

***NEWARK ELIGIBLE METROPOLITAN AREA
HIV HEALTH SERVICES PLANNING COUNCIL***

***COMPREHENSIVE NEEDS ASSESSMENT
EXECUTIVE SUMMARY***

The Newark HIV Health Services Planning Council (Planning Council) is evaluating the needs of four difficult to reach populations: (1) the homeless, (2) older adults, (3) the newly diagnosed, (4) African-American and Latina women with children. The Planning Council is also interested in evaluating the impact of two social issues on the epidemic in the region: (1) violence and (2) welfare reform.

This report presents the findings from primary and secondary research into:

- The needs of each population,
- Effective approaches to bring difficult to reach PLWHA into care,
- Strategies to maintain PLWHA in the care system,
- The effect of violence and welfare reform on PLWHA and their willingness and ability to access care and services.

An extensive literature review was conducted to examine each area, and 38 key informant interviews were conducted. Available New Jersey Department of Health and Senior Services Division of AIDS Prevention and Control Surveillance Unit (NJDAPC) data were reviewed, and the Newark Eligible Metropolitan Area (NEMA) HIV Health Services Planning Council 1999 Comprehensive Needs Assessment data were re-tabulated and analyzed with these populations in mind.

I. THE HOMELESS

ESTIMATES OF HIV POSITIVE HOMELESS

In estimating the number of homeless PLWHA in the NEMA, NJDAPC prevalence statistics were adjusted for the undiagnosed. The county homeless rates, based on the 1999 Comprehensive Needs Assessment Survey were then applied. This yields an estimate of 5,500 to 5,750 HIV+ homeless in the NEMA.

KEY ISSUES

- I.1 Homeless PLWHA are generally very needy. The majority are substance users and many are mentally ill. Others are recently evicted and are experiencing short term “set backs.” Intensive outreach, support services and ongoing interventions are needed to maintain homeless PLWHA in the care system.

- I.2 Affordable, safe housing has been a long standing need of PLWHA.
- I.3 Additional capacity is needed for emergency, transitional and permanent supportive housing throughout the NEMA. A need exists for “youth friendly” shelters that will accommodate adolescents under 18 years of age.
- I.4 All key informants stated that homeless shelters are becoming “more dangerous.”
- I.5 Substance use and blatant intoxication are prohibited at shelters, limiting options for substance users.
- I.6 A need exists for respite or medical day care for the homeless who are ill and cannot be on the street during the day.
- I.7 Adherence to HIV treatment regimes may be difficult in shelters, particularly those that do not admit PLWHA. For those that accommodate PLWHA, the stigma of the disease often causes PLWHA to hide their HIV status and be non-compliant with their medical regimens.
- I.8 Chronically homeless PLWHA tend to be outside the care system. Facilitation, support and incentives may enhance system access.

RECOMMENDATIONS

- I.1 Support the development of additional housing options for PLWHA throughout the NEMA. These include:
- Safe, affordable, permanent housing
 - Transitional housing
 - Residential substance abuse treatment
 - Emergency and transitional housing for women with children
 - Emergency shelter
 - Emergency short term shelter for youth
 - Group homes for youth
 - Wet shelters
- I.2 Develop targeted services for homeless PLWHA. Develop delivery options which facilitate access. Consider providing incentives for utilization.
- Expanded medical treatment for consumers without insurance
 - Transportation
 - Substance abuse treatment, particularly medical detox and appropriate long term follow up treatment after detox
 - Medical day care, respite care, or drop-in centers for ill PLWHA

- I.3 Services are needed for PLWHA to avert homelessness. Services that address issues leading to homelessness, such as substance abuse treatment and mental health therapy and counseling could provide the necessary support to avoid homelessness.
- I.4 Evaluate the number of shelters in the NEMA that do not admit PLWHA and rationale for this exclusion.
- I.5 Evaluate the timeliness of HOPWA payments to landlords. As appropriate, investigate mechanisms to speed payments, including subcontracting HOPWA services.
- I.6 Educate landlords on Section 8, HOPWA and other housing subsidies so that they understand that renting to PLWHA can be a positive, long term relationship.
- I.7 Consider an in-depth study of the service needs of homeless PLWHA and strategies to effectively link them to the care system.

II. AFRICAN-AMERICAN AND LATINA WOMEN WITH CHILDREN

KEY ISSUES

- II.1 The number of HIV+ African-American and Latina women of child bearing age is increasing throughout the NEMA.
- II.2 Women with children confront a wide range of barriers to HIV care and adherence to medical regimens.
- II.3 Ongoing education and support is needed for HIV+ women to become empowered and change their lives.
- II.4 HIV+ women with children need skills and training to move from poverty.
- II.5 Culturally appropriate and culturally sensitive services are essential.
- II.6 Transportation and dental care are service needs of all African-American and Latina women with children. Those outside the care system identified needs for medical care and case management. Other service needs were specific to the population and their current use of the care system.

RECOMMENDATIONS

- II.1 Support programs which empower women to change their lives. The most successful are relationship building, educational and long term in nature (providing support over a period of years).

- II.2 Fund services which support women in adherence to treatment regimens.
- Offer transportation services to appointments that accommodate women and their children.
 - Offer child care services for women during appointment times.
 - Reduce the “hassle” of accessing care by offering convenient locations, appointment times and personal service.
- II.3 Enhance access to care by educating Ryan White Title I funded primary care and other Ryan White Title I service providers about the appropriate use of funds. Work with grantee to devise an enforcement plan.
- Primary care should be available regardless of income or ability to pay.
 - All services should be available to undocumented immigrants without social security number or other paperwork.
- II.4 Develop partnerships for life skill training and vocational training.
- II.5 Offer cultural competency training to Ryan White Title I providers. All levels of employees will benefit from attending. Consider mandatory attendance at this training.
- II.6 Encourage agencies with large numbers of undocumented immigrants to offer “documentation” services.
- II.7 Encourage more aggressive recruitment of Latina and African-American women for support and professional positions at NEMA agencies.

III. OLDER ADULTS

KEY ISSUES

- III.1 The number of older adult PLWHA is increasing throughout the NEMA.
- III.2 A well-documented pattern of shorter survival exists among older adult PLWHA.
- III.3 Older adults may participate in high risk behaviors, both through unsafe sex and injecting drug use, and many deny the need to access counseling and testing.
- III.4 Many older adults have limited understanding of HIV risk factors and disease progression.
- III.5 HIV diagnosis may be delayed since HIV symptoms may appear to be problems of aging.

- III.6 Older adult PLWHA tend to be isolated from their families and friends and often do not disclose their status to people who might provide needed support.
- III.7 Successful education and interventions with older adults utilize peer education and support.
- III.8 Service needs of older adults include dental care, housing, HIV health education/risk reduction and emergency financial assistance.
- III.9 Older adults may serve as caregivers for their infected and/or affected children and grandchildren.

RECOMMENDATIONS

- III.1 Health care providers who treat older patients need to be targeted for education about early diagnosis of HIV/AIDS to improve prognosis.
- III.2 Physicians, physicians' assistants, nurse practitioners need training in adult sexuality and interviewing of older adults to enable them to competently discuss sexuality and HIV risk factors in a nonjudgmental way. This can be accomplished through education and training opportunities.
- III.3 Use education with older PLWHA to improve personal relationships, enhance self-esteem and reduce isolation.
 - Peer-to-peer education is a successful approach to this type of education and support.
 - One-to-one education has been found to be more successful than group forums when dealing with older adults on sensitive issues.
- III.4 Teaching and outreach methods should be tailored to meet the different interests, needs, social contexts of adults age 50 and older.
 - The use of peer-to-peer outreach workers and advocates should be considered for reaching the older adult PLWHA in the NEMA.
 - Collaborate with local agencies in each area, such as Offices on Aging, to inform and outreach to older adults.
 - Senior Clubs.
 - Speakers Bureaus.
 - Nutrition Programs.

- III.5 Use education to encourage older PLWHA to assert themselves in their relationships with their health care providers.
- Enhance doctor-patient communication
 - Offer strategies to improve adherence
 - Provide information on the efficacy of medication
- III.6 Older PLWHA need new and/or additional sources of emotional support such as peer support or counseling services to help deal with the stigma of the disease and to avoid a negative affect on relationships.
- III.7 Support the development of substance abuse treatment targeting older adults. The needs of older adults should be integrated into all treatment modalities.
- III.8 Embed HIV education in health and chronic illness education. Attract participants by providing non-HIV health forums.
- Older adults don't want to be seen picking up a brochure.
 - Send the message, "You can assist us in reaching your family members." "It's not about you, it's about your community." "Listen on behalf of someone else."
- III.9 Target HIV messages to older adults. Use older adults in brochures, posters and other HIV awareness media to demonstrate that it affects all age groups, and older adults are at risk.
- Collaborate with prevention planning groups.
- III.10 Advocate for governmental programs which address HIV as a family disease, providing services which strengthen the family while providing individual support.
- Advocate for senior housing which allows older adults to care for their grandchildren.
 - Advocate for payment to grandparents who provide foster care.

IV. THE NEWLY DIAGNOSED

KEY ISSUES

- IV.1 The number of newly diagnosed consumers in the NEMA decreased significantly over the past five years.

- IV.2 Immediately after diagnosis, consumers risk being lost to the HIV care system, particularly if they are feeling well. Barriers to care among the newly diagnosed include denial, confidentiality concerns, substance use, limited information about services. Child care and transportation are particular barriers for women.
- IV.3 A wide range of approaches exist for linking consumers with services, but the most effective utilize a personal approach and intensive follow up.
- IV.4 The New Jersey Department of Health and Senior Services requirements for counseling and testing dictate development of a risk reduction plan and six months of follow-up for all who are tested. The quality of the counseling and follow-up, however, varies among agencies.

RECOMMENDATIONS

- IV.1 Investigate reasons for the significant declines in HIV diagnoses.
- Is it due to success in disseminating the prevention message?
 - Is the infected population becoming more difficult to reach with counseling and testing?
- IV.2 Target both female and male heterosexuals with prevention and counseling and testing messages. Use culturally sensitive approaches.
- IV.3 Support the development of innovative services that provide personal approaches to moving a newly diagnosed consumer from diagnosis to care.
- The Peer Advocate model has been implemented successfully at DAY AM at UMDNJ.
 - Evaluate the role of peer counselors in supporting newly diagnosed consumers from counseling and testing through diagnosis and into treatment. Evaluate funding opportunities for employing dedicated consumers in these roles. Peer counselors could develop relationships with consumers that are maintained for the length of time deemed appropriate by the treatment team.
 - Investigate a woman helping woman system.
 - Investigate other realistic approaches to personal support for the newly diagnosed and implement as model programs.
- IV.4 Provide more evening and weekend outreach and more culturally appropriate outreach to the Latino community.
- IV.5 Support the development of standards of care for counseling and testing. Encourage a continuous quality improvement (CQI) approach, and counselor training to enhance the quality and uniformity of care delivered.

V. VIOLENCE AND HIV

KEY ISSUES

- V.1 Emotional abuse is the most frequent type of violence experienced by PLWHA. This is followed by physical and sexual violence.
- V.2 Title I case managers, substance abuse counselors, mental health counselors and nurses should be trained to conduct violence assessments with consideration given to incorporating these assessments into standards of care. If violence assessments are conducted, however, personnel must also be trained to understand and provide appropriate intervention.
- V.3 Domestic violence service providers need a greater understanding of HIV disease.
- V.4 Domestic violence may interrupt the victim's adherence with HIV treatment, or it may be a barrier to accessing the HIV care system.
- V.5 HIV positive status can be a catalyst for violence.
- V.6 Few resources are available for men who are victims of violence, particularly gay men who are victims of domestic violence.
- V.7 Youth are exposed to violence, both as victims and as perpetrators.
- V.8 Those in the sex industry are "constantly abused."
- V.9 Women respond to violence and victimization based on their situations and their background: children, race/ethnicity, immigration status, etc.
- V.10 Substance use may develop as a result of victimization.
- V.11 Domestic violence intervention emphasizes client empowerment. This is most frequently accomplished through mental health therapy, education and personal relationships.

RECOMMENDATIONS

- V.1 Build bridges between the HIV service community and the domestic violence community. HIV service providers need education about violence, and violence service providers need to understand HIV.

- V.2 Evaluate the implications of implementing domestic violence screening standards for funded case management, substance abuse treatment, primary care or mental health therapy and counseling. Pilot a training program with a limited number of agencies to evaluate the impact and effectiveness. Implement the program throughout the entire NEMA, if effective.
- V.3 Evaluate the service continuum for female, male and adolescent/young adult violence victims.
- V.4 Service needs of victims of violence include: mental health therapy and counseling, substance abuse treatment, legal advocacy and housing support. Mental health therapy and counseling should be intensive, appropriately treating post traumatic stress disorder.
- V.5 Establish appropriate support systems and services to empower victims of violence. This may be accomplished with skilled professionals and supported by paraprofessionals in peer advocate roles.

VI. IMPACT OF WELFARE REFORM ON PLWHA

The Work First New Jersey Program (WFNJ), implemented in April 1997, is New Jersey's approach to the federal welfare reform program. It allows a total of five years of welfare benefits during an individual's lifetime and includes an immediate work or training requirement. Certain WFNJ cases, such as the elderly, disabled and victims of violence are exempt.

Since its inception, approximately 40% of welfare recipients have left welfare and are working. Many PLWHA fit the profile of those who have not left welfare or who have left welfare and are not working. PLWHA in the NEMA tend to have:

- Less education
- Limited work histories
- Been welfare recipients for many years
- Child care responsibilities that restrict their activities
- Transportation problems
- Health limitations

Case managers cite individual situations in which consumers:

- Waited months or years for benefits
- Were denied benefits even though all necessary paperwork was completed
- Resorted to court hearings to access unjustly denied benefits
- Required three full days of waiting at three different locations to attempt to receive deserved benefits
- Had a significant portion, if not all, of their monthly payment withheld due to "sanctions"

WFNJ requirements are considered “hassles” by many and prevent people from accessing needed benefits. Reduced benefits can result in desperation leading to homelessness, prostitution, substance use, and other HIV risk behaviors.

Case managers report concerns that their clients’ welfare benefits will be discontinued after April 2002, particularly for those who have not worked. They fear that even with completed paperwork to extend benefits, the “system” will “kick them out.”

RECOMMENDATIONS

- VI.1 Develop systems among Title I service providers that reduce the “hassles” in consumers’ lives. For example, if consumers must wait in lines for entitlements, support policies that reduce waiting at Title I service providers.
- VI.2 Educate case managers to ensure that they have a working knowledge of TANF, food stamp, Medicaid and child care benefits that are available to PLWHA. Case managers must understand welfare advocacy and the availability of legal support services.
- VI.3 Educate case managers on basic welfare regulations (i.e., knowledge that consumers have a right to a fair hearing if they are denied benefits for no reason) and how to advocate for consumers when they are having problems with the welfare office.
- VI.4 Partner with services that will provide post-employment support and counseling for PLWHA who are leaving welfare for work. Job turnover during the initial phase of employment is very high, and consumers will benefit from support during this time of change in their lives.
- VI.5 Partner with technical training and education programs to support consumers in developing the skills necessary to get and keep a job. Provide NEMA funded agencies with information for appropriate education and training referral.
- VI.6 Advocate for more prompt decisions regarding SSI eligibility and LTSP benefits for PLWHA.
- VI.7 Evaluate the feasibility of funding a Ryan White case manager at city and county welfare sites. Advocate for a representative who is knowledgeable about HIV.