: "I think it is a suburban phenomenon, not having contacts or a place that you can meet. Morris County has a couple of places you can meet. I don't think Sussex or Warren have a place."

Participants listed a number of places where MSM tend to meet, ranging from areas such as Boonton (Morris County), Paramus (Bergen County), and New Brunswick (Middlesex County). Participants even noted that Gay Men/MSM living in Morris, Sussex, and Warren counties travel to New York City and parts of Pennsylvania in search of good "hang-outs." All the participants agreed that the "action" occurs in urban centers.

Participants noted that risk factors vary by age within Gay Men/MSM. Some commented that the younger men are looking for fun and one-night-stands, whereas older men are looking for something more stable. Not all participants agreed with this, however. One participant noted that engaging in risky behavior was not correlated with age but rather with a person's tendency to have a steady partner. Participants did agree that younger men tend to have an invincibility complex and are therefore more careless in their sexual relationships. One participant stated: "Young people think if I do get it [HIV] I can take these pills and I will be fine."

When prompted to speak about whether risk factors vary by ethnic group, the participants tended to agree that the differences among groups of people were more related to language barriers and differences in levels of education rather than their actual ethnicity or race. It was

noted that risky behavior is closely tied with the availability of information. For example, an ethnic group whose primary language is not English has less access to information on risk reduction as well as basic HIV/AIDS information. This barrier affects people who are at risk for infection and those who are HIV-positive.

### **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.** Participants noted that medical services for people living with HIV/AIDS have improved over time. One participant noted he was diagnosed in 1992. At the time there were only three doctors treating HIV/AIDS in Morris County and today there are many more. Participants agreed they were very satisfied with the HIV medical they receive, but also noted that they have a private doctor and do not use the clinics. However, they commented that they know that continuity of care is a major problem for people who get their care in clinic setting. Participants emphasized that continuity is essential for people living with HIV/AIDS and especially for those who are dealing with co-morbidities.

One participant noted, "I have a specialist in primary care and we coordinate my care on a regular basis and I am very happy. People in Eric Johnson House have other complicating problems, like liver problems, and they need someone who will stay on top of medical issues."

Another participant noted he utilizes clinic services in Morristown by choice because he has developed a relationship with the attending physician and the nurse practitioner. He stated that he advocates for himself and knows how to get what he needs. He is satisfied with his medical care, but can understand how frustrating it can be for people who do not have the same connections he has and are unable to advocate for themselves.

Participants emphasized that it is essential to communicate with your primary care provider and to find a physician you are comfortable with. They noted that they try to educate themselves on new therapies and developments and sometimes they even educate their care providers. Most participants agreed that they did not mind educating their physicians because they were part of a negotiation. One participant stated: "I am gay; I want to be treated by a gay doctor. They understand more and will be more sympathetic. I was lucky to find the doctor I have because he put an ad in a gay newspaper that they hand out at clubs. I kind of educate him. He doesn't specialize in HIV; he has learned lots from me. I tell him about these drugs that I read about and he looks into them."

The participants used either a combination of Medicare and Medicaid or private insurance with some out-of-pocket money to supplement. They noted that the best way to ensure getting quality medical care is to get private insurance through a job. Without these benefits, people are forced either to pay large amounts of money out of pocket or to go to clinics where there is no continuity of care.

Overall, the focus group participants were satisfied with their HIV medical care. However, they emphasized that their responses reflected their own personal experiences, and they know that not everyone who lives in Morris, Sussex, or Warren counties has the same experience.

**Support Services.** Participants noted one of the most important support services is case management. One participant stated: "Case management is important because they can pull all that together for the individual, especially in the first year or so while the person is trying to get their lives back."

Participants agreed that mental health services are also very important to help a person manage their HIV. They mentioned that mental health services can be executed in many different ways such as support groups and one-one-one counseling.

Participants noted they tend to use mental health related services, but rarely use others, such as housing assistance. However, one participant noted he visited a nutritionist when he was first diagnosed. Participants commented that not all gay men are ready to access services such as support groups because they have other needs they feel need to be met first.

He stated: "I think that there is a population of gay men at Hope House who do not come to this group and who need other services more. I know quite a few who come to this group from time to time but don't stay in the group, and I don't know what the underlying cause is. It just seems that the men who are gay and have very basic problems like housing, transportation and medical services don't come and participate." It was also noted that some men may not feel comfortable accessing support groups because of cultural and linguistic differences.

All participants agreed that the support services offered at Hope House in Dover were of good quality and were very beneficial to them. They noted that if you have access to transportation, Hope House is not very far from most places in Morris County. Participants credited some of the success of the support services they utilize to a good client-staff ratio.

### **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**

Insurance. Participants stated a lack of insurance can deter people from accessing care. Medical treatment at the clinics can be very frustrating with long waits and a lack of continuity by health care professionals who treat individuals. They also stated a lack of insurance can lead to increased stress, which does not help the already fragile emotional state experienced by many HIV-positive individuals. This relative instability makes it hard for people to access medical for their HIV.

Transportation. Morris, Sussex, and Warren counties are very spread out and one needs a dependable source of transportation to access the services that are available. Participants stated they know of people who stopped accessing services at Hope House because they lived too far away and no longer had access to a car. Members emphasized that services such as case management and mental health services are very important for HIV-positive individuals, but these services are useless if clients cannot access them due to a lack of transportation.

Housing. Participants noted that a lack of stable housing is a barrier to medical care for people living with HIV/AIDS. This is especially a problem in Morris County where housing is very expensive.

Medications. Participants stated that HIV medications have side effects. As one participant stated, "people really very often get tired of taking the meds and what it is doing to their bodies. They will go off their meds maybe with their doctors agreeing or not." Participants agreed that people get tired of their treatment regimen and this can cause people to drop out of care.

Cultural Barriers. Participants stated they have observed an ethnic gap in the people who access medical and nonmedical services. They attributed this gap to several factors. First, the services may not be culturally appropriate, and groups such as African Americans and Hispanics may not feel comfortable in the settings in which the services are offered. In addition, the services may not be offered in their language, and therefore they are unable to communicate with the service providers. Finally, some participants feel that this gap may be due to differences in levels of education between different ethnic groups.

Lack of Education/Information. Participants noted they feel that too many people living with HIV/AIDS are not well informed about the virus and the services that are available. This lack of information can lead to distrust of medical establishments and of medications.

Fear and Denial. Participants agreed that denial is a major barrier to accessing medical care for HIV. Many people who are HIV-positive have not been able to accept their diagnosis, or feel it is easier not to deal with it. Participants believe this attitude is more prevalent among young men. Other emotional reactions to living with HIV/AIDS, such as depression and anxiety, can also serve as barriers to accessing care.

Stigma and Discrimination. Participants agreed the stigma associated with HIV/AIDS still exists. Stigma is found among medical professionals and in the community. One participant noted that he feels that the stigma is strongest among teenagers. Youth are afraid to get tested and to seek treatment for HIV.

When prompted to speak about whether people refuse to enter a particular building because it is associated with HIV/AIDS, one participant stated, "I had an experience in Sussex County. At one point in time we were right on the main street in Newton and we were the only service available within this particular office. When people walked in off the street into that building people immediately knew that they were going into the AIDS office. We eventually moved to a building containing a lot of other businesses, and clients felt more comfortable coming into that building."

Other participants noted that some people are afraid to go to infectious disease clinics because they feel that they will run in to someone they know. However, one participant figured that anyone he would meet was there for the same reason and therefore he did not let it bother him. He mentioned it takes time to reach a level of comfort.

One participant gave an account of discrimination at the pharmacy. He stated: "I was encountering discrimination in the beginning at the pharmacy because they didn't have my medication on stock, but they had every heart medication on stock. Why did I have to wait? One time I had to wait five days. It is less now, maybe because there are more people on meds. I've also changed pharmacies."

## **Recommendations**

One participant suggested there should be websites or Internet chat rooms where gay men interact and talk to people who have HIV. This can promote an interchange on medications and treatments, and the emotional issues that accompany HIV. The participant stated that he has yet to find a chat room in which the first question is not *what do you look like naked*.

Participants recommended that programs need to help people with legal issues concerning HIV, such as eligibility for disability. People need to be better prepared for when they are not healthy.

One participant noted it is important for programs to address the client as a whole. Many HIV-positive individuals must address mental health issues and substance abuse problems before they are ready to start medically managing their HIV.

Participants noted the need for more educational programs for people living with HIV/AIDS. Such programs would encourage people to advocate for themselves and be better prepared to utilize the services that are available. One participant stated that educational material should be printed in regular magazines and not just medical ones. This would allow the information to reach a wider population, and help people learn about HIV and about all the services in the area. Other members suggested that venues such as schools and churches should also be used to pass information along. The education of people living with HIV/AIDS, the community, and health care professionals will help reduce stigmatization and discrimination

## **Population with Special Needs #6**

### **Women of Childbearing Age (Age 13-44)**

#### **Introduction**

The Women's Focus Group was held on April 22, 2004 at the Planning Council Office in Newark. The purpose of the focus group was to gather information on the HIV care and treatment needs of women living in the Newark EMA.

The focus group of 28 participants was facilitated by Janine Norris, MSW, of the Planning Council staff. Invitations were sent out to numerous agencies providing medical and non-medical services throughout the Newark EMA. Members of the Women's Ad Hoc Committee also assisted in the recruitment of participants. Both consumers and providers were present in the focus group.

#### **HIV Infection Risk Factors and Risk Groups**

Participants agreed that a major risk factor for women is men on the "down low." They noted that many women are not aware that their husbands or partners are involved in sexual relationships with other men. When these men are engaging in same sex relationships, they do not use protection and therefore bring infections such as HIV to the home. Participants also noted that women do not have enough power in their sexual relationships to demand the use of a condom. One participant stated, "Married women are afraid to tell their cheating husbands to use condoms, because if they do, the husbands will think that they (the wives) are cheating." Participants noted the situation is even worse in abusive relationships.

Participants commented that young women are at high risk for HIV infection. One participant noted that teenage girls are engaging in anal sex with their male partners without the use of protection. Anal sex was a common practice because it preserves virginity and pregnancy is not possible. It was also pointed out that older men take advantage of younger women, placing them at high risk. Participants noted that teenagers are misinformed on how sexually transmitted diseases (STDs) and HIV are spread. One participant stated: "Kids will not kiss because they think they can catch HIV, but they will go down on someone."

Focus group members suggested the attitudes of young people also place them at high risk. They described two types of young adults. Some young adults have an invincibility complex and believe that things such as HIV will not affect them or, if they do get infected, that there will be a cure by the time they get sick. Other youngsters have a very bleak outlook on life. They feel that they will not live very long anyway so there is no sense in being careful and worrying about things such as HIV. Participants also noted that gang activity is very prevalent and many people are "sexed-in." In other words, they are coerced into sexual activity as part of the gang initiation process. Participants also stated women on college campuses are at risk because of excessive drinking, pressures to have sex, and rape.

Participants noted that babies who were born HIV-positive have grown up and are now sexually active teenagers. They noted these individuals are not taking the proper precautions and are spreading HIV to their sexual partners.

Participants noted that cultural and religious values place women at risk for HIV infection. Participants cited restrictions on the use of contraceptives and protective barriers imposed by both Catholicism and Islam. They noted that while both religions condemn the use of condoms, other religions have similar restrictions. Participants also commented that certain cultural values also put women at risk. They used the example that Latina women are expected to be submissive, and therefore do not have the power in their relationships to negotiate safer sex practices.

Participants commented that older women (age 50 and older) are also at risk for HIV infection. They remarked that many older women are not well informed about HIV and mechanisms of protection. Post menopausal women do not need to worry about pregnancy and therefore are not inclined to use protective barriers such as condoms because they do not need its contraceptive functions. It was pointed out society is in denial that people over fifty are having sex, and therefore this population is neglected in the design of outreach programs.

Participants commented that current substance abusing habits and mental health disorders increase a woman's risk for contracting HIV. Participants identified lesbians, the formerly incarcerated, and the disabled as risk groups for HIV. Limited outreach programs exist to reach these women and educate them on HIV. The last population the participants identified was sex workers. Women who are involved in commercial sex find it difficult to negotiate safer sex practices. They commented that many women prostitute themselves in order to feed themselves and their families. They referred to this phenomenon as "survival sex."

### **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.** Participants stated there is a lack of respect for clients in medical care settings. Health care professionals appear to have preconceived notions of the clients they serve. Participants stated providers are more concerned with the mode of transmission (sex or drug use) than the current medical complaint.

Participants had mixed reactions to a question on whether the medical care they receive is adequate. They noted it depends largely on where you receive these services. One participant stated: "If I go to a place where they are courteous, it is all right. I have gone to places where you wait all day for services with no food, the people are rude and that is not O.K. They are both out there." In general, participants correlated the quality of the medical care with the attitudes of the providers.

Some participants reported they are not satisfied with the medical care they receive. For example, one participant commented that she has repeatedly complained about pain to her physician, yet there is no note of it in her record and she is still suffering from the pain. Other participants reported similar experiences with their physicians.

Some participants noted medical services are not always culturally and linguistically appropriate. Others commented providers are not always respectful of their clients. Although it is important to be a self-advocate, it is the providers' responsibility to provide respectful, culturally and linguistically appropriate services.

**Support Services.** Participants noted that case management was an essential service to help HIV-positive women navigate the system. They also identified substance abuse and mental health services as very important. Moreover, housing and nutritional services are necessary to help stabilize women living with HIV/AIDS and prepare them to access medical care. Participants expressed concern that services such as acupuncture and massage therapy have been cut. They commented these are necessary services that help keep people connected in the system of care.

Participants also discussed the importance of oral health for people living with HIV/AIDS. They noted dental services are essential, but several participants described their encounters with dentists and stated they were not satisfied with the care they received. One participant noted that a dentist refused to provide care when he discovered she was HIV-positive.

### **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**

Insurance. Participants agreed the lack of adequate medical insurance is a barrier to care. One person commented that many women are eligible for Charity Care and other public services, and many working women have private insurance. However, there are women who find themselves in the middle, neither qualifying for public programs nor receiving medical benefits from a private entity. In her opinion, these women are most likely not to seek medical care for their HIV.

Housing. Participants noted the lack of stable housing is a barrier to medical care for women living with HIV/AIDS. They noted that case managers should help women with their housing situation so that they are more prepared to access medical care for their HIV.

Lack of education. Participants stated there are many HIV-positive women who are not well informed about HIV and are not aware of services that are available. They noted this is a barrier to care, because women are unable to advocate for themselves without information. They commented this lack of information contributes to an HIV-positive women's low self esteem. It was also pointed out that many providers of HIV services are not well informed and are not aware of the needs of the communities they serve.

Fear and Denial. Participants noted many women are in denial that they are HIV-positive. It is common for women to think that if they ignore their condition, it will simply go away. Participants also noted women do not disclose their status because they are afraid of the reactions from their families and friends. They added that women who do not disclose tend not to have a support system to help them access services.

Stigma and Discrimination. Participants agreed that discrimination and the stigma associated with HIV/AIDS still exist. Some women reported that they are looked down upon by staff when they go to seek services. They feel providers have preconceived notions of the women who seek services, and are more interested in how they got infected than providing services.

Participants noted that women sometimes choose not to access services because they are afraid of being identified as a person living with HIV/AIDS by their fellow community members. They clarified that many women avoid accessing service in buildings that are associated with AIDS. Other women are afraid of meeting someone they know within the clinic or agency.

Language. Participants stated most HIV services in the Newark EMA are offered in English, yet they observe that many HIV-positive women in the community speak Spanish and other languages. They described this as a language barrier and noted women are apprehensive of seeking services if providers do not speak their language. Participants commented the presence of an interpreter can cause women to feel very uncomfortable and can be very problematic.

Medications. Participants stated that many HIV medications have severe side effects. Women living with HIV/AIDS can get very frustrated trying to manage these side effects. Some women drop out of care because they feel that they cannot handle the medications.

Coordination of services. Participants noted that when they go to seek services, they are frequently given the “run-around.” They commented that the lack of coordination of services causes frustration in many women who eventually drop out of care.

Child care. Participants noted that a majority of women are caretakers of children. If these women do not have access to child care services, they are unable to seek medical care. One woman stated: “I think women need child care assistance, because she is the person who takes care of everyone else and places her health care last.”

Hours of Operation/Time. Participants noted that the hours of operation of most HIV service agencies do not correspond to the free time that many women have. They also commented that one frequently has to wait for long periods of time before you are served. They noted many women do not have time to spend a whole day waiting to be attended and therefore they do not access the services.

## **Recommendations**

Participants suggested that more programs should be developed to help empower HIV-positive women. They noted that it is important for women to be empowered so that they can stand up for themselves and feel free speaking about their concerns. One participant suggested developing a peer navigator program in which women with more experience living with HIV/AIDS can help newly diagnosed women at their medical appointments. Peer navigators could also help women when they just need to talk.

One participant suggested co-location of services, eliminating the need to “race around town” to access services. Other participants suggested that services should be offered after 5:00 p.m. to allow working women to access services.

Participants suggested that providers of HIV services should have to partake in continuing education activities so they are aware of how HIV is impacting the communities they serve.

Participants agreed that women respond to incentives, and suggested that more programs offer incentives to increase the amount of women who access services.

## **Population with Special Needs #7**

### **Older Adults (Age 45+)**

#### **Introduction**

The Older Adults (45 and older) Focus Group was held at NJCRI in Newark on May 26, 2004. The purpose of the focus group was to gather information on the HIV care and treatment needs of individuals age 45 and older living in the Newark EMA.

The focus group of 14 participants was facilitated by Deborah Funderburk and Tyrone Mans, members of the Planning Council's Infected/Affected Caucus. Invitations were sent out to numerous agencies providing medical and non-medical services throughout the Newark EMA as well as to members of the Infected/Affected Caucus. Both consumers and providers were present in the focus group.

#### **HIV Infection Risk Factors and Risk Groups**

Participants noted the biggest risk factor for people 45 and older in comparison to other groups is lack of information. These individuals, raised in a different generation, are not as informed as younger members of society. They also stated older adults are not as open to discussing critical issues such as sex and HIV. This close minded attitude puts them at high risk.

When prompted to identify subgroups within the population "older adults," participants noted these subgroups are the same as in the general population. Participants listed gay men/MSM, lesbians, injection drug users, and heterosexuals.

All participants agreed that risk factors vary by culture. One participant mentioned that in some cultures it is acceptable for men to have more than one partner or wife. A culture that allows for multiple sex partners puts both men and women at high risk for infection. Another participant noted that although it may not be a cultural norm, she has witnessed a lot of sexual promiscuity in her community.

Many participants commented that in the African American community, there is the "down low" phenomenon among men in which men live dual life styles and are having sexual relationships with both men and women. One participant noted that when he was living in the South, the "down-low" culture was more prevalent among whites, and he speculates that African American men are not the only ones engaging in a "down low" life style in Newark. Other participants added there is a down-low phenomenon among women as well but it is often overlooked. (That is, women who are married but engaging in sex with other women.)

According to participants, risk factors do not vary geographically. They explained there is a significant amount of interchange between people living in urban, suburban and rural areas. One participant did not believe that risk patterns vary geographically because "Suburban men come to the city to get their tricks and then they take it [HIV] back home with them."

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

**Medical Care.** Participants noted they are personally satisfied with the medical services they receive. Some participants commented that in the past they did not have the same level of satisfaction with their medical care. Moreover, they were sure that there are many people who are still not satisfied with their medical care. They noted insurance is a key to getting adequate care.

Participants also discussed the importance of being a self advocate. One participant stated, "I am getting to the point where it [medical care] is getting adequate since I have started asking questions."

When prompted to discuss whether the medical services they receive are culturally and linguistically appropriate, all participants answered that in their own experience they were. However, a few participants noted this may not be true for everyone who seeks medical care, especially those whose primary language is not English.

Participants suggested that older adults need to be offered a comfortable environment to seek medical services for their HIV. It is important for health care providers to respect their patients and listen carefully to their health concerns. In order for this level of respect to occur, providers need to move away from some of the preconceived notions they have about older adults.

Participants mentioned an HIV diagnosis is often overlooked in older adults. Some signs and symptoms of HIV/AIDS mimic signs of aging. This similarity, coupled with the fact that some health care professionals don't see older adults as an "at risk population" impedes diagnosis and results in many older adults being undiagnosed and untreated.

Participants reported they usually feel respected by their personal physicians. Some participants noted that they had bad experiences in the past but have since changed doctors. However, some participants noted they did not feel the same level of respect in the hospital setting. One participant suggested that consumers should be aware of what hospitals their physician is affiliated with. He also suggested consumers should carry a list of their medications with them, so that if they are unable to properly communicate with the hospital staff, they can check the list and not be prescribed something that can have a bad reaction with one of their medications.

One woman noted that some physicians cannot see beyond the HIV. Sometimes when you describe symptoms you are experiencing, the physician tends to say it is just a reaction to the medication or a symptom of HIV. She emphasized that physicians need to examine people carefully to see what the true cause of a particular set of symptoms is. She feels some doctors do not want to examine HIV-positive individuals. She told the story of a friend who had to go to three hospitals to treat her bleeding before someone diagnosed her with ulcerative colitis. She stated: "What upsets me is that the other doctors didn't want to look for the real problem because she was HIV-positive." Other participants commented they know that this experience is not unique and this sort of situation is very common in urban hospitals.

**Support Services.** Participants listed case management, mental health, and transportation as essential support services to help keep people connected with medical care. They also noted that housing and nutritional services are necessary to help stabilize some people living with HIV/AIDS and prepare them to be ready to access medical care.

Participants were also particularly concerned with the need for more mental health services. Most participants stated they used mental health services in a variety of forms, including one-on-one counseling sessions and support groups; however they had mixed reactions regarding levels of satisfaction with mental health services.

Participants also noted nutritional services are an essential service to help maintain people in medical care. One participant stated: "I think nutritional counseling is one of those non-medical services that the population needs to access, because the over 45 have specific nutritional needs with or without the virus, due to the process of aging." Participants agreed and added that nutritional services in the form of food distribution are also an essential support service.

**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**

Insurance. Participants agreed that lack of insurance is a major barrier to accessing medical care. Many HIV-positive individuals who do not have private insurance to pay for their medical care depend on public services such as Supplemental Security Income (SSI), Social Security-Disability (SSD), and Medicaid. Participants commented that eligibility requirements for these programs are constantly changing. They noted the lack of information on the programs themselves serve as a barrier to care. One participant noted she had SSI and Medicaid. She stated she was informed she could keep the Medicaid if she returned to work. Upon returning to work part-time she stopped receiving SSI and Medicaid benefits and she had to fight and struggle to get the benefits back for a long time. She stated: "Someone had dropped the ball on me so that was a major barrier for me as far as staying in medical care."

Transportation. Participants agreed that transportation is a barrier to accessing medical care. Participants noted many people cannot access the services that exist for people living with HIV/AIDS, because they do not have the means to get to their appointments. They noted that, in general, public transportation is relatively easy to access in urban areas but this may not be the case for older adults with physical disabilities. One participant stated that in order for people to access services for their HIV, "they need to feel safe coming and going."

Housing. Participants noted the lack of stable and affordable housing is a barrier to care for HIV-positive individuals. They commented that housing brings a certain level of stability to a life, allowing people to deal with essentials such as food, which eventually prepares them to access medical services. One participant stated: "Housing, if you have that, is one of the big expenses that you don't have to worry about. Then all the other things will take care of themselves."

One participant stated she is currently living in transitional housing. She spoke about her history with substance use and stated she is ready to move into a more stable housing

environment, but does not know how to go about doing this or what services are available to help her.

Nutrition. Participants noted the lack of adequate nutrition impedes a person's ability to access medical care. They commented this is especially true for older adults who already have special dietary needs that accompany aging. One participant stated: "What the nutritionist tell you to eat is very expensive and cost prohibitive." Participants agreed that feeding oneself always takes precedence over seeking medical care for HIV.

Medications. Participants stated that HIV medications have side effects such as neuropathy, chronic fatigue and anemia. Many times these side effects can resemble signs of aging and physicians do not take appropriate action to address them. Participants agreed that people get tired of their treatment regimen and this can cause people to drop out of care.

Lack of Education/Information. Participants agreed that many older adults are not very well informed about HIV and services available for people living with HIV/AIDS. This lack of information leads to the survival of rumors and misconceptions and causes people to distrust the system.

Participants also noted that health care professionals are misinformed. One participant stated: "A lot of doctors don't know. A positive lady just had a baby and they told her to breast feed and she said no."

Participants agreed that the lack of information on the part of either the community or individual, or even on a professional level can lead to people not accessing medical and support services for their HIV.

Stigma and Discrimination. Participants agreed stigmas associated with HIV/AIDS still exist. Because of these stigmas, people are reluctant to share their diagnosis with family members who could serve as a support network and help people get into and stay in medical care.

One participant testified that in her experience, the stigma associated with her addiction was more detrimental. She noted she was able to tell her family about her HIV diagnosis before revealing her addiction to injecting drugs.

Participants agreed that stigma exists both at the community level and in the health care realm. Participants described physicians as "standoffish" when they realize a patient is HIV-positive. Participants knew of cases in which physicians refused to treat HIV-positive individuals.

Participants noted that one stigma or misconception greatly affecting the ability of older adults to access care for HIV is the notion that "seniors don't get HIV."

## **Recommendations**

Participants commented on the need for more support groups specifically for older adults living with HIV/AIDS. Participants suggested these groups should not only be hosted in AIDS service organizations, but in places where older adults feel more comfortable, such as senior centers. Participants noted that most support groups are divided by mode of transmission and do not

group people into other significant social groups. One participant suggested that support groups could be hosted in senior buildings since many older adults have limited mobility. Other participants expressed concerns that this might make some individuals uncomfortable because they do not want people in their community to know their HIV status.

Participants also suggested having programs directed towards seniors regardless of their status, which contain both fun activities and educational lessons on HIV. This would allow older adults to attend HIV programs, and not be singled out as a person living with HIV/AIDS. Although they commended the work of various entities, participants noted that churches and other social organizations should be more involved with planning HIV-related programs for older adults.

Participants noted there is a need for more reliable and safe transportation services to assist older adults to get to their medical appointments. Participants also requested an increase in housing and nutritional services for HIV-positive older adults.

## **Population with Special Needs #8**

### **Homeless**

#### **Introduction**

The Homeless Focus Group was held on May 26, 2004 at St. Bridget's in Newark. The purpose of the focus group was to gather information on the HIV care and treatment needs of homeless PLWHA living in the Newark EMA.

The focus group of 24 participants was facilitated by Carla Potter, Health Educator of the Newark Department of Health and Human Services (DHHS), and Santos Morales, of St. Bridget's. Invitations were sent out to numerous agencies providing medical and non-medical services throughout the Newark EMA. Members of the Planning Council's Infected/Affected Caucus also assisted in the recruitment of participants. Both consumers and providers were present in the focus group.

#### **HIV Infection Risk Factors and Risk Groups**

Participants commented that two major risk factors in the homeless population are injection drug use and sex. They noted that when people are looking to get high, they are not concerned about protecting themselves from HIV infection. Participants stated that people get sloppy and careless when they are high (or want to get high) and do not take proper precautions to protect themselves by using condoms or clean needles. One participant stated: "The way I see it with my own eyes, the IV person shares needles just to get high. 'Cause I will tell them straight up I got the virus, with some that don't matter. That's how I see it and I see it with my own eyes." Participants also noted people will get involved in commercial sex work in order to pay for their next drug hit.

Participants noted that many homeless individuals regularly encounter violence and listed this as a risk factor. Several participants explained that people are left with open wounds, which leaves them with the risk of infection if their attacker is HIV-positive. One participant stated men use their penis like guns and do not care about getting infected or infecting others. Others agreed and noted men frequently refuse to wear a condom when women request one. Most participants agreed this careless and reckless behavior is largely due to the loss of hope in the lives of homeless individuals.

When prompted to discuss the different subgroups within the category "homeless," participants noted there is no one face of homelessness. They pointed out that people of all ethnicities, ages, and genders can be homeless. One participant, however, noted there is a significant portion of homeless individuals who are illiterate. He noted that not being able to read and write is a risk factor because it limits your access to prevention information and it lowers your self esteem.

## **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.** Most of the Essex County participants agreed they were satisfied with the medical services they receive. However, the Morris County participants noted that the services available to them were not satisfactory and it is hard to access them.

Participants did not provide details about the medical care they receive. The facilitators prompted participants to talk about several topics including cultural competence and respect from providers. Participants focused their discussion on support services and barriers to care.

**Support Services.** Participants listed housing, nutritional services, transportation, case management, and mental health and substance abuse services as essential for homeless individuals living with HIV/AIDS.

Participants noted that access to shelters is unequal across the EMA. Participants from Essex County noted there are many shelters available but many people choose not to use them because they have rules, such as curfews, and people would rather be outside at night chasing drugs. One participant stated, "Homeless people have an opportunity to go into the shelters, but since they are using drugs and alcohol they would rather sleep in the park than make the curfew at the shelter." Participants from Morris County responded that shelters are not available and they live in a tent in the woods.

Participants noted that having stable housing would make accessing health care services easier. Some of the participants stated they depend on Section 8 or Housing Opportunities for Persons With AIDS (HOPWA) to help pay for their housing.

Participants identified nutritional services as essential. They stated that HIV-positive individuals have particular nutritional needs. Participants noted, however, that homeless people have trouble getting basic nutrition and need nutritional services to help them manage their HIV.

Participants noted that transportation services are necessary to help people access other support services and medical care. They also listed case management as an essential support service. Participants noted that while case managers help consumers access services, they are not always compassionate and are sometimes rude. One participant commented that he had a rude case manager, so he went to a different agency. He remarked that most people would have dropped out of care if they had encountered that case manager.

The final services participants listed are mental health and substance abuse services. Participants agreed a high percentage of homeless people living with HIV/AIDS also suffer from mental health disorders and most of them are drug addicted. These services can help stabilize them and prepare them to access primary medical services for their HIV.

## **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**

Transportation. Participants noted that the lack of transportation is a barrier to accessing HIV services. They also commented that transportation services are not equally accessible across the Newark EMA. It was mentioned that there are more services available in Essex County than in Morris County.

Fear and Denial. Participants commented that many HIV-positive homeless individuals are in denial of their diagnosis and do not seek medical care. One participant noted that more information can help people come to terms with their diagnosis and better manage their HIV. Participants also remarked that HIV-positive homeless individuals do not seek medical care because they fear providers will not treat them well when they seek care.

Lack of Education/Information. Participants noted that many homeless individuals living with HIV/AIDS are not well informed about the virus and the services that are available. This lack of information can lead to distrust of the medical establishment. Participants also noted that people who are not well informed are not able to serve as self-advocates.

One participant noted he could not read, and knows that other homeless people are in the same situation. He commented it is hard for people with limited education to access information on HIV services. He also stated he is looked down upon by providers when they realize he cannot read. Others agreed that many people do not get connected into the system because they are illiterate.

Since many providers are not aware of the special needs of homeless people, clients become dissatisfied with the services they receive and eventually they drop out of care. Participants also noted there is a lack of coordination between providers, which causes people to get lost in the system and leads to frustration among clients.

Current Substance Abuse. Participants noted that a large percentage of homeless individuals are current substance users. They commented that drug habits prevent people from accessing basic services, such as housing/shelters, as well as other necessary services, such as substance abuse treatment and medical care for their HIV.

Medications. Participants noted that in their experience, many HIV-positive homeless individuals sell their medications either to pay for necessities such as food or to pay for drugs. They noted this contributes to people dropping out of care and noncompliance with their medical regimen.

Other priorities. Participants agreed that homeless individuals tend to prioritize other aspects of their lives, such as food and shelter, higher than HIV medical care. As one participant put it: "If you are homeless, getting to the doctor is the least of your worries; it is a very low priority item." Participants noted the priorities of basic needs might keep people from getting basic care. They commented that if people need to choose between going to a food pantry and sitting in a clinic for medical care, they will choose the food. They added that homeless people will make a similar choice between shelter and medical care.

Housing. Participants agreed that housing provides people with stability and therefore enables them to access medical care. It was also noted that homelessness contributes to people

staying out of care in several ways. First, homelessness causes depression and a loss of hope. When people are in this state of mind, they are not ready to access medical care. Second, homeless individuals prioritize getting food and shelter over medical care. Finally, they choose not to access care because they frequently cannot get a shower and are afraid of the reactions of medical professionals to their hygienic state.

One participant stated, "The biggest problem for a person with the virus is proper housing. That's the biggest thing. A person with the virus really needs their own apartment where they can bathe properly every day, they can eat properly every day, have sufficient food every day, and go and come like a normal person."

Participants noted there are homeless individuals who have previous criminal records, and that to their knowledge, people with criminal records are not eligible for housing services.

Insurance. Participants noted the majority of homeless people are unemployed and therefore do not have insurance. They commented that having private insurance is the best way to ensure access to good quality medical care. It was generally agreed that medical care is cost prohibitive without insurance. One participant stated, "Not having money and being homeless played a big part in my not getting medical care." Participants also commented they have been denied services because they do not have insurance.

Stigma and Discrimination. Participants noted that the stigma associated with HIV still exists. They commented that providers of HIV services are lacking in people skills. One participant stated that people will stand back when they see a client who has lesions or other signs of AIDS. Others testified that when they seek services, the providers seem "standoffish" and refuse to touch them. One participant said that after he used a pen to fill out the forms, the provider refused to take the pen back. It was generally felt that providers have preconceived notions about people who are HIV-positive. These attitudes affect the quality of care HIV positive people receive, and many drop out of care because of the disrespectful way in which they are treated. One participant stated the main reason he does not seek care is the way people look at him.

## **Recommendations**

One participant noted that clients who do not speak English can usually have an interpreter translate for them. He suggested that interpreters should also be available for people who cannot read. He commented that if interpreters for the illiterate are available, more people would be encouraged to access HIV services.

Participants suggested that people living with HIV/AIDS should have priority in public housing assistance programs as well as on lists to enter shelters and transitional housing facilities.

Participants noted it is important for people living with HIV/AIDS to be empowered. They noted that empowerment can help people advocate for themselves and help providers understand their needs. Participants also noted the importance of getting involved and helping advocate for those who are unable to advocate for themselves. They commented that empowerment comes from education, and suggested more programs be established to reach out to homeless individuals to educate them about HIV and available services.

Participants suggested housing should be addressed in addition to medical care for HIV. One participant stated, "Show them that they need medical treatment but in the process help them to work towards getting that apartment, and if you do, they will be more compliant and work more at it." Other participants agreed, and noted that people will not be motivated to seek medical care when they are living out in the streets or in a shelter.

Participants noted that in their community, the most common mode of infection is injection drug use. They recognized that the virus is also spread through sex. Participants commented they have witnessed vans distributing free condoms to encourage people to engage in safe sex and to protect themselves and others. Some participants suggested that clean needles should also be distributed to help prevent further spread of the virus. One participant stated: "I see them handing out condoms, but the biggest path of this virus getting around is IV drugs. Just like they give out condoms, they need to give out needles, and since it's not available they need a place where a person can say 'I'm an IV drug user and I need clean needles.' We are losing too many lives behind the needle." Proponents of needle exchange in the group noted that people cannot be arrested for carrying clean needles because it is not considered drug paraphernalia since people such as diabetics need to carry needles for their insulin. However, not all participants were in favor of needle exchange. Those opposed to needle exchange noted that it does not make sense that someone carrying a clean needle for IV drugs cannot be arrested for possession of drug paraphernalia, but someone carrying a straight shooter for coke can be arrested.

## Comparison of All Focus Groups

### Introduction

A total of eight focus groups were conducted to evaluate the care and treatment needs of the following special need populations: Youth (age 13-24), Substance Users (IDUs and Other Non-IDUs), MSM of Color, White/Anglo MSM, Women of Childbearing Age (age 13-44), Older Adults (age 45+) and Homeless individuals. The previous section analyzed discussions that occurred within each focus group. This section will compare and contrast the results of all eight groups.

The tables in this section provide snapshot views of the discussions that occurred across the focus groups. Discussion follows each table. 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 average focus group size was approximately 13 participants; the smallest group had four participants and the largest group had 28 participants. Focus groups were conducted in Morris and Essex counties. Attempts were made to have PLWHA from all five counties in the Newark EMA participate.

### HIV Infection Risk Factors and Risk Groups

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

With respect to exposure category or modes of transmission, across the board, participants noted the two major risk factors are injection drug use and unprotected sex. Participants remarked that substance abuse is prevalent among all populations such as teenagers, older adults, men, women, and the homeless. They noted the main source of infection among substance users is the sharing of needles and cookers. Participants in various focus groups noted that 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. They also pointed out that people will get involved in sex work to pay for the drugs. The Women's focus group noted that women will turn to sex work to pay for basic necessities and to feed their families. Many participants commented on the inconsistent condom use among sex workers, which 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. Participants also noted that in their experiences, risk factors vary by age. Young MSM and transgendered are high risk groups and are more likely to engage in risky sexual behavior. The MSM focus group in Essex County also noted that 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.

**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	√					√			2
Youth (general)	√	√	√			√		√	5
Young MSM	√			√	√				3
Transgendered Youth	√			√					2
Older Adult Women						√	√		2
Gay Men/ MSM				√	√		√		3
Older Adult MSM				√	√		√		3
Older Adults (general)		√					√	√	2
Formerly Incarcerated				√		√		√	3
Men on the “DL”				√			√		2
Partners of Men on the “DL”				√		√	√		3
Children born HIV-positive		√				√			2
Sex Workers			√			√		√	3
Lesbians						√	√		2
IDU	√	√	√			√	√	√	6
Non-IDU	√	√	√			√	√	√	6
Illiterate								√	1

**Youth.** Participants of both Substance Abuse focus groups as well as participants from the Youth, Women’s, and Homeless focus groups identified youth as a high risk group. All

participants commented they are witnessing an increase in risky behavior among the young people in their community. They are experimenting with injecting and non-injecting drugs and are engaging in sexual relationships at very young ages. Some groups noted that drug choices vary between rural and urban areas, but that many young people travel between the areas in search of different drugs.

Young Women. Participants of both the Youth and Women's Focus Groups identified young women as a high risk group. They noted that young women engage in risky behavior such as unprotected anal sex. Participants emphasized that women are willing to practice unsafe sex in an attempt to hold on to their partner. They remarked that 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. Both MSM focus groups and the Youth Focus Group identified young MSM as a high risk group. Participants noted that young men are experimenting with their sexuality and are engaging in unprotected sex. They also noted that over the last few years, HIV rates have been rising in this population and remarked on the importance of reaching 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. Participants of the MSM Focus Groups and the Youth Focus group also identified transgendered youth as an at risk population, noting that many of them have been kicked out of their homes and are living on the streets.

Children Born HIV-Positive. Participants in the Essex Substance Abuse focus group and the Women's focus group discussed the risks of children born HIV-positive. Participants in both groups noted that children born HIV-positive in the 1980's and 1990's are now teenagers and young adults. Many are experimenting with sex and drugs. Participants reported many of these young people do not disclose their status. The result is they are placing their partners and peers at risk for infection.

**Older Adults.** Several focus groups discussed the increase of HIV prevalence in older adults. Participants of these focus groups noted one of the biggest risk factors for older adults is the lack of information about HIV and modes of transmission, information the younger generations have more knowledge about and access to. They commented that older adults are not very open to talking about sex. They also noted there are older adults who abuse injected and non-injected substances. It was pointed out that seniors resist being labeled as a high-risk group.

Older Women. Participants of the Women's and the Older Adult focus groups identified older women as a high risk group. They noted older women are not well informed about HIV. Participants commented that many older women do not use protective barriers because they no longer need the contraceptive function of these devices. They remarked society tends to deny that women over age 50 have sex, which is far from reality.

Older MSM. Three focus groups discussed the risks of older adult MSM – both MSM focus groups and the Older Adults focus group. Participants agreed that many older MSM are not as aware of the benefits of using condoms.

**Men on the “Down-Low”.** Participants of the Essex County MSM focus group, the Women’s and Older Adults focus groups discussed the concept of “down-low” and how it affects the risks of people living in their community. 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. These groups noted that men on the “down low” and their female partners are both at risk for HIV infection.

Men on the “down low”. Participants of the MSM focus group in Essex County and the Older Adults focus group discussed the risks of men on the “down low.” They noted that 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”. Several focus groups discussed the impact of the “down-low” culture on women. Participants of the Essex County MSM focus group, Women’s focus group, and Older Adult’s focus group commented that these men are partaking in unsafe sexual practices outside the home and are, in turn, infecting their female partners. They agreed that women do not have enough power in their sexual relationships to demand the use of a condom.

**Substance Users.** Six of the eight focus groups identified substance users as an important risk group in their community. These groups were the two Substance Abuse focus groups (Essex and Morris counties), the Youth focus group, the Women’s focus group, the Older Adults focus group, and the Homeless focus group. Most participants in these groups noted there are several factors that 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 of the Women’s focus group, Substance Abuse focus group in Morris County and Homeless focus group commented that people in their communities trade sex when they are attempting to get high. They do not take proper precautions in these commercial sex transactions, putting themselves at high risk for infection. Participants of the Women’s focus group also stated that women engage in commercial sex to pay for basic necessities and to feed themselves and their families. All participants who discussed sex workers noted that in most cases prostitutes do not have the power to negotiate safe sex.

**Formerly Incarcerated/Recently Released.** The MSM focus group in Essex County and the Women’s and Older Adult focus groups noted that the formerly incarcerated/recently released are an at risk group. They commented that many people released from jail or prisons are both HIV-positive and substance addicted. Participants commented 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. The **Table 2-3** indicates whether the participants of each focus group were satisfied with their medical care. **Table 2-4** is a list of the different factors the focus group participants identified as contributing to the quality of medical care. This table identifies these factors and the focus group that discussed them.

**Table 2-3: 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>

Only participants of three focus groups agreed that they were satisfied with the care that they receive. People in the MSM and the Substance Use Focus Groups in Morris, Sussex, and Warren counties, and those in the Older Adults Focus Group noted 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.

As seen in **Table 2-4** below, 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.

**Table 2-4: 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		√	√	√	√		√		5
Doctor-Patient Communica- tion			√	√					2
Respect for Clients/Pro- vider Attitude	√	√		√		√	√		5
Self-Advocacy			√	√	√	√	√	√	6
Continuity of Care					√				1
Wait times/ hours of operation	√					√			2
Cultural & Linguistic Competency						√		√	2

Insurance. Participants of five focus groups stated that insurance is the best way to guarantee access to good quality medical care. Participants from the MSM and Substance Use focus groups in both the tri-county area (Morris, Sussex, and Warren counties) and Essex County, in addition to the Older Adults' focus group, 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 participants agreed that medical care with insurance was of much higher quality. A few participants noted that they have had a 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. Two focus groups discussed the importance of doctor-patient communication and noted that people will be more satisfied with their care if the doctor or support staff took the time to explain diagnoses, treatments, and medications. Participants in the tri-county Substance Use focus group and in the Essex MSM focus group emphasized that 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. Participants from the Older Adults', Women's, Youth, Substance Abuse in Essex County, and MSM in Essex County focus groups discussed the influence of provider attitudes on the perception of quality medical care. Participants in these groups noted that medical and support staff in various agencies are disrespectful of their HIV clients and often stigmatize and treat them in a condescending manner. They noted that the

manner in which a person is treated is often more important than the physicians ability to demonstrate their high level of medical expertise.

Self-Advocacy. Self-advocacy was the most common factor participants identified as affecting the quality of medical care. Participants in the MSM focus groups in both Essex and Morris counties, along with those in the Older Adults', Homeless, Women's, and tri-county Substance Use focus groups commented that, although it is the provider's responsibility to ensure that the client understands all information conveyed, it is essential for HIV-positive people to be empowered so they can serve as self-advocates and actively 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. Only participants in the MSM focus group in Morris County listed continuity of care as an important factor for quality medical care. They noted that 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. The Youth and Women's focus groups noted they were not satisfied with the medical care services in their community because of the hours of operation. The women noted it is hard for working women to access care between the hours of 9:00 a.m. and 5:00 p.m. The youth made similar remarks and stated that people who are in school cannot access services during regular business hours. The women also remarked that 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. The Women's and the Homeless focus groups discussed cultural and linguistic competency as a determinant of good quality health care. Participants in both groups remarked that many services are not offered by culturally or linguistically competent providers and noted this leads to a breakdown in communication between provider and client.

**Support Services.** Table 2-5 below lists of all the support services which the participants of all eight focus groups identified 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. Participants of the MSM and Substance Abuse focus groups of Morris County, and the Women's, Homeless, and Older Adults' focus groups listed case management as an essential service to keep PLWHA in medical care. In all of these groups, people commented that case management is the key service to help coordinate all services relied upon by PLWHA. Participants emphasized that case management services are especially important for the newly diagnosed or for people who are just entering the system of care. Most participants in these five focus groups remarked that they are satisfied with the case management services they receive. However, some noted that case managers have been rude and condescending and they feel that 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.

**Table 2-5: 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			√		√	√	√	√	5
Complementary Services					√				1
Dental Care					√				1
Housing			√	√	√	√	√	√	5
Legal Services	√								1
Mental Health	√	√			√	√	√	√	6
Nutritional Counseling				√	√	√	√	√	5
Programs for recently incarcerated,		√		√					2
Substance Abuse Service		√	√			√		√	4
Transportation	√	√			√	√	√	√	6

Dental Services. Only participants in the Women’s focus group mentioned the importance of dental services. They noted that dental health is very important for people living with HIV/AIDS. It was stated, however, that they are not satisfied with the dental services they have accessed and described the dentist and staff as discriminatory and rude.

Housing. Participants of both MSM focus groups, the Substance Abuse focus group in Morris County, and the Women’s, Older Adults’ and Homeless focus groups identified housing as an important support service. All groups noted that housing makes accessing medical care easier. They stated that it offers PLWHA stability in their lives. Participants of the MSM/Essex and the Homeless focus groups emphasized that people who are homeless will not seek primary medical care because they are more concerned with finding shelter or their next meal. The MSM/Essex focus group was particularly concerned with the homeless youth.

Legal Services. Two groups, MSM in Morris County and Youth, noted that legal services were an essential for people living with HIV/AIDS. However, their legal concerns were quite different. Most participants of the MSM focus group were over the age of 45. Their primary concern regarding legal services was seeking advice on Social Security and other benefit packages. They wanted to know how to prepare in the event that they got sick. The youth focus group was primarily concerned with access to HIV testing and care and treatment. Participants of this group noted that parental consent is needed to access these services. They noted that legal services would help minors navigate the system and/or file for emancipation.

Mental Health. Six focus groups discussed mental health services and their importance to people living with HIV/AIDS. These groups were MSM (Morris County), Substance Abuse (Essex), Youth, Women's, Older Adults and Homeless focus groups. Participants of all six groups noted that 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. Participants of the Substance Abuse, Homeless, Women's, and Older Adults' groups particularly noted the importance of linking mental health and substance abuse services.

Nutritional Services. Nutritional Services was listed as an important support service in five of eight focus groups. Participants of the both MSM groups, Women's, Homeless, and Older Adult focus groups noted that HIV-positive individuals have particular nutritional needs and commented that nutritional counseling can help people manage their HIV. They commented that proper nutrition helps stabilize them. Participants of the Homeless focus group stated that nutritional services in the form of the distribution of food is very important because people will not worry about going to the doctor when their primary concern is finding their next meal.

Programs for the Formerly Incarcerated. Participants of the MSM focus group in Essex County and the Substance Abuse focus group in Essex County noted that many people are HIV-positive when discharged from jail or prison. They noted that programs for the formerly incarcerated can help link these individuals into medical care and other support services.

Substance Abuse Services. Four groups discussed the importance of the substance abuse services. Participants of both Substance Abuse focus groups, the Women's and Homeless focus group noted that injection drug use is one of the primary modes of transmission in their communities. They noted that most people must address their addiction first in order to access primary medical care and other services to manage their HIV. Participants also commented that there is a need to condense Substance Abuse and Mental Health Services.

Transportation. Participants of seven focus groups (all but Women's) commented that transportation services are essential to link people into and maintain them in medical care. They noted that many HIV services exist but people cannot access reasonable and reliable transportation. Participants agreed that transportation is a major barrier to care for people living in Morris, Sussex, and Warren Counties where public transportation systems like the ones 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 2-6** lists the major services identified by the eight focus groups, which, if not available to PLWHA, act as barriers to care. The indicated focus groups identified these services as vital to help maintain PLWHA in medical care.

Table 2-6: 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. Two focus groups identified child care as a barrier to care for people living with HIV/AIDS. Participants in both groups remarked that women who do not have access to child care services are unable to seek medical care. They noted that women tend to be the primary care taker of partners, parents, children, and other family members. Many of these women work and need help with their care taking responsibilities so that they have the time to go to the doctor.

Coordination of Services. Three focus groups noted the importance of coordination of services. The Homeless and Older Adult focus groups were particularly concerned with the coordination of mental health and substance abuse services. They noted that these linkages can eventually help get HIV-positive people into medical care. Participants of the Women's focus group remarked that there is a need to better coordinate all HIV-services. They noted that women can get lost in the system of care and the coordination of services can help maintain them in medical care.

Cultural and language barriers. Only two focus groups discussed cultural and language barriers to accessing HIV services. Participants in the Morris County Substance Abuse and the Women's focus groups noted that 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. Participants in these two focus groups also commented that adjustments are not made in programs and agencies to approach sensitive issues such as drugs and sexuality in different cultural groups.

Fear/Denial. Six focus groups identified fear and denial as major barriers to care (all but Substance Abuse in Essex and Older Adults). Participants in all six of these focus groups remarked that many people fall into denial after they receive an HIV-positive diagnosis and refuse to seek medical care. They noted that some people think that since they do not look or feel sick, it is not really serious. Participants in these focus groups also noted that many people keep their HIV-status a secret because they fear the repercussions of disclosing to friend, families, and coworkers. Participants remarked that 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. Three focus groups mentioned hours of operation and/or lack of time as a barrier to care. Participants in all three groups commented that it is difficult for people to take time off of work to go to a medical appointment and most services are offered between 9:00 a.m. and 5:00 p.m. Participants in the Youth focus group made similar remarks regarding people who are in school during the day. In all three groups it was also noted that 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. Six of the eight focus groups listed housing as a major barrier to care (all except Youth and MSM in Morris County). Participants remarked that there is a lack of affordable housing especially in Morris County. Participants in the Homeless and Older Adult focus groups commented that housing brings a certain level of stability to a life and allows people to deal with essentials such as food and eventually prepares them to access medical services.

Immigration Status. Only participants in the Substance Use focus group in Essex County listed immigration status as a barrier to care. It was noted that undocumented individuals do not seek medical care because the fear deportation.

Insurance. Six focus groups identified the lack of insurance as a major barrier to medical care (all but Youth and Substance Abuse in Essex County). Participants agreed that 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. Participants commented that people in their community are not aware of available HIV services. This lack of information prevents people from advocating for themselves. The MSM focus group in Morris County and the Older Adult focus group noted that a lack of information leads people to distrust medications and the medical establishment. Participants in the Morris County Substance Abuse group and the Older Adult focus group commented that providers are not always well enough informed to offer appropriate services to the communities they serve.

Legal Barriers. Only 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. The following five focus groups listed medications as a major barrier to care: MSM in Morris County, both Substance Abuse groups, Older Adults and Homeless. Participants in all five groups 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. Three focus groups identified mental health and/or substance use as a barrier to medical care. Participants in the Substance Abuse focus group in Essex County noted that many people living with HIV/AIDS are dealing with substance abuse and mental disorders or distress. Participants in the Substance Abuse focus group in Morris County and the Homeless focus group focused more on the barrier that current substance use creates. The three focus groups commented that people need help addressing these issues before they can properly medically manage their HIV.

Nutrition. The Older Adult and Homeless focus groups were the only two to identify nutrition as a barrier to care. Participants noted that the 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 eight focus groups identified stigma and discrimination as major barriers to care. Participants in all groups agreed that stigma associated with HIV/AIDS still exists. It was noted that 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. Participants also remarked that staff and clinicians sometimes discriminate against HIV-positive individuals and frequently look down on them.

Transportation. Seven of the eight focus groups identified transportation as a major barrier to care (all but Women's group). All participants noted 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**

**Table 2-7** lists of the major recommendations made to respond to the barriers to care participants of all eight focus groups identified. The table identifies the recommendations and the focus group that discussed them.

**Table 2-7: 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
Increase advocacy		√	√			√		√	4
Internet discussion forums				√	√				2
Intervention programs to show realities of HIV	√								1
Legal help	√				√				2
More interpreters								√	1
More night	√	√				√			3

services							
More reliable, safe transportation				√			1
More support groups				√			1
Needle Exchange						√	1
Peer navigation programs	√			√			2
Targeted outreach programs	√	√	√	√	√		5

Co-location of services. Participants of the Women’s focus group were the only ones to recommend the co-location of services for people living with HIV/AIDS. They noted that a variety of service should be offered in one location to minimize the time and travel people need to invest in their care. They noted that more people would access services in such a setting.

Educational Programs for providers. Most of the focus groups noted that there is a need for the community and people living with HIV/AIDS to be more educated regarding HIV/AIDS and available services. Three focus groups namely the MSM focus group in Morris County, the Substance Use focus group in Essex County, and the Women’s focus group, commented that providers should be more educated on HIV and how it affects the people in the communities they serve. Participants of these focus groups suggested the development of educational programs for providers. They noted that these programs 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 group was the importance of self-advocacy to ensure quality care. Six of the eight focus groups, namely Gay Men in Essex County, Gay Men in Morris County, Youth, Women, the Homeless, and Older Adults, recommended the development of empowerment and educational workshops for people living with HIV/AIDS. They noted that 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. Several focus groups, such as the Women, Substance Use in Morris County, and Youth, discussed the image of Magic Johnson as a face of HIV/AIDS. However, only the participants of the Youth focus group discussed in detail the effect of this type of “role model” on people living with HIV/AIDS and people who are at high risk. They noted that for them, Magic Johnson is not a good model because they do not consider him a reflection of their community. They recommended that people from the community should serve as role models and spokespersons regarding sensitive issues such as HIV. They noted that a real role model would have more success encouraging people to get tested and/or getting people into medical care.

Improve Coordination of Services. Participants in the Substance Abuse focus group in Essex County and the Homeless focus group suggested that services for people living with HIV/AIDS should be better coordinated. They noted that 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. Many focus groups noted that housing provides people living with HIV/AIDS with the necessary level of stability to access medical services. Participants in three groups (MSM in Essex County, the Homeless, and Older Adult) recommended an increase in housing services for people living with HIV/AIDS. Participants of the MSM focus group in Essex County particularly noted the need for housing services for youth who are currently living on the streets. Those in the homeless focus group recommended that people living with HIV/AIDS should have priority on lists for housing services.

Incentives. Participants in the Substance Use focus group in Morris County, the Youth focus group, and the Women's focus group recommended that more HIV/AIDS service agencies should offer incentives to encourage people living with the virus to access care.

Increase Advocacy. Four of the focus groups recommended more advocacy to help people connect into medical care (Substance Use in Essex County and Morris County, Women and Older Adults). They noted the importance of advocacy at a community level to help maintain services in the community and help people access these services.

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

Intervention Programs to show realities of HIV/AIDS. The Youth focus group was the only one to suggest 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. The Women's focus group and the Homeless focus group suggested that services should be more linguistically competent. Participants in the Homeless focus group recommended that 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. The Women's focus group commented that 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. Several focus groups, such as the Substance Use focus group in Essex County, the Youth focus group, and the Women's focus group, recommended that HIV service providers offer services after regular business hours. Participants in these three groups commented that 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 the support groups noted that transportation as a major barrier to medical care but only the Older Adults' focus 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. The Older Adults' focus group was the only one to suggest more support groups. The participants commented that most support groups are arranged by mode of transmission. They recommended the implementation of support groups that serve populations such as older adults and not modes of transmission.

Needle Exchange. The Homeless focus group was the only group to discuss needle exchange programs. Participants in this group 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. Both the Women's and Youth focus groups recommended the development of peer navigation programs. Participants in both groups suggested that these 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. Five focus groups suggested that outreach programs should be individually designed to reach out to the target populations. They recommended the development of target outreach programs that would reach out 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. Participants in the Youth focus group recommended that service should be offered in anonymous locations that have no particular association with HIV/AIDS.