

People Living
with HIV/AIDS
in Western New York

2004

Survey Results



Presented by the PLWHA Committee—AIDS Network of Western New York, Inc.

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Introduction

The survey was first developed and conducted in 1997 by the PLWHA (persons living with HIV/AIDS) Committee of the AIDS Network of Western New York, Inc. Through this survey, the committee can monitor the self-reported behaviors, knowledge, and beliefs of those individuals living with HIV/AIDS throughout Western New York. The survey provides an instrument that assists the region in assessing the HIV service delivery gaps, priority settings, and related strategy recommendations. The survey was conducted in 1997, 1999, 2001 and 2004. It has evolved and been modified to include a wider range of specified topics, increase data reliability, and assure the privacy and confidentiality of all people participating.

The 2001 Survey

309 people living with HIV/AIDS residing in the eight counties of Western New York completed the survey from October 2003 - May 2004. Respondents were compensated \$3 and/or given other token incentives for participating in the survey. The survey represents a sampling of 6.5% of all those estimated to be living with HIV/AIDS in Western New York.¹ The survey margin of error is +/- 5.5%.

The 2004 survey was administered through various methods: 1) random one-to-one interviews were conducted by committee members at several locations; 2) the committee in conjunction with service providing agencies and employees administered the survey to clients accessing services, and 3) committee members privately administered surveys to other persons living with HIV/AIDS known personally by them, especially concentrating on those not accessing services.

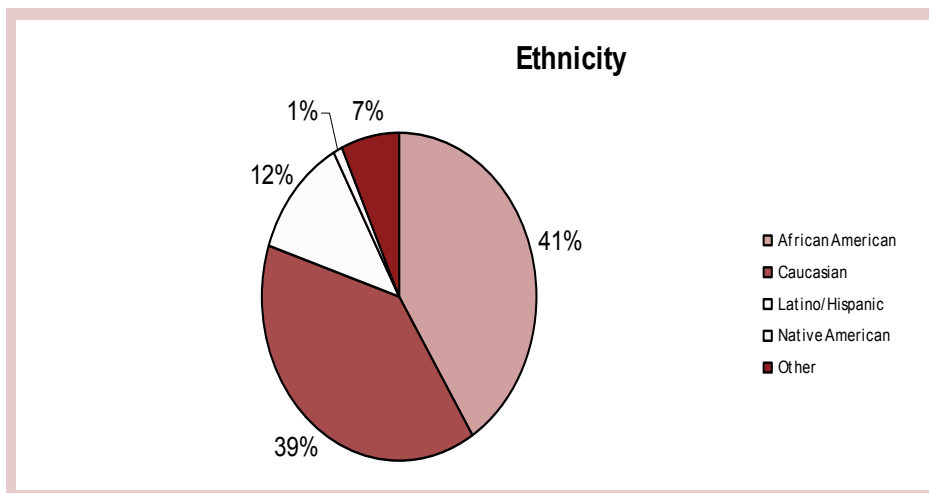
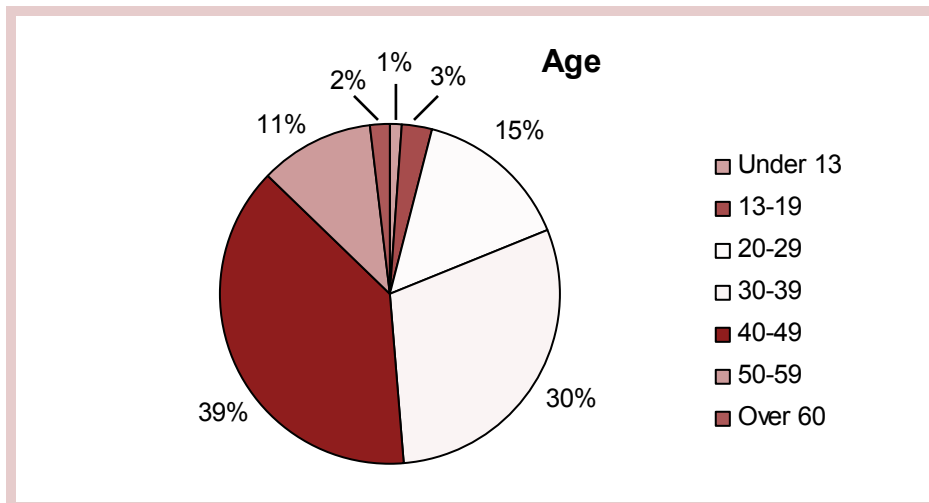
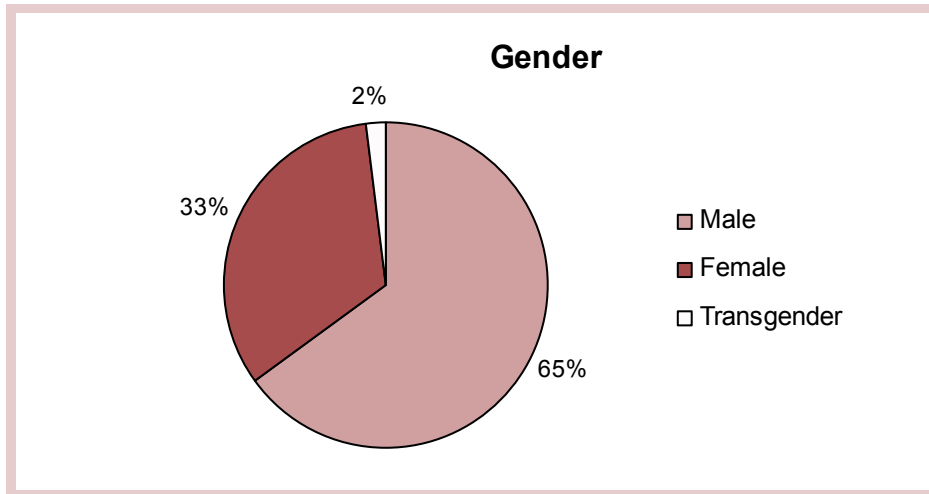
¹ As reported by AIDS Network Data Collection Committee Report April 2004

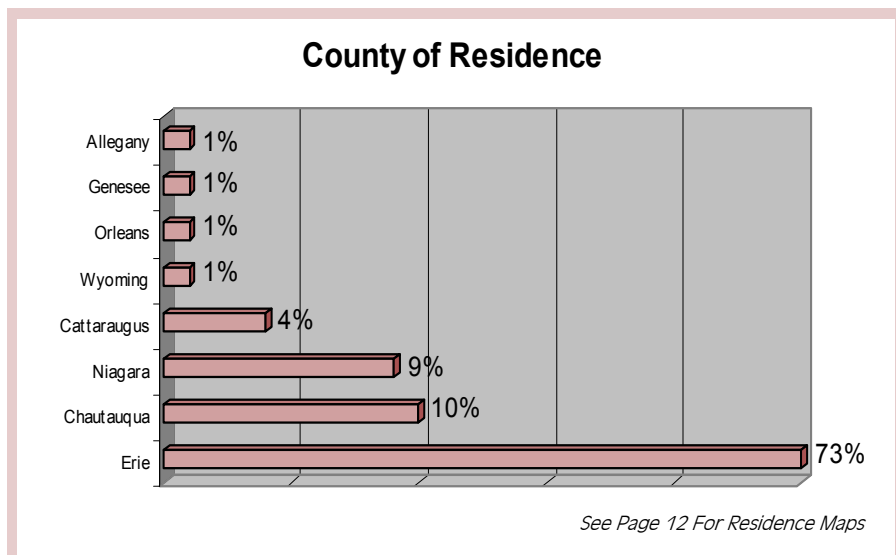
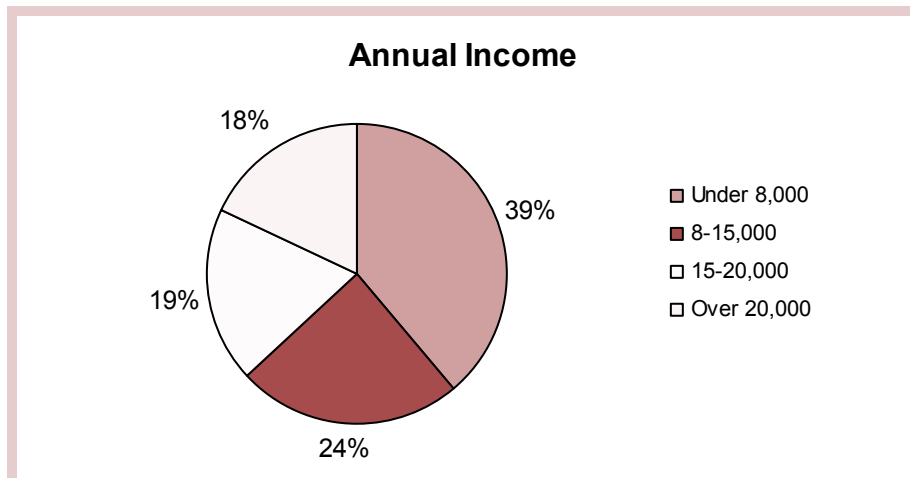
Did You Know?

Of the PLWA/HIV responding to the 2004 survey. . .

- ◆ The majority are Male (65%); African American (41%); Ages 40-49 (39%); do not have children (54%); and earn less than \$8,000 annually (39%).
- ◆ 41% are afraid to disclose their HIV status.
- ◆ 16% are unaware of New York State's AIDS Drug Assistance Program (ADAP).
- ◆ 56% are unaware of New York State's Expanded Syringe Access Project (ESAP).
- ◆ 27% missed medical appointments because of transportation problems.
- ◆ 55% feel that workers in benefit/entitlement agencies are not informed nor educated about HIV/AIDS. 40% do not feel that workers in these agencies treat them fairly or with respect.
- ◆ 64% have been treated for depression, excessive worrying, emotional concerns, or attempted suicide. 59% feel that they need emotional treatment/counseling now.
- ◆ 25% reported they were hit, threatened or abused by their partner.
- ◆ 54% are unemployed. 57% of these individuals stopped working because of their HIV status.

Demographics

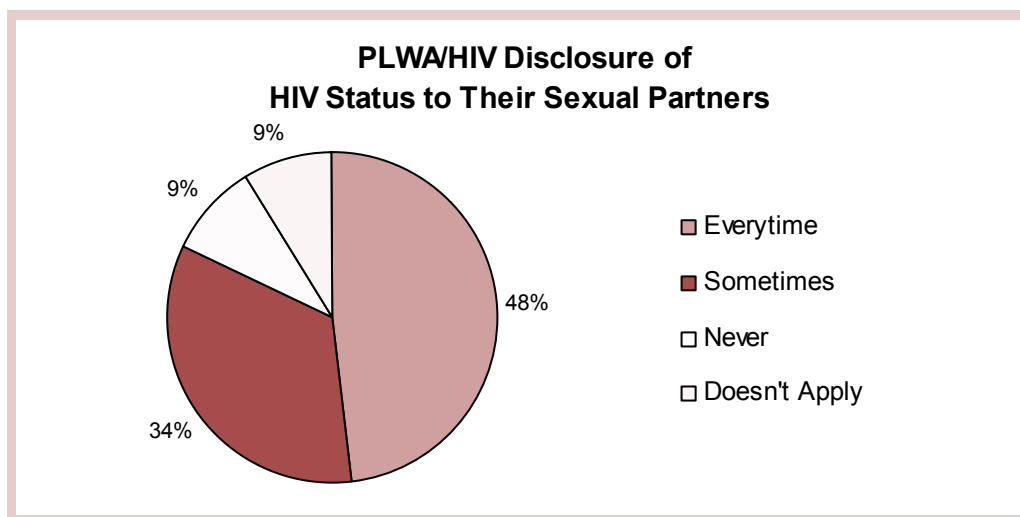
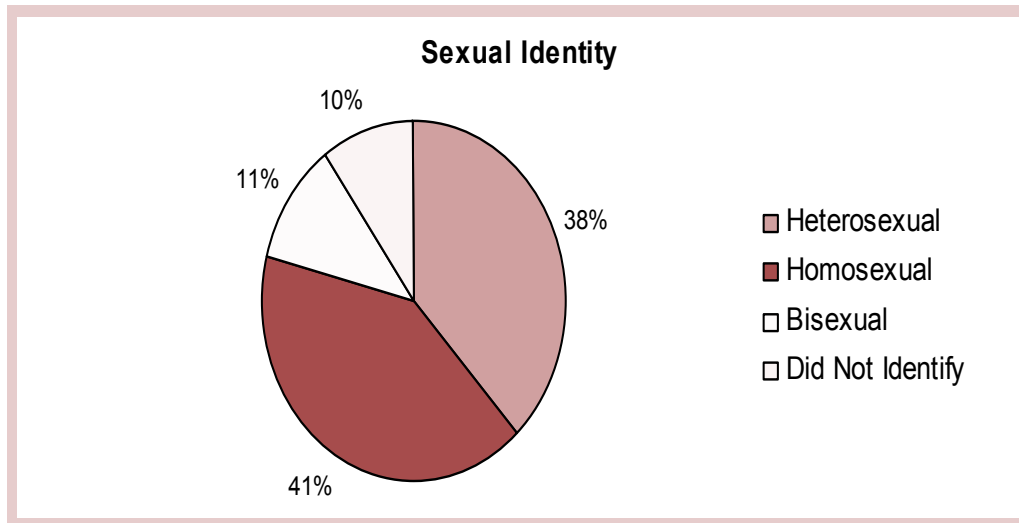




Miscellaneous

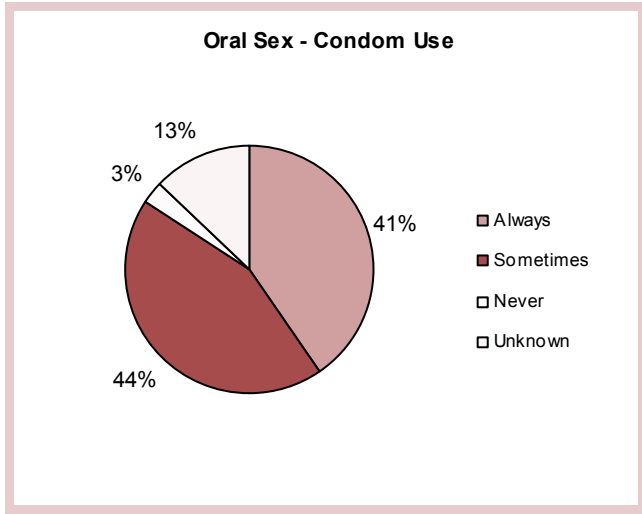
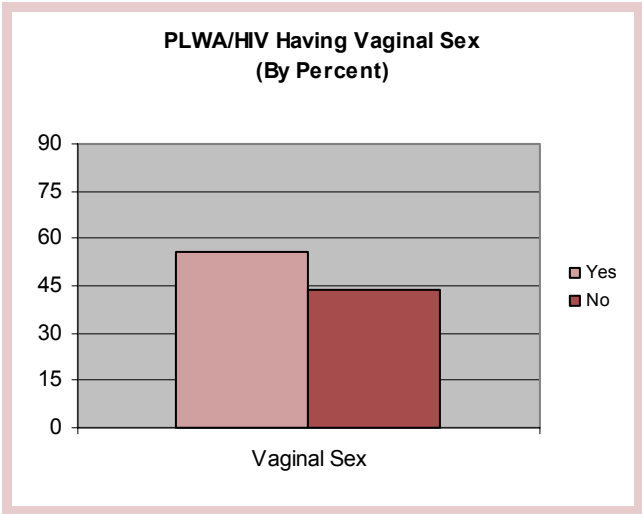
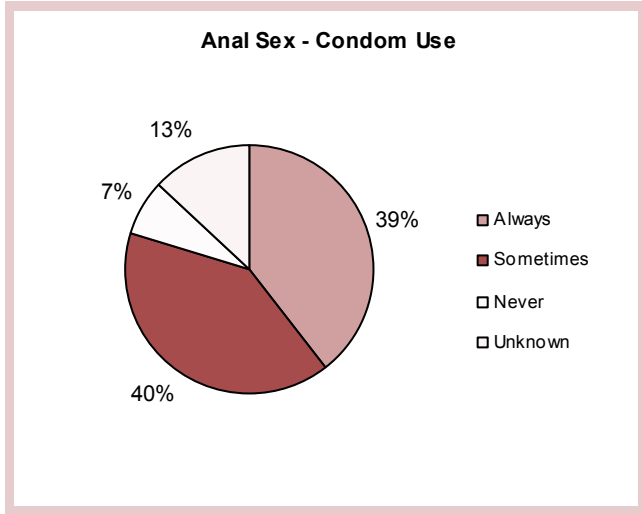
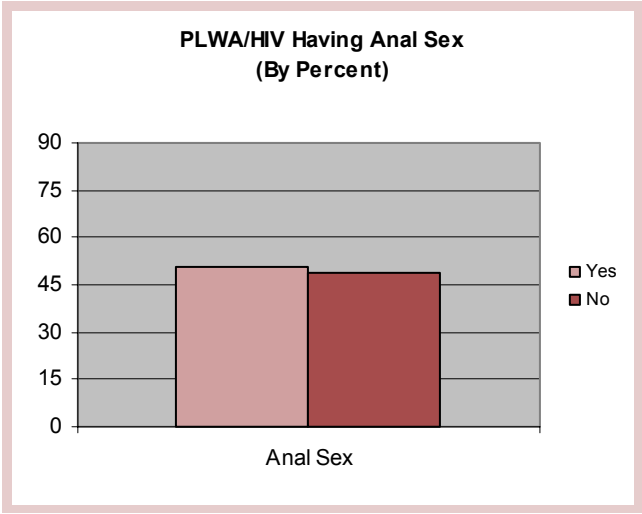
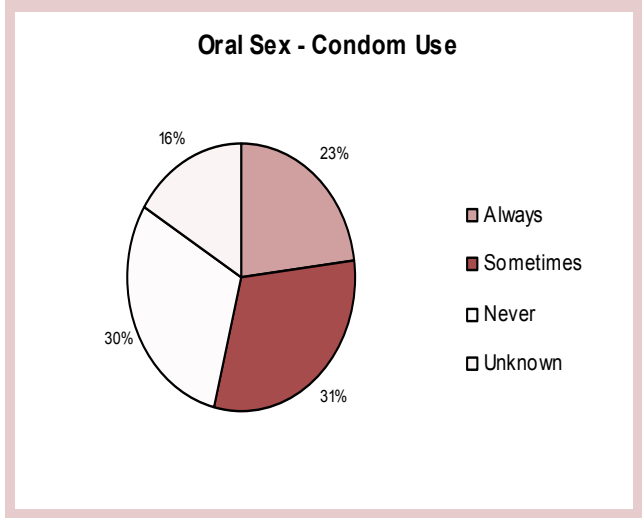
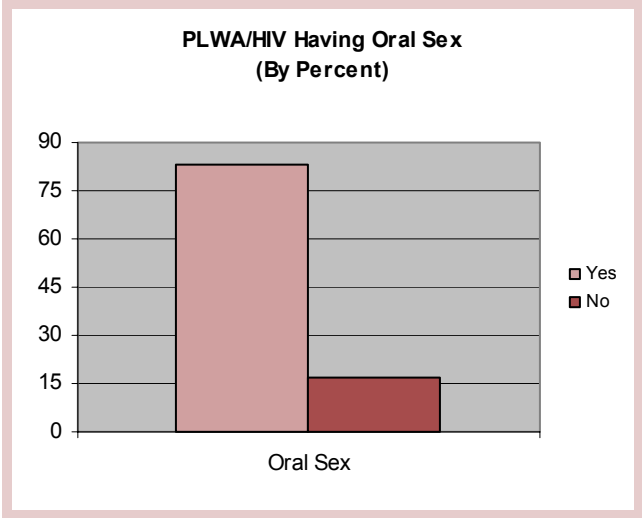
- 59% of respondents identified as Single, while 23% identified as Married or having a Domestic Partner.
- 98% are U.S. citizens, while 2% identified as Documented Immigrants; 1% Undocumented Immigrants; and 1% North American Indians.
- 92% identify English as their primary language.
- 32% have spent time in jail or prison.
- 4% of respondents have had HIV less than one year; 22% one to five years; 39% five to ten years; and 38% more than ten years.
- 83% reported they tested positive in New York State.

Identity & Sexual Behavior



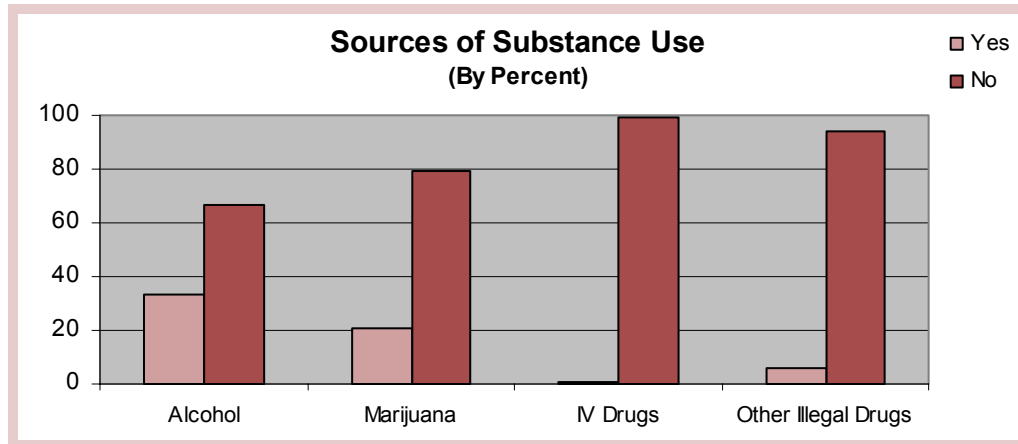
Miscellaneous

- 85% of all respondents reported having sex with another person since testing HIV positive. This is a decrease from the 2001 survey result of 92%.
- 15% report they have not had sexual relations since testing HIV positive. This is an increase from the 2001 survey result of 8%.
- At least 44% of all respondents reported that they engaged in some form of unprotected sex since testing HIV positive. This is an increase from the 2001 survey result of 24%, the 1999 survey result of 33% and the 1997 result of 38%.



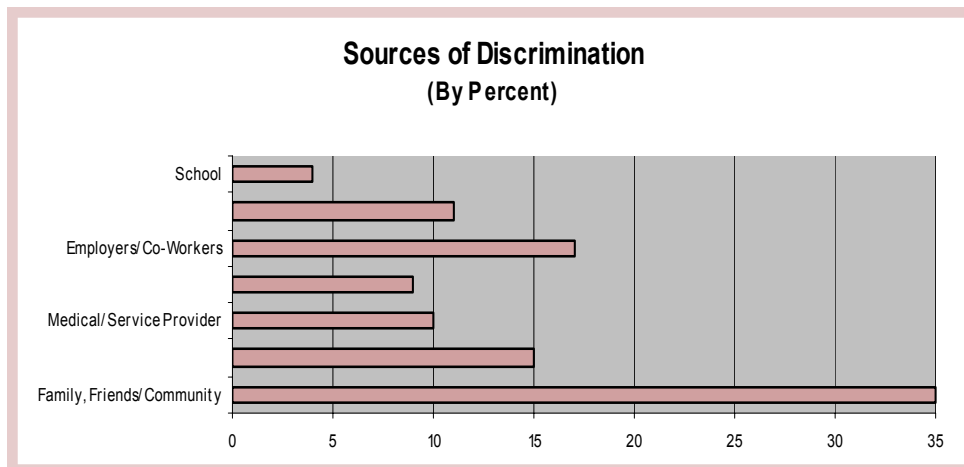
Alcohol and Other Substance Use

- 33% of respondents reported using alcohol in the past 6 months.
- 14% reported that their substance use interferes with their daily life or their health.
- 33% reported that their substance use resulted in not practicing safe sex and 7% reported that their use of drugs and/or alcohol resulted in them using unclean needles.
- 14% reported that their drug or alcohol use has caused them to miss HIV related appointments.
- 1% reported that they had shared needles in the past 6 months.
- 56% have not heard of the New York State Expanded Syringe Access Project (ESAP).



Disclosure & Discrimination

- 88% disclosed their HIV status to someone other than their health care provider. This is a decrease from the 2001 survey result of 73%.
- 41% are afraid to disclose their status. This is a slight decrease from the 2001 survey result of 42%.
- 34% reported that they have been discriminated against because of their HIV status. This is a slight decrease from the 2001 survey result of 35%.
- 4% reported they took legal action because of this discrimination. There is no change from the 2001 survey result.

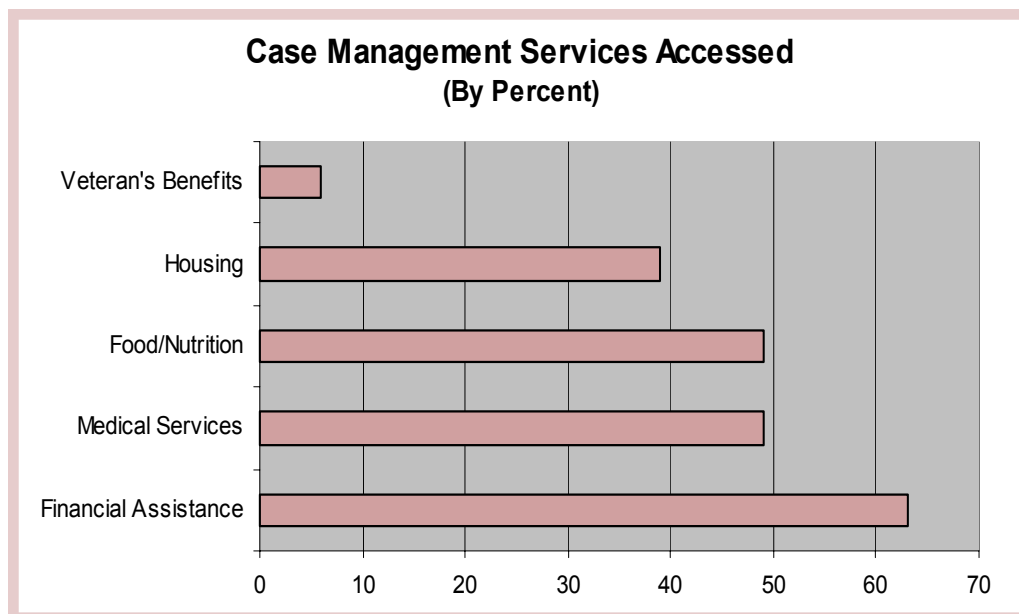


Benefits & Entitlements

- 59% of all respondents report receiving some form of public benefits or entitlements. (WIC, Veterans Benefits, Housing Assistance, HEAP, Public Assistance, Section 8 Housing, Social Security, Food Stamps, etc.)
- 33% of PLWA/HIV have had problems (with workers, shutoffs, waiting lists, etc.) in obtaining benefits/entitlements. This is a decrease from the 2001 survey result of 44%.
- 55% feel the workers in these agencies are not informed nor educated about HIV/AIDS. There is no change from the 2001 survey results.
- 40% feel they are not treated fairly or with respect by the workers in these agencies. There is no change from the 2001 survey results.

Case Management

- 57% of respondents reported having a case manager.
- All 57% reported that their case manager helped them to meet their basic needs.
- 17% reported being on a waiting list for services.



Women & Children

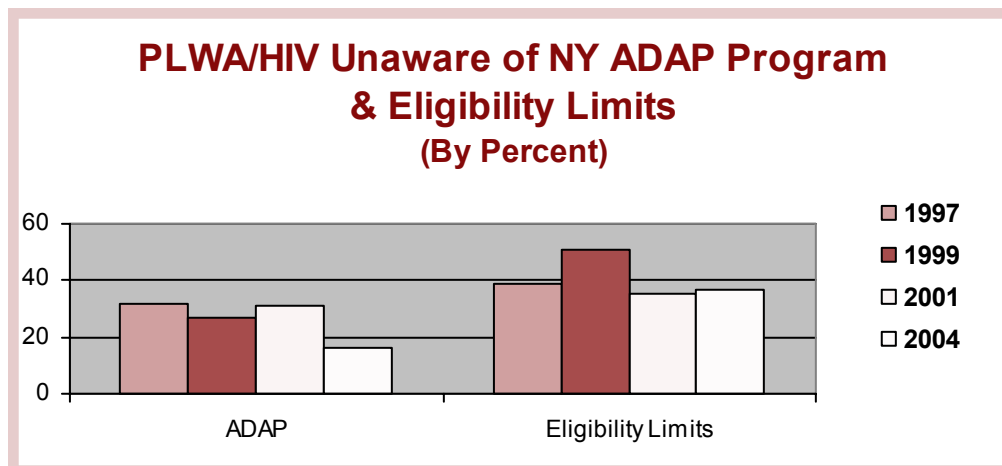
- 45% of respondents (both male and female) have children. This is an increase from 2001 when 29% reported having children and a decrease from 1999 when 53% reported having children.
- 68% of these children have been tested for HIV and 9% have tested HIV positive. The 2001 survey results reflected 60% of respondents children had been tested for HIV and 8% tested HIV positive.
- 45% of PLWA/HIV parents have a legal plan in place to take care of their children in the event of their death. This is an increase from the 2001 survey result of 39%.
- 3% of the female respondents reported that they were currently pregnant.
- 77% of the female respondents reported to have ever been pregnant.
- 44% reported that they were offered HIV testing while pregnant. This is an increase from 2001 when 37% reported they were offered HIV testing while pregnant.
- 46% reported being pregnant and HIV positive at the same time. This is a significant increase from 2001 when 15% reported being pregnant and HIV positive.
- 26% reported they knew they were HIV positive before becoming pregnant. This is a significant increase from 2001 when 6% reported they knew they were HIV positive before becoming pregnant.

Medical Care & Mental Health

- 91% reported they are currently under a doctor's care.
- 51% reported seeing a doctor during their appointments, 30% reported seeing a nurse practitioner or physician assistant, and 19% were unsure or did not respond.
- 13% reported having difficulty keeping appointments because their health care provider was unavailable to see them.
- 64% of the respondents have been treated for depression, excessive worrying, emotional concerns, or attempted suicide and 59% currently feel they need counseling. In 2001 59% reported being treated and 41% felt they currently needed counseling.
- 25% reported that they have been hit, threatened or abused by their partner. This is decrease from 2001 when 33% reported being hit, threatened or abused by their partners.

Medications & Health Insurance

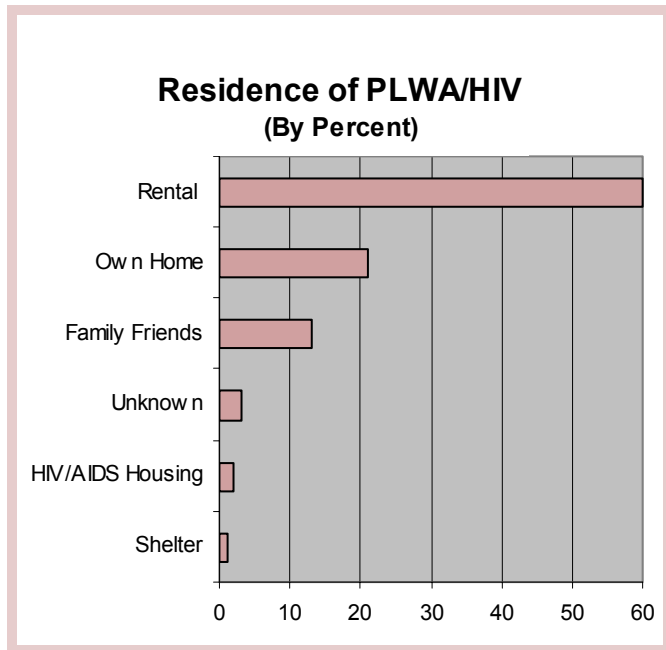
- 91% reported they have some form of health insurance.
- 78% reported they are currently taking HIV-related medications. This is an increase from the 2001 survey result of 70%.
- 53% of those not currently taking HIV-related medications reported that they had taken them previously but stopped.
- Of the respondents not taking HIV-related medications, 34% reported they stopped due to side effects, 21% reported their doctor told them to, and 13% reported their substance use interfered with taking the medications.



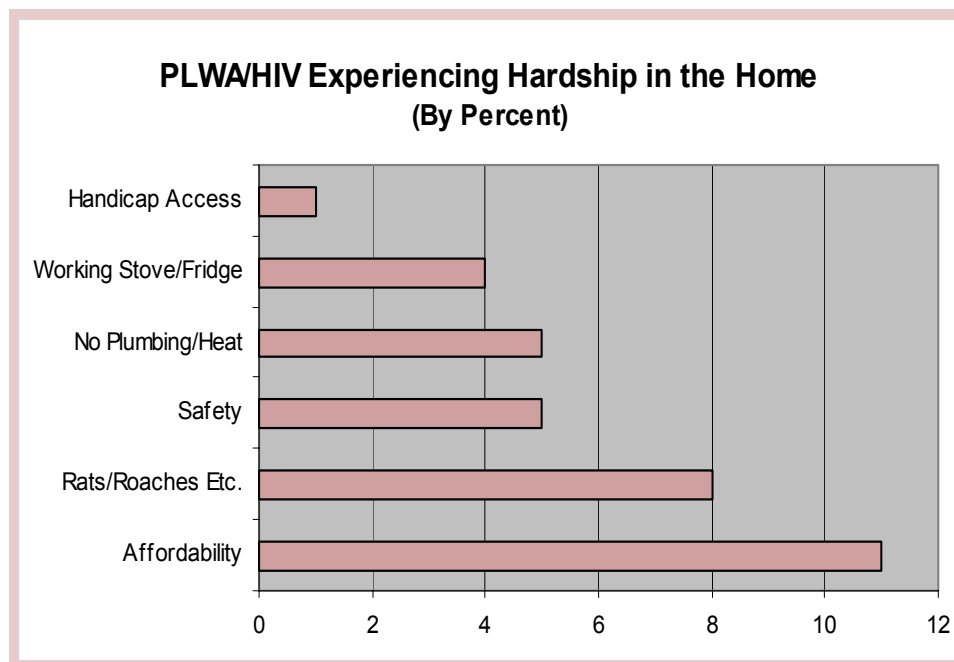
Employment

- 54% of PLWA/HIV reported they were unemployed. This is a decrease from the 2001 survey results of 63%.
- 36% of those unemployed feel well enough to work. There is no change from the 2001 survey.
- 57% of those unemployed stop working because of their HIV status.
- 57% of those unemployed said they would return to work if they could be guaranteed their current medical benefits. This is an increase from the 2001 survey results of 42%.

Housing

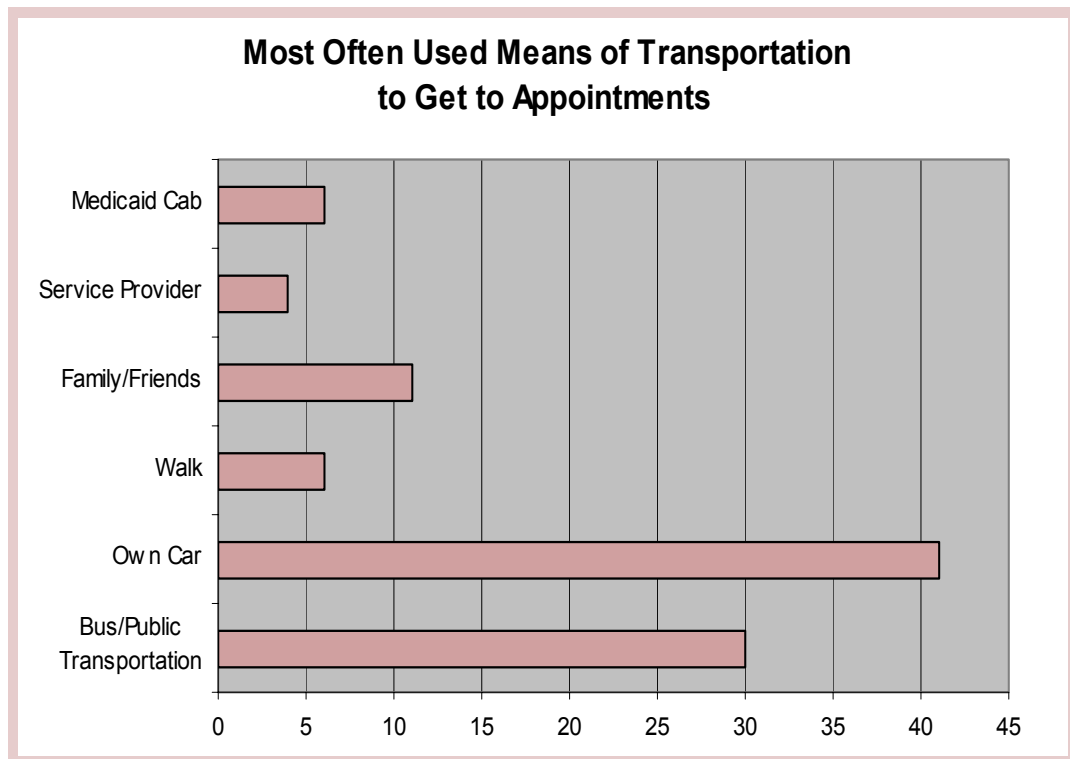
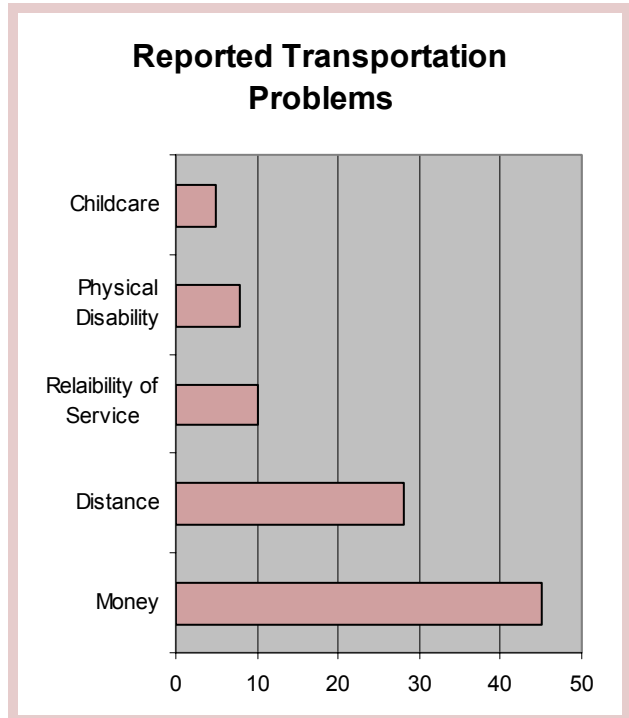


- 11% have spent time on the streets or in an emergency shelter since testing HIV positive.
- 17% of these respondents have spent time on the streets or in an emergency shelter within the last month while 26% within the last 6 months to one year.
- 60% of respondents live in a rental unit and 21% own their own home..
- 1% currently live on the streets or depend on emergency shelters.



Transportation

- 27% of respondents report they have missed appointments because of transportation problems in the past six months .
- 41% use their own automobile as the most often used means of getting to appointments while 30% use public transportation.
- 6% walk to their appointments and 11% obtain a ride with friends or family members.
- 4% Obtain a ride from their service providers to get to appointments, 6% use a Medicaid cab, and 1% utilize a funded Ryan White transportation program.



Conclusion

In conclusion, this report describes the results of the 2004 Western New York People Living with HIV/AIDS Survey. The results of this study can be used to help make important inferences concerning the priorities of PLWA/HIV residing in Western New York, and can provide input into the program development and modification.

Through analysis of these results, the AIDS Network and its members can determine some of the needs of PLWA/HIV and stimulate discussion regarding the development and implementation of effective HIV/AIDS related services. This can only help to further support and enrich the lives and futures of all those impacted by HIV and AIDS throughout the region.

For More Information



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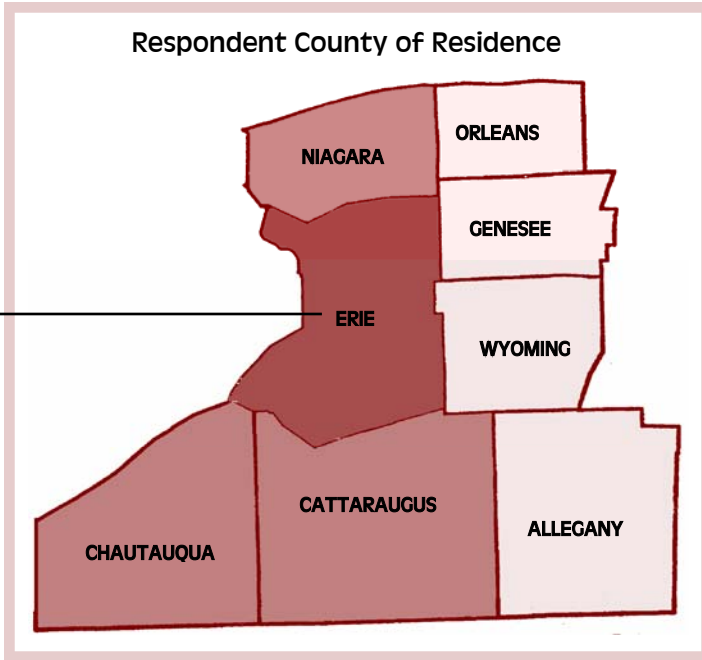
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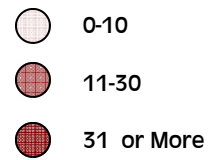
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Residence Maps

Respondent County of Residence



Number of Respondents



Greater Buffalo Area Respondents (By Zip Code)

