

2009

# consumer survey results

AIDS  
**network**  
of Western New York

40 gates circle buffalo, ny 14209  
(716) 882-7840 [www.aidsnetwork.net](http://www.aidsnetwork.net)

# table of contents

Introduction . . . . .	2
Did You Know?. . . . .	2
Demographics . . . . .	3
Identity & Sexual Behavior . . . . .	5
Alcohol & Other Substance Use . . . . .	7
Disclosure & Discrimination . . . . .	7
Benefits & Entitlements. . . . .	8
Case Management . . . . .	8
Women & Children . . . . .	9
Legal . . . . .	9
Medical Care & Mental Health . . . . .	9
Medications & Health Insurance . . . . .	10
Employment . . . . .	10
Housing . . . . .	11
Transportation . . . . .	12
Conclusion . . . . .	13
Residence Maps. . . . .	14

# introduction

The survey was first developed and conducted in 1997 by the Consumer Involvement 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 HIV service delivery gaps, priority setting, and related strategy recommendations. Conducted every other year, the survey has evolved and been modified to include a wider range of specified topics, increased data reliability, and assure the privacy and confidentiality of all people participating.

## **The 2009 Survey**

250 people living with HIV/AIDS residing in the eight counties of Western New York completed the survey from September 2008 - March 2009. Respondents were compensated \$5 and/or given other token incentives for participating in the survey. The survey represents a sampling of 9% of all those estimated to be living with HIV/AIDS in Western New York.<sup>1</sup> The survey margin of error is +/- 6.3%.

The 2009 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.

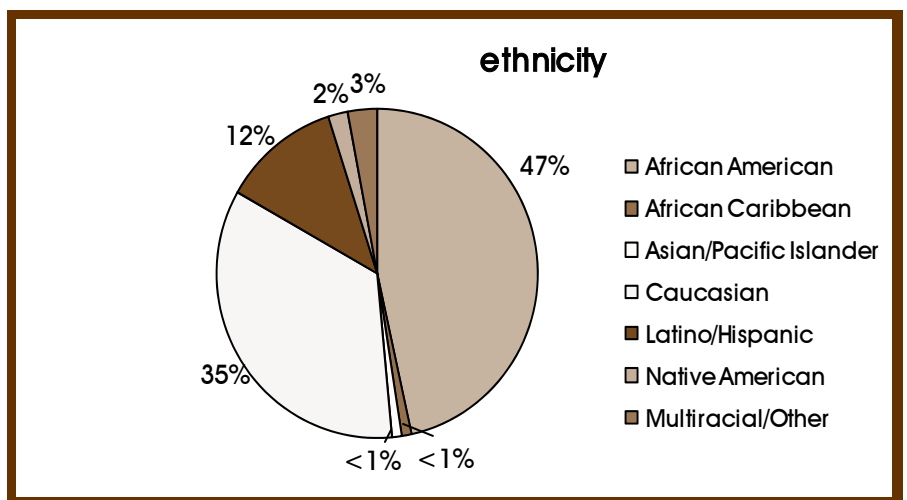
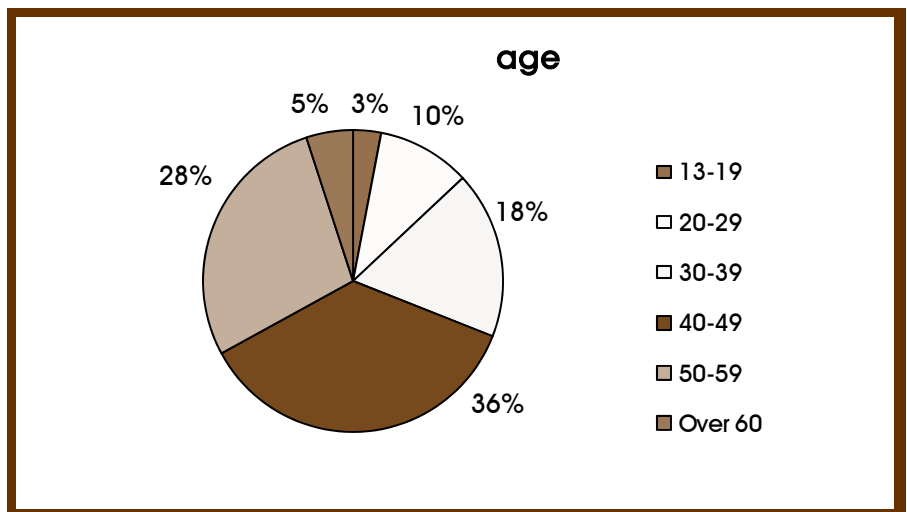
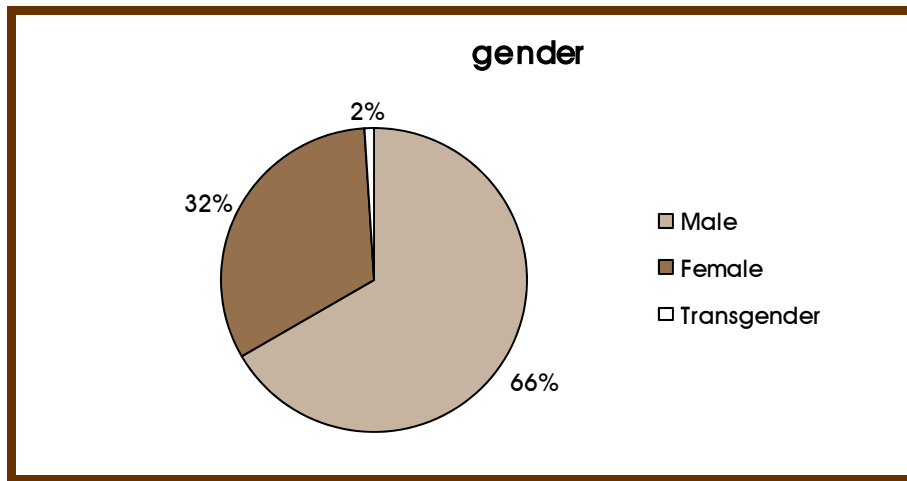
<sup>1</sup> As reported by AIDS Network Data Collection Committee Report 2007-2008

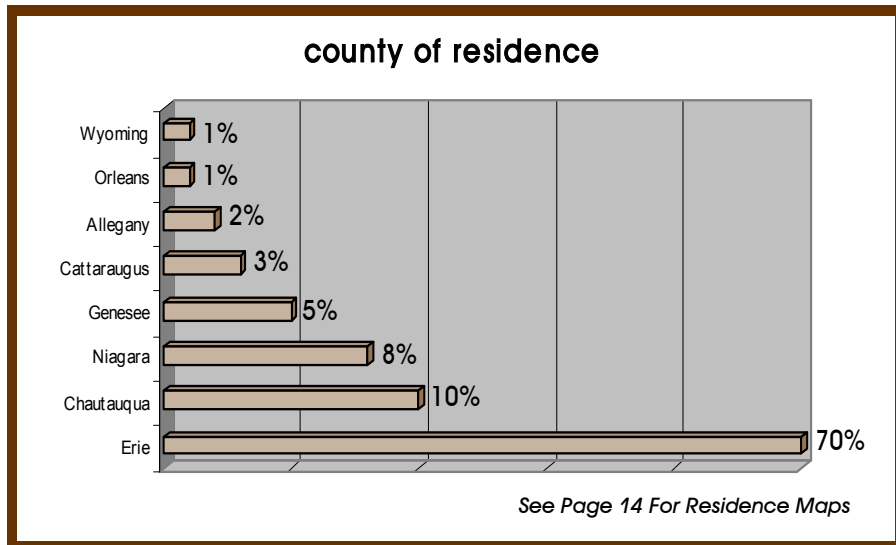
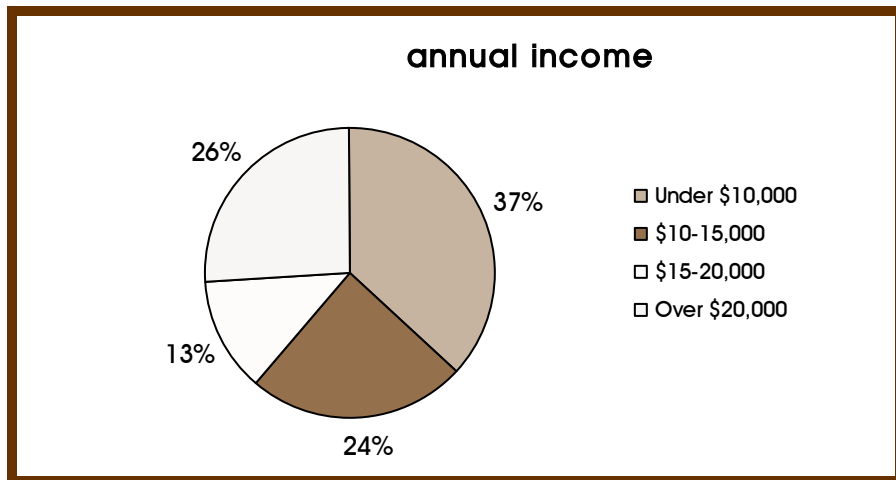
## did you know?

### **of the PLWA/HIV responding to the 2009 survey. . .**

- 66% are male; 47% African American; 69% age 40 or over; 46% have children and 61% earn less than \$15,000 annually.
- 58% are unemployed. 46% of these individuals stopped working because of their HIV status.
- 62% are afraid to disclose their HIV status.
- 18% are unaware of New York State's AIDS Drug Assistance Program (ADAP).
- 33% missed medical appointments because of transportation problems.
- 84% of respondents reported using alcohol and 50% reported using marijuana in the past six months.
- 73% have suffered from depression, excessive worrying, emotional concerns, or attempted suicide. Of these, 24% have never received treatment.
- 23% reported they were hit, threatened or abused by their partner.
- 88% reported having sex with another person since testing HIV positive with 54% having some form of unsafe sex.

# demographics

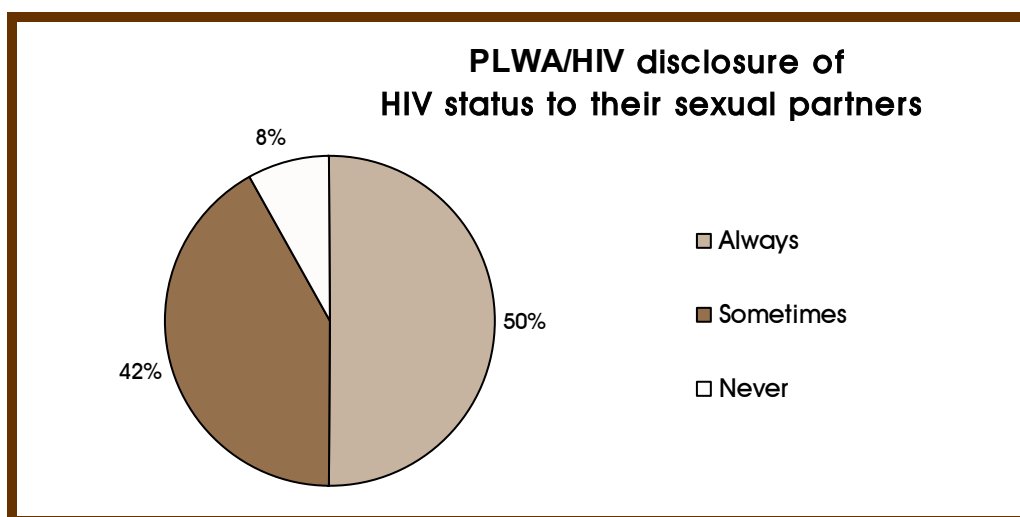
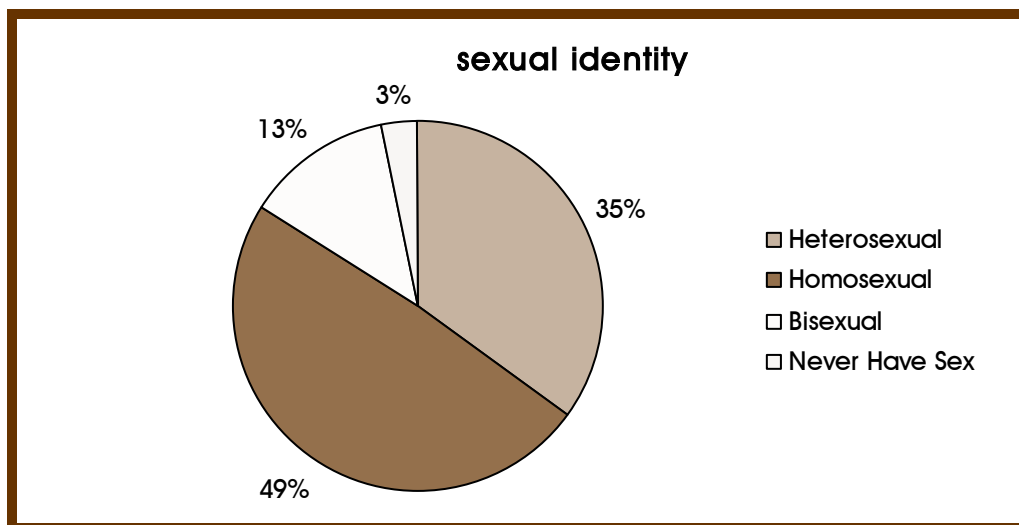




### miscellaneous

- 60% of respondents identified as single, while 19% identified as married or having a domestic partner.
- 99% are U.S. citizens, while 1% identified as documented or undocumented immigrants.
- 94% identify English as their primary language.
- 9.5% have spent time in jail or prison in the past year.
- 10% of respondents have had HIV less than one year; 19% one to five years; 21% five to ten years; and 50% more than ten years.
- 81% reported they tested positive in New York State.

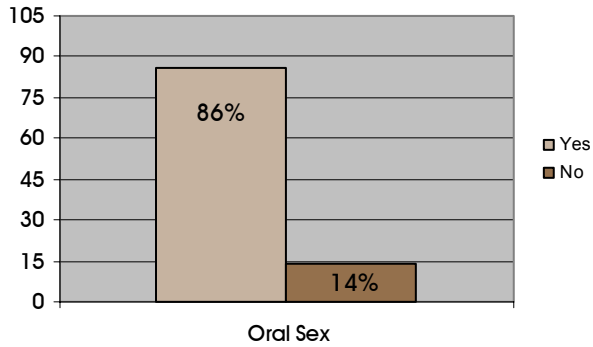
# identity & sexual behavior



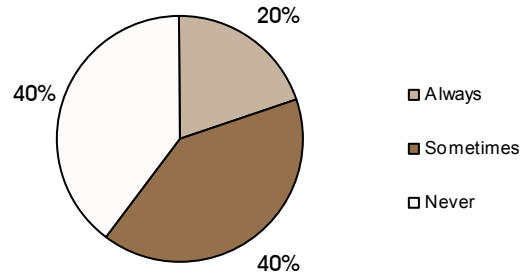
## miscellaneous

- 88% of all respondents reported having sex with another person since testing HIV positive. This is an increase from the 2007 survey result of 84%. (2004 = 85%; 2001 = 92%)
- 20% reported always using condoms for oral sex, 52% always using condoms for vaginal sex and 36% always using condoms for anal sex. (2007 = 31%, 57%, 37%) (2004 = 23%, 41%, 39%)
- At least 54% of all respondents reported that they engaged in some form of unprotected sex since testing HIV positive. This is an increase from the 2007 survey result of 45%. (2004 = 44%; 2001 = 24%; 1999 = 33%)

**PLWA/HIV having oral sex  
(by percent)**

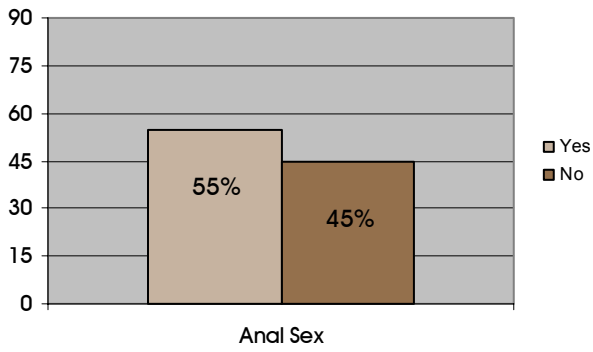


**oral sex - condom use  
2009**

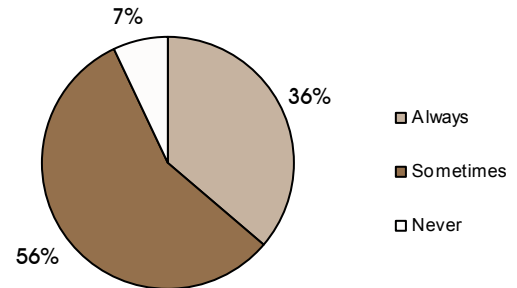


2007 - Always 31%; Sometimes 37%; Never 32%

**PLWA/HIV having anal sex  
(by percent)**

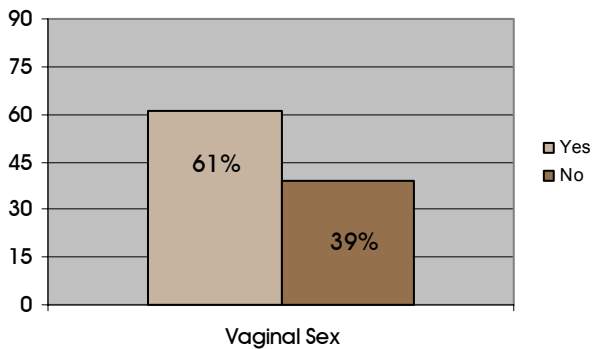


**anal sex - condom use  
2009**

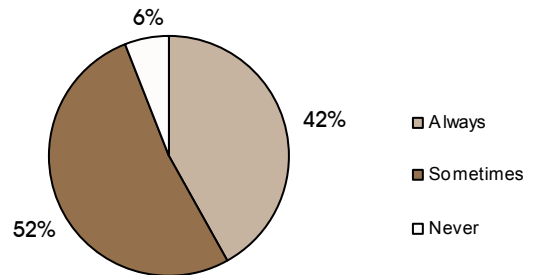


2007 - Always 37%; Sometimes 45%; Never 18%

**PLWA/HIV having vaginal sex  
(by percent)**



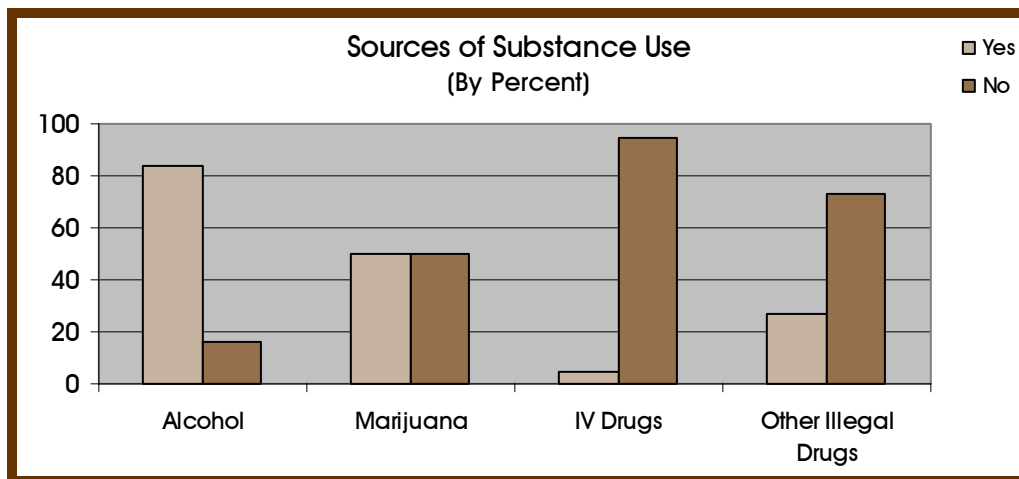
**vaginal sex - condom use  
2009**



2007 - Always 57%; Sometimes 52%; Never 5%

# alcohol and other substance use

- 84% of respondents reported using alcohol in the past 6 months and 50% reported using marijuana. This is a significant increase from the 2007 survey results of 49% and 27% respectively.
- 32% reported using illegal drugs other than marijuana, an increase from the 2007 survey result of 17%. (2004 = 6%)
- 27% reported that their substance use interferes with their daily life or their health. There was no change from the 2007 results. (2004 = 14%)
- 28% reported that their substance use resulted in not practicing safe sex and 5% reported that their use of drugs and/or alcohol resulted in them using unclean needles. In 2007, 22% reported their substance use resulted in not practicing safe sex and 5% reported that their use of drugs and/or alcohol resulted in their using unclean needles. (2004 = 33% and 7%)
- 17% reported that their drug or alcohol use caused them to miss HIV related appointments. This is a decrease from the 2007 survey result of 18%. (2004 = 14%)
- 1% reported that they had shared needles in the past 6 months. (2007 = 1%)



# disclosure & discrimination

- 51% told their sexual partners of their HIV status, this is a decrease from the 2007 survey result of 58%. (2004 = 48%)
- 62% reported they are afraid to disclose their status to others. This is an increase from the 2007 survey result of 57%. (2004 = 41%)
- 36% reported that they have been discriminated against because of their HIV status. This is an increase from the 2007 survey result of 31%. (2004 = 34%)
- 10% reported they took legal action because of this discrimination. There is no change from the 2007 survey results. (2004 = 4%)

## benefits & entitlements

- 66% 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.)  
(2007 = 64%; 2004 = 59%; 2001 = 50%)
- 45% of PLWA/HIV have had problems (with workers, shutoffs, waiting lists, etc.) in obtaining benefits/entitlements. (2007 = 48%; 2004 = 33%; 2001 = 44%)
- 16% feel the workers in these agencies are not informed or educated about HIV/AIDS. There is a significant decrease from the 2007 survey results of 77%.  
(2004 = 33%; 2001 = 55%; 1999 = 35%)
- 8% feel they are not treated fairly or with respect by the workers in these agencies. There is a significant decrease from the 2007 survey results of 70%.  
(2004 = 40%; 2001 = 55%; 1999 = 42%)

## case management

- 59% of respondents reported having a case manager. This is a decrease from the 2007 result of 62%. (2004 = 57%; 2001 = 65%)
- 26% of respondents have had 3 or more case managers in the past year and 10% have had to wait 6 months or longer to receive a new case manager.  
(2007 = 17% & 10% respectively)
- 15% reported being on a waiting list for services (2007 = 18%; 2004 = 17%; 2001 = 20%). 19% of the 2008-2009 respondents reported waiting for a year or more.
  - ◇ Of those respondents on a waiting list for services 55% were waiting for housing services/section 8; 15% for lunch/nutritional programming; 9% case management services and 6% for Social Security benefits.

## women & children

- 46% of respondents (both male and female) have children. This is an increase from 2007 when 42% reported having children. (2004 = 45%; 2001 = 29%)
- 66% of these children have been tested for HIV and 2% have tested HIV positive. The 2007 survey results reflected 66% of respondent's children had been tested for HIV and 7% tested HIV positive. (2004 = 68% & 9% respectively)
- 3% of the female respondents reported that they were currently pregnant.
- 79% of the female respondents reported to have ever been pregnant.
- 22% reported they knew they were HIV positive before becoming pregnant. (2007 = 22%; 2004 = 26%; 2001 = 6%; 1999 = 20%)
  - ◊ Of these women, 79% reported their pregnancy was unplanned an increase from the 2007 survey results of 62%.

## legal

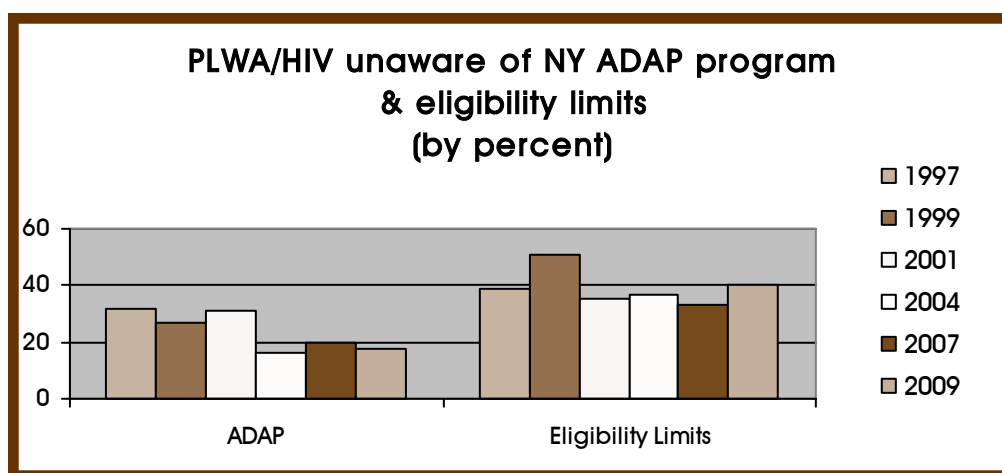
- 47% of PLWA/HIV parents have a legal plan in place to take care of their children in the event of their death. (2007 = 49%; 2004 = 45%)
- 44% of respondents (male and female) do not have a current health care proxy; 63% do not have a current living will. (2007 = 46% & 63%)

## medical care & mental health

- 97% reported they are currently under a doctor's care with 86% seeing their doctor every one to six months. (2007 = 93% & 86%)
- 27% reported difficulty keeping appointments because their health care provider was unavailable to see them.
- 73% of the respondents have suffered from depression, excessive worrying, emotional concerns, or attempted suicide. This is a significant increase from the 2007 survey results of 66%, 2004 results of 64%, and 2001 results of 59%.
  - ◊ Of the 2008 respondents reporting suffering from depression, excessive worrying, emotional concerns, or attempted suicide 24% report never receiving related treatment. (2007 = 18%)
- 23% reported that they have been hit, threatened or abused by their partner. (2007 = 23%; 2004 = 25%; 2001 = 33%)

# medications & health insurance

- 99% reported they have some form of health insurance.  
(2007 = 95%; 2004 = 91%; 2001 = 92%; 1999 = 69%)  
◊ 64% Medicaid; 29% Medicare; 33% ADAP; 26% Private Insurance
- 83% reported they are currently taking HIV-related medications.  
(2007 = 78%; 2004 = 78%; 2001 = 70%; 1999 = 84%)
- 75% of those not currently taking HIV-related medications reported that they had taken them previously but stopped. (2007 = 59%; 2004 = 34%)
- Of the respondents not taking HIV-related medications, 34% reported they stopped due to side effects, 31% reported their doctor told them to stop, and 14% reported their substance use interfered with taking the medications.



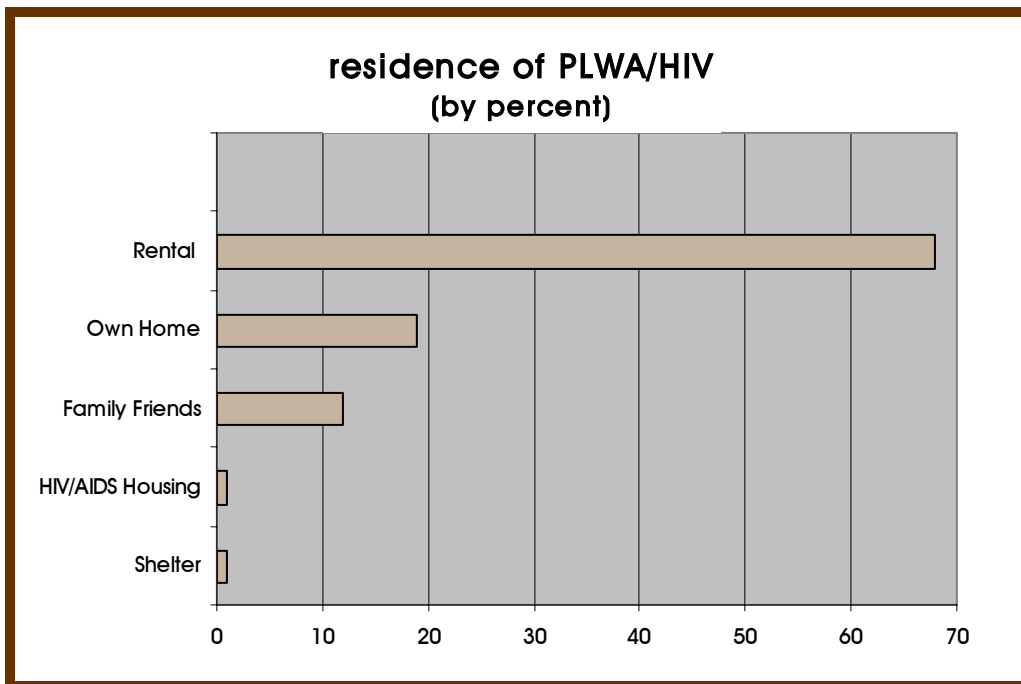
- 66% were unaware that the APIC program can help cover insurance premiums, deductibles and/or copayments.

# employment

- 58% of PLWA/HIV reported they were unemployed.  
(2007 = 63%; 2004 = 54%; 2001 = 63%; 1999 = 64%)
- 46% of those unemployed feel well enough to work.  
(2007 = 34%; 2004 = 36%; 2001 = 36%; 1999 = 54%)
- 46% of those unemployed stopped working because of their HIV status.  
(2007 = 46%; 2004 = 57%)

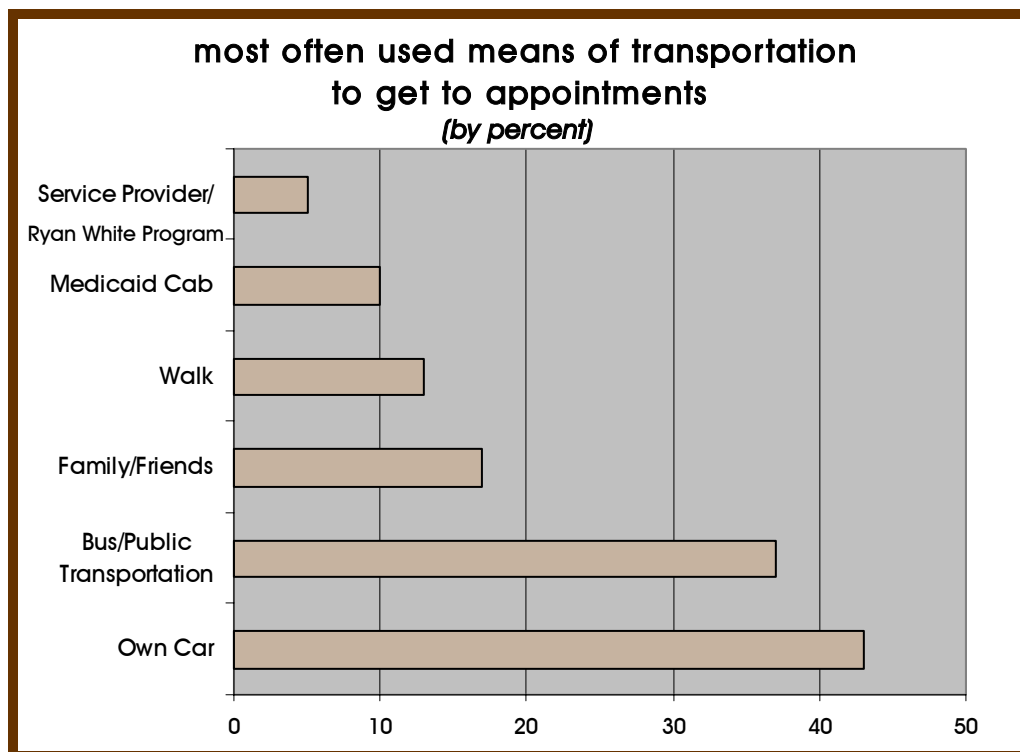
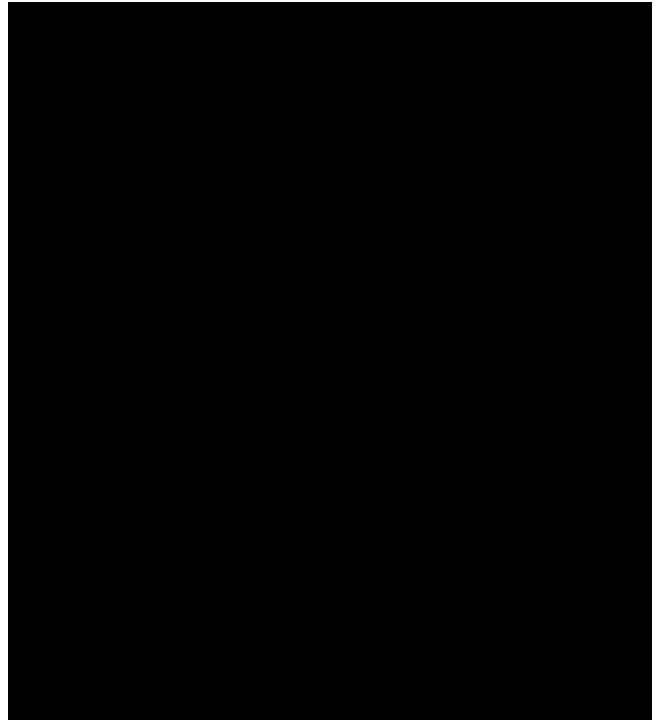
# housing

- 25% have spent time on the streets or in an emergency shelter since testing HIV positive. (2007 = 23%; 2004 = 11%; 2001 = 35%; 1999 = 23%)
- 14% of these respondents have spent time on the streets or in an emergency shelter within the last month (2007 = 17%; 2004 = 17%; 2001 = 12%).  
39% within the past year (2007 = 46%; 2004 = 26%; 2001 = 36%; 1999 = 23%)
- 1% currently live on the streets or depend on emergency shelters.  
(2007 = 3%; 2004 = 1%; 2001 = 4%)
- 68% of respondents live in a rental unit and 19% own their own home.



# transportation

- 33% of respondents report they have missed appointments because of transportation problems in the past year.
- 29% reported transportation problems for medical appointments and 30% had problems for support services.
- 43% use their own automobile as the most often used means of getting to appointments while 37% use public transportation.
- 13% walk to their appointments and 17% obtain a ride with friends or family members.
- 5% obtain a ride from their service providers to get to appointments, 10% use a Medicaid cab, and 4% utilize a funded Ryan White transportation program.



## conclusion

In conclusion, this report describes the results of the 2009 Western New York People Living with HIV/AIDS Consumer 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 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



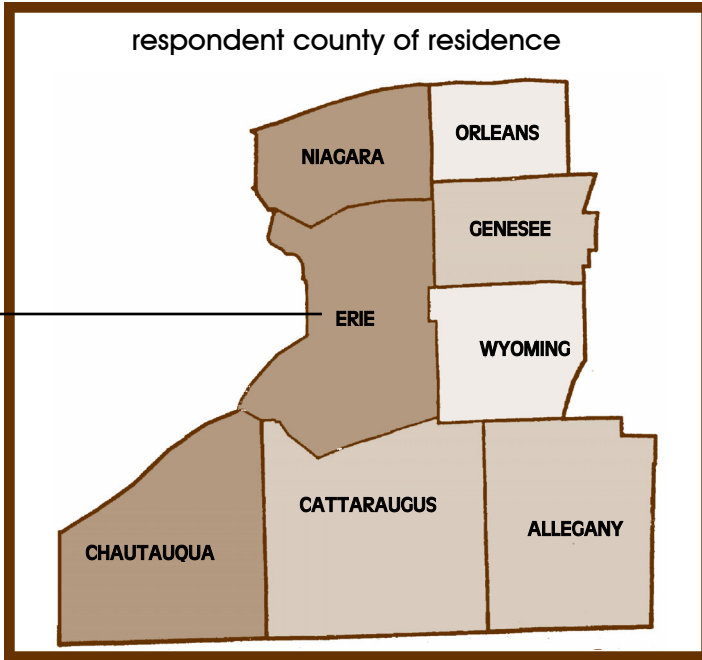
40 Gates Circle, Suite 100  
Buffalo, NY 14209

Phone: (716) 882-7840  
Fax: (716) 882-2139  
E-Mail: [aidsnet@pce.net](mailto:aidsnet@pce.net)

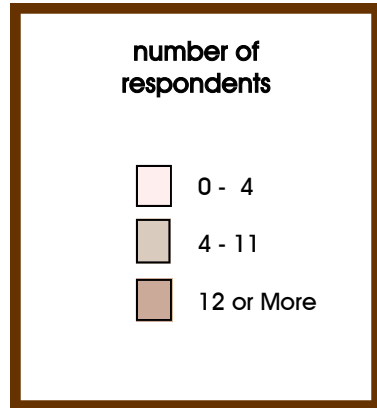
*Funding for this publication was provided by a  
Ryan White Title II CARE Act grant from the  
NYSDOH-AIDS Institute  
Health Research, Inc.  
June 2009*

# residence maps

respondent county of residence



number of respondents



greater buffalo area respondents (by zip code)

