



AIDS Network of Western New York

2003 Service Delivery Plan Update

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POLICY SUPPLEMENT

Western New York Public Policy Overview

As HIV related health and social service needs become increasingly complex and the resources to support them diminish, understanding the policy environment in which these changes are taking place becomes essential. Several developments in the New York public policy environment that may affect access to HIV services in the Buffalo-Niagara region are addressed in the content of this policy overview.

- *HIV Names Reporting and Partner Notification*: Data from the new HIV Names Reporting and Partner Notification system are slowly emerging to provide New York State with the unprecedented ability to track HIV cases throughout New York State.
- *Expanded Syringe Access Demonstration Program (ESAP)*: In 2000, the New York State Legislature authorized ESAP to expand access to sterile needles and syringes. Both Erie and Chautauqua counties have developed model programs in response to ESAP.
- *Housing Opportunities for People with AIDS (HOPWA)*: As of FY 1999, Buffalo became a new recipient of HOPWA funds receiving \$352,000 for the Eligible Metropolitan Statistical Area, which includes Erie and Niagara counties. Since the initial allocation, the formula grant has increased to \$446,000 for FY 2002. Network members report that accessing HOPWA funding has become increasingly difficult since 1999 for HIV/AIDS housing providers.
- *Ryan White CARE and Emerging Communities*: Buffalo-Niagara Falls recently qualified for enhanced funding under a new provision included in the 2000 reauthorization of the federal Ryan White CARE Act. This new funding provides supplemental grants to states to support HIV services in cities reporting between 500 and 1,999 AIDS cases in the past five years. While these additional funds are greatly needed, the small yearly allocations are not sufficient to implement new or to significantly expand existing programs.
- *Medicaid Managed Care Special Needs Plans (SNPs)*: New York State is the first in the country to establish SNPs for people with HIV related illness. However, regions outside of New York City are not likely to be served by a SNP during the period of time that this Service Delivery Plan will be utilized.
- *Welfare Reform*: Federal and State advocates for individuals and families who need public assistance are uncertain whether a newly configured Congress will usher in new restrictions in a re-authorized welfare bill including provisions, which may impact the ability of people with HIV to receive public assistance.

Introduction

Many HIV policy issues that have emerged over the past five years are relevant to the provision of HIV services in Western New York. A review of these issues helps to provide a context for the understanding of the epidemiological data, community needs, and the service prioritizations presented in 2003 Service Delivery Plan Update.

Raymond Smith, editor of the widely read HIV/AIDS newsletter, *Body Positive*, noted, “on June 5, 2001, the United States and the world mark[ed] an unhappy anniversary: the 20th anniversary of the report of the first cases of AIDS in the medical literature. On that date in 1981, the first cluster of unexplained cases of immune deficiency was officially announced in the *Morbidity and Mortality Weekly Report*, a publication of the national Centers for Disease Control and Prevention. Between 1981 and June 1999, a total of 711,344 cases of AIDS were reported in the US.”¹ New York State surpasses all States in the country with 132,086 cumulative AIDS cases reported between 1981 and 1999.²

Twenty years later, New York continues to lead the country in AIDS cases among adults and adolescents. For every known case of AIDS, there are an estimated two to three people who are HIV positive and unaware of their status.³ Women, especially women of color, men who have sex with men and injection drug users have borne the brunt of the AIDS impact in New York. While deaths from AIDS have declined since the 1996 advent of HAART therapy, the absolute number of people living with HIV and AIDS has increased as people are living longer with HIV and/or not progressing to AIDS diagnoses.⁴

One of the chief groups at risk for AIDS continues to be African Americans, who are 10 times more likely to have AIDS and to die from it than Caucasians. African-Americans and Latinos are disproportionately impacted by HIV infection and AIDS mortality – and to a greater degree than had been suggested by previous epidemiological profiles.⁵

While New York City is the well known center of New York State’s epidemic, the growth of HIV and AIDS in regions outside of the New York City has been no less alarming. AIDS outside of New York City mirrors the population trends in the city and, except for a host of issues that are specific to upstate urban, rural and suburban parts of the State, the challenge of HIV/AIDS is as complex as it is in New York City. The Western New

¹ The Kaiser Family Foundation Capitol Hill Briefing on HIV/AIDS, *The State of the HIV/AIDS Epidemic in America*, April 2000.

² The Kaiser Family Foundation Capitol Hill Briefing on HIV/AIDS, *The State of the HIV/AIDS Epidemic in America*, April 2000.

³ United Way of New York City, *HIV/AIDS in New York City: A Strategy for Improving Odds, Options and Quality of Life*, July 2002.

⁴ Department of Health and Human Services, Centers for Disease Control and Prevention, *HIV/AIDS Surveillance Report: Year End Edition, Volume 13. No.2*

⁵ http://www.kff.org/content/2001/3183/aids20_africanamerican.pdf

York region, comprised of urban centers, suburban communities and rural areas encompassed by eight counties, is a prime example of the unique impact of HIV/AIDS outside of New York City.

HIV Name Reporting and Partner Notification

In July 1998, New York joined 32 other States in instituting HIV reporting by name and partner notification. The law was passed with the stated goals of “achieving a complete epidemiological picture of the HIV epidemic in New York” and “to encourage voluntary partner notification efforts.”⁶ Before passage of the new law, New York State required reporting only of AIDS diagnosis to local and State Departments of Health, which has been in place since 1981. The HIV reporting law was implemented in New York State on June 1, 2000.⁷

The new law requires that “every physician or other person authorized by law to order diagnostic tests and make a medical diagnosis (i.e., physician assistant, nurse practitioner, counselor/ tester) or any laboratory performing such test will be required to immediately report the case to the State Department of Health.” HIV reporting is required upon *initial diagnosis of HIV*, upon *initial diagnosis of HIV related illness*, and at *the onset of AIDS as defined by the Centers for Disease Control and Prevention (CDC)*.⁸

Additionally, the law amends the State’s HIV confidentiality law to allow for, but not mandate, partner notification of all contacts of those living with HIV and AIDS. Contact has been defined by the law and regulations to include sexual and drug sharing contacts as well as “a person who the [HIV positive person] may have exposed to HIV under circumstances that present a risk of transmission.” The legislation requires that health care providers report the names of sexual and needle-sharing partners, known to the provider, as well as the names of any partners the patients choose to disclose to the state health department.⁹ Partner notification will be conducted without disclosing the identity of the HIV positive individual. There will be no criminal penalty against the HIV positive person who does not cooperate with the partner notification provisions of the law.¹⁰

⁶ New York State Department of Health AIDS Institute letter and draft amendment to Title 10 NYCRR Part 63 regulations and impact statement which implement Chapter 163 of the Laws of 1998, New York State’s HIV reporting and partner notification law, March 1999.

⁷ New York AIDS Coalition, *HIV Reporting and Partner Notification Law Update*, November 1998.

⁸ New York State Department of Health AIDS Institute letter and draft amendment to Title 10 NYCRR Part 63 regulations and impact statement which implement Chapter 163 of the Laws of 1998, New York State’s HIV reporting and partner notification law, March 1999.

⁹ New York State Department of Health, *New York State’s HIV Reporting and Partner Notification*, <http://www.health.state.ny.us/nysdoh/hiv aids/hivpartner/intro.htm>

¹⁰ New York State Department of Health AIDS Institute letter and draft amendment to Title 10 NYCRR Part 63 regulations and impact statement which implement Chapter 163 of the Laws of 1998, New York State’s HIV reporting and partner notification law, March 1999.

Surveillance

In March 2002, New York State released an epidemiological update to State HIV/AIDS data that included a report from initial data detailing the first seven months of HIV name reporting. The overview in this Update draws heavily on information from that report and focuses on statewide data that exclude New York City figures as a broad estimation of epidemiological changes in the Western New York region.

The addition of New York's new HIV data substantially affected national HIV and AIDS statistics. From June 2000 through December 2001, New York reported HIV (not AIDS) cases, which represented 12% of all cases of HIV reported to the CDC. During 2001, New York reported HIV (not AIDS) cases, which represented 38% of all cases reported from areas reporting in the country that year.¹¹

Information specific to the Western New York region is difficult to discern because epidemiological data included in the update did not include regional information beyond Statewide, New York City and Outside of New York City categories. As of May 2001, a total of 16,866 HIV and AIDS cases were reported for initial diagnosis that occurred between June 1, 2000 and December 31, 2000.¹² While the vast majority of the total cases were in New York City, *4,272 (28%) were from counties outside of New York City.* Of the confirmed cases across the State, 2,817 (17%) were initial or new HIV diagnoses. Note: not all HIV cases reported in 2001 reflected new diagnoses, rather, the HIV cases reported include cases diagnosed during previous years.

Partner Notification

Again, information specific to the Western New York region is difficult to discern because epidemiological data included in the update did not include regional information beyond Statewide, New York City and Outside of New York City categories.

In all areas outside of New York City, the Partner Assistance Program (PNAP) staff contact health care providers regarding individuals who are newly diagnosed with HIV for the purpose of assisting with voluntary partner notification, even if the provider did not specifically request PNAP assistance. PNAP staff also contact providers when a provider requests partner notification assistance with a reported case of HIV illness or AIDS. Additionally, PNAP staff contact providers by telephone to follow up on laboratory reports of newly diagnosed HIV infections for which a provider report has not been received.¹³

¹¹ Department of Health and Human Services, Centers for Disease Control and Prevention, *HIV/AIDS Surveillance Report: Year End Edition, Volume 13. No. 2*

¹² Donna Glebatis, Director of New York State HIV/AIDS Bureau of Epidemiology, AIDS Advisory Council meeting, September 2002.

¹³ New York State Department of Health Bureau of HIV/AIDS Epidemiology, Implementation of the New York State HIV Reporting and Partner Notification Law: Report on Activities Conducted 6/1/2000 through

As of May 2001, New York State health care providers reported a total of 3,564 confirmed cases of HIV, HIV illness or AIDS from June 1, 2000 to December 31, 2000. Of these, 3,290 (91%) were initial HIV diagnoses. More than half of the cases reported through health care providers included partner information with 60% of these cases with partner information from health care providers outside of New York City. Partner notifications were completed on 64% of the 593 identified partners who lived outside of New York City.

At a May 2002 AIDS Advisory Council, state health officials reported that there were no incidences of confidentiality breaches or inappropriate notifications. Although privacy concerns are legitimate and understandable, the benefits from early identification and treatment have quieted much of the protest against names reporting. Additionally, more accurate information about HIV infection provides the region with compelling data that can be used to access increased resources and to plan services.

Expanded Syringe Access Demonstration Program

On January 1, 2001 the New York State Expanded Syringe Access Demonstration Program (ESAP) was enacted. The law allows injection drug users to obtain syringes without a prescription from pharmacies and health care providers registered with the State Department of Health for a three-year demonstration period ending January 2003, when the legislature will reconsider the future of the program following a mandated evaluation of the program's effects. The New York State Department of Health AIDS Institute developed the law's regulations and is in charge of its implementation.

ESAP's dual objectives are to 1) promote access to sterile syringes to reduce the exposure to and transmission of HIV and other blood borne infections among injection drug users and 2) ensure safe disposal of needles and syringes. These goals are especially important in New York with an estimated 200,000 injectors, about 18,000 adults living with AIDS acquired through injection drug use and an additional 20,000 people living with AIDS indirectly acquired through injection drug use (e.g., sexual partners and pediatric cases). These staggering rates characterize New York as having the largest HIV/AIDS epidemic in the world among injection drug users.

Widespread access to sterile syringes is an important public health imperative. Given that syringe exchange programs distribute less than 2% of the needed syringes, access to sterile syringes through other sources, such as pharmacies and health care providers, is especially important.

The ESAP law provides for the following ¹⁴ :

12/31/2000, Epidemiological Update New York State 2002-2003 Submitted in Support of the New York State HIV Prevention Update 2002-2003.

¹⁴ <http://www.health.state.ny.us/nysdoh/hivaids/esap/regover.htm>

- Licensed pharmacies, health care facilities and health care practitioners who can otherwise prescribe hypodermic needles or syringes may register with the NYS Health Department to sell or furnish up to 10 hypodermic needles or syringes to persons 18 years of age or older.
- People who are at least 18 may legally obtain and possess hypodermic needles and syringes through ESAP - - without a medical prescription.
- Pharmacies may not advertise availability of hypodermic needles or syringes without a prescription and they must keep them in a manner that makes them available only to pharmacy staff (i.e., not openly available to customers).
- Hypodermic needles and syringes provided through ESAP are accompanied by a safety insert explaining proper use, risk of blood borne diseases, proper disposal, dangers of injection drug use, how to access drug treatment as well as information about HIV/AIDS.

An independent evaluation was a mandated component of the law and was charged with assessing the impact of ESAP on needle and syringe sharing, substance abuse, pharmacy practice, criminal activity, accidental needlesticks among law enforcement, sanitation and other personnel, syringe disposal and various methods of education on safe use and proper disposal. In September 2002, the subcommittee of the New York State AIDS Advisory Council charged with evaluating the ESAP program completed a series of meetings to monitor these specific areas of ESAP and developed a report for the Governor and the NYS Legislature. In March 2003, the state announced that a five-year continuation of the law was signed.

One of the areas of concern was the issue of disposal. The State Department of Health provided resources and technical assistance to a variety of demonstration programs across the State to address disposal and consumer awareness of ESAP. The Erie County Department of Health Bureau of Community Wellness AIDS Education Program initiated a Syringe Expanded Access and Disposal Project (SEAD) to develop a community based syringe access and safe disposal demonstration project in Erie County. SEAD worked with 142 pharmacies, 12 hospitals, 50 nursing homes and 3 article 28 facilities in Erie County. These providers and community members developed a community system of syringe access and safe disposal by encouraging partnerships and collaborations.

AIDS Community Services developed informational brochures for Chautauqua County to educate the public about ESAP and to provide a guide to participating pharmacies. This was an important initiative since the law prohibits pharmacies under ESAP to advertise their participation in ESAP.

Housing Opportunities for People With AIDS (HOPWA)

The purpose of HOPWA is to provide states and localities with the resources and incentives to devise long-term comprehensive strategies for meeting the housing and support service needs of low-income persons with AIDS and HIV-related diseases. A broad range of housing-related activities may be funded under HOPWA, including, but not limited to: project or tenant based rental assistance; supportive services; short-term rent or mortgage payments to prevent homelessness; and technical assistance in establishing/operating a community residence. The FY 2000 allocation is \$1.89 million.¹⁵

The Eligible Metropolitan Statistical Area (EMSA) for the City of Buffalo is administered by the Department of Community Development. As of FY 1999, Buffalo became a new recipient of HOPWA funds receiving \$352,000 for the EMSA, which includes Erie and Niagara counties. As of FY 2000, the City of Buffalo Department of Community Development was designated to administer the HOPWA program. The Department also administers the Emergency Shelter Grant, Community Development Block Grant and HOME programs. Funds are to be allocated to the primary providers of housing and services to HIV positive individuals. In addition, these providers have identified gaps in services available to developmentally disabled and handicapped persons with AIDS.

Buffalo HOPWA Funding FY1999-FY2002

FY 1999	\$ 352,000
FY 2000	\$ 364,000
FY 2001	\$ 412,000
FY 2002	\$ 446,000

In FY 1999 program year, the Department prepared an RFP and assembled an application review panel. Members of the AIDS Network of Western New York, which includes staff members from the Erie and Niagara County Health Departments, were invited to participate in the evaluation of applications to the program. The Department is also collaborating with a statewide housing needs assessment for persons and families affected by HIV/AIDS to help determine how to better meet the housing needs in the region. It is expected that recommendations regarding policy and programs will be provided as a product of that analysis.

¹⁵ <http://www.otda.state.ny.us/otda/bhs/default.htm#hopwa>

Ryan White Comprehensive AIDS Resources Emergency (CARE)

The Ryan White CARE Act is the Federal initiative that provides grants to states to provide HIV care. In New York State, Ryan White CARE Act funds are the second largest funding source after Medicaid in providing services to people with HIV/AIDS.¹⁶ The CARE Act funds are used to provide primary medical care, viral load testing, treatment information, adherence support, case management, and other essential support services. The providers funded by Ryan White include hospitals, community health centers, and community based organizations (CBOs). The distribution of funding is categorized as follows:¹⁷

- **Title I:** Provides emergency assistance to eligible metropolitan areas (EMAs) most severely affected by HIV/AIDS. Funding is awarded based on a formula and supplemental basis to EMAs. New York's Title I EMA includes New York City and the lower Hudson Tri-County region including Westchester, Putnam and Rockland Counties.
- **Title II:** Provides grants to all 50 states, the District of Columbia, Puerto Rico, Guam, the US Virgin Islands and eligible Pacific Territories and Jurisdictions to provide health care and support services for people living with HIV/AIDS. Title II funds may be used for a variety of services including home and community based services, continuation of health insurance coverage and direct health and support services. Title II funds AIDS Drug Assistance Programs (ADAPs), which are state administered and authorized under Title II of Ryan White CARE. ADAPs provide HIV related prescription drugs to under-insured and un-insured individuals living with HIV/AIDS.
- **Title III:** Supports early intervention services for low income, medically underserved individuals with HIV in existing primary care systems and planning grants to communities and health care services groups in planning efforts to develop health care centers, health care for the homeless and Federally Qualified Health Centers (FQHCs).
- **Title IV:** supports the development and operation of primary care systems and social services for women, infants, children and youth, and the linking of these care systems with HIV research and clinical trials. Services include primary and specialty medical care, psychosocial services, and outreach and prevention services.
- **Part F: Dental Reimbursement:** assists accredited dental schools and post-doctoral dental programs with uncompensated costs incurred in providing oral health treatment to patients with HIV infection.

¹⁶ AIDS in New York State, New York State Department of Health, 1998-1999

¹⁷ Henry J. Kaiser Family Foundation, *State Health Facts Online*, <http://www.statehealthfacts.kff.org>

- **Part F: AIDS Education Training Centers (AETC):** support a network of regional centers that conduct targeted, multi-disciplinary education and training programs for health care providers of clinical care for persons with HIV/AIDS.
- **Special Projects of National Significance (SPNS):** support innovative demonstration projects that provide services to underserved and vulnerable populations.

New York Distribution of Ryan White CARE Act Funding By Title, FY2000				
	NY \$	NY %	US \$	US %
Title I	114,887,742	39	526,811,000	34
Title II (Includes ADAP)	138,462,204	48	794,314,000	52
Title III	19,652,170	7	125,077,795	8
Title IV	8,768,322	3	45,418,166	3
SPNS	5,896,471	2	21,714,256	1
AETC	3,714,785	1	28,141,799	2
Total	291,381,694	100	1,541,477,016	100

In recent years, the development of new treatments has resulted in a reduction in the rate of deaths from AIDS. This increased longevity among people with HIV has been attributed partly to services provided by Ryan White grantees as well as to the new treatment regimes. In fact, Ryan White providers have experienced from 30 to 40 percent increases in the number of new patients since 1997.¹⁸ This increase in the number of people living with AIDS who access care services is explained by the success of new treatments when coupled with support services.

For areas outside of New York City, Ryan White Title II provides the primary resources for a wide variety of HIV/AIDS related care and support services.

A large proportion of the federal funds that support HIV/AIDS services outside of New York City are Ryan White Title II funds, administered by the New York State Department of Health. New York State, similar to many states, uses Ryan White Title II funds to

¹⁸ National Organizations Responding to AIDS, *Fiscal Year 2003, HIV/AIDS Appropriation Recommendations: Strategy for Building A Stronger Response to HIV/AIDS at Home and Abroad*, May 2002.

coordinate care across the entire state, to fund local HIV consortia and support critical primary care and support needs. Regional priority setting for service needs are formulated through a variety of planning processes that include providers and people living with HIV and AIDS such as the Ryan White Title II CARE Networks through their Service Delivery Plans.

New York State Ryan White CARE Act Title II Funding FY2000

Base	ADAP	CBC/MHAI	Emerging Communities	Total*
\$42,210,323.00	\$102,865,986.00	\$1,349,052.00	\$1,403,665.76	\$147,829,026.76

*Total excludes ADAP Supplemental amount

States with more than one percent of total U.S. AIDS cases must contribute a match of their own resources; New York contributes more than \$14 million in state funding to the ADAP program to supplement federal ADAP funds and to ensure that HIV-infected New Yorkers have access to new drugs and technologies.¹⁹ In New York, ADAP also supports programs that serve uninsured people who are not eligible for Medicaid and who lack adequate private insurance and supports ADAP Plus, which covers some ambulatory care; and HIV Home Care. New York received almost \$1.35 million of an available \$7 million for the Minority HIV/AIDS Initiative, which is designated to increase minority participation in ADAPs and provide linkages to other HIV care services.²⁰ In February 2003, the state announced changes to ADAP’s reimbursements to manage increased costs including limits on medication refills, dental coverage, and clinic visits as well as restrictions on brand-name drugs when generics are available.

Minority HIV/AIDS Initiative (MHAI)

In October 1999, at the prompting of the Congressional Black Caucus (CBC), the Clinton administration declared HIV/AIDS in racial and ethnic minority communities “a severe and ongoing health crisis.” The Department of Health and Human Services (DHHS) in collaboration with the CBC, announced a new funding allocation of \$156 million, which grew to \$381 million for fiscal year 2002 to address this crisis among HIV+ members of racial/ethnic minority communities such as African Americans, Latinos, Asian Pacific Islanders, Native Americans and Alaskan Natives/Native Hawaiians through increased funding and outreach to these communities. DHHS distributes this funding across several of its agencies including HRSA which administers

¹⁹ New York State Department of Health, *About the AIDS Institute*, April 1999.

²⁰ National Organizations Responding to AIDS, *Fiscal Year 2003, HIV/AIDS Appropriation Recommendations: Strategy for Building A Stronger Response to HIV/AIDS at Home and Abroad*, May 2002

Ryan White funds (32%), SAMHSA, the federal Substance Abuse and Mental Health agency (27%), the Centers for Disease Control and Prevention (25%) and the HHS Office of the Secretary and Office of Minority Health (13%).²¹

Emerging Communities

In an acknowledgement of the growth of AIDS cases in areas outside of the Title I Eligible Metropolitan Areas (EMAs), a provision was included in the 2000 reauthorization of the CARE Act. It enables Title II to provide supplemental grants to states to support HIV services in emerging communities (EC): cities reporting between 500 and 1,999 reported AIDS cases in the most recent five years. Eligibility based on AIDS cases is anticipated to change and this will impact formula awards from year to year. In light of this, newly eligible EC regions must adjust service needs and issues around funding that will likely fluctuate, or, in some cases, may be eliminated. For example, the AIDS Institute informed the Network on March 7, 2003, that the 2003-2004 EC contract would be \$24,605 less than the 2002-2003 contract year, totaling \$214,143.

In New York State the following regions have been identified as ECs: Albany-Schenectady-Troy, Buffalo-Niagara Falls, Rochester and Syracuse. In 2001, the New York State Statewide AIDS Service Delivery Consortia charged the HIV Care Networks for the corresponding Emerging Communities with creating subcommittees to identify service needs for their areas. The top three service needs were then submitted to the State for a competitive funding process. The Buffalo-Niagara Falls EC subcommittee prioritized the following HIV service for EC funding:

- Expanded Case management w/ availability of direct emergency financial assistance
- Outreach and client advocacy
- Substance abuse counseling

Medicaid Managed Care and SNPs

In an effort to control Medicaid expenditures, the State of New York has been advancing an initiative to enroll all Medicaid recipients in managed care plans. Voluntary enrollment in managed care has been an option for recipients for many years. Despite this, few individuals have chosen to enroll.²² In an effort to expand managed care enrollment, the State submitted a waiver application to the Health Care Finance Administration (HCFA), which oversees Medicaid and Medicare, requesting the ability to mandate enrollment in managed care for most Medicaid recipients. The first stages of mandatory enrollment in New York City started in August 1999. As of December 2001,

²¹ National Organizations Responding to AIDS, *Fiscal Year 2003, HIV/AIDS Appropriation Recommendations: Strategy for Building A Stronger Response to HIV/AIDS at Home and Abroad*, May 2002

²² Current NYC enrollment in Medicaid Managed Care (mostly voluntary) totals 375,000.

New York State had approximately 831,430 Medicaid recipients enrolled in Managed Care.

The Medicaid waiver application, called the Partnership Plan, contained a unique element: it authorized the establishment of specialty managed care plans or Special Needs Plans (SNPs). These plans are only for Medicaid recipients living with HIV/AIDS or those with serious mental illness. The federal government approved the New York State waiver application including the provision for SNPs.

Through a competitive process in 2000, the Department of Health selected eight applicants for certification to become HIV SNPs. While it was expected that the SNPs would be operational by 2001, the first HIV SNP is likely to be operational sometime in 2003. Erie County was the only upstate area that was identified as a potential area to be served by the SNP proposed by Fidelis. At this time however, State Department of Health officials do not foresee SNP development in the upstate region in the near future since the primary emphasis is on start up enrollment and operations of the downstate SNPs.²³

It has been assumed that if and when the state determines that the SNPs are able to provide adequate, accessible and high quality care, enrollment into SNPs or managed care will be mandatory for people living with HIV/AIDS. Despite the current 2003-2004 state budget deficit, DOH officials assure the continued commitment of resources to the start up and operations of the HIV SNPs.

As a pre-licensing requirement, the SNPs must demonstrate that they have in place networks of providers for the entire range of health care, behavioral health, and case management services. The role and required participation of community-based organizations (CBOs) in the HIV SNPs are major issues under discussion and negotiation. The New York State Department of Health has emphasized the need for the HIV SNPs to provide key community based services, such as COBRA community follow-up case management, in affiliation with CBOs in the initial years of SNP operations.

There is still a great deal of uncertainty regarding the initial and eventual role of CBOs in the HIV SNPs. This lack of clarity makes planning problematic for these organizations. The driving question is: to what degree would their ability to charge fees from SNPs conflict with the CBOs role in advocating for client needs? Another key factor for many CBOs is that they have not had any experience providing services that have traditionally been funded by Medicaid. The actual role to be played by CBOs in the operations of the SNPs remains to be seen and will depend on the policy decisions made by the State and the practices of the organizations licensed to manage the SNPs.

²³ November 2002 e-mail correspondence with Ira Feldman, New York State Department of Health.

The financial viability of the SNPs has also been questioned. There is concern that paying-out inpatient costs from the capitated rate that is allocated per SNP enrollee will impact on access and quality of care. This financial structure would have a greater impact in areas like Western, NY with limited patient numbers than in the downstate region.

Welfare Reform

Federal welfare legislation is currently in the process of being re-authorized. November 2002 elections created major shifts in Congress that has impacted the re-authorization process. Many New Yorkers have come up on time limits for receiving assistance and are subject to mandatory work assignments. Furthermore, screening for alcoholism/substance abuse continues to be fraught with complications. Federal and State advocates for individuals and families who need public assistance are uncertain whether a newly configured Congress will usher in new restrictions in a re-authorized bill including provisions that may impact the ability of people with HIV to receive public assistance.

Since the passage of the 1996 Personal Responsibility and Welfare Reform Act, federal and state policies have dramatically affected the ability of low-income families and individuals to access benefits and services. Welfare reform has included stringent limits on accessing benefits, time limits for receiving assistance, drug/alcohol testing, and mandatory work rules (“workfare”). Even though individuals with disabilities are able to avoid time limits on receiving assistance and mandatory work assignments, people with HIV face challenges in continuing to receive public assistance. First, they must be aware of their HIV status and be willing to have it be publicly known. Second, they must have sufficient HIV related illnesses to meet disability tests. And finally, if they are determined to have alcoholism/substance abuse problems, they must be willing to enroll in licensed treatment programs.

Welfare reform ended the long standing Aid to Families with Dependent Children and Home Relief programs. In their wake have come the time-limited Family Assistance and Safety Net programs. Individuals, who are not HIV+, or those who do not identify themselves as such, can only receive benefits for five years (Family Assistance) or two years (Safety Net-individuals) and all those who are able will be required to enroll in mandatory work programs. Whether HIV positive people must enroll in workfare will depend on their health status and their ability to produce medical documentation.

Medicaid eligibility is no longer directly tied to public assistance eligibility. Although this provides the opportunity for individuals who are not eligible for Family Assistance or Safety Net programs to obtain health coverage, advocates who work with the New York City Medicaid Managed Care Task Force report that it has also led to inaccurate and inappropriate dis-enrollment from Medicaid and an increase in home visits to document continuing Medicaid eligibility.

Recent immigrants face considerable barriers to obtaining services under welfare reform. Legal immigrants, who arrived in this country after August 1996, cannot qualify for Family Assistance or Food Stamps until they have been in the country for five years. Safety Net benefits including emergency Medicaid (for single individuals) may be obtained for up to two years, but potential recipients face a one-year New York State residency requirement. National advocacy efforts by immigrant rights groups to address these issues in the re-authorized TANF legislation have been stymied by the lack of movement on reauthorization in general.²⁴

People with HIV face another hurdle related to alcoholism/substance abuse. HIV positive people who refuse drug or alcohol assessments, drug testing, or a referral to drug treatment, if it is determined to be needed, will not be able to receive Family Assistance, Safety Net, or Medicaid benefits.

²⁴ National Immigration Law Center, *Immigrant Priorities For TANF Reauthorization*, January 31, 2002.

EXECUTIVE SUMMARY

This report is a 2003 update of the *Service Delivery Plan* of the *Western New York HIV Care Network*. The region covered by the Network includes eight counties containing a diverse mix of urban, suburban and rural areas. It includes Buffalo, the state's second largest city, as well as small rural communities which draw migrant and seasonal workers. Medical providers in the region include: two tertiary care hospitals (AIDS Designated Centers), one for adults and one for pediatrics; two community providers with HIV experienced physicians; and several other hospitals and community health providers with limited HIV/AIDS experience.

The purpose of this report is to support community targeted planning and needs assessment by providing up-to-date data to the Network and other interested providers and consumers. It provides data from both published and unpublished state and local sources on recent trends in the HIV epidemic and includes limited new data collected from surveys and focus groups involving providers and consumers.

This update was conducted in two phases by consultants working closely with the Service Delivery Plan Committee of the AIDS Network of Western New York. The lead consultant was Kelly McGowan. In 2000, she worked with the Hudson Planning Group, a non-profit planning and technical assistance organization based in New York City, to assemble epidemiological data and to develop original data collection instruments and methodologies. In 2002 and 2003, Ms. McGowan and consultants from Upstream Consulting updated the epidemiological data and community input. Throughout both phases, the Service Delivery Plan Committee reviewed interim runs of epidemiological data, survey instruments and methodology, convened focus groups, and organized community forums. This Update adds to, but does not supplant, the many critical service needs identified in the 1996 Service Delivery Plan and the 2000 Plan Update.

Epidemiological Highlights

Of the eight counties in the region, Erie County (excluding the City of Buffalo) has the highest rate of AIDS cases (excluding the State prisoners) with a cumulative case rate of 62.2 per 100,000 population. Although this exceeds the rate for the state exclusive of New York City, it is far below the statewide rate when New York City is included. Buffalo, with a case rate of 359 per 100,000 population has an AIDS rate that is substantially greater than the statewide rate and that of the country as a whole.

Consistent with trends across the state and the country, the number of new AIDS cases continued to decrease between 1995 and 1997. However, data available through 2000 shows that the rate of decrease slowed significantly. This data covers AIDS cases, not HIV infection, and new cases of AIDS have been diminished by improved HIV treatments that have significantly slowed disease progression. Although AIDS cases have declined among both men and women, the most significant declines occurred

among men. The percentage of women among all people living with AIDS in the region has increased slowly for the past five years. As of 2000 data, women comprised about a third of all living AIDS cases. The greatest number of AIDS cases in the region are among people between 30 and 39 years of age (43%) followed by those in the 40 to 49 age bracket (27.2%).

Cumulatively, across the entire history of the AIDS epidemic, more Whites than Blacks have been affected but among those currently living with AIDS, Blacks comprise 45%, Whites comprise 37%, and Hispanics comprise 15%. Among those living with AIDS, 42% are attributable to male-to-male sexual transmission with an additional 4% citing both injection drug use and male-to-male sex as the risk factor leading to infection. While the percentage of cases attributable to male-to-male sex has decreased slightly since 1990, Black and Latino men have increasingly become a larger percentage of the new AIDS cases diagnosed with MSM risk. In 1998, white men comprised slightly more than half of living AIDS cases and around 30% of new AIDS diagnosis with MSM risk compared to 75% of all new cases in 1990. 2000 data shows that this trend continues with white men who have sex with men making less than a quarter of all living AIDS cases in Western New York.

Through the Comprehensive Newborn Screening Program, the State of New York tests all newborns for the presence of HIV. Although this test is not a definitive indication of the newborn's HIV status, it is conclusive with regard to the mother's status. Through this screening program, New York has been able to gather data on the dimensions of HIV infection among women who give birth in the state. In 1998, the HIV seroprevalence rate for the Western New York (or Buffalo Ryan White region) was .13% or just slightly above the state average (24 women identified as HIV+ out of 18,237 women tested). In 1997 and 2000, the seroprevalence rate for the region was .10%, which is the lowest rate for the region since 1993. HIV infection among childbearing women in the region is almost exclusively among women of color.

The number of newly diagnosed Pediatric AIDS cases, however, has declined due in part to the impact of AZT therapy in reducing HIV transmission from mother to newborn. According to the New York State Department of Health, no new cases among children aged 13 and under were diagnosed or reported between 1997 and the winter of 2002. At the end of 2002, however, two previously undiagnosed infants seroconverted. This raised the known living pediatric AIDS cases to 21 in the region.

Injection drug use is attributable to about a third of cumulative and living AIDS cases in the region. Injection drug use has increased as a percentage of total cases over the past 10 years and Blacks comprise more than half of the living cases where injection drug use is the identified risk factor. People with histories of injection drug use face additional risks. Hepatitis C is an emerging public health threat in the state that has the potential to have as great an impact as HIV. State health officials estimate that over three quarters of drug users are likely to be infected with Hepatitis C after two years of injecting. New York State reporting requirements and limitations in current testing

technology complicates efforts to obtain accurate data on Hepatitis C prevalence in the region.

Key Issues

The epidemiological analysis and the data generated from surveys, focus groups, and community forums led to the identification of a number of significant issues which may help to guide service delivery planning for the region.

There is widespread concern among providers in the region that there are significant numbers of people living with HIV infection who are not connected to services and, because of this, do not access care until their health status has significantly deteriorated. Since these are people who are not connected to services, it is difficult to be certain of their numbers or characteristics. However, an examination of data such as enrollment in ADAP (the AIDS Drug Assistance Program – a key point of entry into care insofar as it provides payments for medical services to people without insurance or other benefits) reveals that over half begin to receive assistance when they are already diagnosed with AIDS (35%) or when they have advanced HIV disease (14%). Among the factors that seem to be related to people remaining outside of the HIV care system are: stigma/discrimination related to HIV status; insufficient awareness of the benefits of early access to treatment; and people who have a number of critical issues in their lives such that being HIV seropositive is less significant than being homeless, out of work, in complex domestic relationships or struggling with substance abuse issues.

Fear of discrimination related to HIV status and the related sense of stigma about being HIV positive are very significant concerns in the region. There are significant reports of people being denied housing based on their HIV status – discrimination that is clearly contrary to federal fair housing laws. Other people seem reluctant to accept services from agencies that are known as AIDS Services Organizations. Consumers and providers both suggest that increased peer involvement in counseling and mentoring can be very effective in assisting HIV positive people in adjusting and accessing required services and treatments.

It is not surprising, given the large distances included in the Western New York region, and high rates of poverty among people living with HIV/AIDS, that transportation is a major issue. It impacts on the ability to find and secure decent housing and accessing health care and other services. Given the concerns of stigma and discrimination, consumers are seeking transportation services that are anonymous or mainstream, e.g. non-agency identified vans. People living in rural areas have particular problems: not only are the distances longer and public transportation less available but they have to travel into urban areas in order to access state of the art health care.

A recently implemented transportation support program operated by the Red Cross was highly utilized before being retracted. It has since been reinstated with additional reporting and processing requirements that have created barriers to access. An

Advisory Group composed of both consumers and providers is currently addressing many of these challenges. Also, many case managers have been willing to use their own vehicles to transport clients except that many are not adequately reimbursed for the expenses they accrue on behalf of their clients.

Housing is a significant issue. There is a lack of adequate housing and high cost utilities in the region, a shortage of supportive housing, the homeless shelter system is overburdened, there is discrimination in the private sector, and there are gaps in the services infrastructure in order to assist people in remaining housed. Even those PLWH/A who are eligible for Section 8 housing have to wait many years to secure assistance.

Not only is there a need for additional housing services but the absence of adequate housing stock and supportive housing influences consumer ability to access the multiple HIV related medical and support services that are necessary to stabilize their health and become independent. According to providers, the homeless shelter system is overburdened and available beds are often dispersed across broad geographical areas, which are exacerbated by the transportation crisis. As a result, providers and consumers, forced to cope with the existing gaps in housing services, have created a *de facto* system for meeting the needs of PLWH/As with multiple diagnoses and frailties. Often, they are housed in psychiatric wards and general population nursing homes where the staff are not trained or prepared to handle HIV-related health and psychosocial issues.

On June 6, 2003, the only minority controlled AIDS service organization in the region, Geneva B. Scruggs Community Health Care Center (GBS) located on the East Side of the City of Buffalo, closed its doors due to lack of financial viability. The agency had employed 57 people and provided medical services to approximately 1,100 individual patients per month. Approximately 120 of these patients were receiving HIV primary medical care and/or HIV/AIDS supportive services. Beginning June 9, 2003 a transition team was established to provide continuity of care and assistance in choosing alternative medical and supportive service providers. The transition team will provide interim health care and/or case management services for a two-month period. Medical and/or case management records will be transferred to Lifetime Health, custodian of Medical Records during this interim period.

Service Priorities

In March 2001, the Board of Directors of the Western New York CARE Network prioritized the top three service delivery gaps. The Board reaffirmed these priorities on June 12, 2002:

1. *Lack of Outreach* impacts on the service delivery systems ability to identify underserved people living with HIV/AIDS and to connect them to care.

2. *Lack of Incentives* to recruit and retain experienced case manager and support staff to meet increasing needs of people living with HIV/AIDS and other diagnoses, including chemical dependency and mental illness.
3. *Lack of Supportive Services* and Coordination of services for individuals and families with inadequate and/or unstable housing.

During the Summer of 2003, the Board will use the findings contained in the 2003 Update to assess the Network priorities.

SECTION I. INTRODUCTION

This update consists of an executive summary, five principal sections and a policy supplement:

- *Policy Supplement*, provides an introduction and a discussion of policy issues affecting the delivery of HIV/AIDS services in Western New York.
- *Executive Summary* highlights the primary epidemiological findings and network priorities.
- Section I, *Introduction* is an introduction to the purpose and the community processes involved in developing the Service Delivery Plan.
- Section II *Description of Local HIV/AIDS Epidemic* provides an Epidemiological Profile of the HIV epidemic as it affects the Region. Data presented include published reports and runs of non-published data from County and State sources.
- Section III, *Services in the Comprehensive Continuum of Care*, provides an overview of core services in the region and an analysis of the significant findings.
- Section IV, *Needs Assessment*, identifies health care and support service needs and gaps and prioritizes special needs in the community.
- Section V, *Recommendations to Address Needs*, outlines the community and Network process for addressing needs.
- Section VI, *Action Plan*, provides a brief outline of the goals and objectives and the ongoing update and renewal process of the Service Delivery Plan.

1. PURPOSE AND USE OF THE SERVICE DELIVERY PLAN

This report is an update of the *Service Delivery Plan* of the *AIDS Network of Western New York*, originally completed in 1996. Its purpose is to update that plan, providing information on trends in the HIV epidemic, highlighting significant policy changes, and identifying current and unmet services needs. The objective is to provide the Network and other interested community members with more current information that can serve as the basis for program planning and for securing resources to address HIV/AIDS related service needs.

2. LOCAL PROCESSES TO DEVELOP THE PLAN: STRUCTURE AND PARTICIPATION

Members of the Service Delivery Plan (SDP) Committee of the AIDS Network of Western New York began meeting early in 2000 to oversee the development of an Update of the 1996 Service Delivery Plan. The SDP Committee hired Kelly McGowan and consultants from Hudson Planning Group, Inc., a non-profit planning, technical assistance and consulting group, to complete the Update and collaborate with the Committee to define the parameters of the study. The Hudson Planning Group (HPG) team presented preliminary epidemiological data and a plan for original data collection – focus groups, surveys, and review of reports – to the Committee in March 2000. HPG and SDP committee members continued to work closely with each other to develop and implement original data collection. HPG then analyzed the epidemiological and original data and presented the final draft of the 2000 Service Delivery Plan Update to the SDP committee on Monday, July 31, 2000.

Late in 2002, the AIDS Network of Western New York again retained Kelly McGowan and her new consulting group, Upstream Consulting, to update the Service Delivery Plan. Upstream restructured the SDP format to reflect the outline requested by the New York State Department of Health. Upstream also revised and updated the Epidemiological section and incorporated findings from the 2002 Regional Gaps Analysis.

3. COMMUNITY PROCESS FOR PLAN REVIEW

Service Delivery Plan Committee and the consultant will agree on a final draft of the 2003 Service Delivery Plan Update by the end of March 2003. The draft will then be submitted to the Board of Directors for review. The Board of Directors will reevaluate the Network Priorities in light of the epidemiological and community input updates.

Feedback from consumer and providers will be accepted by the Network in written form and through discussion groups hosted by the Service Delivery Committee.

Annual updates of components of the SDP will be conducted over the next five years. Specific areas will be targeted each year. The plan for areas to be updated will be driven by community feedback and direction from the New York State Department of Health.

SECTION II. DESCRIPTION OF LOCAL HIV/AIDS EPIDEMIC

This section presents epidemiological data collected for the development of the 1996, 2000 and 2003 Service Delivery Plans of the AIDS Network of Western New York. The first part describes the methodological issues and is followed by a review of the epidemiological data.

Methodology

The information presented in this update has been compiled from a range of published and unpublished sources and limited new data assembled for this report. The data were collected through a search of available reports, responses to specific data requests, unpublished findings, and literature prepared, for the most part, by county and state agencies and advocacy and planning groups. This includes already existing Network resources and original data collection by Network members. The data provide regional and county specific information on the impact of the HIV epidemic in Western New York.

Most of the data collected for the 2002 Update is derived from the New York State Department of Health and the AIDS Institute. The State Department of Health generally defines the eight counties of the Western New York region as the Buffalo Ryan White region. Some data are available by specific counties; some data are only available on an aggregated regional basis. Socioeconomic and health data are generally available by case figures as well as rates per 100,000 of the population. Rates are used frequently in this report because they take into account smaller overall population sizes and better reflect the true burden of disease in a given area. Comparison with the Western New York region is made between other Upstate regions or New York State exclusive of New York City figures.

There is also data available by individual counties of Western New York as well as zip codes within each county. For the purposes of this report, we generally present data aggregated for the Western New York region and highlight county specific data, wherever available and where it sheds light on the nature of the epidemic.

1. EXISTING AND NEW DATA

Cumulative vs. Living AIDS Case Data

Living AIDS cases or Presumed Living data provide a current picture of people living with AIDS in the Western New York Region. This data is distinct from cumulative AIDS case data that includes both cases known to be living and deceased. Cumulative AIDS case data are helpful to determine the impact of AIDS on a given area. AIDS cases by Diagnosis Year provide useful trend information. Living AIDS case data was provided for the Update analysis but caveats must be kept in mind when using it. Most published

data on living AIDS cases includes the inmate population resident in State prisons in the region. Since the service providers affected by this Service Delivery Plan Update do not, for the most part, serve inmates, data including inmates is of a slightly less useful.

Another important factor to consider are the special efforts undertaken to protect the confidentiality of individuals in the AIDS registry. Data in most published sources are censored when fewer than five individuals are identified within a region by risk, race, sex and age group. This policy is especially important in rural areas where there are a small number of cases and revealing factors such as race, age, sex, etc. could violate individual anonymity. Data censored for confidentiality reasons are combined with data from individuals whose exposure category was unknown (Other/Unknown).

AIDS Cases and Corrections

In 1997, the New York State Department of Health Bureau of HIV/AIDS Epidemiology began conducting AIDS surveillance case finding in New York State Prisons. See Section VII, Figure 1. According to the 2001-2002 Edition of AIDS in New York State:

Until 1997, data on prison inmates were excluded from regional analyses. In order to help readers who are planning local resources and programs, data on prisoners is now included in data for the county in which the prisoner is housed at the time the AIDS diagnosis was made. As a result, counties housing Department of Correctional Services facilities may show increases in the number of cases attributed to them.²⁵

The Western New York region is home to ten counties and eleven state correctional facilities. The presence of the New York State facilities has an impact on the HIV and AIDS data for the region. According to *AIDS in New York State*, individuals who are diagnosed with AIDS while in New York State Department of Correction facilities are classified within the AIDS Surveillance Case Registry based on the prison location, rather than the inmates home zip code. Subsequently, New York State Department of Community Health indices and the AIDS Institute Community Needs Index Report (discussed below) include data from correctional facilities.

While this reporting system eliminates redundancy across the State, it can 'skew' AIDS data by showing high numbers of AIDS cases in regions with correctional facilities. This is relevant when the data is used to determine service needs for CARE Networks in both the region of the correctional facility – which usually does not provide services to the incarcerated – and the region where the formerly incarcerated return to access HIV and AIDS services. The data does not adequately indicate where the incarcerated persons living with HIV will reside upon release.

Similarly, HIV and AIDS data for people who are held in local county or federal facilities are included in the data for the general population. There are no federal facilities in

Western New York and inmates are generally held in county facilities for twelve months or less. Most published data on Western New York includes HIV/AIDS cases among those in New York State correctional facilities. Where possible, this Update uses both sets of data and indicates whether inmates are included or excluded.

The impact of the inmate population in Western New York is not insignificant. Among all living AIDS cases in the Western New York region, 31% are among inmates. As will be described below, there are significant differences in AIDS data including and excluding inmates by race, gender and risk. Although risk of transmission among inmates is not uniformly known, New York State Department of Health epidemiologists and authors of *AIDS in New York State* note that more than 88% of cases from NYS correctional settings are attributable to injection drug use.²⁵

The salient point is that although inmates are included within the epidemiological data, they are unlikely to be placing demands on service providers in the region. With the exception of some use of the acute care hospitals and the work of community based organizations under contract with the New York State Department of Health's AIDS Institute, health care for the incarcerated state inmates is provided by the Division of Correctional Services. Once the inmates are released, by and large, they return to their home communities, which are primarily outside of the Western New York region.

Community Needs Index and Community Health Profile Data

The New York State Department of Health AIDS Institute produces a yearly report called the *Community Needs Index*. This is a widely used report that serves as a resource for HIV/AIDS related needs assessments, program planning, and evaluation. It aggregates data on a statewide, regional and county basis, well as providing zip code specific data. On the regional level, it provides summary tables and thematic maps by county that displays levels of service need in local communities as indicated by the Community Need Index (CNI) as well as the ten health statistics used in the CNI calculation.

The CNI is a planning tool that uses such factors as AIDS prevalence and other indicators of "risky" behavior to measure the impact of HIV/AIDS in a given area. It provides a composite measure that takes into consideration the multiple sources of HIV/AIDS-related service need. The computation of the index is based on a statistical model that combines ten health statistical rates into a single scoring system. These indicators include one year average cases from 1995-2000 of Cocaine Hospital Discharges, Opioid Hospital Discharges, Low Birth Weight, Sexually Transmitted Diseases, Teenage Pregnancy, Newborn Seroprevalence, Male HIV Discharges, Female HIV Discharges, AIDS Cases, Men Who Have Sex With Men (MSM) and other AIDS cases.

²⁵ New York State Department of Health, *AIDS in New York State*, 1998-1999 Edition, p132

Community Needs Index Fact Sheet²⁶

1. *The CNI is designed as a summary measure to describe the level of need among geographic units and therefore should not be used to infer risk factor or level of risk for any individual living in a particular ZIP code.*
2. *It is important to recognize that every community has needs for HIV/AIDS-related services. The designation of high, moderate, and low need to a ZIP code is relative and therefore should be considered in the context of the statistical area where the ZIP code is located.*
3. *The CNI and the ten health statistics used in the report are based on data that are subject to random and systematic errors. In addition, these data may not show the most current level of need due to lag time in data reporting.*
4. *The CNI indicates, at the aggregate level, where clients with different levels of service need resided during a given period of time. High need areas do not necessarily represent the locations where high-risk behavior has taken place. In fact, people who are at risk of HIV infection may have performed risky behavior outside their residence ZIP codes.*
5. *It should be noted that the address of a hospital patient shows the ZIP code of the patient residence, not the ZIP code of the hospital. However, most of the databases used in calculating the CNI do not identify prisoners separately, and those that do, cannot allocate prisoners back to their home addresses. For inmates from state correctional facilities seeking inpatient care, their addresses are the addresses of the facilities. The ZIP codes for hospitalized inmates are that of the prisons which referred them. Therefore, users should be aware of the presence of a correctional facility in a ZIP code when interpreting the CNI, or any indicator rate that is higher relative to the surrounding areas. ZIP codes with one or more state and federal correctional facilities are identified in all relevant tables and maps in the report.*

Additionally, the New York State Department of Health provides County Health Indicator Profiles, which are summaries of selected statistics for each county. A number of different data sets similar to those used in the CNI are used in these profiles²⁷.

²⁶ New York State Department of Health AIDS Institute, Office of Program Evaluation, *What is the Community Needs Index*, 1999 Edition

For the purpose of the 2003 Update, we combine selected HIV/AIDS, HIV risk and other health indicators into one table that gives an overview for each county. We also make a comparison of county data with Western New York regional data and New York State data. The New York State figures exclude New York City.

HIV Surveillance

In March 2002, New York State released an epidemiological update to State HIV/AIDS data that included a report about initial data detailing the first seven months of HIV name reporting. The overview in this Update draws heavily on information from that report and focuses on statewide data that excludes New York City figures as a broad estimation of epidemiological changes in the Western New York region.

The addition of New York's new HIV data substantially affected national HIV and AIDS statistics. From June 2000 through December 2001, New York reported a total of HIV (not AIDS) cases represented 12% of all cases of HIV reported to the CDC. During 2001, New York reported HIV (not AIDS) cases, which represented 38% of all cases reported from areas reporting in the country that year.²⁸

Information specific to the Western New York region is difficult to discern because epidemiological data included in the update did not include regional information beyond statewide, New York City and Outside of New York City categories. As of May 2001, a total of 16,866 HIV and AIDS cases were reported for initial diagnosis that occurred between June 1, 2000 and December 31, 2000.²⁹ While the vast majority of the total cases were in New York City, 4,272 (28%) were from counties outside of New York City. Of the confirmed cases across the State, 2,817 (17%) were initial or new HIV diagnoses. Note: not all HIV cases reported in 2001 reflected new diagnoses, rather, the HIV cases reported include cases diagnosed during previous years.

²⁷ NYS DOH County Health Indicator Profiles: The Socio-Demographic section uses population data estimates where provided by the NYSDOH Bureau of Biometrics. The unemployment data were provided by the New York State Department of Labor. Deliveries were extracted from the New York State birth files. The Perinatal Health section uses data extracted from the New York State birth, death, fetal death and abortion files. Mortality data was extracted from death files with population estimates provided by the NYSDOH Bureau of Biometrics. Hospitalizations were extracted from the Statewide Planning and Research Cooperative System (SPARCS) data files. Disease Mortality data was taken from various New York State Department of Health (NYSDOH) disease registries including AIDS/HIV and Reportable Diseases.

²⁸ Department of Health and Human Services, Centers for Disease Control and Prevention, *HIV/AIDS Surveillance Report: Year End Edition, Volume 13. No.2*

²⁹ Donna Glebatis, Director of New York State HIV/AIDS Bureau of Epidemiology, AIDS Advisory Council meeting, September 2002.

Table 1: Number of Unduplicated HIV AIDS Reports Confirmed by Region

Cases Tested/Diagnosed June 1, 2000-December 31, 2000, New York State

Confirmed Cases	NYS Outside of NYC		NYC		Total NYS	
	Number	%	Number	%	Number	%
Initial HIV Diagnosis	672	14	2,145	18	2,187	17
Initial HIV Illness	2,534	54	6,502	53	9,036	53
Initial AIDS Diagnosis	1,516	32	3,497	29	5,013	30
Total Cases Confirmed	4,722	100	12,144	100	16,866	100

Source: NYSDOH Bureau of HIV/AIDS Epidemiology

The data for confirmed cases diagnosed from June 1, 2000 to December 31, 2000 for New York State excluding New York City, shows significant differences in gender, age and race distributions across the HIV, HIV symptomatic and AIDS cases diagnosed during this period. Among newly diagnosed HIV cases outside of New York City, there were a greater proportion of females (34%) than among the AIDS cases. Additionally, the data showed that the proportion of younger cases (under 30 years of age) among those diagnosed with HIV was nearly twice that of cases diagnosed with AIDS.

Among newly diagnosed HIV cases, Whites comprised a smaller proportion (23%) than they did of AIDS cases (30%) and African Americans comprised a greater proportion (53%) than they did of AIDS cases (46%). The proportion of Latino cases was similar for both HIV and AIDS cases. This data suggests that the outside of New York City, the population of those who are newly diagnosed with HIV (though not necessarily newly infected) versus newly diagnosed with AIDS tend to be younger, African American, and female. The data also suggests that fewer whites than people of color are progressing to full-blown AIDS more than whites. As more cases are both reported and confirmed by the new surveillance system, more details are expected to emerge about race, gender, geography and risk of transmission.

Regional Context

The Counties of Western New York

The impact of HIV/AIDS cannot be isolated from the social and economic realities of the area. Certain non-HIV specific health and social indicators in the region and in specific counties correlate with the relative impact of AIDS in the area.

The Western New York Region consists of eight counties: Allegany, Cattaraugus, Chautauqua, Erie, Genesee, Niagara, Orleans and Wyoming with the 2000 Census population being reported at 1,591,708, a reduction of more than 43,000 since the population estimate for 1998. The City of Buffalo, the second largest city in New York, is reported to have a 2000 population of 292,648, a 10% reduction since the 1998 estimate. (Note: much of the data included in this document uses different population data. For instance, the CNI report for 2000 uses 1996 pop estimates).

The region contains urban, suburban and rural areas as well as diverse socioeconomic levels that vary by county. Five Native American reservations are located within Western New York: the Tuscarora Nation which makes its home near Sanborn; the Tonawanda Band of Senecas, near Akron; the Seneca Nation of Indians which includes the Cattaraugus reservation near Gowanda; the Allegany Reservation which includes the city of Salamanca; and the Oil Springs Native American Reservation near Cuba. There are also seasonal migrant farm workers who principally work in Chautauqua, Niagara and Orleans counties.

CNI Maps supplied by the New York State Department of Health, AIDS Institute, Office of Program Evaluation, show that high need areas are distributed across each of the eight counties in the WNY region. (For a copy of the latest edition of the Community Need Index, contact the Office of Program Evaluation and Research, NYSDOH AIDS Institute, cnihelp@health.state.ny.us or fax: 518-402-6813). Some of these areas reflect the inclusion of state prisons. However, there are a number of areas within counties that indicate notable AIDS prevalence and/or risk factors that suggest the need for intervention programs. The county tables in the CNI report include information on a range of health status and HIV-risk indicators, which can provide additional context for analyzing HIV services needs.

Three key factors emerge from examining the CNI maps and tables. First, *The rural counties tend to have significantly less access to private health insurance*. This is based on the insurance status of newborn babies. The data are aggregated for Medicaid and self-pay. Medicaid clients with HIV/AIDS will be able to access health care services; self-pay clients would have considerably greater difficulty accessing medications and services.

Second, *the State prison population tends to skew the data*. For instance, the 2000 Edition of the CNI shows that Wyoming County has one of the highest rates of New Male AIDS Cases at 248/100,000, which is due to two State correctional facilities (Wyoming and Attica) in the northwestern part of the county. This is an issue because the State includes inmates with AIDS in the AIDS Case Registry. Counties with prisons have, not surprisingly, disproportionate numbers of AIDS cases. Inmates receive

services from the Corrections Department and not, for the most part, from providers included within the Service Delivery Plan.³⁰

Table 2: Western New York AIDS Data by County Cases per 100,000 as of 1999

WNY County	Population	Rate of New Male AIDS	Rate of New female AIDS	STDs	Cocaine Dis-charges	Opiad Cases	Total AIDS
<i>Allegany</i>	51,545	75	21	17	17	35	8
<i>Cattaraugus</i>	85,814	58	40	23	186	38	25
<i>Chautauqua</i>	142,008	68	40	63	245	110	13
<i>Erie</i>	965,457	229	86	156	831	375	32
<i>Genesee</i>	61,699	83	2	37	317	151	9
<i>Niagara</i>	221,785	84	39	101	577	135	10
<i>Orleans</i>	46,388	88	332	63	147	57	147
<i>Wyoming</i>	44,446	248	27	4	91	36	149
NYS Regions							
<i>Western NY</i>	1,619,142	172	73	118	626	263	32
<i>Nassau</i>	2,669,473	214	109	43	262	184	35
<i>Hudson</i>	2,092,938	325	178	47	421	282	66
<i>Northeast</i>	1,459,215	211	81	55	239	118	40
<i>Central NY</i>	1,479,022	148	35	90	178	57	37
<i>NY-Penn</i>	312,371	115	50	47	365	92	12
<i>Finger Lakes</i>	1,262,356	197	87	193	409	149	35
<i>NY City</i>	7,333,265	1,503	751	272	981	1032	113
<i>NY State</i>	18,227,782	728	370	157	607	528	113

Source: Community Needs Index, Western New York Region, 2000 Edition. The populations noted on this table based on unpublished data that utilized the populations included in the table.

Third, Western New York’s cocaine and opiad discharges and STD rates per 100,000 population are higher than other regions outside of New York City. Erie County has particularly high Cocaine and Opiad discharges, 831/100,000 and 375/100,000 respectively, which contribute to Western New York having the highest rates in these

³⁰ An exception to this may be hospitals that serve areas that include prisons.

areas outside of New York City. The STD rate for Erie County is second only to the Finger Lakes region outside of New York City. While, Western New York's Total AIDS Cases per 100,000 were in the middle range across the state, these indicators suggest that the conditions are in place for seroconversion rates that may exceed the other regions.

AIDS Care in WNY Counties: New Patients

Data are available through ECMC, the Western New York AIDS Designated Center, for 2002 on all of the new HIV/AIDS clients enrolled in their clinics. Of the new patients in WNY counties, 88 (70%) are male and 37 (30%) are female. Among new patients who are male (see Section VII, Figure 13), Whites comprise 41% of the group, Blacks 39%, Hispanics 16%, Native Americans 2% and Asians one percent. The most common risk/exposure categories for male rural patients are MSM (43%), heterosexual risk (26%) and IDU (23%). Forty-four percent of the new male patients are age 40-49 and 34% are in the 30-39 age category. Among female new patients (See Section VII, Figure 14) in rural counties, 43% are Black, 35% White, 16% Hispanic and 5% Native American. The most common risk/exposure factor for women is heterosexual risk, with almost 80% in this category of risk. The 40-49 year-old age category is also the most common for women (30%), followed by 30-39 (27%).

AIDS Care in Rural Areas

A member of the CARE Network conducted an internal survey of patients enrolled in newly established rural HIV/AIDS clinics. The part-time clinics make HIV medical specialists available to communities that cannot sustain full time clinics due to low overall patient rates. The preliminary data from 2002 enrollments gives a basic profile of the patients who reside in rural counties.

Of the new patients in rural areas, over 67% (n=64) are male. The majority of patients are aged 40-49 (38%), followed by the 30-39 (31%) and 20-29 (10%) year old age categories. Moreover, the majority of new patients are White (79%), while African-Americans account for 16% of the new patients and American Indians/Alaskan Natives for 4%. No new patients self-reported as Asian, Hispanic, or more than one race.³¹

Impact of HIV/AIDS

AIDS in Western New York

Of the eight counties that comprise the Western New York region, Erie County leads in the number of AIDS cases and the prevalence of HIV infection. With a 1998-estimated population of 980,000, the Erie County cumulative AIDS case rate is 62.2 per 100,000

³¹ "AIDS Institute Aggregate Report" from the Erie County Medical Center AIDS Program, dated 2003.

This excludes the City of Buffalo, which has a cumulative case rate of 359 per 100,000 substantially greater than that for the state as a whole or the country. See Section VII, Figure 2. illustrates patterns of cumulative AIDS case rates in the US to the year 1997. Evident from this schematic, New York State has the highest AIDS incidence of any state, although New York City accounts for most of the prevalence of infection. Section VII, Figure 3, compares cumulative case rates in Erie County, Buffalo, the Western New York Region as well as statewide and across the country.

The 2003 Service Delivery Plan Update analyzed CNI reports for the counties of the Western New York region. There are limitations to the CNI data, as presented in the Community Needs Index Fact Sheet above. However, CNI data combined with the most recent HIV and AIDS data collected for the Update helps to provide a current view of the epidemiology of AIDS and HIV and attendant service needs.

Many published sources of HIV/AIDS information aggregate data in a way that makes observation of trends difficult. This is especially true in Western New York where the HIV and AIDS cases, especially those outside of the City of Buffalo, comprise small numbers and/or information was collected in aggregate during a certain time frame (1985-1995). For the SDP Update, trend data for four years or more was available for adult AIDS cases by age, gender and risk of transmission. Multi-year data was also available for HIV infection in women (newborn screening program) as well as TB and select sexually transmitted diseases (STDs).

In 1993, the Centers for Disease Control and Prevention expanded the AIDS case definition for adults and adolescents. The expanded definition of AIDS includes HIV infection with a CD4 count of 200 or less, individuals with pulmonary TB, recurrent pneumonia or invasive cervical cancer.³² All of the data that was used for the SDP update have been adjusted for the 1993 AIDS case definition change.

AIDS Cases by Gender

New AIDS cases among men and women decreased steadily in the last 5 years. However, women have become a larger percentage of new cases during that same period, increasing from just more than 10 percent of all cases in 1990 to almost 28 percent in 2000. See Section VII, Figure 4.

As discussed in the Methodology section, the inclusion of inmates in Western New York data significantly increases the incidences of AIDS. For example, the number of known living AIDS cases among women in the region more than doubles when the 193 women living with AIDS who are housed in State correctional facilities are included in the data. The increase in AIDS cases among men is also significant, increasing 60 percent when inmates are included.

³² New York State Department of Health, *AIDS In New York State 2001-2002 Edition*, pp 57-58

When the data excludes inmates, it appears that risk behavior is tied to gender in Western New York. When assessing risk behavior by gender, especially, it is important to exclude inmates due to the large number of unidentified risk behavior in the State facilities.

For example, among women inmates, the risk is 'unidentified' for almost 28% of living AIDS cases. See Section VII, Figure 5. Injection drug use and heterosexual transmission are the primary sources of HIV infection for women (this is also true for inmates). Among all living AIDS cases excluding inmates, almost 80% of the heterosexual risk cases are among women. MSM behavior is the predominant risk behavior with heterosexual risk totaling only 4 percent for men living with AIDS in Western New York. See Section VII, Figure 6.

AIDS Cases by Age

Section VII, Figure 7, shows the distribution of AIDS Cases excluding inmates by age. Percentages of AIDS cases by age have been fairly consistent in the Western New York Region since 1996. The greatest number of cases is among those 30-39 years of age (43%) followed by those 40-49 years of age (27%). AIDS case data by age from 1990 does not show risk of transmission, which makes the observation of trends in age by risk difficult to assess.

AIDS Cases by Race

Section VII, Figure 8, shows the racial composition of cumulative AIDS cases in Western New York, excluding inmates, through the end of 2000. Although the prevalence has been highest among Whites over the entire course of the epidemic, Blacks currently outnumber Whites among those currently living with AIDS in the region who are not inmates. Among living AIDS cases, Whites comprise 37%, Blacks comprise 45%, and Hispanics comprise 15%. (AIDS cases are dramatically higher among communities of color than among Whites when inmates are included.)

While Whites continue to represent the majority of the living AIDS cases (excluding inmates) in which MSM is the transmission risk, the percentage of Blacks among new MSM related diagnoses has doubled – from 25% to 50% – since 1990. Blacks comprise 35% and Latinos represent 6% of living AIDS cases in which MSM is the risk. On the other hand, people of color comprise the majority of IDU related living AIDS cases with Blacks comprising more than 55%, Latinos comprising 23%, and Whites comprising 20%. As a cohort, Blacks comprise most of the living AIDS cases attributable to heterosexual risk (53%), with Whites comprising 25% and Latinos comprising 17% of these cases. The percentage of new AIDS diagnosis with heterosexual risk among people of color has continued to increase since 1990.

AIDS by Risk³³

As shown in Section VII, Figure 9, 39% of the living AIDS cases are attributable to male-to-male transmission among Western New Yorkers and another 4 percent are men who have both risk factors of MSM and injection drug use behavior. Cumulatively, however, MSM risk comprises 44% of AIDS cases, in part reflecting an epidemic that has been primarily among men. Section VII, Figure 10.

White men (most of whom are between the ages of 30-39) who have sex with men make up more than 23% of all living AIDS cases in Western New York. Blacks with injection drug use as a risk comprise almost 19% of all living AIDS cases in the region. Almost 10% of all cases among adults living with AIDS in the region are among Black heterosexuals.

The percentage of cumulative AIDS cases attributable to male-to-male sexual transmission (MSM) has decreased slightly since 1990. The number of new AIDS cases among MSMs peaked in 1994 and decreased to 23 new cases in 1999. Presently, almost half of the living AIDS cases related to MSM risk are among 30-39 year olds while just over 4% are among 13-24 year olds and 13% are among 25-29 year olds.

Injection drug use and heterosexual risk, on the other hand, have steadily increased as a percentage of total cases since 1990. Even so, new AIDS cases among IDUs and heterosexual risk have decreased slightly since 1996, although not as dramatically as new cases among MSMs.

Section VII, Figures 11 and 12, shows the transmission risk associated with the known living AIDS cases among men and women. Among women living with AIDS, 30% of cases are attributable to injection drug use (injection drug use of the individual women or sex with an injecting drug user) and 58% of cases are attributable to heterosexual transmission (attributed to women who have no personal risk other than unprotected sex with men who are not known to be injection drug users). If trends continue, many of the 13% undetermined cases will most likely be attributed to IDU.

Of cumulative AIDS cases, injection drug use and heterosexual sex are also the leading risk of transmission among women in the Western New York region. Information on HIV infection among women of childbearing age is more complete and provided in more detail below.

³³ Risk information is generally collected on AIDS case reports but is not always available.

2. SPECIAL POPULATIONS

HIV Infection Among Women

Since 1984, a Comprehensive Newborn Screening Program has been conducted in New York, in which blood specimens are collected from every newborn in the state. In 1996, New York became the first and only state to test the specimens for HIV antibodies and notify the mother of the results. Mandatory HIV testing of newborns began February 1, 1997. A positive test indicates the HIV antibody status of the mother but does not definitively reveal the HIV status of the newborn infant. Through this screening program, New York has been able to gather data on the dimensions of HIV infection among women who give birth in the state. The Newborn Screening Program tested 251,546 women statewide who gave birth from January 1, 2000 to December 31, 2000 and, of these, 0.33% (830 women) tested positive.

Section VII, Figure 15, shows that the Western New York's HIV seroprevalence rate among women of childbearing age declined between 1994 and 1997 before rising to its seven-year peak in 1999. At that time, it was significantly higher than the state average of .12% (1 in 833 women). By 2000, new data showed that the rate dropped slightly below the state average to .10%.

Section VII, Figure 16, shows the HIV seroprevalence rates by race. The sharp increase among Latina women in 1995 is due to an increase from 4 HIV positive births to Latinas in 1994 to 8 HIV positive births out a total of 521 births and 524 births, respectively. Overall, the chart demonstrates that HIV infection among women in the Western New York region is almost exclusively among women of color.

Section VII, Figure 17, shows the relationship between newborn HIV seroprevalence and the age of the mothers. Not surprisingly, the highest incidence is among mothers younger than 29. The prevalence rates of women below the age of 19 have been increasing slightly since 1993 while the rate among women over 19 years of age has slightly decreased since 1997.

Pediatrics

There are a cumulative total of 19 pediatric AIDS cases in the Western New York region. About 53% of these children were Black and the remaining 42% were among White and Latino children.

The number of newly diagnosed Pediatric AIDS cases, however, has declined due in part to the impact of AZT therapy in reducing HIV transmission from mother to newborn. According to the New York State Department of Health, no new cases among children aged 13 and under were diagnosed or reported between 1997 and the winter of 2002.

At the end of 2002, however, two previously undiagnosed infants seroconverted. This raised the known living pediatric AIDS cases to 21 in the region.

Substance Use

Substance use in Western New York continues to be closely linked with AIDS. Injection drug use is attributable to 30.5% of cumulative AIDS cases and IDUs make up 28% of WNY living AIDS cases.³⁴ Community Needs Index data for the Western New York region also reveals troubling statistics. Cocaine and Opioid (Heroin) discharge data are used as risk indicators in New York State areas in which HIV infection could potentially spread. Cocaine and Opioid discharges are derived from New York State Hospital inpatient discharge data; a cocaine discharge is a patient file that includes some clinical indication of cocaine or heroin use. It does not mean that the drug use was the cause of hospital admission.³⁵

The Western New York region and Erie and Niagara counties have the highest per 100,000 cocaine discharge rates in the state outside of New York City. Given the large urban populations within these counties, this is not surprising. The per 100,000 opioid or heroin rates are not nearly as great in comparison. This suggests the need for a closer examination of non-injection drug use related HIV risk. In recent years, Erie County Medical Center has noted that a pattern of non-adherence and continued substance use are key factors in known HIV deaths.

New York State Department of Health officials have reported a decrease of HIV/AIDS infection among injection drug users. Among injection drug users in State drug treatment and syringe exchange programs, the rate of HIV/AIDS infection decreased from 27.2 percent in 1990 to just 5.58 percent in 1999.³⁶ The decline was attributed to the success of needle exchange programs and AIDS education programs, in addition to a 50 percent reduction over the decade in the number of substance users who inject drugs. This decline among new injection drug users may be due in part to the increased purity of street heroin that, because it is so potent, can be ingested nasally rather than by injection.³⁷ As Hepatitis C infection and disease increases its prevalence among injection drug users (discussed below) it can be assumed that older people living with AIDS in WNY who have injection drug histories will be at increased risk for Hepatitis C infection and disease.

Tuberculosis and AIDS

³⁴ Link to findings from WNY Consumer Survey that over 31% of PLWH/A engage in some form of alcohol or other drug use and describe their use as chronic or problem use.

³⁵ Interview with Dennis Tsui, New York State Department of Health AIDS Institute, June 2000

³⁶ New York State Department of Health, *AIDS in New York State*, 2001-2002 Edition, p. 63.

³⁷ Unger, Ed, *Medical Tribune*, 40(16): 6, 1999

General TB data for Western New York shows that cases steadily declined from 59 cases in the entire region in 1994 to 38 in 2001. Erie County collects detailed TB data including race, ethnicity, foreign-born incidents, and TB and HIV cases. The data shows that since 1991, Whites have made up 30 to 60 percent of the cases among Erie residents. In 1999, Whites were just more than half of all cases. The other cases were among Blacks and Asians. Since 1991 in Erie County, TB cases among Asians have ranged from 6 to 29% of all cases, which is significantly higher than their representation in the general population. Also, foreign-born residents have been close to 30% of all TB cases since 1996.³⁸

While information about tuberculosis (TB) and HIV cases is not available for Western New York as a region, data shows that in Upstate New York (excluding New York City) the percent of known HIV status was 44% among TB cases in 1998 and 1999.³⁹ In Erie County – the County with the highest AIDS rate in the region – 5 people were living with TB and AIDS in 1991, a high of 7 in 1993, and 3 in 1999.

Hepatitis C

Hepatitis C (HCV) is an emerging public health issue that some New York State authorities claim will have a similar if not greater impact than HIV.⁴⁰ Hepatitis C, like Hepatitis A and B, is reportable in New York State. Primarily afflicting injection drug users, Hepatitis C damages the liver and has an incubation period of 15-20 years. HCV and HIV share transmission routes. There are estimates that one-third of people infected with HIV are also infected with HCV and up to 90% of HIV infected IDUs may have been exposed to Hepatitis C and Hepatitis B.⁴¹ In addition, a study of young injection drug users (with a mean age of 25) in Harlem found that over half of the IDUs studied, including one third who had injected for a short period of time (less than 5 years) were infected with HCV.⁴² New York State health officials estimate that after two years of injecting drugs, 75-85% of users will be infected with HCV.⁴³

While Western New York providers have seen an alarming number of HCV cases among clients living with HIV, New York State public health authorities have been working actively to develop better ways to monitor and treat HCV.⁴⁴ HCV surveillance

³⁸ New York State Department of Health, Erie County TB Control Program, *Community TB Profile, 1999*, March 2000.

³⁹ New York State Department of Health, *AIDS in New York State*, 2001-2002 Edition, p. 69.

⁴⁰ New York State Department of Health, Bureau of Communicable Disease Control, *Viral Hepatitis and HIV: A Question and Answer Sheet*, DOH Publication #9296, May 1999.

⁴¹ Center for Drug Use and HIV Research, Institute for AIDS Research at the National Development and Research Institutes, *CDUHR News*, Volume 3, Issue 1, Spring/ Summer 2000.

⁴² Diaz T., Edwards V., Susser E., Vlahov D., *HIV Prevalence of Hepatitis C among Young Injection Drug Users in Harlem, New York City*, Center for Urban Epidemiological Studies, New York Academy of Medicine.

⁴³ New York State Department of Health, Division of Epidemiology, Communicable Disease Frequency Table, 1996-1998, unpublished data.

⁴⁴ Based on internal statistics from GBS, ACS and ECMC, August 2000.

is complicated by the fact that only *new, acute* cases of HCV are reportable to New York State Department of Health. HCV surveillance techniques are unable to accurately distinguish between new, acute cases (less prevalent) and existing, chronic cases (more prevalent).⁴⁵

This dilemma is exemplified by the HCV surveillance data that was available for the Western New York region and Erie County. New York State Department of Health received 238 reports of Hepatitis C in New York State, excluding New York City from 1998-2000.⁴⁶ The overall case rate per 100,000 was 12.2 for all of Western New York in 2000. In contrast, Erie County reported 1,365 cases of HCV last year (a 30% decrease from 1999 when 2000 cases were reported in Erie County).⁴⁷ The New York State HCV case data were probably confirmed by a less widely available confirmatory test to which the county has limited access. Erie County data includes chronic Hepatitis C and false positives (people with Hepatitis C who may have “cleared” or been treated and may no longer be infected).

Immigrants and Migrants

Concrete epidemiological data is difficult to secure for non-U.S. born residents of the United States, and specifically for the Western New York Region. This is due in part to the number of undocumented and illegal immigrants for whom no data is collected as well as to the lack of breakouts by region outside of New York City for the existing data.

The Buffalo area, however, does attract a large percentage of the immigrant population in New York State outside of the New York City area. This is partially due to the presence of the only Executive Office of the Immigration Court outside of New York City, which draws immigrants and refugees to the region. According to data specialists with Immigration and Naturalization Services, *most* of the immigrants to New York State who were not counted in New York City data are considered to be located in the Buffalo Region.

While the Western New York Region may reflect a large number of immigrants and a significant number of migrants, there is no mechanism for determining rate of HIV/AIDS. This is particularly relevant considering that nearly a third of the state’s 3.2 million uninsured residents are not citizens. It can be assumed that those immigrants and migrants that are infected are likely to encounter many barriers to health care access.⁴⁸ Barriers to health care and social services, including lack of insurance and language

⁴⁵ Interview with Stan Kondracki, New York State Department of Health, Division of Epidemiology, Disease Surveillance, September 1, 2000.

⁴⁶ New York State Department of Health, Bureau of Communicable Disease Control.

⁴⁷ Reportable Communicable Diseases in Erie County: <http://www.erie.gov/health/stats.phtml>

⁴⁸ Sandman, D.R. (1999). Health Care in New York City: Understanding and Shaping Change. Commonwealth Fund Issue Brief.

issues, create the potential for HIV/AIDS infection to go unmonitored and treated among these populations in New York State.

Table 3: Estimates for Legal Immigration to Western New York

Destination of Immigrants:	1995	1996	1997	1998	1999	2000	2001
New York State	128,406	154,095	123,716	96,559	96,969	106,061	114,116
New York City	111,687	133,168	107,434	82,175	80,893	85,867	92,361
NY State Minus NYC	16,719	20,927	16,282	14,384	16,076	20,194	21,755

*Source: Annual Report: Legal Immigration, Fiscal Year 1998. Office of Policy and Planning. U.S Department of Justice, Immigration and Naturalization Service, May 1999.
<http://www.ins.usdoj.gov/graphics/aboutins/statistics/IMM2001.pdf>*

According to New York State Department of Labor statisticians, migrant workers in the area are primarily from Mexico and Jamaica with a recent increase of Ecuadorians. The data collection for migrant workers by the Department of Labor includes only documented workers during harvest season, which may undercount the actual number of migrant workers due to exclusion of undocumented persons or over count due to duplicated reporting. There is no definitive data on the incidence of HIV among migrants in the Region or the state as a whole, although one provider in the region reported that it did serve migrants in its HIV case management services.

Table 4: Migrant Workers by County During Harvest Season

County	Migrant Workers
Niagara	370
Orleans	605
Genesee	150
Wyoming	700
Allegany	75
Cattaraugus	110
Chautauqua	510
Western New York Region	2,520

Source: State of New York Department of Labor, Rural Employment Data, unpublished estimates based on data collected during September 1999, as of November 2002.

Sexually Transmitted Diseases⁴⁹

Nationally, in areas of high HIV infection, STDs have been equally prevalent. STD rates are an indicator of unprotected sexual risk and, therefore, the presence of STDs facilitates the transmission of HIV infection. STDs have also attracted a great deal of national focus due to the high rates of chlamydia among young women. Chlamydia, if left untreated, can lead to pelvic inflammatory disease (PID) and infertility.⁵⁰ The disease is especially difficult to diagnose in men so most data on chlamydia include females only.

Notably, in 2000, New York State became the 49th state to institute a statewide chlamydia surveillance system. In other parts of New York State, chlamydia is reaching epidemic proportions, especially among young women under the age of 19. Erie County has reported the number of chlamydia cases as 875, 2,934 and 2,665, respectively for years 2000-2002. However, at this point no breakdown of these cases by gender, other demographics or HIV/AIDS status is available. When more comprehensive chlamydia epidemiological information is available, Western New York figures should be examined closely.⁵¹

In New York, the counties and localities are responsible for reporting all cases of sexually transmitted diseases (excluding chlamydia) to the state department of health. The only identifying demographic in these reports are gender and age. Reports are sent to the State by providers and by labs although the cases are counted only if they are confirmed by a laboratory result. The County Departments of Health provide treatment and follow-up care and report this to the State as well. Private physician's offices rarely submit STD reports.

Statewide between 1996 and 1999, syphilis and gonorrhea patterns remained stable. Data for gonorrhea in 2000, however, shows a dramatic increase in Erie County. Gonorrhea rates in Erie County have been significantly higher than the rest of the State and in 2000 was more than twice the rate of all counties outside of New York City. The available data for Erie County show that the rate of disease among people under 19 years of age has been between 30 and 40 percent of all cases over the past ten years. The rate among young women has been increasing while the overall rate of young men has been decreasing. However, the overall number of gonorrhea cases for Erie county

⁴⁹ Based on an interview with Eugene Tobey, Public Health Representative IV, New York State Department of Health, Bureau of STD Control, May 16, 2000 and July 12, 2000.

⁵⁰ The Henry J. Kaiser Family Foundation, *Sexually Transmitted Diseases in the United States*, Fact Sheet, February 2000.

⁵¹ Although AIDS Network of Western New York providers supplied HPG with internal, agency specific chlamydia statistics, these data were inconclusive and could not be generalized for the region or the specific providers. In the absence of a statewide surveillance system that has a test result confirmatory capability, the dimensions of chlamydia in Western New York are difficult to measure.

for the year 2002 was reported as 1,758, which is significantly lower than the case rate of 2,442 for the prior year.⁵²

Data for gonorrhea rates in Erie County show that younger women and older men have become the largest portion of all cases in the region which could support anecdotal reports that they are partnering with each other and are engaged in risky sexual behavior. Research indicates that older men are more likely to have multiple sex partners than younger men and to engage in more sex and drug related risk behavior and, therefore, present a greater HIV transmission risk.⁵³ Also, according to a national survey, older men engaging in sexual relations with younger women is a common phenomenon, disproportionately so in African-American and Latino/a communities. This implies that young women in Erie County, especially in communities of color, are engaged in risky sexual behavior.

Efforts to reduce the incidence of syphilis nationally and in New York State have been generally successful. Unlike gonorrhea rates, the Erie County rate of early syphilis detection is well below the statewide rate as is the Upstate New York rate. Erie county reported 10 cases of syphilis for the year 2002, which is a significantly reduced number compared to 129 in 1993.

Men who have Sex with Men (MSM)

Almost 40% of cases are attributable to male-to-male transmission among Western New Yorkers living with AIDS. Three-and-a-half percent of the cases involve both risk factors of men having sex with men and injection drug use. White men (most of whom are between the ages of 30-39) who have sex with men make up more than 22% of all living AIDS cases in Western New York.⁵⁴

A 1999 Centers for Disease Control and Prevention study of men who have sex with men ages 15 to 22 (conducted in seven cities, including New York City) found that blacks are almost five times as likely as their white counterparts to be HIV-positive. In sum, as the CDC recently declared, Black gay and bisexual men are one of the most at-risk groups for HIV⁵⁵ This is difficult to view among the very small population (4%) of AIDS cases among 13-24 year olds for whom MSM was the risk of transmission.

In June 2000, the CDC released a report that stated AIDS cases have declined among gay men who inject drugs. CDC officials attribute the decline to increased use of antiretroviral therapy that delays disease progression. The study found that the proportion of all AIDS cases among gay intravenous drug users fell from 8% in 1990 to

⁵² <https://commerce.health.state.ny.us/hin/hinapps/commdis/annoo/rates4.html>.

⁵³ Advocates for Youth Web Site, www.advocatesforyouth.org/factsheet/FSYNGWOM.HTM, *Young Women of Color and the HIV Epidemic*, July 2000.

⁵⁴ NYDOH Date as of 12/20/01 for cases reported through December 31, 2000

⁵⁵ Kai Wright, AIDS and Black New Yorkers: Homophobia, Racism, and Rejection Fuel Rising Infections: Black, Gay, At-Risk, Village Voice, June 21-27, 2000

5% in 1998.⁵⁶

Moreover, in the fall of 2002, the CDC released data on the rates of syphilis in New York City. In 2001, after steadily declining for 10 years, cases of primary and secondary syphilis more than doubled in New York City. Of the 263 cases reported, 93% were among men and 79% of these men reported having male sexual partners. Of these MSM, 49% further reported that they were infected with HIV. This increase is troubling both because it signals a rise in unprotected sex, and because being infected with syphilis increases a person's risk of transmitting HIV.⁵⁷

3. CONSUMER AND PROVIDER INPUT

The collection of community impressions of emerging needs is an excellent means for assessing the significance of patterns in the epidemiological data and their impact on service delivery. It should be noted that surveys with small samples, the nature of focus group interviews and open public forums sometimes generate skewed results that emphasize certain needs and not others. Therefore, the original data gathered from consumers and providers should be viewed as anecdotal rather than as rigorous scientific findings.

Consumer identified needs and gaps in available services are vital for the assessment and prioritization of service delivery needs for the region. Consumers are active participants in several Network committees including the PLWH/A Advisory Committee and the SDP Committee. Therefore, a participatory process with consumer input has been integral throughout the planning and the collection of data for the Update. Also, the Network is structured to involve consumers throughout the ongoing process of prioritizing needs and implementing work plans.

In 2000, the consultants worked closely with the Network to gather original data from the community. This was necessary to broaden the understanding of service delivery issues that were identified by the Network following the review of the epidemiological profile of the region that was available mid-2000. The original data was gathered through four methods: surveys, public hearings, focus groups, and regional reports and position papers. Hudson Planning Group collaborated with the Service Delivery Plan Committee in the design and implementation of the surveys and focus group protocols.

The consultants also worked closely with the Western New York CARE Network in 2003 to include community input, which was facilitated by the simultaneous process of the Regional Gaps Analysis (RGA). Summaries from 22 local RGA Discussion Groups were integrated into the 2003 Update document. The findings of reports and position papers

⁵⁶ Kaiser Daily HIV/AIDS Update, June 2, 2000.

⁵⁷ Morbidity and Mortality Weekly (2002). Centers for Disease Control. Vol. 51, No. 38: 853-858.

<http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5138a1.htm>

conducted by the Network since the 1996 Service Delivery Plan are also incorporated into the report when relevant.

Section IV: Assessment of Needs discusses the original information collected from the community for the Service Delivery Plan Updates in 2000 and 2003, the Western New York Regional Gaps Analysis 2003, and other data and information generated by committees of the AIDS Network of Western New York since the 1996 Service Delivery Plan.

This section introduces the data collected by the PLWA Advisory Group through their semi-annual local *Consumer Survey* process that helps to describe the local HIV/AIDS epidemic. More than three hundred people living with AIDS or HIV in Western New York completed the *2001 and the 1999 Consumer Surveys*, which is significant considering that the known living AIDS cases in the Region is 769 (many more people are living with HIV who have not received an AIDS diagnosis). The respondents were representative of the people living with HIV/AIDS in terms of such factors as gender, race, age, county of residence, and income.

Table 5: Demographics of Consumer Survey Respondents and AIDS Cases (N=300)

	Year	Male	Female	African American	White	Latino	Under 20 yrs	20-39 yrs
Survey Respondents	1999	59%	38%	46%	34%	18%	4%	55%
	2001	68%	27%	45%	33%	14%	1%	63%
Living AIDS Cases⁵⁸	1999	76%	24%	45%	39%	13%	4%	57%
	2001	75%	25%	46%	37%	15%	5%	57%
Cumulative AIDS Cases⁵⁹	1999	80%	20%	41%	46%	11%	1.6%	60%
	2001	80%	20%	42%	46% ⁶⁰	11%	5%	56%

The majority of the respondents were male and between 3 and 5 percent self-reported to be transgender. (See Table 5 above) Almost half were African American and a third

⁵⁸ NYS DOH, Bureau of HIV/AIDS Epidemiology, *Presumed Living AIDS Cases by Selected Year of Diagnosis in the Buffalo Ryan White Region by Selected Characteristics*, Data as of December 20, 2001, 2000.

⁵⁹ NYS DOH, Bureau of HIV/AIDS Epidemiology, *Cumulative AIDS Cases in the Buffalo Ryan White Region by Selected Characteristics*, Data as of December 20, 2001.

⁶⁰ The high rate of cumulative cases among Whites is due to the early spread of HIV among communities of White MSM. The rate of transmission increased in communities of color and surpassed that of White MSM in the early 1990s.

were White followed by Latino/a. Native Americans were 2% of survey respondents in 2001, which is slightly higher than the cumulative AIDS cases rate of .28% (five known cases among Native Americans in the region). In 2001, one third of the respondents were under 30 years old with the majority between 30 and 49 years. Sexual identity of respondents was split evenly between heterosexual and homosexual at about 40% each in 1999 with the remaining 21% self-selecting a bisexual identity. In 2001, thirty-seven percent of respondents reported being heterosexual, forty-five homosexual, and 10% bisexual.

The average household income for both samples was greatly below the \$29,765 median income⁶¹ for the region with more than half receiving less than \$8,000 per year and about a third between \$8,000 and \$20,000. Although all counties were represented, Erie residents comprised 75% of the respondents followed by Niagara residents at 11%. Almost all were U.S. citizens.

The *Consumer Survey* findings prioritized transportation and housing as central needs impacting on all HIV/AIDS service delivery. (The *Provider Survey* discussed below shows a parallel finding.) Half of the consumers reported having missed appointments due to transportation problems. The most common transportation problems reported were money and distance. In 1999, only a quarter of the total indicated that they had utilized transportation services in the past year.

In 2001, thirty-six percent reported having spent time on the streets or in an emergency shelter within the last month and 12% within the last 6 months. In 1999, more than a third reported problems accessing safe and affordable housing, while only half accessed some form of housing assistance. Slightly less than half of consumer respondents indicated that they were afraid to disclose their HIV status and more than a third had experienced discrimination based on their HIV status in the past year. This issue was also reflected by the respondents to the *Provider Survey* who perceived that fear of disclosure influenced access to and retention in services.

In the 1999 consumer survey, only 69% of the respondents had some form of health insurance, which is about 15% below the statewide average.⁶² Although 92% said they were under the care of a physician. Medicaid, ADAP, and the State's Child Health Insurance Program should provide extensive enough coverage so that virtually all people living with HIV/AIDS can access some form of health insurance. And, given the high costs for medications and the need for consistent contact with a primary care provider, lack of insurance is a major impediment to maintaining quality of life.

⁶¹ Buffalo-Niagara Falls, NY National Compensation Survey, July 1999. U.S. Dept. of Labor Bureau of Statistics, July 1999. <http://stats.bls.gov/special.requests/ocwc/oclt/ncsocs/ncs/ncbl0085.pdf>

⁶² AIDS Institute of New York State Department of Health data presented in 'Clinical Plenary: Treatment Update' by Dr. John Bartlett. Ninth Statewide HIV/AIDS Policy Conference. May 24, 2000.

The 2001 consumer survey raises some other significant service delivery issues. The first is that 44% of respondents reported having problems in obtaining benefits or entitlements. Furthermore, 55% felt that the workers in social service agencies are not informed nor educated about HIV/AIDS and 40% felt that they do not treat them fairly or with respect. This may be indicative of a case management services delivery problem. Other significant findings are that 33% of respondents reported being hit, threatened or abused by their partner(s), and 59% reported being treated for depressions, excessive worrying, emotional concerns, or attempted suicide. Furthermore, 41% reported the need for current emotional treatment or counseling.

4. Summary of Significant Findings and Trends

Of the eight counties in the region, Erie County (excluding the City of Buffalo) has the highest rate of AIDS cases (excluding state prisoners) with a cumulative case rate of 62.2 per 100,000. Although this exceeds the rate for the state excluding New York City, it is far below the statewide rate when New York City is included. Buffalo, with a case rate of 359 per 100,000 members of the population has an AIDS rate that is substantially greater than the statewide rate and that of the country as a whole.

Consistent with trends across the state and the country, the number of new AIDS cases continued to decrease between 1995 and 1997. However, data available through 2000 shows that the rate of decrease slowed significantly. This data covers AIDS cases, not HIV infection, and new cases of AIDS have been diminished by improved HIV treatments that have significantly slowed disease progression. Although AIDS cases have declined among both men and women, the most significant declines occurred among men. The percentage of women among all people living with AIDS in the region has increased slowly for the past five years. As of 2000 data, women comprised about a third of all living AIDS cases. The greatest number of AIDS cases in the region is recorded among people between 30 and 39 years of age (43%) followed by those in the 40 to 49 year age bracket (27.2%).

Cumulatively, throughout the history of the AIDS epidemic, more Whites than Blacks have been affected but among those currently living with AIDS, Blacks comprise 45%, Whites comprise 37%, and Hispanics comprise 15%. Among those living with AIDS, 42% are attributable to male-to-male sexual transmission with an additional 4% citing both injection drug use and male-to-male sex as the risk factor leading to infection. While the percentage of cases attributable to male-to-male sex has decreased slightly since 1990, Black and Latino men have increasingly become a larger percentage of the new AIDS cases diagnosed with MSM risk. In 1998, white men comprised slightly more than half of living AIDS cases and around 30% of new AIDS diagnosis with MSM risk compared to 75% of all new cases in 1990. Year 2000 data shows that this trend

continues with white MSMs making less than a quarter of all living AIDS cases in Western New York.

Through the Comprehensive Newborn Screening Program, the State of New York tests all newborns for the presence of HIV. Although this test is not a definitive indication of the newborn's HIV status, it is conclusive with regard to the mother's status. Through this screening program, New York has been able to gather data on the dimensions of HIV infection among women who give birth in the state. In 1998, the HIV seroprevalence rate for the Western New York (or Buffalo Ryan White region) was .13% or just slightly above the state average (24 women identified as HIV positive out of 18,237 women tested). In 1997 and 2000, the seroprevalence rate for the region was .10%, which is the lowest rate for the region since 1993. HIV infection among childbearing women in the region is almost exclusively among women of color.

While no newly diagnosed Pediatric AIDS cases had been reported between 1997 and the winter of 2002, the recent seroconversion of two previously undiagnosed infants, has raised provider concerns.

Injection drug use is attributable to about a third of cumulative and living AIDS cases in the region. Injection drug use has increased as a percentage of total cases over the past 10 years and Blacks comprise more than half of the living cases where injection drug use is the identified risk factor. People with histories of injection drug use face additional risks. Hepatitis C is an emerging public health threat in the state, having the potential to have as great an impact as HIV. State health officials estimate that over three quarters of drug users are likely to be infected with hepatitis C after two years of injecting. New York State reporting requirements and limitations in current testing technology complicates efforts to obtain accurate data on Hepatitis C prevalence in the region.

5. IMPLICATIONS/CONCLUSIONS

The available epidemiological data for Western New York tells a story that is being repeated across the state and the country. Individuals are living longer with HIV and AIDS and, overall, new pediatric AIDS cases have greatly reduced. However, these small victories, mostly due to medical advances, have not significantly reduced the impact of the disease on certain communities. Specifically, communities of color continue to be impacted at greater proportions and continuously comprise a greater portion of the people living with HIV and AIDS. Based on data from AIDS health clinics, this appears to be true for rural communities in Western New York as well as for urban centers. Women, and subsequently women of color, also continue to comprise a greater portion of the population living with the virus. The recent seroconversion of two newborns might in fact be an outcome of these trends.

In conclusion, these trends emphasize the importance of service delivery to meet the needs of the most impacted communities. The remainder of this document looks closely at the service delivery systems in Western New York. An important query will be the accessibility of services to communities of color and women.

SECTION III. SERVICES IN THE COMPREHENSIVE CONTINUUM OF CARE

1. CORE/ESSENTIAL SERVICES

At the time that this document went to print, fifty agencies provided HIV/AIDS related services to the Western New York HIV CARE Network region. Thirty-five of them provide Medicaid fee-for-service care including: AIDS adult day health care, AIDS home care, HIV primary care, AIDS specialty services, AIDS nursing care, and intensive family centered case management and community follow-up. Twenty-two of the agencies hold 40 HIV/AIDS-related service contracts with the New York State Department of Health AIDS Institute. Sixteen of the contracts are to provide prevention and supportive services.

On June 6, 2003, the only minority controlled AIDS service organization in the region, Geneva B. Scruggs Community Health Care Center (GBS) located on the East Side of the City of Buffalo, closed its doors due to lack of financial viability. The agency had employed 57 people and provided medical services to approximately 1,100 individual patients per month. Approximately 120 of these patients were receiving HIV primary medical care and/or HIV/AIDS supportive services.⁶³

As the insert, ***AIDS Institute Contracts Serving Western New York***, demonstrates, contracts are dispersed across a range of provider types and address a wide range of service needs. The contracts are distributed to community-based organizations, broad-based social service providers, county departments of health, and medical centers. Medical providers in the region include: two tertiary care hospitals (AIDS Designated Centers), one for adults and one for pediatrics; two community providers with HIV experienced physicians; and several other hospitals and community health providers with limited HIV/AIDS experience.

2. ANALYSIS OF SIGNIFICANT FINDINGS

While the service delivery system for Western New York is relatively comprehensive and diverse, gaps in services delivery are evident. The Network has identified two primary service gaps and two emerging service issues that are highlighted below.

Service Gaps:

- general access for rural residents
- housing and related supportive services

⁶³ Beginning June 9, 2003 a transition team was established to provide continuity of care and assistance in choosing alternative medical and supportive service providers. The transition team will provide interim health care and/or case management services for a two-month period. Medical and/or case management records will be transferred to Lifetime Health, custodian of Medical Records during this interim period.

Emerging Service Issues:

- primary and specialty care provided by HIV specialists
- mental health services for PLWH/As and, especially, for the multiply diagnosed

A majority of the service providers are located in the vicinity of the city of Buffalo where the epidemic is centered. This impacts on the access for rural residents. While much has been done in the past five years to improve access to the rural counties, providers and consumers continue to identify concerns about the disparity, which are highlighted in Section IV. A recently awarded SAMSHA grant will attempt to address the barriers associated with centralized service providers serving the entire geographic region by developing a better network of care with increased outreach components. The goal of the funding is to prevent PLWH/As from “falling through the cracks”.

In the meantime, there continues to be a gap in housing related services for PLWH/As in the region. A new program that was implemented in August 2001 – Geneva B. Scruggs (GBS) Community Health Care Center’s HOPWA program, *All About Home* – demonstrates the need for housing assistance. The project dispersed 116 short-term grants to 93 households in which 97 individuals with HIV/AIDS (representing about 12-13% of the known living AIDS cases in the region) resided during its first year in operation. Most of the participating individuals/households had less than 30% of the regions median income. The assistance was intended to provide small assistance grants, for individuals in the process of moving and/or who had moved in the previous 18 months. Presently, a statewide needs assessment is being conducted to fully ascertain the housing needs across New York State. Network providers are participating in the study, which they hope will provide data that will be helpful in their efforts to increase funding of housing and related support services.

There is also a recognized gap in the service delivery of mental health services for PLWH/As. Anecdotally, it appears that mental health, substance use, and HIV are often conflated: in part due to misdiagnosis and partially due to gaps in the service system. Medical and social work professionals have reported that mental illness in substance using patients is often undiagnosed as their clients bounce between community based counseling services and chemical dependency programs. The Network has identified the need for a local needs assessment to better understand how mental health needs are presently being addressed and where and how to best fill in the gaps.

Another emerging concern that transgresses both urban and rural concerns is access to HIV specialists for primary care services. The Western New York CARE Network has identified service gaps in the availability of primary and specialty medical care for people living with HIV and AIDS in the region. These gaps are in addition to the consumer barriers that are examined in other sections of this document including transportation, changes in the health care environment for Medicaid recipients, and discrimination issues. Evidently, the service system cannot efficiently and effectively meet the medical needs of the current population; a condition that is expected to worsen

in the next few years if current trends remain the same. Already, the PLWA Committee has expressed concern that limited physician choice is impacting on health outcomes.

The three major HIV provider sites – Erie County Medical Center (ECMC), AIDS Community Services (ACS), and GBS – have had great difficulty replacing HIV specialist physicians when they leave. At the time this report went to publication, ECMC had been trying to recruit an HIV specialist for 10 months without success. A second HIV specialist at ECMC is scheduled to leave the area in June 2003. Also, two private HIV primary care providers stopped taking new HIV patients recently. This raises special concerns for a region that has not attracted new physicians to HIV care in several years. There are also significant gaps in the availability of medical specialties. The Network has identified service delivery gaps in the following areas:

- *Dermatology*: Currently, there are no HIV experienced Dermatologists in the area and only two clinics, Kaleida at Buffalo General and Roswell Park Cancer Institute, provide dermatology consultations for Medicaid recipients. Therefore, the wait for consultations can be several months.
- *Pain Maintenance*: The region is without a pain clinic that addresses HIV issues or accepts Medicaid patients.
- *OB/GYN Care*: Only one OB/GYN in the region, based at ECMC, provides HIV care. He is assisted by two nurse practitioners at Children's Hospital. While other physicians and nurse practitioners in the region provide general pelvic and pap exams for their patients, they all must depend on referrals to the same OB/GYN when specialty care is indicated.
- *Pediatric Care*: Children's Hospital in Buffalo has the only physician and nurse practitioner providing HIV pediatric specialty care in the region.

Rural communities have been faced with a shortage of HIV specialists for many years. One of ECMC's physicians is the only HIV specialist providing care at three Southern Tier off-site clinics and prisons. Other than the limited assistance provided by a nurse practitioner from Erie County Medical Center, the program has been unsuccessful in attracting additional physicians to the rural clinics. This does not go unnoticed by the community; providers, consumers, and community members have expressed concern that the entire rural HIV primary care system is dependent on one dedicated physician.

Many of the rural counties in WNY expressed concern about access to HIV care in their areas at many forums within the AIDS Network of WNY. The WNY Service Delivery Plan has demonstrated this service delivery gap since its first version and, as a result, there has been some improvement in the past 5 years. The NYSDOH AIDS Institute responded to local concern offering an opportunity for grant support to rural health clinics. ECMC applied and was funded in 1998. At that time, the Chautauqua County Health Department had been treating some HIV patients in the Southern Tier counties.

The ECMC model targeted the HIV patients in remote areas of the Southern Tier counties. A part time physician, nurse, and case manager provided home visits to HIV patients. The rural program started with 12 HIV patients and has evolved into a program serving over 100 HIV patients at three clinic sites - Dunkirk, Jamestown, and Olean. Strong collaborations developed through this initiative with the Chautauqua County Health Department, other Southern Tier county health departments, AIDS Community Services, and Chautauqua Opportunities. Also Children's Hospital and Child and Family Services have assisted HIV rural patients with services. The positive outcome of this project has been attributed to extensive regional planning and collaboration.

SECTION IV. ASSESSMENT OF NEED

1. IDENTIFICATION OF HEALTH CARE AND SUPPORT SERVICES NEEDS AND GAPS

Methodology

Community involvement was integral to identifying gaps and needs in supportive services and health care. In 2000 and 2003, the consultants worked closely with the Network to gather original data from the community. Also, summaries from 22 local Discussion Groups were contributed by the Regional Gaps Analysis (RGA) that was conducted in 2002. The findings of reports and position papers conducted by the Network since the 1996 Service Delivery Plan (SDP) are also incorporated into the report where relevant. (See Appendix 1 for a table listing all sources)

This section discusses the original information collected from the community for the SDP Updates in 2000 and 2003 as well as the Western New York Regional Gaps Analysis 2003, and other data generated by committees of the AIDS Network of Western New York since the 1996 Service Delivery Plan.

The goals and the methodology incorporate the four primary issues that are being considered in the Service Delivery Plan Update:

1. Availability and quality of services in the community.
2. Access to service and service barriers.
3. Concerns, needs, and priorities of the community.
4. Gaps in service and emerging service needs

Data was collected through:

- *Focus Groups*: Based on the Network's prioritization of 'the unconnected', a consumer and a provider focus group were conducted in 2000. The focus

groups were designed to provide a forum for gathering qualitative information about 'the unconnected' through in-depth discussions with providers and recently connected consumers.

- *Provider Survey*: In 2000, the Network distributed a Provider Survey and about half of the thirty-four (34) HIV/AIDS service providers completed and returned it. The services provided by the responding organizations were diverse and covered the broad continuum of services for people living with HIV/AIDS. About half provided substance use, mental health, medical, and some form of housing assistance services. Almost 90% provided referrals and more than half offered case management.
- *Community Forums*: Community forums were held in 1996 and 2000. The SDP Committee utilized Public Forums for the 1996 Service Delivery Plan and the 2000 Update to provide an opportunity for friends, family, and concerned community members to participate in the process of identifying and prioritizing service needs in Western New York.
- *Discussion Groups*: In 2002, The Regional Gaps Analysis conducted 22 Discussion Groups to gather community feedback regarding HIV prevention services in the area. Summaries of the discussion group content and participant profiles are included in the Regional Gaps Analysis document. In summary, of the 269 participants, 155 were from Erie County with the remaining distributed among Allegany, Chautauqua, Genesee, Orleans, Cattaraugus, Niagara, and Wyoming counties. About 65% were female, 2% transgender and the remaining identified as male. 57% reported to be white, 24% African American, and 13% Latino. Most were heterosexual with 20% identifying as homosexual and 6% bisexual.

Six of the discussion groups were held in collaboration with the county AIDS task force meetings, which expanded participation outside of Erie County. Groups were also convened for impacted populations including:

- Regional HIV/AIDS Community Educators
- Immigrant/Migrant Farm Workers
- Deaf and Hard of Hearing
- M.O.M.S. Program
- Men of Color Who Have Sex with Men
- Communities of Faith
- Men Who Have Sex with Men
- Substance Use Community
- Hispanic Community
- Gay, Lesbian, Bisexual, and Transgender College Students
- HIV-Affected Children's Group

Also, five AIDS Network Committees participated. These were committees formed to discuss the following subject areas:

- Case Management
- Community Awareness
- Minority Concerns
- PLWHA
- Women, Children, and Young Peoples

Findings

Population Groups Presenting the Greatest Unmet Need:

MICA diagnosed people living with HIV/AIDS were frequently identified as presenting significant needs that have not been addressed. The need for a broader understanding of harm reduction in general HIV-related services and for harm reduction-oriented housing was also indicated. The other three population groups identified as having a high rate of unmet service needs were; PLWH/As who were homeless or under-housed; homosexual and men who have sex with men – specifically adolescents and men of color; and parents – specifically young mothers and single parent families. Other groups that were mentioned as having significant unmet needs included Hispanic women, the under/uninsured, people living with AIDS and dementia, migrant workers, and the mentally ill.

Consumers and providers expressed concern that youths were not receiving sufficient HIV/AIDS education and prevention and that the services available to them were limited both by capacity and in their ability to address the needs of at-risk youth. Their primary concern was that youth “have nowhere to go” to be educated, empowered, and supported to address risky sexual behavior and drug use. They felt that the need for a more open dialogue about sexuality and drug use was paramount to addressing the needs of youth who have been infected by HIV and who feel themselves to be completely isolated from support and understanding in most communities. According to the participants, most youth culture, both MSM and heterosexual, is permeated with ignorance and fear about HIV. This creates barriers to youth accessing the care and services that they need.

Women needs were addressed in the focus groups and discussion groups. One highlight was the lack of coordination between general women’s health and family services and HIV wellness. There appears to be a consumer perception that general providers of women’s health services are isolated or completely separate from HIV/AIDS service providers or that there is very little communication or interaction between the two. This further isolates women living with HIV in the community. Due to fear of stigmatization, women are reluctant to be identified as PLWH/As (as are many other groups), which is often a barrier to accessing known HIV/AIDS providers. This

creates a dilemma for HIV service agencies that must balance the need for consumer confidentiality with the obvious need for community education and outreach.

Unmet Service Needs Presented by Clients:

Providers identified housing, transportation, and MICA services as unmet service needs presented by clients. This was true for providers both in urban and non-urban locations. Housing was often cited as a barrier to clients remaining connected to services. Residential treatment beds, including HIV-targeted substance abuse and MICA beds, as well as harm reduction-oriented housing were specified as housing related service needs. Other service needs referenced included community outreach and education about available services, COBRA case management, legal services, pastoral care, and support groups.

Consumers expressed concern that many PLWH/As who are resistant to accessing care, do not connect to services until their health deteriorates to the point where they require hospitalization. Apparently at this late stage, HIV provider interventions in a hospital setting with sick patients have been effective at connecting patients to on-going care. Providers reiterated that early intervention services are needed in the region to help connect people to medical care.

As recognized by the Network, the need for adequate housing is significant in the Western New York Region. Many consumers related their own difficulty finding adequate permanent housing and expressed concern that there was not enough supportive housing in the region. One participant was placed in a general population nursing home following hospitalization, which he interpreted as being sent to a “hospice where people go to die.” Another source of frustration was the lack of support for the process of locating apartments to rent, which was exacerbated by the lack of access to or affordability of transportation.

The providers explained that the ability of clients to afford car services and the limits (and cost) of public transportation is wedded to the housing crisis for people with HIV. Since the region is without a scattered-site housing provider, the search for housing requires the consumer to conduct multiple trips to view apartments, negotiate with landlords, and process rent reimbursements.

Barriers Affecting Client Access to and Retention in Services:

Consumers and providers alike expressed concern about barriers to access for special populations including English as a second language speakers, migrants/immigrants, and members of the deaf community. Some of the barriers blocking effective treatment access these community’s providers’ lack of understanding of their special needs as well as a lack of up-to-date and appropriate outreach strategies and literature.

Consumers expressed concern that many members of their community are most likely living with HIV but are not getting tested. Even after notification of their status,

participants indicated that fear of discrimination, lack of knowledge about HIV/AIDS, and active substance use were common barriers that prevented newly diagnosed PLWH/As from engaging in services.

There was also considerable concern that the level of knowledge about HIV medical care in their communities was either outdated or inaccurate. A participant in the 2000 consumer focus group, for example, reported that he knew many injection drug users who believed that HIV medications caused death.

Other commonly expressed barriers were client fear of discrimination and the lack of involvement in HIV/AIDS issues by the religious and faith community. Language issues were also considered a significant barrier among the providers that do not specifically target immigrants. In fact, when the 2000 provider survey sample group is controlled for providers not offering special programs for immigrants, language and cultural issues emerge as the most significant barrier reported.

Apparently, the dependence on the case manager for transportation and advocacy during the search for housing was a major cause of provider stress and a barrier to retaining clients. Consumers and providers reiterated that the need for transportation and adequate housing were significant barriers to maintaining client health. Providers expressed concern about the quality of the housing stock that is affordable. Providers said they often worked with individuals who moved from “one deplorable situation to another” in dire attempts to find appropriate housing. The lack of government or private landlord accountability in the area has created a situation where legal assistance, although in short supply, has often become a vital and necessary component of efforts to stabilize clients in safe and affordable housing. Since stable and adequate housing is the foundation from which an individual can maintain health and well being, this cycle of frustration and dependency has a far-reaching effect on the overall health of a large portion of PLWH/As in the region.

Organizational Capacity Issues:

Not surprisingly, the greatest concern among providers was the shortage of staff and of HIV/AIDS-specific funding to develop programs and to provide staff development. The lack of administrative and development staff was mentioned as an issue affecting service provision. Other organizational issues expressed in the provider survey were the need for staff training and, in one case, the need to expand program space.

Consumers expressed concern that as a result of the a shortage of frontline HIV providers, staff must prioritize who is most in need of assistance and that this results in attention and care being focused on those who present as the sickest. Many participants reported experiences with providers in which their needs were minimized due to their apparent good health. Overall, their perception was that frontline providers, especially case managers, were overburdened by their caseloads and tended to operated in a ‘triage’ culture that elevated crisis care over prevention and health

maintenance. Providers and consumers in the 2002 discussion groups expressed concern that HIV service staff is underpaid and, as a result, high staff turn over lowers quality and continuity of care.

While consumers said peer education and support was important in the areas of HIV education, medication adherence, and prevention programs, they criticized the effectiveness of the existing peer programs. Discussion group participants expressed a need for renewed outreach strategies, updated materials, and extensive training for outreach workers and peers.

2. SPECIAL ISSUES AND NEEDS

The epidemiological analysis and the data generated from surveys, focus groups, and community forums led to the identification of a number of significant issues which may help to guide service delivery planning for the region.

The Unconnected

There is widespread concern among providers in the region that there are significant numbers of people living with HIV infection who are not connected to services and, as a result, do not access care until their health status has significantly deteriorated. Since these are people who are not connected to services, it is difficult to be certain of their numbers or characteristics. However, an examination of data such as enrollment in ADAP (the AIDS Drug Assistance Program – a key point of entry into care as it provides payments for medical services to people without insurance or other benefits) reveals that about half begin to receive assistance when they are already diagnosed with AIDS (35%) or when they have advanced HIV disease (14%). See Section VII, Figure 18. Among the factors that seem to be related to people remaining outside of the HIV care system are: stigma/discrimination related to HIV status; insufficient awareness of the benefits of early access to treatment; and burdensome socioeconomic issues, such as homelessness, unemployment and domestic relationships, which are seen as outweighing concerns about personal health.

The SDP Committee identified the service needs of ‘the unconnected’ as a special issue to be addressed by the community needs assessment that was conducted specifically for the 2000 Update.

‘The unconnected’ are defined as people living with HIV/AIDS in the Western New York Region who are not engaged in HIV services. This includes individuals who have tested positive for the HIV virus and have not enrolled in or have not remained in HIV-related medical care and social services. ‘The unconnected’ also includes high-risk individuals who are living with HIV but have not tested for the virus because they choose not to know their status. Non-connection, whether the individual PLWH/A knows their status or not, may be due to personal choice, stem from lack of education about living well with HIV, or be an outcome of barriers to accessing and retaining services. A better

understanding of the reasons that PLWH/As remain ‘unconnected’ to HIV services is a crucial step to identifying HIV service priorities for the Western New York region.

In its *May 2000 Report* and *July 2002 Report*, The Data Collection Committee reported a large gap between the total number of PLWH/As and the number receiving medical services in the Western New York Region. The number of unduplicated PLWH/As receiving medical services was totaled from data collected by the committee directly from HIV medical providers in the region. The latter number was compared to the total number of PLWH/As, which was interpreted from New York State and CDC data from 1990 through 2000. The Network’s analysis resulted in the 2002 finding that about 62% of PLWA/Hs in the region were ‘unconnected’ to medical providers.

Unpublished ADAP data from the AIDS Institute may support the Network’s Data Committee deduction that a larger percent of people *living with HIV* who have not received an AIDS diagnosis are not connected to medical care in the region. The Data shows that between 1997 and 2001, a high rate of individuals were diagnosed with AIDS prior to their enrollment in ADAP.⁶⁴ See Section VII, Figure 18. Since ADAP enrollment is established for persons who are in the process of being accepted for or are not eligible for Medicaid, this finding suggests that many PLWH/As did not have health insurance prior to their AIDS diagnosis. Overall, more than half of the ADAP enrollments occurred after the individual experienced HIV related illness – in 2001, forty-nine percent (down 8% since 1999) were either HIV symptomatic or diagnosed with AIDS at the time of their enrollment. This data implies that many PLWH/As were ‘unconnected’ to medical care during a period of living with HIV disease.

The SDP committee speculated that ‘the unconnected’ were, often, PLWH/As who had accessed services in the past and then “fell out” of services due to barriers ranging from service gaps to personal barriers. The qualitative data collection for the 2000 Update was designed to expand the understanding of these assumptions. The surveys and focus groups solicited information about blocks to access, analyzing concrete service barriers such as lack of transportation to personal barriers such as fear of discrimination based on HIV status.

Discrimination

Fear of discrimination related to HIV status and the related sense of stigma about being HIV positive are very significant concerns in the region. There are significant reports of people being denied housing based on their HIV status – discrimination that is clearly contrary to federal fair housing laws. Other PLWA seem reluctant to accept services from agencies that are known as AIDS Services Organizations. Consumers and providers both suggest that increased peer involvement in counseling and mentoring

⁶⁴ NYSDOH –AIDS Institute, HIV Uninsured Care Programs 1997-1999, unpublished Data collected for this report.

can be very effective in assisting HIV positive people in adjusting and accessing required services and treatments.

Transportation

It is not surprising, given the large distances included in the Western New York region, the inclement climate, and high rates of poverty among people living with HIV/AIDS, that transportation is a major issue. It impacts on the ability to find and secure decent housing and accessing services. Given the concerns of stigma and discrimination, consumers are seeking transportation services that are anonymous or mainstream, e.g., not in para-transit or agency identified vans. People living in rural areas have particular problems: not only are the distances longer and public transportation less available but they have to travel into urban areas in order to access state of the art health care.

Housing

Housing is a significant issue. There is a lack of adequate housing, high cost utility rates and a shortage of supportive housing. The homeless shelter system is overburdened. There is discrimination in the private sector; and there are gaps in the services infrastructure put in place to assist people in remaining housed.

3. PRIORITIZED NETWORK NEEDS

This section identifies potential service needs for people living with HIV and AIDS in the Western New York Region. The areas highlighted are based on information collected from the consumer and provider surveys, focus groups, expert interviews and updated epidemiological data. The information presented will assist the Network in identifying needs and provides a planning resource to help community members and service providers anticipate and develop strategies.

The findings are grouped below by population and are not rated according to priority of need. This is intentional since the Update is designed to *inform* the Network's prioritization process. Five service needs, however, stand out due to their far-reaching impact on service delivery in Western New York. Therefore, this section begins with an overview of these overarching issues.

Key Issues

The Needs Assessment revealed that both concrete and qualitative issues are significant in understanding the barriers that prevent people living with HIV/AIDS from accessing and remaining connected to HIV care. While available epidemiological data do not permit a precise determination of who the unconnected are, the community

needs assessment indicates that a high rate of the unconnected are represented in the NYSDOH AIDS Institute Statewide AIDS Service Delivery Consortia (SASDC) special needs groups. Women, adolescents, MICA diagnosed, immigrants and migrants, substance users, and MSMs were identified by providers and consumers as experiencing gaps in services and confronting barriers that prevent them from engaging in services. All of these groups experienced, to a greater or lesser extent, the five overarching issues discussed below.

Transportation

Transportation emerged from the qualitative data analysis as an unmet need across both urban and rural areas impacting the ability of PLWH/As to access and maintain comprehensive services. Consumers, providers, and the Network highlighted the lack of accessibility of transportation as a major barrier to accessing needed care. While some medically eligible PLWH/As are able to access Medicaid reimbursed ambulatory services for primary care appointments, the majority of consumers are dependent on travel assistance through tokens and transportation provided by case managers and other providers.

For clients needing taxicab service, increased insurance and licensing fees for cab companies has resulted in reduced fleets and transportation services. Environmental factors – inclement weather throughout the winter months and the broad geographical areas served by most HIV service providers – also intensify the importance of transportation assistance in the provision of comprehensive care to PLWH/As.

An interesting finding in recent years at rural HIV site clinics is a 95% appointment adherence rate. Patients in rural clinics have found ways to get to the clinics located closer to home and local community service agencies have provided assistance. A recently implemented transportation support program operated by the Red Cross was highly utilized before being rescinded. Since reinstatement, changes in the administration of this program have created some challenges in monitoring, access and processing due to layered paperwork and limited case managers at many provider sites. An Advisory Group composed of both consumers and providers is currently addressing many of these challenges as the program is reestablished for community use.

Service Need Implications:

- Program analysis, evaluation, data collection and needs assessment surrounding newly funded and established transportation assistance and related programming.

- Streamlined administrative processes and paperwork reduction to facilitate a timely and efficient delivery of funded programs and services.
- Evaluation and resolution of recent loss of transportation support in Niagara County.
- Availability of confidential personalized transportation services for individuals and families to access multiple services as well as to maintain independent living – food shopping, housing search, etc.

Housing

Not only is there a need for additional housing services but the absence of adequate housing stock and supportive housing influences consumer ability to access the multiple HIV related medical and support services that are necessary to stabilize their health and become independent. According to providers, the homeless shelter system is overburdened and available beds are often dispersed across broad geographical areas, which are exacerbated by the transportation crisis.

The Housing Needs for Persons Living with HIV/AIDS: Comprehensive Housing Affordability Strategy 1999 developed by the Network's Housing Committee determined that de facto housing assistance for persons living with AIDS and HIV in the region is costly and inefficient. The *de facto* system used for PLWH/As with multiple diagnoses and frailties are housed in psychiatric wards and general population nursing homes. Staff in these facilities are not trained or prepared to handle HIV-related health and psychosocial issues. Also, families and individuals capable of independent living often lose contact with HIV care due to the chaotic process of finding and maintaining affordable and adequate housing. This leads to missed appointments– and therefore ill health and higher cost care – and inefficient use of resources.

Network members also report barriers to the disbursement of HOPWA funds by The City of Buffalo. The City has administered HOPWA funding for Erie and Niagara County since 1999. During this time, providers have reported administrative barriers to the processing of funding applications and the disbursements of funds.

Service Need Implications:

- Program analysis, evaluation, data collection and needs assessment surrounding newly funded and established HIV/AIDS specific and non HIV/AIDS specific housing programs.

- Increased legal support for housing related issues ranging from discrimination to benefits advocacy.
- The development of a comprehensive regional housing plan and the efficient, adequate delivery of HOPWA funds to providers and consumers. City of Buffalo and Network collaboration necessary.
- Enhancement and/or development of congregate and supportive housing and related services for PLWH/As. (For example: those with dual diagnoses and HIV related health needs, single parents and their children, male & female domestic violence victims, etc.)
- Streamlined administrative processes and paperwork reduction to facilitate a timely and efficient delivery of funded programs and services.

Fear of Discrimination

The community needs assessment indicated significant fear of discrimination based on HIV status, which constituted a barrier to accessing services. According to the respondents, stigma related to HIV/AIDS diagnoses and outdated community based understanding of HIV has an enormous effect on initial engagement in services.

Both providers and consumers indicated that the best way to connect PLWH/As to services is through face-to-face community based outreach and, especially, through the involvement of other PLWH/As. The PLWA Advisory Committee Recommendations memos from April 2000 and 2002 advise, respectively, that:

Peer navigators act as role models for the newly diagnosed and assist in overcoming the fear, stigma and isolation that often accompanies an HIV diagnosis... Persons living with HIV/AIDS benefit from peer interaction and support [and that] agencies should describe how HIV-positive persons from target populations have been involved in the design of activities and how they will be involved in the delivery and evaluation of the services.

A program in Erie County was recently awarded an AIDS Institute contract to establish the use of peer navigators.

Within the Network, there is a sentiment that participation by the faith community is central to changing the judgmental culture that is the root of this discrimination. Findings from the PLWA Spiritual Needs Assessment, June 12, 2000 supports the importance of the faith community to PLWH/As in the region showing that 67 percent of the respondents had a current faith affiliation and, overall, respondents had a very high rate of a belief in a 'power greater than myself'. Recently, advocates for the involvement of the faith community in efforts to change the stigma attached to HIV and AIDS were enthusiastic about the success of 'National HIV Test Day' activities. Faith organizations

including leadership from African American Clergy, PLWH/As and HIV/AIDS service providers collaborated to promote HIV counseling and testing. Recent regional efforts include an AIDS Institute sponsored series of regional partnership building meetings with faith community leaders and community-based organizations titled “Meeting on Common Ground: The Role of Faith-Based Communities in HIV/AIDS”.

Service Need Implications:

- Social marketing campaign to re-educate Western New York communities about living well with HIV lead by a committee of PLWH/As representing special needs groups and geographical regions, religious leaders, and representatives of community based social services.
- Expansion of coordination of peer involvement in outreach campaigns and community follow-up efforts conducted by community and hospital based providers.
- Program analysis, evaluation, data collection and needs assessment surrounding newly funded and established peer navigation and related programming.
- Expansion of regional linkages and participation with faith community leaders and community-based organizations.

The Unconnected

ADAP data for Western New York shows that almost 60% of individuals only enroll at advanced stages of HIV illness, thereby losing benefits of preventive health care. Additionally, the Needs Assessment revealed a belief among consumers that case managers provide “more care” to sicker PLWH/As. As a consequence, for unconnected PLWH/A, re-connection to services happens during periods of health related need. Hospitals appear to be a primary point of connection for many PLWH/A. Community based HIV service providers rarely have the setting or the opportunity to engage PLWH/As in early disease stages. Instead, individuals become engaged in HIV services during hospitalization.

Substance use also contributes enormously to clients’ inability to stay engaged in health care and social services. Both focus groups suggest that the unconnected are not people who have *never* accessed services, but are people who *have* accessed services and then, for a variety of reasons, dropped out of care.

Service Need Implications:

- Program analysis, evaluation, data collection and needs assessment surrounding newly funded ADAP enrollment grants and related programming.

- Continued support of peer involvement in outreach campaigns and community follow-up efforts conducted by community and hospital based providers.
- Continued design and development of programs, strategies and activities to engage at-risk populations within the region.

Case Management

Recently, the Emerging Communities Work Group identified Case Management as a primary need. Case management is a theme that appears throughout the four overarching issues – transportation, housing, fear of discrimination and the unconnected – highlighted above. Many of the ‘Service Need Implications’ presented are case management issues. For example, the primary finding for addressing transportation needs rests on the ability of community based case managers to provide individual transportation services to their clients. This level of client need combined with, what providers report to be “layers of duplication and accountability for funded provided services”, raises both capacity and quality control issues for the case management providers in the region.

Service Need Implications:

- Comprehensive assessment of the capacity of case management providers in the region to provide transportation and follow-up services.
- Development of case management staffing and incentive structures that encourage staff retention.
- Expansion of peer involvement in case management as outreach and community follow-up workers and support for supervision of peers’ activities.
- Regional education on the levels of case management services and the development of improved strategies to encourage increased case conferencing and reduce duplication of services.
- Streamlined administrative processes and paperwork reduction to facilitate a timely and efficient delivery of funded programs and services.

Women and Pediatric AIDS Cases

Women continue to be a small percentage of the AIDS cases in Western New York, although their percent of the total has been slowly increasing. In the urban centers, black and Latina women are disproportionately affected. Providers also report that younger women with children have increased difficulty managing and utilizing available health and supportive services.

The number of newly diagnosed Pediatric AIDS cases has declined due in part to the impact of AZT therapy in reducing HIV transmission from mother to newborn. According to the New York State Department of Health, no new cases among children aged 13 and under were diagnosed or reported between 1997 and the winter of 2002. At the end of 2002, however, two previously undiagnosed infants seroconverted. This raised the known living pediatric AIDS cases to 21 in the region.

Service Need Implications:

- Continued support of permanency planning resources in the region, particularly in the rural areas. These services must be comprehensive and address the social and legal issues facing the parent with AIDS as well as the psychosocial needs of their children.
- Strategize and deliver service delivery models that would effectively engage women and their families into the existing HIV/AIDS continuum of care earlier in their disease process.
- Development of peer centered, community-based programs for young women and their male partners that address HIV, STDs, pregnancy and general health.

Adolescents

Comments from younger members (diagnosed before 20 years of age) of the 2000 Consumer Focus Group suggested that existing HIV/AIDS services are very adult focused. They cited an absence of services that address HIV positive youth and at-risk youth in settings that are youth friendly. Providers and consumers reiterated this concern in the 2002 discussion groups. There are a number of hospital-based HIV/AIDS health services that focus on adolescents. STD rates from the epidemiological analysis point to risky sexual behavior that is primarily occurring among females under the age of 19. Among 13-24 year olds living with AIDS in Western New York, more than 85% of the cases are attributable to sexual risk.

Service Need Implications:

- Expand community based support and outreach services for youth living with HIV/AIDS or at high risk.
- Integration of HIV/AIDS counseling and testing and care services within youth service agencies as well as supportive funding of HIV rapid testing.
- Transitional services for HIV infected and affected adolescents from pediatric to adolescent primary care.
- Better integration and coordination of HIV services into adolescent primary care in order to provide more age appropriate services.

Immigrants and Migrants

As discussed in depth in the Epidemiological Section, data is difficult to secure for non-U.S. born residents of the United States, and specifically in the Western New York Region.

Recent immigrants face considerable hurdles to obtaining services. Legal immigrants who have arrived in the US after 1996 cannot qualify for Family Assistance or Food Stamps until they have been in the country for five years; Safety Net benefits, including emergency Medicaid (for single individuals) can be obtained for up to two years but potential recipients face a one year New York residency requirement. A regional medical provider reports an adolescent immigrant recently presented to their clinic with symptoms and subsequently tested HIV positive. Little is known about links to care for pediatric and adolescent immigrants.

The state ADAP and ADAP Plus programs do offer benefits to immigrants (both documented and undocumented), permitting access to medications and primary care. Given that so many other programs are barred to immigrants and the fear surrounding undocumented people, it is likely that immigrant use of the ADAP programs is limited. It would be important for the Network to monitor ADAP utilization trends within the Western New York community and surrounding areas.

Issues relating to the undocumented include the fear of deportation and reluctance to access health care and social services, especially HIV related. Most statewide analysis focuses on documented immigrants. It is difficult to estimate the number of undocumented immigrants, including migrant workers in the State outside of Western New York. It is also difficult to know how many of that number resides and/or works in the Buffalo or the surrounding community.

Service Need Implications:

- Further tracking of epidemiological data and needs assessment analysis of the impact of HIV and AIDS on the immigrant community is implicated.
- Case management is a particularly important need among the immigrant and migrant populations. They have even greater difficulty in accessing services and systems, experience barriers due to language, and have justifiable concerns about deportation. Even though the ADAP program will cover HIV related medications, it is not clear that physicians will prescribe them to this population without advocacy and follow-up provided by case managers.
- Outreach is important to inform immigrants and migrants of the possibility of obtaining services through the ADAP program and providing a linkage to case management services.

Men Who Have Sex with Men

Men who have sex with men (MSMs) account for more than half of all living AIDS cases among Western New York men. Cumulatively, in the Western New York Region, MSM has been the risk of transmission in about half of the cases. Risk of transmission among male AIDS cases in Western New York has been primarily among MSM or IDU, with the former more prevalent among whites and the latter more prevalent among blacks. AIDS cases attributable to MSM risk tend to be the cases that are not heavily represented in the statistics including inmates. The epidemiological analysis shows that the percentage of AIDS cases attributable to male-to-male sexual transmission has decreased slightly since 1990. The number of new AIDS cases among men who have sex with men peaked in 1994 and has decreased since then. Nationally, federal health officials are concerned about increasing HIV infections among gay and bi-sexual men in communities that have demonstrated effective prevention practices.

Additionally, in 1998, the CDC expressed concern that prevention efforts among young and minority men in particular were not as effective. Because many men of color who partner with men do not identify as gay, they often do not respond to prevention messages targeting gay men and are unlikely to seek testing and other HIV-related services.

Service Need Implications:

- Cultural and language competent community-based services targeting MSMs.
- Increased awareness and health promotion education campaigns targeting both gay-identified and non-gay-identified populations of MSMs.

- Community based services that fully address the needs of MSMs, including health care and social services that address both HIV and non-HIV related issues, such as mental health services, sexuality, STDs, drug and alcohol abuse.
- Better integration of MSM related issues into service and programs that target youth.
- Strategize and deliver service delivery models that would effectively engage MSM, their partners and their families into the existing HIV/AIDS continuum of care.

Substance Users and MICA Diagnosed

Substance abuse and HIV are virtually inseparable barrier and services issues. Regardless of the population affected, service providers must always be prepared to address a range of issues related to chemical addiction. The lack of immediate linkages from health and social settings to appropriate drug treatment and the limited availability of appropriate levels of drug treatment services in the area were also critical issues identified by both sets of focus group members.

More specifically, there is a strong sentiment in the region for the necessity of HIV/AIDS services within mainstream drug treatment programs. Substance abuse and HIV services for populations with special needs are also needed. Services for women with children, MSMs and active, non-injection drug users were specifically identified as presenting unique challenges in accessing services.

The emerging Hepatitis C epidemic will have a profound impact on people living with HIV, especially in communities like Western New York where high AIDS rates are attributed to injection drug use. In New York State, it is estimated that as many as three quarters of all injection drug users are infected with Hepatitis C and that as many as 40 percent of all HIV infected people are co-infected with Hepatitis C.

Services addressing the needs of substance users in the region are mostly based in Buffalo. The only syringe exchange program is located in the City of Buffalo at Kaleida Health's Project Reach Program. Horizon Health Services offers an alternative therapies and a mental health program. The Viral Hepatitis Integration Project (VHIP) also serves the eight county region. A recently awarded SAMSHA grant will attempt to address the barriers associated with service providers serving the entire region by developing a better network of care with increased outreach components. The goal of the funding is to prevent PLWH/A from "falling through the cracks".

Another significant issue for substance users is the impact of welfare reform. Individuals receiving public assistance are screened for alcoholism/substance abuse. Those determined to be in need of treatment are referred to licensed treatment providers. The regulations require that individuals who refuse treatment be denied public assistance and Medicaid benefits, which could further limit their ability to connect to needed HIV-related services.

Service Need Implications:

- Further tracking of epidemiological data and needs assessment analysis of the impact of HIV and AIDS on the substance use community is implicated.
- Specialized programs to support treatment for HIV positive individuals with multiple diagnoses.
- Continued support and availability of regular provider trainings across intersecting areas of substance abuse, mental illness and HIV/AIDS.
- Increased MICA screening to confirm diagnosis and to assess the need for MICA services.
- Education and integration of programs for identification and treatment of Hepatitis C. These services will be an important component in all HIV programming.
- Respite housing for parents and their children during mental health, alcohol and/or drug treatment.
- Strategy for abstinence and non-abstinence based service delivery models that integrate substance use services and HIV prevention into the HIV/AIDS continuum of care.
- Ongoing monitoring and analysis of emerging data of the impact of welfare reform on the ability of drug users to access and retain public benefits is needed in targeted areas of Western New York with high rates of dependence on public benefits, HIV infection, and substance use.

SECTION V. RECOMMENDATIONS TO ADDRESS NEEDS

1. NETWORK PROCESS

The Network process for addressing needs in the community is driven by the prioritization of needs that will be outlined in the 2003 Service Delivery Plan Update. These needs will be the focus for the region's service delivery enhancement efforts for the following five years. The next comprehensive update of the Service Delivery Plan will be completed in 2008. During each of the preceding years, the Network will identify specific target areas for review. The plan for areas to be updated will be driven by community feedback and direction from the New York State Department of Health.

2. COMMUNITY PROCESS

Community members from the Western New York Region participate in the development of service delivery in the region through several formal processes engaging consumers, providers and the community-at-large. Needs assessment activities, discussion groups and public forums were used in this update and will continue to be used in the development of future updates.

The Network's Board of Directors, Committee members, and workgroup participants are comprised of various representatives of the community including: the service sector, rural residents, communities of color, persons living with HIV/AIDS, elected officials and other interested parties.

Full AIDS Network Membership meetings are held quarterly and open to any interested individual or agency. The meetings include an 'open forum' utilized for public comment on Network issues, suggestions or feedback. The Network accepts written comments pertaining to the service delivery update content or process at anytime.

3. ISSUES AND SOLUTIONS

The Service Delivery Plan Committee will continue to meet regularly to discuss emerging issues, community feedback, process refinement and strategies for the development of future updates.

Providers will contribute significantly to the process of addressing the prioritized regional needs identified in the Update. The AIDS Service Providers (ASOs) in the region will

continue to incorporate the Updates findings and the recommended prioritization of needs in their internal strategic planning and program evaluation processes. The regional ASOs also incorporate the prioritized needs in their efforts to coordinate service of delivery and to build effective collaborations.

SECTION VI. ACTION PLAN

1. GOALS AND OBJECTIVES

The Network's primary goal is to ensure comprehensive and quality care for all persons at risk for or living with HIV/AIDS in the Western New York Region. The Service Delivery Plan addresses the objective to determine regional service priorities and to identify emerging needs. The activities that the Network will complete to meet this objective are:

Dates	Activities
Sept 2002 – March 2003	Complete 2003 Service Delivery Plan document
April 2003 – June 2003	Identify service gaps and available resources
October 2003 – March 2004	Create and implement an action plan
June 2003 – Sept 2008	Identify emerging needs and key recommendations

2. PLAN UPDATE AND RENEWAL PROCESS

The Network will conduct a comprehensive update of the Service Delivery Plan every five years. The 2003 Update will be completed by March 2003. The following comprehensive update of the Service Delivery Plan and will not begin until 2008. During each of the preceding years, however, the Network will identify specific target areas for review. The Network is committed to conducting annual needs assessments to ensure that emerging needs are addressed.

The 2003 Update has two phases of development. First, the Service Delivery Plan Committee and the consultant complete an update of the epidemiological data, service delivery systems, and community needs assessment. In April 2003, the Committee will report these findings to the Board of Directors and Committee Chairpersons. The document will then be printed and submitted to Network members, consumers, and other interested community members during the Spring of 2003. The document will also be submitted to the New York State Department of Health to inform statewide planning activities.

The Board of Directors will then complete the second and final phase of the 2003 Service Delivery Plan Update. From June through September 2003, they will review the

findings and recommendations outlined in the plan and review the proposed priorities and emerging needs. They will consider the four primary issues addressed in the Update:

- Availability and quality of services in the community.
- Access to service and service barriers.
- Concerns, needs, and priorities of the community.
- Gaps in service and emerging service needs.

If indicated, after comprehensive review and discussion, Board members will make recommendations for proposed changes to the Network priorities. Once agreement has been reached, the Board will vote to validate the Network's priorities.

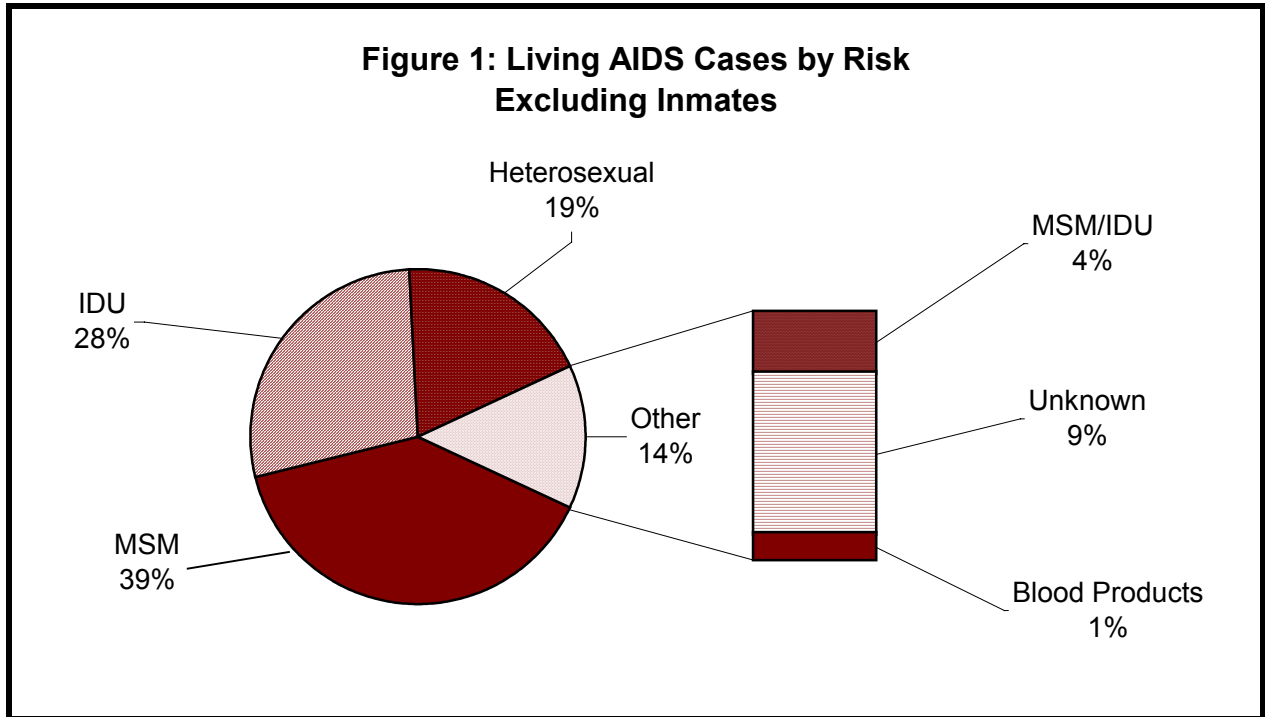
From October 2003 through March 2004, the Network will develop a Strategic Action Plan for addressing the prioritized service gaps. Community members from the Western New York Region participate in the development of service delivery in the region through several formal processes. The content of the 2003 Update includes extensive needs assessment activities conducted with consumers and providers. Also content from discussion groups conducted during the winter of 2002 for the Regional Gaps Analysis were incorporated. Discussion groups were convened to represent community members with specific needs including communities of faith, communities of color, men who have sex with men, immigrant/migrants, the deaf and hard of hearing, HIV-affected children, college students who identify themselves as gay, lesbian, bisexual, transgendered and finally, residents of rural counties.

Also, the Network's Board and Committee members are comprised of representatives from the service sector, consumers, rural residents, communities of color and persons living with HIV/AIDS. Findings from discussion groups with the Networks five Committees – Case Management, Community Awareness, Minority Concerns, PLWHA, Women, Children, and Young Peoples – were included in the Update.

The Network also hosts and facilitates forums throughout the year to allow community members to speak out about service delivery issues. A forum will be held in 2003 to introduce the primary components of the Update. Feedback and comments from community members will be recorded and considered when the Network chooses an issue to be assessed during the annual Update.

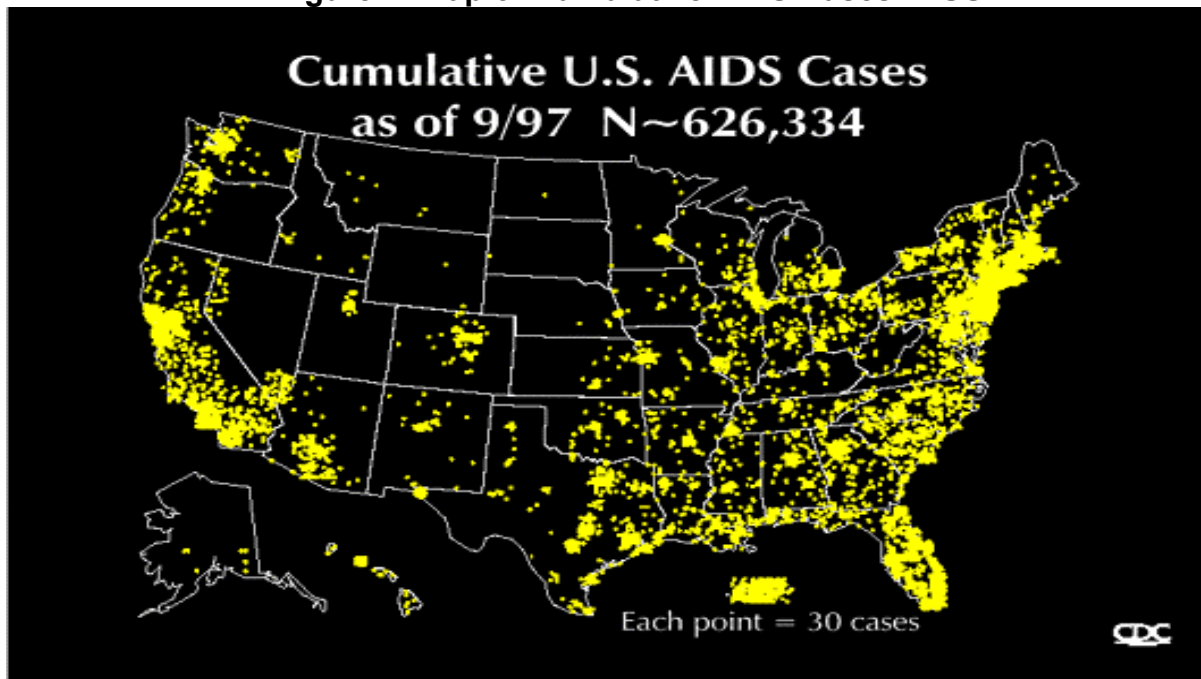
SECTION VII. FIGURE INSERT

- a. Figure 1: Living AIDS Cases by Risk Excluding Inmates
- b. Figure 2: Map of Cumulative AIDS Cases in US
- c. Figure 3: Cumulative Adult AIDS Cases per 100,000 by Region
- d. Figure 4: Cumulative WNY AIDS Cases by Gender for 1990 and 2000
- e. Figure 5: Living AIDS Cases Among Women by Risk Include/Exclud Inmates
- f. Figure 6: Male Living AIDS Cases by Risk Including and Excluding Inmates
- g. Figure 7: Cumulative AIDS Cases by Age Diagnosed Excluding Inmates
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- i. Figure 9: Living AIDS Cases by Risk Including and Excluding Inmates
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- k. Figure 11: Living AIDS Cases Female
- l. Figure 12: Living AIDS Cases Male
- m. Figure 13: New ECMC Male Patients 2002
- n. Figure 14: New ECMC Female Patients 2002
- o. Figure 15: Western New York HIV Newborn Seroprevalence
- p. Figure 16: HIV Newborn Seroprevalence by Race
- q. Figure 17: HIV Newborn Seroprevalence by Age
- r. Figure 18: Clinical Status of ADAP Enrollees

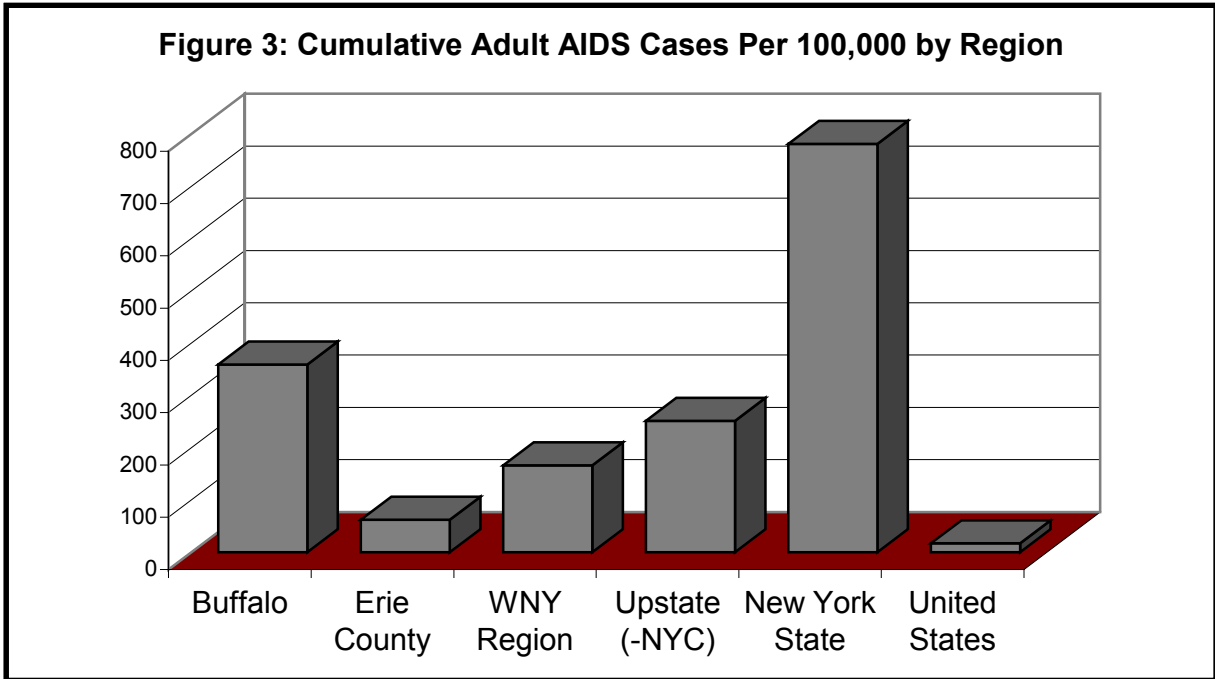


Source: NYS DOH, Bureau of HIV/AIDS Epidemiology, *Presumed Living AIDS Cases by Selected Year of Diagnosis in the Buffalo Ryan White Region by Selected Characteristics*, Data as of December 20, 2001

Figure 2: Map of Cumulative AIDS Cases in US

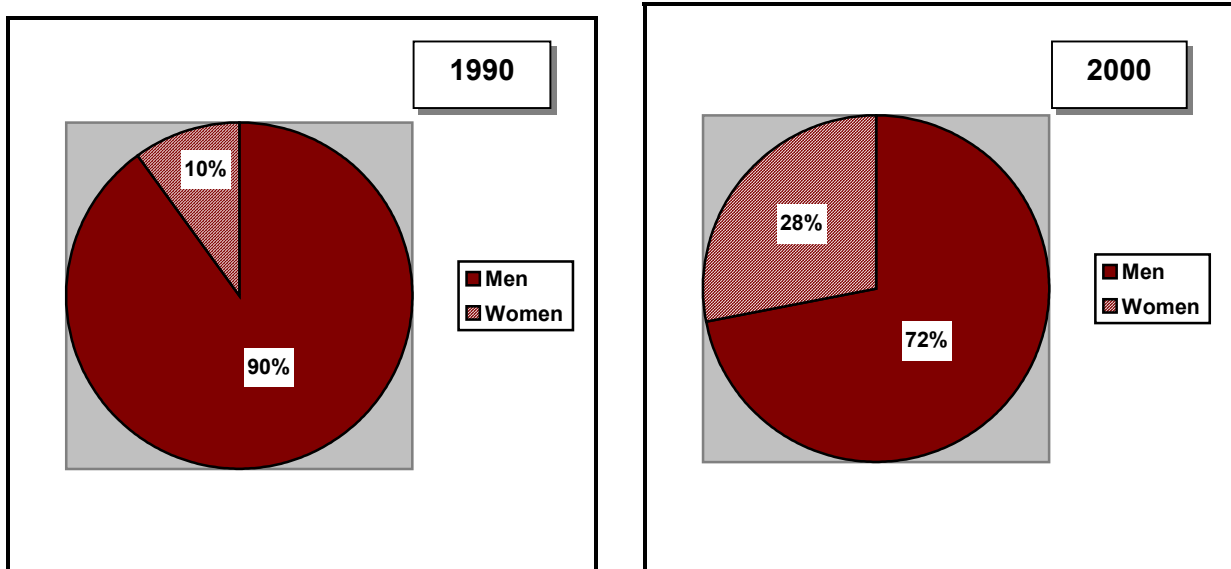


Source: Centers for Disease Control, Cases reported as of 1997

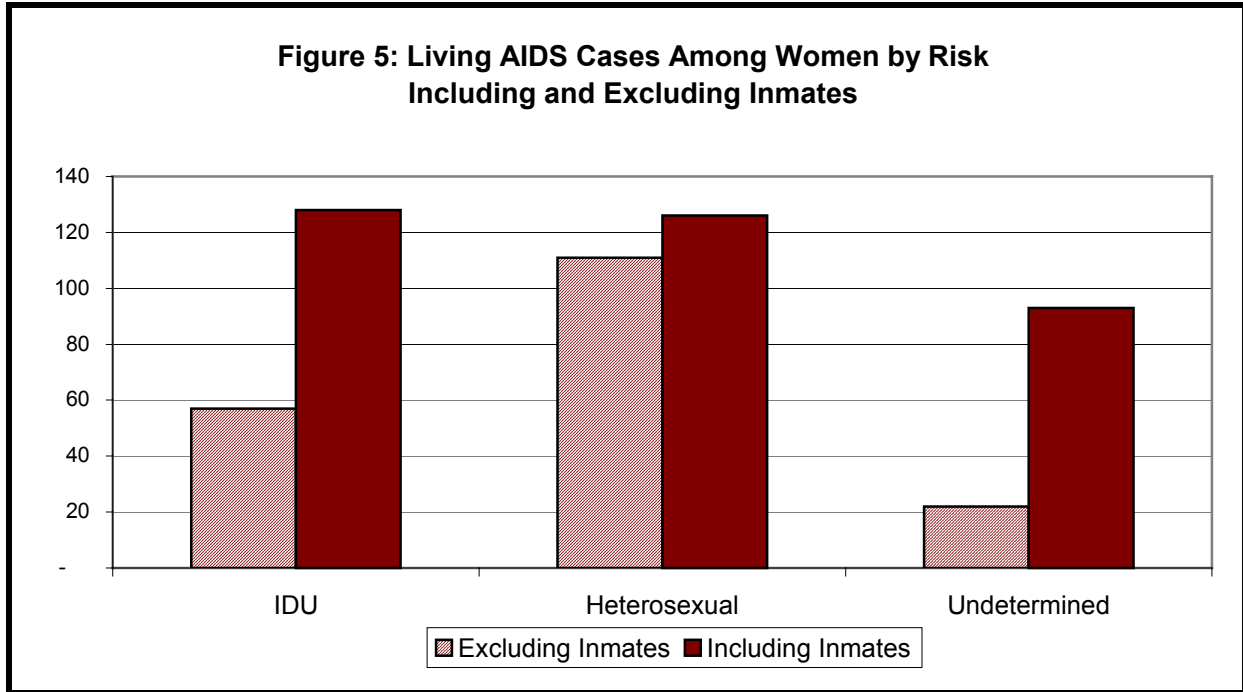


Sources: NYS DOH, *AIDS in New York State, 2001-2002 Edition*, Section 9, p. 108 & Centers for Disease Control and Prevention, *HIV/AIDS Surveillance Quarterly Update*, US HIV and AIDS cases reported through December 2000

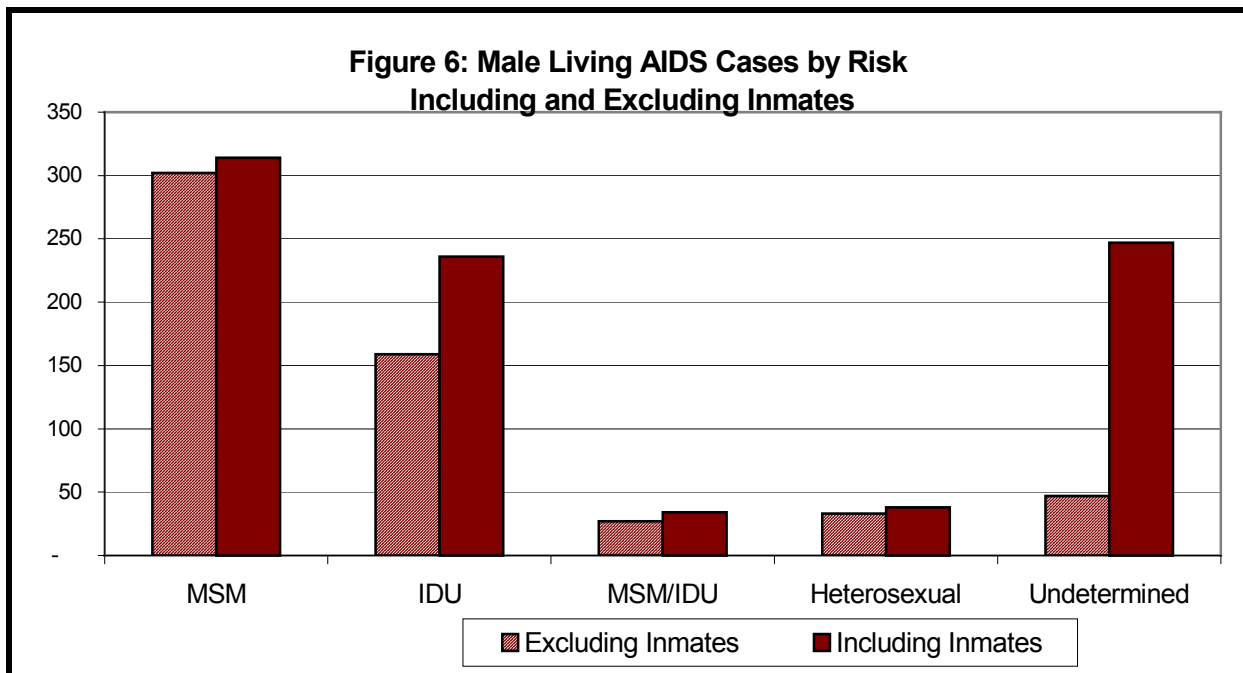
Figure 4: Cumulative WNY AIDS Cases by Gender for 1990 and 2000



Source: NYS DOH, Bureau of HIV/AIDS Epidemiology, *Cumulative AIDS Cases in the Buffalo Ryan White Region by Selected Characteristics*, Data as of December 20, 2001.

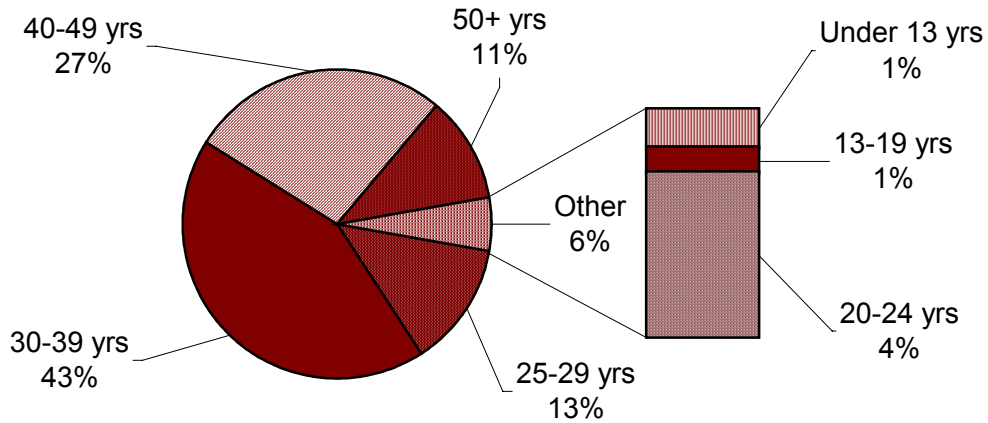


Source: NYS DOH, Bureau of HIV/AIDS Epidemiology, *Presumed Living AIDS Cases by Selected Year of Diagnosis in the Buffalo Ryan White Region by Selected Characteristics*, Data as of December 20, 2001.



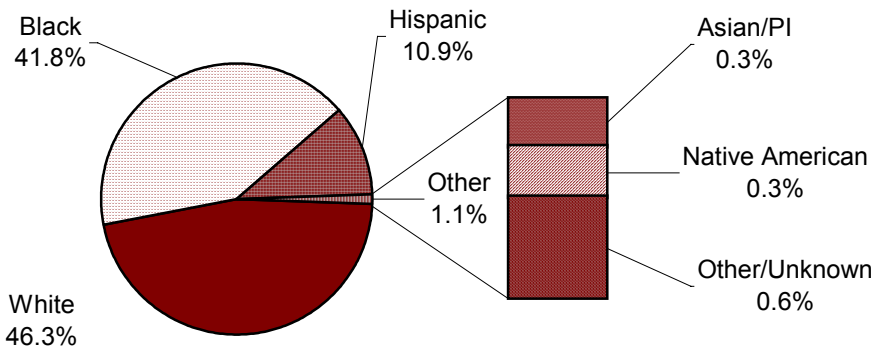
Source: NYS DOH, Bureau of HIV/AIDS Epidemiology, *Presumed Living AIDS Cases by Selected Year of Diagnosis in the Buffalo Ryan White Region by Selected Characteristics*, Data as of December 20, 2001.

Figure 7: Cumulative AIDS Cases by Age Diagnosed Excluding Inmates

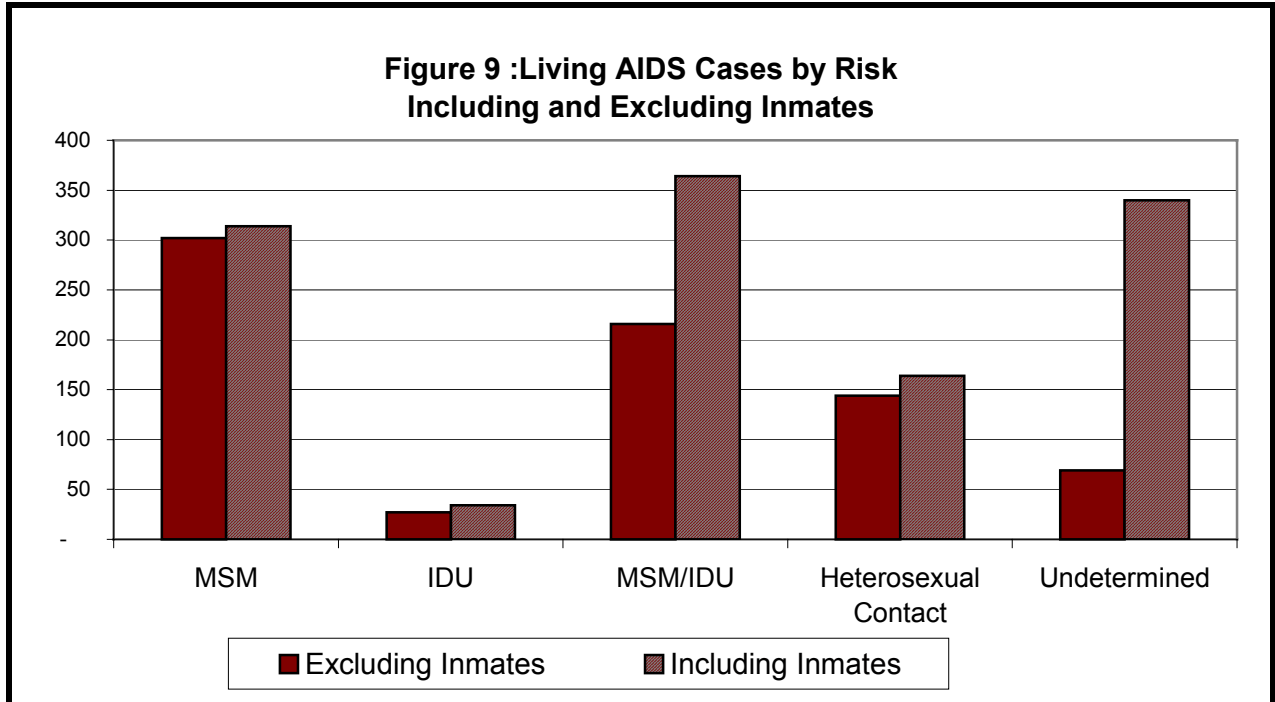


Source: NYS DOH, Bureau of HIV/AIDS Epidemiology, *Cumulative AIDS Cases in the Buffalo Ryan White Region by Selected Characteristics*, Data as of December 20, 2001.

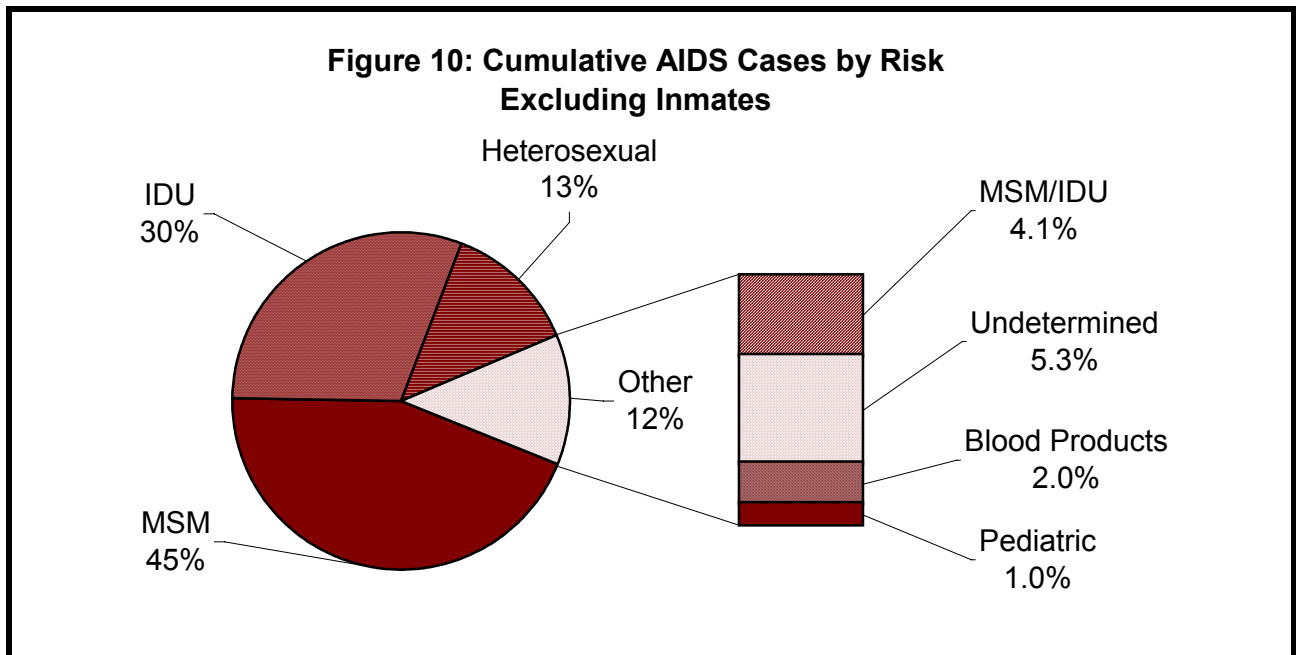
Figure 8: Cumulative AIDS Cases by Race Excluding Inmates



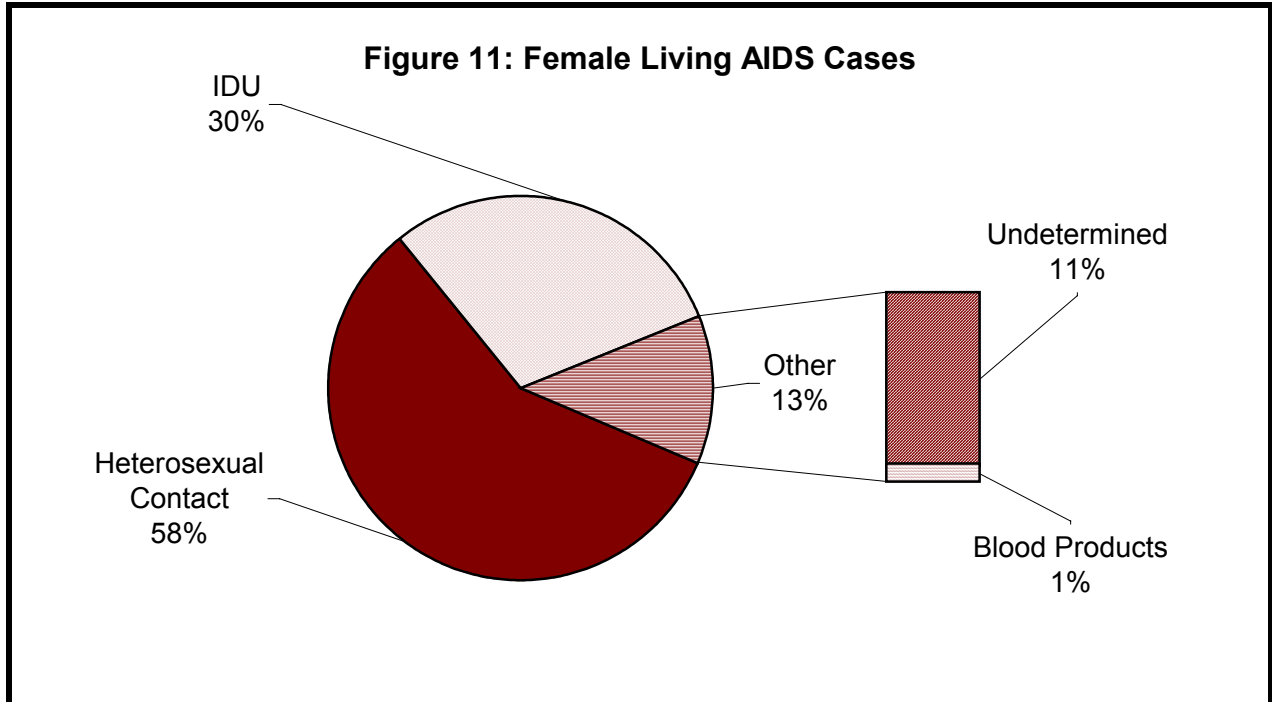
Source: NYS DOH, Bureau of HIV/AIDS Epidemiology, *Cumulative AIDS Cases in the Buffalo Ryan White Region by Selected Characteristics*, Data as of December 20, 2001



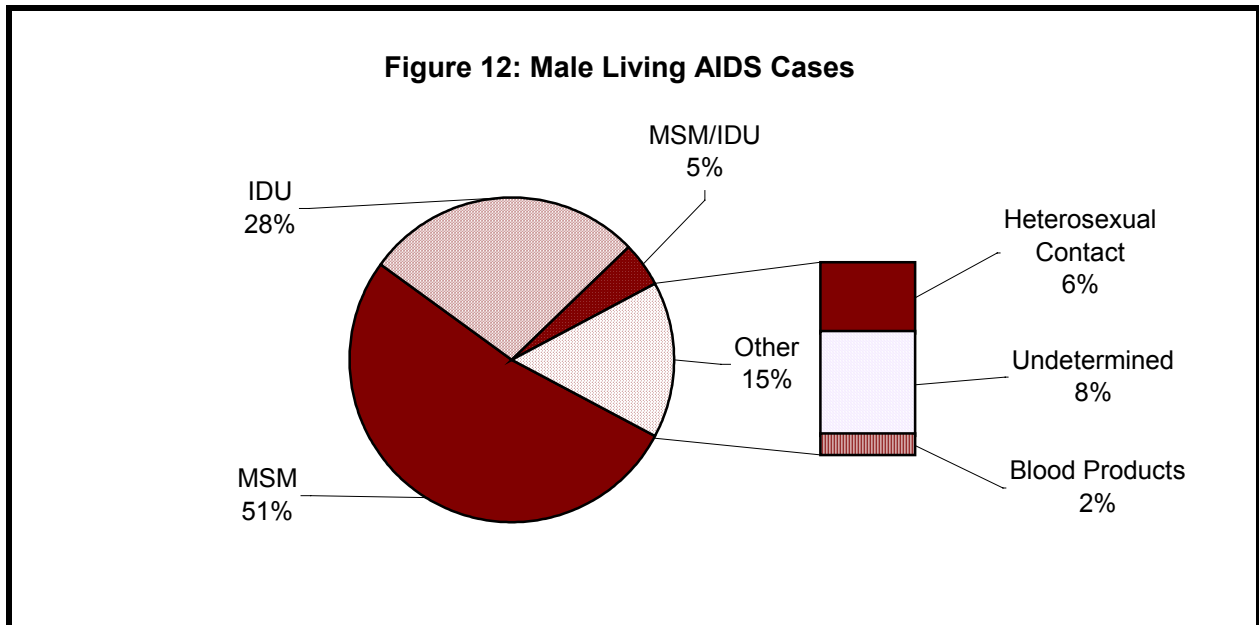
Source: New York State Department of Health (NYS DOH), Bureau of HIV/AIDS Epidemiology, *Presumed Living AIDS Cases by Selected Year of Diagnosis in the Buffalo Ryan White Region by Selected Characteristics*, Data as of January 20, 2001.



Source: NYS DOH, Bureau of HIV/AIDS Epidemiology, *Cumulative AIDS Cases in the Buffalo Ryan White Region by Selected Characteristics*, Data as of December 20, 2001.

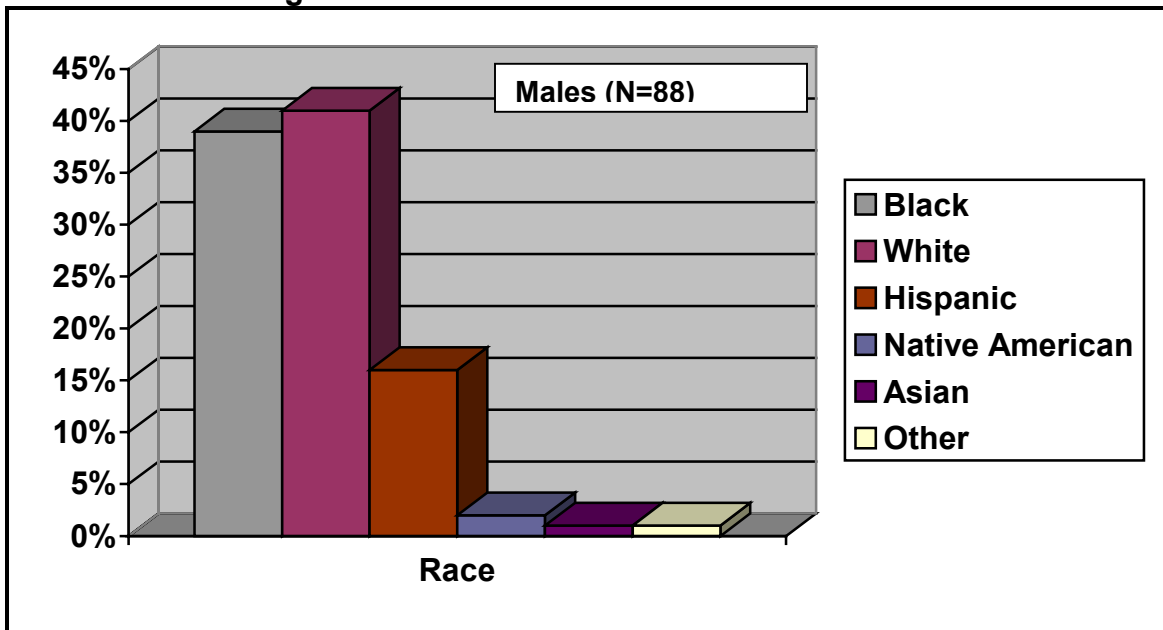


Source: NYS DOH, Bureau of HIV/AIDS Epidemiology, *Presumed Living AIDS Cases by Selected Year of Diagnosis in the Buffalo Ryan White Region by Selected Characteristics*, Data as of December 20, 2001, 2000.



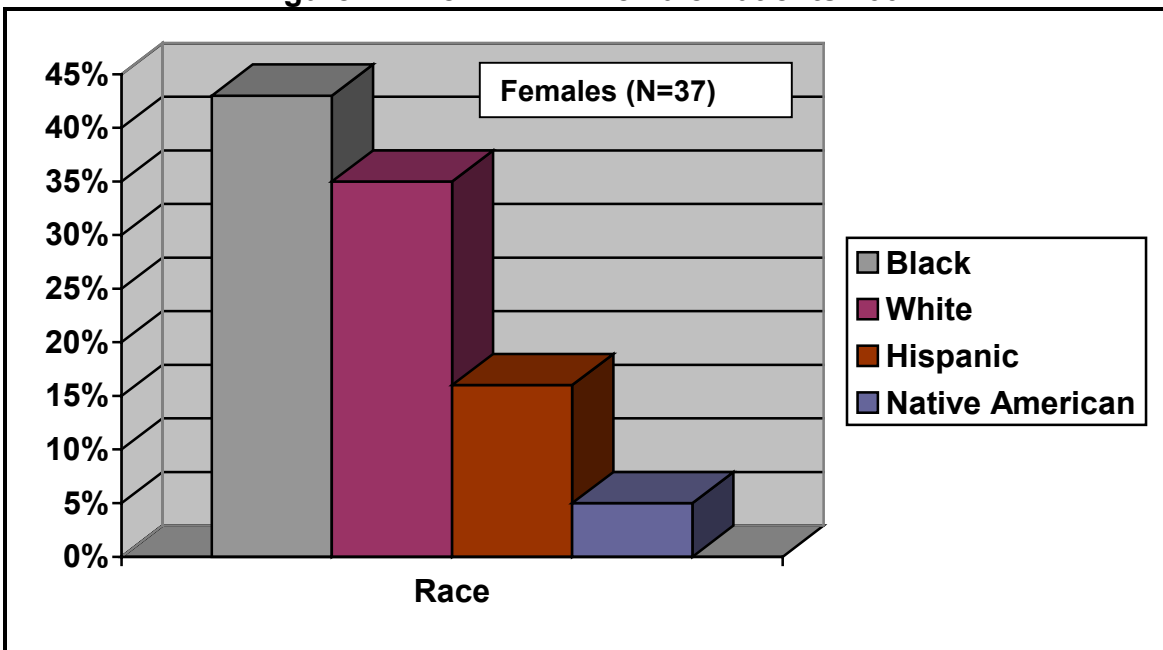
Source: NYS DOH, Bureau of HIV/AIDS Epidemiology, *Presumed Living AIDS Cases by Selected Year of Diagnosis in the Buffalo Ryan White Region by Selected Characteristics*, Data as of December 20, 2001.

Figure 13: New ECMC Male Patients in 2002

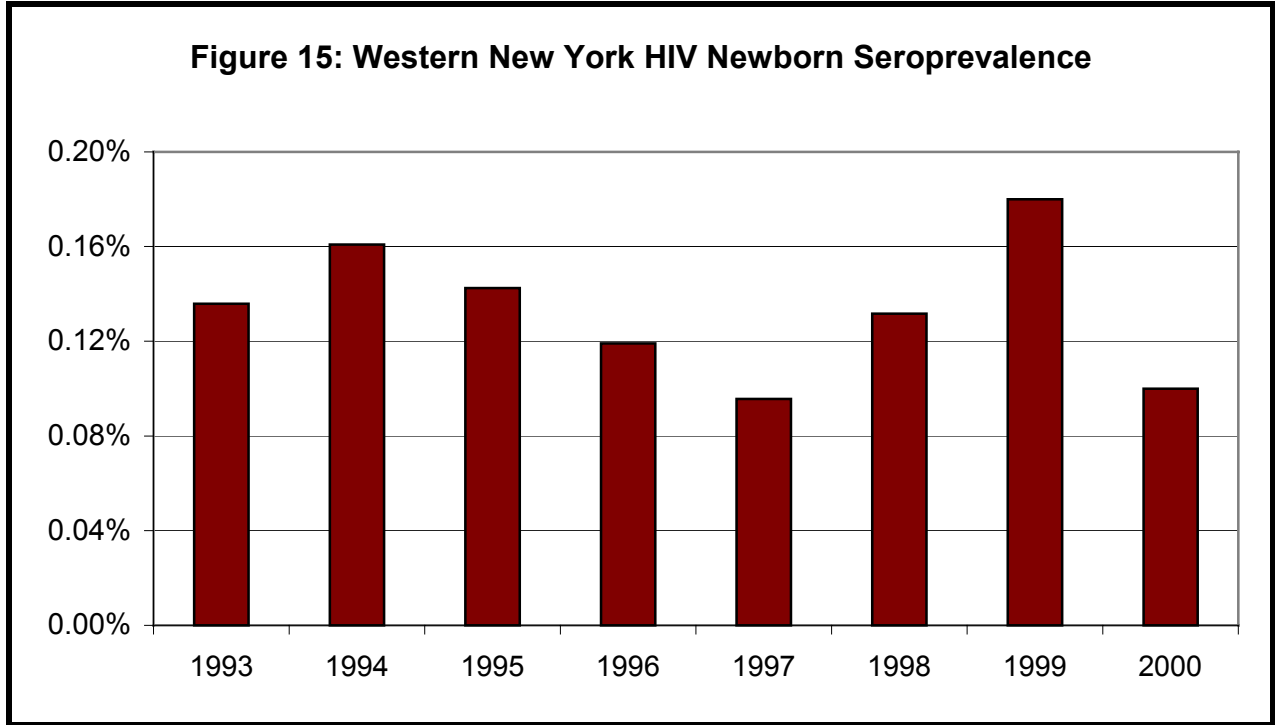


Unpublished data provided by Network member

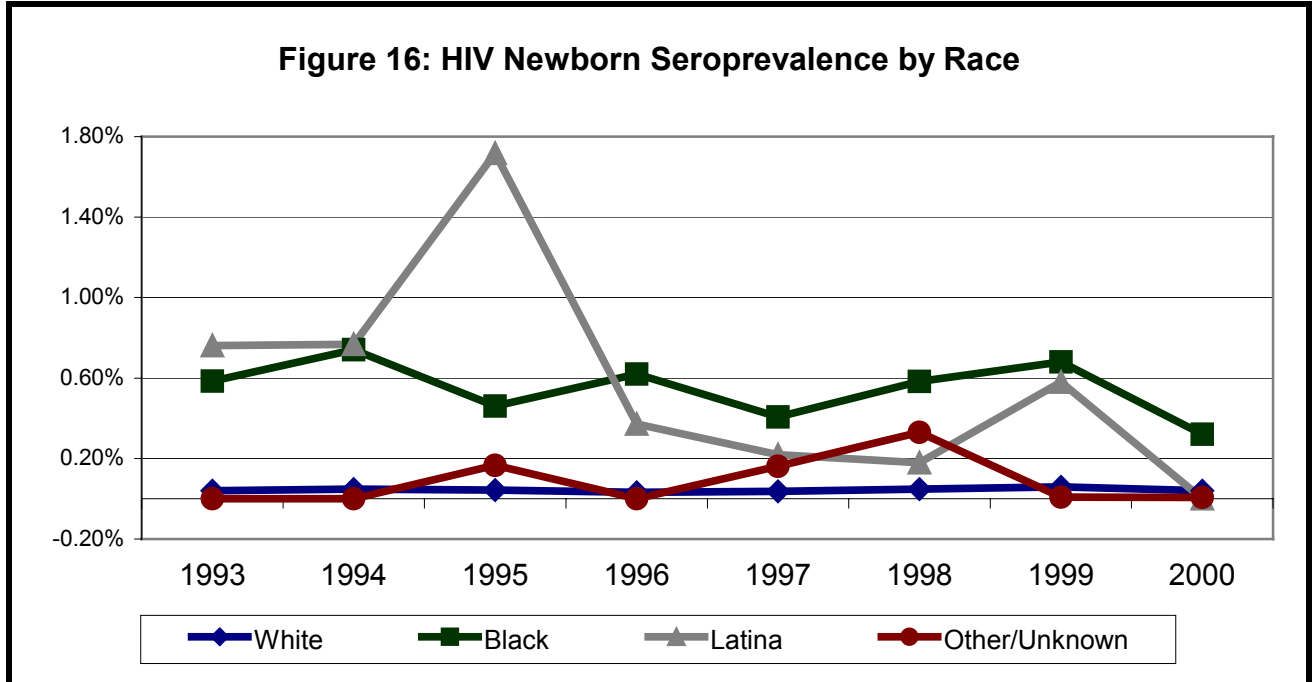
Figure 14: New ECMC Female Patients 2002



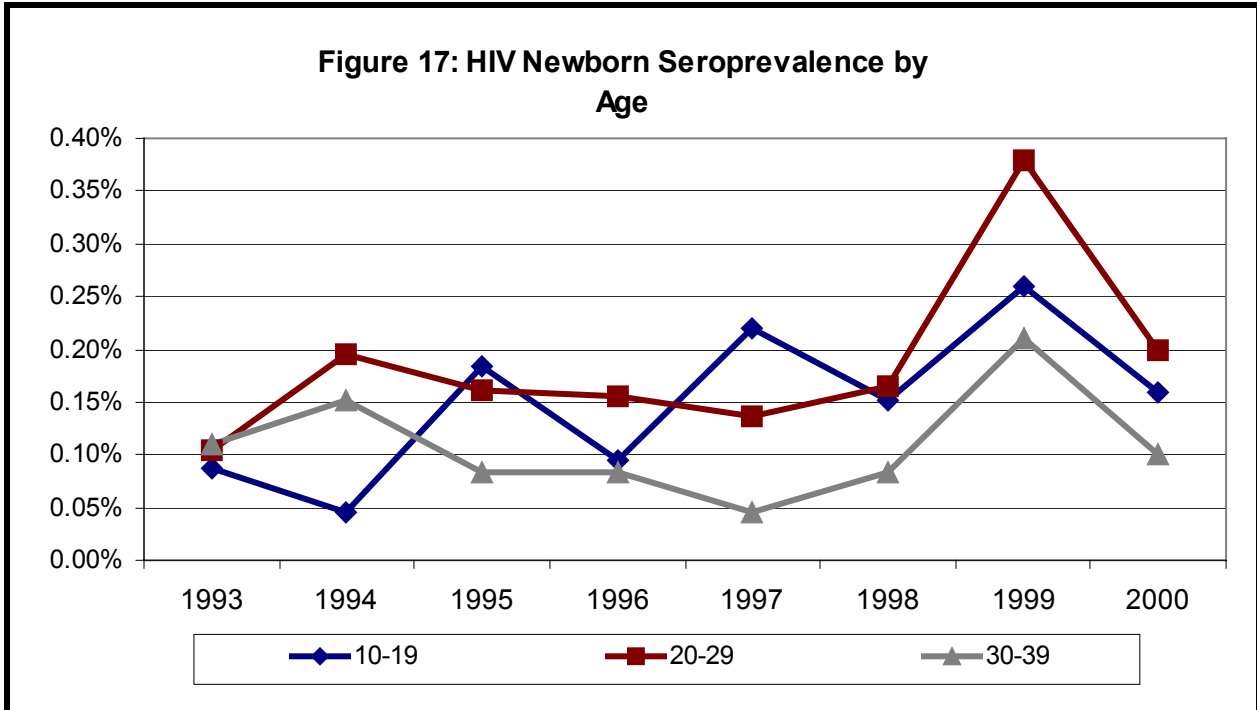
Unpublished data provided by Network member.



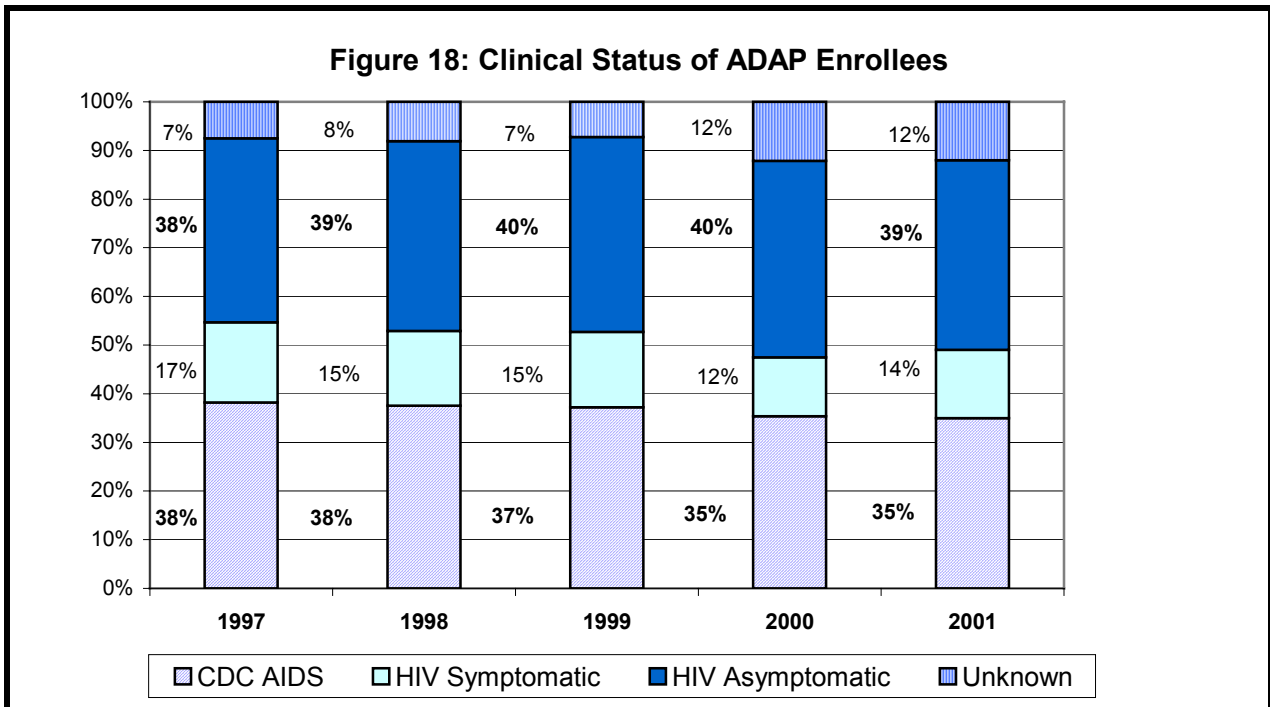
Source: AIDS Network of Western New York, Service Delivery Plan, September 1996 & NYS DOH, *NYS Comprehensive Newborn Screening Program, Annual Summary Report*, 1999 and 2000 Editions



Source: AIDS Network of Western New York, Service Delivery Plan, September 1996 & NYS DOH, *NYS Comprehensive Newborn Screening Program, Annual Summary Report*, 1999 and 2000 Editions



Source: AIDS Network of Western New York, Service Delivery Plan, September 1996 & NYS DOH, *NYS Comprehensive Newborn Screening Program, Annual Summary Report, 1999 and 2000 Editions*



Source: NYS DOH - AIDS Institute, *HIV Uninsured Care Programs*, unpublished data, 2001.

SECTION VIII. APPENDICES AND ATTACHMENTS

Appendix 1. List of Data Sources

Epidemiological Data

New York State Sources

New York State Department of Health-- Bureau of HIV/AIDS Epidemiology

AIDS Institute/Office of AIDS Epidemiology, AIDS Surveillance Quarterly Update, for cases reported through December 2000

New York State Department of Health AIDS Institute Office of Program Evaluation and Research, *1999 Community Needs Index for Western New York and HIV Services*, January 2000

New York State Department of Health AIDS Institute Office of Program Evaluation and Research, *2000 Community Needs Index for Western New York and HIV Services*

New York State Office of Alcohol and Substance Abuse Services, *Current Drug Use Trends in New York City*, December 1998

New York State Department of Health, *About the AIDS Institute*, July 1999

New York State Department of Health, *AIDS in New York State*, 2001-02 Edition

New York State Department of Health -Bureau of Tuberculosis Control, March 2002

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Finalized Report: PLWA Spiritual Needs Assessment, June 12, 2000

Housing Needs for Persons Living with HIV/AIDS: Comprehensive Housing

Affordability Strategy 1999

Data Committee Report: May 2000

1999 PLWA Advisory Committee Recommendations

Western New York Regional Gaps Analysis: 2001-2002

Appendix 2. List of Committees and Members

Committees

Board of Directors
By Laws Committee
Case Management
Community Awareness
Data Collection
Executive
Financial Resources
Minority Concerns
Nominating
Persons Living with HIV/AIDS
Service Delivery Planning
Women, Children & Young People

Service Delivery Plan Committee Members

Helen Evans – Allegany County AIDS Task Force
Paul Kokoszka – Community Member
John Miller – AIDS Community Services
John Morgan – Men of Color Health Awareness Project
Mark Nowak – Community Member (Committee Chairperson)
Anthony Perri – Geneva B. Scruggs
Babette Sullivan – Children’s Hospital of Buffalo
Kati Walsh – Erie County Medical Center
Mary Ellen Wilber – Genesee County AIDS Task Force, Erie County Department of Health

Appendix 3. Provider and Consumer Surveys

i. Provider Survey: 2000

The data collected in this survey will be utilized to update the AIDS Network of Western New York's Service Delivery Plan. The Plan is an important resource that documents the impact of HIV and AIDS in Western New York. Your contribution is extremely important to the Plan's ability to address the service needs of people living with HIV/AIDS [PLWH/A] in Western New York. Thank you for taking time to respond as accurately as possible. Please call Patrick Letourneau at 716-882-7840 or Kelly McGowan at 212-627-7900, ext. 235, if you have any questions.

Organization: _____

Organization zip code(s): _____ County(s): _____
[Please include the zip code(s) and county(s) for all sites]

Representative completing form: _____ Title: _____

Phone: _____ Fax: _____ Email: _____

1. Agency Information

*a. **Clients Served:** To the best of your ability, write in the number of clients enrolled/provided services by your agency over the past twelve months. Please count individual clients, not number of contacts with those clients. For example, a case management program would count the number of individual clients enrolled during the year, not the number of contacts made or service units provided to those clients.*

Number of clients enrolled/provided agency wide: _____

Number of clients enrolled/provided HIV/AIDS services: _____

b. Wait-list: Has your agency wait-listed clients for HIV/AIDS services in the past year?
 Yes No

If yes, for which services? _____

c. Agency Type: Check all that apply

Community Based Organization

City, County, or State Agency

Licensed Medical Provider

Consumer Group

HIV/AIDS Focused Mission

Other: _____

d. Agency Budget: Check off the box next to the range that represents the *entire* agency budget *including* funding for HIV/AIDS services.

- Less than \$500,000
- \$500,000 - \$999,999
- \$1,000,000 - \$3,000,000
- \$3,000,000 - \$5,000,000
- More than \$5,000,000

e. Agency Funding for HIV/AIDS Services: Please indicate the sources of funding for HIV/AIDS related services provided by the agency.

- Federal *[please specify]*
 - Center for Disease Control and Prevention (CDC)
 - Substance Abuse and Mental Health Services Administration (SAMHSA)
 - Ryan White: Title II Title III Title IV
 - Other Federal: _____
- New York State *[please specify]*
 - New York State Department of Health/ AIDS Institute
 - [please specify]* _____
 - New York State Office of Alcoholism and Substance Abuse Services(OASAS)
 - Other New York State funding _____
- Other Government Sources *[please write in]*
 - _____
 - _____
- Non-Government Funding Sources *[please write in]*
 - _____
 - _____

2. Client information

Primary Populations Provided HIV/AIDS Services: Please **check the box** next to all populations to whom your agency provided HIV-related services in the past twelve months. Also, use the space after each population to **write in the percentage** of each population group who were enrolled/provided HIV-related services. Determine the percentages, to the best of your ability, from data collected over the past twelve months.

a. Residence: *[Percentages in section a. should total 100%]*

- City of Buffalo _____ Rural _____ Incarcerated _____
 Migrant Worker Camp _____ Other _____

b. Gender: *[Percentages in section b. should total 100%]*

- Women _____ Men _____ Transgender _____

c. Race: *[Percentages section c. should total 100%]*

- African American _____ Asian/ Pacifica Islander _____
 Latina/o _____ Native American _____
 White _____ Other: _____

d. Age: *[Percentages in section d should total 100%]*

- Pediatric: under 13 _____ Adolescent: 13-19 _____
 Adults: 20 plus _____ *[write in percentage of adults here OR specify age groups below]*
 20-29 _____ 30-39 _____ 40-49 _____ 50+ _____

e. Substance Users: _____ *[Please write in the percentage of your clients who reported substance use in the past twelve months. Check off the drug use reported by these clients below.]*

- Marijuana Alcohol Crack/Cocaine
 Heroin Injection Drug Use Other _____

f. Immigrants: _____ *[Please write in the percentage of your clients who were immigrants here. Use the space below to indicate the country of origin of your immigrant clients. The percentages below should total 100%.]*

- Caribbean _____ African _____ Latin American _____
 Asian _____ Other _____

g. Risk Groups: *[Please check the risk group category and write in percentages for your clients living with HIV/AIDS. Since this section is seeking unduplicated responses, the percentages in section g. should total 100%]*

- | | |
|--|---|
| <input type="checkbox"/> Men Who Have Sex With Men (MSM) _____ | <input type="checkbox"/> Heterosexual _____ |
| <input type="checkbox"/> Intravenous Drug Users (IDU) _____ | <input type="checkbox"/> MSM/IDU _____ |
| <input type="checkbox"/> Hemophiliacs _____ | <input type="checkbox"/> Blood Products _____ |
| <input type="checkbox"/> Perinatal _____ | |
| <input type="checkbox"/> Other: _____ | <input type="checkbox"/> Unknown _____ |

h. Special Populations: *[Please check all the boxes below that apply to your clients living with HIV/AIDS. Also, write in the percentages they represent of your total HIV/AIDS population. The percentages probably will not total 100%]*

- | | |
|---|--|
| <input type="checkbox"/> Probation/Parole _____ | <input type="checkbox"/> Incarcerated _____ |
| <input type="checkbox"/> Mentally Ill _____ | <input type="checkbox"/> MICA _____ |
| <input type="checkbox"/> TB positive _____ | <input type="checkbox"/> Hepatitis positive _____ |
| <input type="checkbox"/> Sex Workers _____ | <input type="checkbox"/> Women Who Have Sex With Women _____ |
| <input type="checkbox"/> Homeless _____ | <input type="checkbox"/> English as a Second Language _____ |
| <input type="checkbox"/> Other: _____ | |

i. Please write-in and briefly describe the **population groups** presenting to your agency the greatest unmet service needs. *[Note: question 3.j. on page 6 provides space to comment on the nature of the unmet service needs]*

1. _____
2. _____
3. _____

3. Agency Services

HIV Prevention Services Provided:

- a.** Does your agency provide HIV prevention services? Yes No
If yes, what services: _____
- b.** Does your agency provide HIV testing and Counseling? Yes No

Services Provided to People Living with HIV/AIDS: Please check the box next to all the services your agency provides to PLWH/A.

c. Substance Use Services: *[please specify below]*

- | | | |
|---|---|-------------------------------------|
| <input type="checkbox"/> Medical Detox | <input type="checkbox"/> Residential Rehab | <input type="checkbox"/> Methadone |
| <input type="checkbox"/> Harm Reduction | <input type="checkbox"/> Recovery Readiness | <input type="checkbox"/> Outpatient |
| <input type="checkbox"/> Other: _____ | | |

d. Medical Services: *[please specify below]*

- | | | |
|--|--|-------------------------------------|
| <input type="checkbox"/> Primary Care | <input type="checkbox"/> HIV Specific Care | <input type="checkbox"/> Viral Load |
| <input type="checkbox"/> Pediatric | <input type="checkbox"/> Clinical Trials | <input type="checkbox"/> In-patient |
| <input type="checkbox"/> Pharmacy | <input type="checkbox"/> Alternative/Holistic | <input type="checkbox"/> OBGYN |
| <input type="checkbox"/> Treatment Adherence | <input type="checkbox"/> Directly Observed Therapy/Related TB Care | |
| <input type="checkbox"/> Other: _____ | | |

e. Mental Health Services: *[please specify below]*

- | | | |
|--|---|--|
| <input type="checkbox"/> Crisis Intervention | <input type="checkbox"/> Psych Evaluation | <input type="checkbox"/> Outpatient |
| <input type="checkbox"/> Day Treatment | <input type="checkbox"/> Psych In-Patient | <input type="checkbox"/> MICA Services |
| <input type="checkbox"/> Individual Counseling | <input type="checkbox"/> Group Therapy | <input type="checkbox"/> Peer Counseling |
| <input type="checkbox"/> Other: _____ | | |

f. Housing Services: *[please specify below]*

- | | |
|---|---|
| <input type="checkbox"/> Housing Placement | <input type="checkbox"/> Congregate Housing |
| <input type="checkbox"/> Financial Assistance for Housing | <input type="checkbox"/> Emergency Shelter |
| <input type="checkbox"/> Other: _____ | |

g. Support Services: *[please specify below]*

- | | | |
|--|--|----------------------------------|
| <input type="checkbox"/> Permanency Planning | <input type="checkbox"/> Transportation | <input type="checkbox"/> Legal |
| <input type="checkbox"/> Case Management | <input type="checkbox"/> Food/nutrition | <input type="checkbox"/> Hotline |
| <input type="checkbox"/> Peer Program | <input type="checkbox"/> Pastoral/Spiritual Counseling | |
| <input type="checkbox"/> Other Services: _____ | | |

h. Referral Services: *[please specify services referred to in the past year below]*

- | | |
|--|---|
| <input type="checkbox"/> Housing Services | <input type="checkbox"/> Substance Use Services |
| <input type="checkbox"/> Mental Health Services | <input type="checkbox"/> Medical Services |
| <input type="checkbox"/> Food/nutrition Services | <input type="checkbox"/> Legal Services |
| <input type="checkbox"/> Entitlements | <input type="checkbox"/> Permanency Planning |
| <input type="checkbox"/> Other: _____ | |

j. Please write-in and briefly explain the top three **unmet service needs** presented by your clients.

1. _____
2. _____
3. _____

3. Barriers to Service.

Organizational capacity: Use the space below to explain any issues related to agency infrastructure that effect your ability to provide services to people living with HIV/AIDS.

- a. Financial Management: _____
- b. Development/Funding: _____
- c. Human Resources/Staffing: _____
- d. Technology/Computers: _____
- e. Facility/Location: _____
- f. Other infrastructure issues: _____
- _____

g. Please write-in and briefly explain the top three **organizational capacity issues** that affect your agency's ability to provide services to people living with HIV/AIDS.

1. _____
2. _____
3. _____

Client experience: Use the space below to explain barriers faced by your clients that may affect their ability to access or retain services with your agency.

h. Child Care: _____

i. Transportation: _____

j. Housing: _____

k. Culture/Language: _____

l. Fear of Discrimination:

Sexuality: _____

HIV status: _____

Other: _____

m. Lack of Religious/Faith-based Organization's involvement in HIV/AIDS: _____

n. Other: _____

p. Please write-in and briefly explain the top three **barriers faced by clients** limiting their ability to access and remain connected to HIV/AIDS services.

1. _____
2. _____
3. _____

4. Emerging Needs: Please write in and briefly explain the top three HIV/AIDS issues that will need to be addressed in the next few years:

1. _____

2. _____

3. _____

5. Additional Comments: Please comment on service gaps, barriers to service, and emerging needs. *[Continue on a separate page if needed.]*

ii. Consumer Focus Group Intake and Questions: 2000

This form is anonymous: please do not write your name anywhere on the page!

4. Who are you? [Check off the box next to what best describes you]:

a. Gender: **Female** **Male** **Transgender**

b. **Nationality:** Were you born in the United States? Yes No

If no, where were you born? _____

c. Race/Ethnicity:

African American (non-hispanic) *Asian/Pacific Islander* *Latina/o*

Native American *White* *Caribbean*

Other: _____

d. **Age:** *13-19 years old* *20-29* *30-39* *40-49*

50-59 *60-69* *70 or older*

e. **Drug Use:** *I did **not** use drugs or alcohol in the past year*

*I did **use** drugs and/or alcohol in the past year:*

f. **When** did you find out that you are HIV positive? _____

g. Please check all the boxes below that you know to be true:

I am HIV positive *I do not know my HIV status*

I have been diagnosed with mental illness *I have been addicted to drugs*

I was homeless in the past *I am homeless now*

I see a medical provider regularly *I have health insurance*

I am a parent *I care for an HIV positive child*

English is my second language *I have been MICA diagnosed*

Questions:

1. Let's start by going around the room and saying how you found out about this focus group. Who told you or brought you here? As discussed earlier, please do not use your name.
2. Why do you think some people living with HIV/AIDS in your community do not have medical or other HIV social services?
3. If any of you or people you know LWH/A have been without **medical care**, explain why and for how long? If you/they got care, explain how?
4. If any of you or people you know LWH/A have been without **health insurance**, explain why and for how long? If you/they got insurance, explain how?
5. If any of you or people you know LWH/A have been **without adequate housing**, explain why and for how long? If you/they got housing, explain how?
6. If any of you or people you know LWH/A have not gotten services or missed appointments due to being homeless, explain?
7. If any of you or people you know LWH/A have not gotten services or missed appointments due to **language or cultural differences** with providers, explain.
8. If any of you or people you know LWH/A have not gotten services or missed appointments due to **lack of transportation**, explain.
9. If any of you or people you know LWH/A have not gotten services or missed appointments due to **fear of discrimination or HIV disclosure**, explain.
10. If any of you or people you know LWH/A have not gotten services or missed appointments due to **other issues**, explain them.
11. What are some things/issues/needs that you or people you know LWH/A have tried to take care of, but could not find help with? Explain.

Optional question if rural participants are present:

12. If any of you or people you know LWH/A have not gotten services or missed appointments due to **lack of local HIV medical care**, explain.

iii. Provider Focus Group Intake and Questions: 2000

The information from this form is anonymous and confidential. The data collected from several of these forms may be summarized in the 2000 Update.

5. Agency Information

[Please include the zip code(s) and county(s) that you serve]

a. Zip code(s) served: _____

b. County(s) served:

- | | | | |
|----------------------------------|-----------------------------------|--------------------------------------|-------------------------------------|
| <input type="checkbox"/> Erie | <input type="checkbox"/> Niagara | <input type="checkbox"/> Orleans | <input type="checkbox"/> Genesee |
| <input type="checkbox"/> Wyoming | <input type="checkbox"/> Allegany | <input type="checkbox"/> Cattaraugus | <input type="checkbox"/> Chautauqua |

c. Describe the target population served by your case management program:

d. Has your program wait-listed clients for case management in the past year?

Yes No

6. Client information *[to the best of you ability, check all of the boxes that apply to clients who you have served in the past year]*

- | | | |
|--|---|---|
| <input type="checkbox"/> Women | <input type="checkbox"/> Men | <input type="checkbox"/> Transgender |
| <input type="checkbox"/> African American | <input type="checkbox"/> Asian/ Pacific Islander | <input type="checkbox"/> Latina/o |
| <input type="checkbox"/> Native American | <input type="checkbox"/> White | <input type="checkbox"/> Other race/ethnicity |
| <input type="checkbox"/> Pediatric: under 13 | <input type="checkbox"/> Adolescent: 13-19 | <input type="checkbox"/> Adults: 20 and older |
| <input type="checkbox"/> Perinatal cases | <input type="checkbox"/> Families | <input type="checkbox"/> Homeless |
| <input type="checkbox"/> Sex Worker | <input type="checkbox"/> MSM | <input type="checkbox"/> WSW |
| <input type="checkbox"/> Substance Users | <input type="checkbox"/> MICA Diagnosed | <input type="checkbox"/> Intravenous Drug Users |
| <input type="checkbox"/> Mentally Ill | <input type="checkbox"/> TB positive | <input type="checkbox"/> Hepatitis positive |
| <input type="checkbox"/> Recently released | <input type="checkbox"/> Incarcerated | <input type="checkbox"/> Migrant Workers |
| <input type="checkbox"/> Immigrant | <input type="checkbox"/> English as a Second Language | |
| <input type="checkbox"/> Other: _____ | | |

Questions:

1. What are your referral sources for new clients?
2. Explain briefly how your program conducts outreach to bring PLWH/A into case management.
3. What are the most effective methods of outreach to new clients?
4. Describe the people living with HIV/AIDS in your service community who are the most difficult to bring into case management in the first place? What are their presenting needs?
5. Describe the people living with HIV/AIDS in your service area who are the most difficult to retain in case management and other health and social services and why?

[From this point forward 'new clients' refers to any PLWH/A who has visited your program at least once or who began the intake process. Include those who may not have become officially enrolled 'clients']

6. How common is the need for housing services among new clients and what options do you have to address their needs? Describe the impact that being homeless or under housed has on your ability to retain clients and to connect them to health and other social services.
7. How common is the need for MICA services among new clients and what options do you have to address their needs? Describe the impact that being MICA diagnosed or MICA qualified has on your ability to retain these clients and to connect them to health and other social services.
8. How common is the need for transportation among new clients and what options do you have to address their needs? Describe the impact that lack of transportation has on your ability to retain these clients and to connect them to health and other social services.
9. How common is the need for language or cultural barriers among new clients and what options do you have to address their needs? Describe the impact this has on your ability to retain these clients and to connect them to health and other social services.
10. How common is it that clients miss appointments with you or your referrals due to fear of discrimination or HIV disclosure and what resources do you have to address this issue? Describe the impact this has on your ability to retain these clients and to connect them to health and other social services.
11. How common is it that clients miss appointments with you or your referrals due to lack of local access to medical care facilities and what options you have to address their needs? Describe the impact this has on your ability to retain these clients and to connect them to health and other social services.
12. What are the service components necessary to retaining clients who are difficult to reach and engage in case management? In health care? In other social services?
13. What is an HIV/AIDS service need that no one is addressing?
14. What emerging HIV/AIDS service needs will have to be addressed in the next few years?

iv. Public Forum Agenda and Questions: 2000

Facilitator Guidelines for AIDS Network of Western New York's Public Forums

The public hearings are an opportunity to gather input from the broader community of people living with AIDS and HIV, their partners, family, friends, and providers regarding:

Access to services/Service Barriers,
Availability and Quality of services,
Concerns, Needs and Priorities,
Gaps in Service/Emerging Service Needs.

Suggested facilitator questions to illicit discussion:

What are the barriers to accessing HIV service related services?

What are the most important HIV services?

What are the most important HIV/AIDS services and why?

What should be done to improve existing services?

What is an HIV/AIDS service need that no one is addressing?

v. PLWH/A Consumer Survey Questions: 2001

AIDS Network of Western New York, Inc.

The following survey is directed to people who are HIV positive or living with AIDS. Your input is very important to us. Please answer every question completely and honestly. All individual answers are confidential and no names are used in this survey.

1. Gender:
Male Female Transgender

2. Which ethnic group do you most identify yourself as?
African American Latino/a-Hispanic
Native American Multiracial
African Caribbean White/Caucasian
Asian/Pacific Islander Other

3. Age:
Under 13 13-19
20-29 30-39
40-49 50-59
60 & over

4. Marital Status:
Single Married
Same-sex partnered Divorced
Widowed Separated

5. Yearly income:
Under \$8,000 \$8,000-\$15,000
\$15,000-\$20,000 over \$20,000

6. What county do you live in?
Allegany Cattaraugus
Chautauqua Erie
Genesee Niagara
Orleans Wyoming

7. Residency Status?
U.S. Citizen Legal Immigrant (Green Card)
Illegal Immigrant

8. Did you test HIV positive in New York State?

9. How long have you had HIV?
Under 1 year 1-5 years
5-10 years over 10 years
10. Do you have sex with?
Only people of the same sex
Only people of the opposite sex
Sometime with people of the same sex and
Sometimes people of the opposite sex
Never had sex with other people
11. Since testing HIV positive have you had:
Unprotected oral sex
Unprotected anal sex
Unprotected vaginal sex
I have not had sex since testing positive
12. Have you ever heard of the reality female condom?
a) If **Yes**, have you ever used a female condom
13. Have you ever been hit, threatened or abused by your partner?
14. Have you told anyone about your HIV status other than your health care provider?
15. Are you afraid to tell anyone about your HIV status?
16. Have you been discriminated against because of your HIV status?
A) If **Yes**, was the source of discrimination:
Employers, coworkers Family/Friends or the Community
Church/Clergy Medical or Service Providers
The prison system Housing
School
- B) Did you take legal action because of this discrimination?
17. Do you have children?
If **Yes**, a) Have your children been tested for HIV
b) Are any of your children HIV positive?
c) Do you have a legal plan to take care of your children in the event of your death?
18. If female:
a) Are you now pregnant?
b) Have you ever been pregnant?
If yes, c) were you pregnant? Before 1997 after 1997
d) Were you offered HIV testing during your pregnancy
e) Have you been pregnant and HIV positive at the same time?

- f) Did you know you were HIV positive before becoming pregnant?
19. Do you have health insurance?
If **Yes**, do you have
Medicaid Medicare
ADAP Private Insurance
HMO
20. Are you aware of New York State's AIDS Drug Assistance Program?
A) Did you know a single person whose income is \$44,000 or less is eligible for the AIDS Drug Assistance Program (ADAP) program?
21. Do you work?
If **No**, a) Do you feel well enough to work
b) Full time
c) Part time
d) Would you return to work if you could be guaranteed your current medical benefits.
22. Has your employment status changed since you tested HIV positive?
23. Are you under a doctor's care?
24. Are you currently taking HIV/AIDS medications?
a) If No, Have you ever taken HIV/AIDS medications?
b) If you stopped taking medications why did you stop?
Side effects Doctor told you to Substance use
25. Since testing HIV positive have you been treated for depression, excessive worrying, emotional concerns, attempted suicide etc?
a) Do you feel you need emotional treatment/counseling now?
26. Do you receive:
Food Stamps Section 8 Housing Veterans Benefits
Social Security HEAP WIC
Public Assist. Check Housing Assistance Emergency shelter allowance
a) Have you had any problems (with workers, shutoffs, waiting lists, etc) in getting any of these benefits?
b) Do you feel the workers in these agencies are informed and educated about HIV/AIDS?
c) Do they treat you fairly and with respect?
27. Do you currently have an HIV/AIDS case manager?
a) Do you feel your case manger has helped you with your needs?

28. Are you currently on a waiting list for any services?
If **Yes**, please specify
29. In the past six months have you used:
Alcohol Marijuana IV Drugs
Shared Needles Other illegal Drugs
a) If **Yes**, has your substance use interfered with your daily life or your health?
30. Has using drugs and/or alcohol ever resulted in you not:
Practicing safer sex? Using clean needles?
31. Has your drug/alcohol use caused you to miss HIV related appointments?
32. In the past six months, have you missed appointments because of transportation?
33. Is transportation currently a problem for you getting to:
Medical appointments Social functions
Support Services Personal activities
a) If **Yes**, is the problem?
Distance Childcare Money Physical Disability
Reliability of services other
34. How do you most often get to your appointments?
Own car Walk Bus/public transportation
Ride with friends/family Service Provider Medicaid cab/tokens
35. Where do you currently live?
Own home Live with friends/family
Shelter Rental (apt.)
HIV/AIDS group housing On the street
36. Since testing HIV positive have you ever spent the night in an emergency shelter or on the street?
If **yes**, how long ago?
Less than a month 1-6 months
6 months to a year more than a year ago
37. In the past year have you had any of the following problems where you live?
Working stove/refrigerator Physical/Handicap Access
No plumbing/heat Affordability
Safety Rats, Roaches, etc,
Other

38. What are the last four digits of your social security number?

39. What is your zip code?

Comments:

vi. Western New York Regional Gaps Analysis Discussion
Group Questions: 2001-2002

Question to Guide discussion Regional Gaps Analysis (RGA)

- 1) Who is at highest risk for HIV infection in the region?
- 2) Are there specific things in the region that increase that risk?
- 3) What is being done in the region to prevent HIV infection among those at highest risk?
- 4) What more can be done in the region to prevent HIV infection, especially among those at highest risk?
- 5) What is being done in the region to meet the HIV prevention needs of people with HIV infection? What more can be done?
- 6) Is there anything currently being done to prevent HIV infection in the region that is not working?
- 7) Where in the region should HIV prevention efforts be focused?
 - Geographic areas?
 - Community settings?
 - Types of providers?

What would help providers in the region do a better job of HIV prevention?

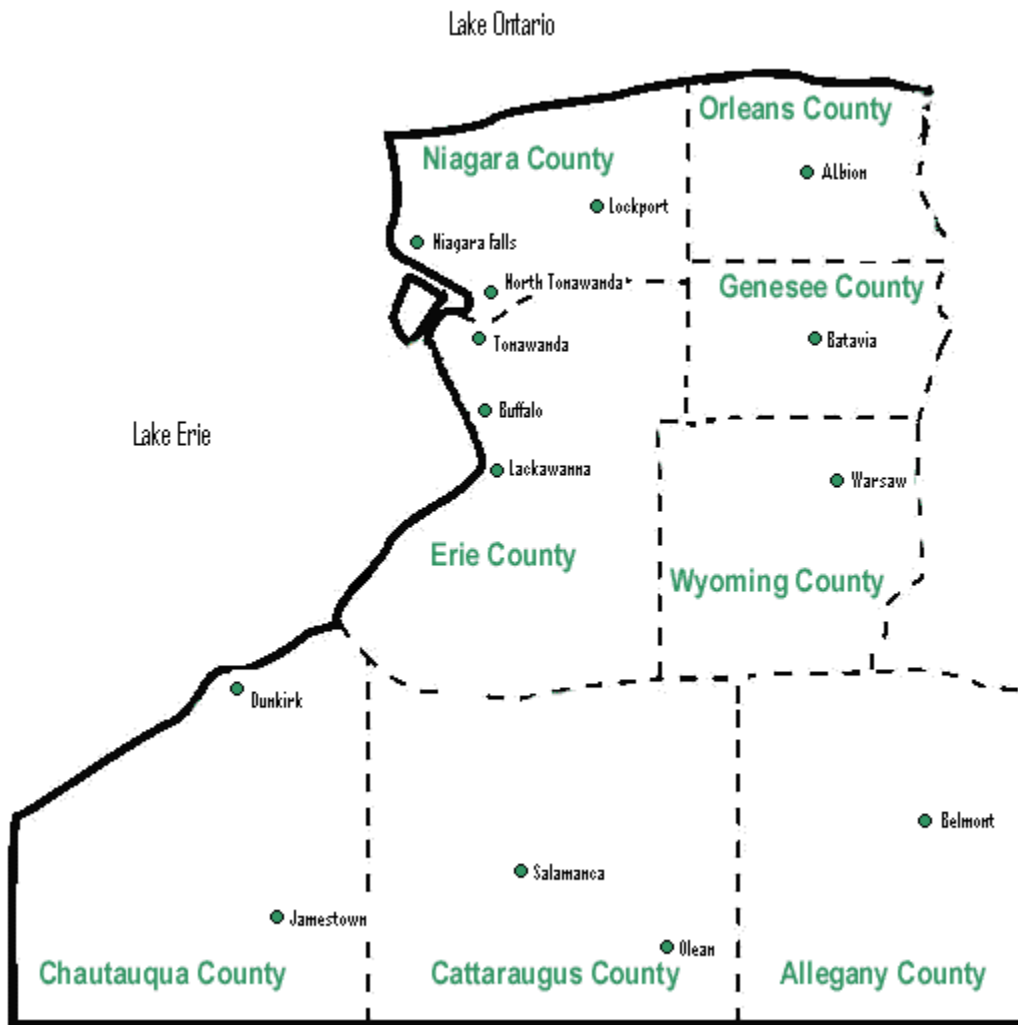
vii. Análisis de Brecha Regional (ABR)

Preguntas para guiar la discusión de grupos

1. ¿Quién está más expuesto a un alto riesgo de una infección de VIH en esta región?
2. ¿Hay unas cosas específicas en esta región que aumenta el riesgo?
3. ¿Qué se está haciendo en esta región para prevenir la infección de VIH en gente de alto riesgo?
4. ¿Qué más se puede hacer en la región para prevenir la infección de VIH, especialmente entre personas de alto riesgo?
5. ¿Qué se está haciendo en la región para alcanzar las necesidades de prevenir VIH con las personas infectadas con VIH? ¿Qué más se podría hacer?
6. ¿Hay algo actualmente que se pueda hacer para prevenir la infección del VIH en esta región y que no este trabajando?
7. ¿Dónde deben enfocarse los esfuerzos de prevención en esta región?
 - Áreas Geográficas
 - Lugares Comunitarios?
 - Tipos de Proveedores?
8. ¿Qué ayudaría a los proveedores en nuestra región para hacer un trabajo mayor de prevención de VIH?

Appendix 4 : WESTERN NY REGIONAL MAP AND CITIES

WESTERN NEW YORK REGIONAL MAP



**WESTERN NEW YORK REGION
CITIES, TOWNS & VILLAGES**

Cities

Batavia – Genesee County
 Buffalo – Erie County
 Dunkirk – Chautauqua County
 Jamestown – Chautauqua County
 Lackawanna – Erie County
 Lockport – Niagara County
 Niagara Falls – Niagara County
 North Tonawanda – Niagara County
 Olean – Cattaraugus County
 Salamanca – Cattaraugus County
 Tonawanda – Erie County

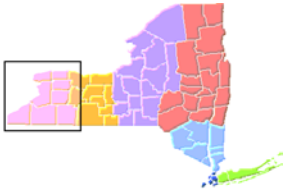
Towns

Alabama – Genesee	Cherry Creek – Chautauqua	Hartland – Niagara	Persia – Cattaraugus
Albion – Orleans	Clarence – Erie	Hinsdale – Cattaraugus	Pike – Wyoming
Alden – Erie	Clarendon – Orleans	Holland – Erie	Poland – Chautauqua
Alexander – Genesee	Clarksville – Allegany	Hume – Allegany	Pomfret – Chautauqua
Alfred – Allegany	Clymer – Chautauqua	Humphrey – Cattaraugus	Porter – Niagara
Allegany – Cattaraugus	Colden – Erie	Independence – Allegany	Portland – Chautauqua
Allen – Allegany	Coldspring – Cattaraugus	Ischua – Cattaraugus	Portville – Cattaraugus
Alma – Allegany	Collins – Erie	Java – Wyoming	Randolph– Cattaraugus
Almond – Allegany	Concord – Erie	Kendall – Orleans	Red House – Cattaraugus
Amherst – Erie	Conewango – Cattaraugus	Kiantone – Chautauqua	Ridgeway – Orleans
Amity – Allegany	Covington – Wyoming	Lancaster – Erie	Ripley – Chautauqua
Andover – Allegany	Darien – Genesee	Leon – Cattaraugus	Royalton – Niagara
Angelica – Allegany	Dayton – Cattaraugus	LeRoy – Genesee	Salamanca – Cattaraugus
Arcade – Wyoming	Dunkirk – Chautauqua	Lewiston – Niagara	Sardinia – Erie
Arkwright – Chautauqua	Eagle – Wyoming	Little Valley – Cattaraugus	Scio – Allegany
Ashford – Cattaraugus	East Otto – Cattaraugus	Lockport – Niagara	Shelby – Orleans
Attica – Wyoming	Eden – Erie	Lyndon – Cattaraugus	Sheridan – Chautauqua
Aurora – Erie	Elba – Genesee	Machias – Cattaraugus	Sherman – Chautauqua
Barre – Orleans	Ellery – Chautauqua	Mansfield – Cattaraugus	Somerset – Niagara
Batavia – Genesee	Ellicott – Chautauqua	Marilla – Erie	South Valley – Cattaraugus
Belfast – Allegany	Ellicottville – Cattaraugus	Middlebury – Wyoming	Stafford – Genesee
Bennington – Wyoming	Ellington – Chautauqua	Mina – CHautauqua	Stockton – Chautauqua
Bergen – Genesee	Elma – Erie	Murray – Orleans	Tonawanda – Erie
Bethany – Genesee	Evans – Erie	Napoli – Cattaraugus	Villanova – Chautauqua
Birdsall – Allegany	Farmersville – Cattaraugus	New Albion – Cattaraugus	Wales – Erie
Bolivar – Allegany	Franklinville – Cattaraugus	New Hudson – Allegany	Ward – Allegany
Boston – Erie	Freedom – Cattaraugus	Newfane – Niagara	Warsaw – Wyoming
Brant – Erie	French Creek – Chautauqua	Newstead – Erie	Wellsville – Allegany
Burns – Allegany	Friendship – Allegany	Niagara –Niagara	West Almond – Allegany
Busti – Chautauqua	Gaines – Orleans	North Collins – Erie	West Seneca – Erie
Byron – Genesee	Gainesville – Wyoming	No. Harmony – Chautauqua	Westfield – Chautauqua
Cambria – Niagara	Genesee – Allegany	Oakfield – Genesee	Wethersfield – Wyoming
Caneadea – Allegany	Genesee Falls – Wyoming	Olean – Cattaraugus	Wheatfield – Niagara
Carlton – Orleans	Gerry – Chautauqua	Orangeville – Wyoming	Willing – Allegany
Carroll – Chautauqua	Grand Island – Erie	Orchard Park – Erie	Wilson – Niagara
Carrollton – Cattaraugus	Granger – Allegany	Otto – Cattaraugus	Wirt – Allegany
Castile – Wyoming	Great Valley – Cattaraugus	Pavilion – Genesee	Yates – Orleans
Centerville – Allegany	Grove – Allegany	Pembroke – Genesee	Yorkshire - Cattaraugus
Charlotte – Chautauqua	Hamburg – Erie	Pendleton – Niagara	
Chautauqua – Chautauqua	Hanover – Chautauqua	Perry – Wyoming	
Cheektowaga – Erie	Harmony – Chautauqua	Perrysburg – Cattaraugus	

Villages

Akron – Erie
Albion – Orleans
Alden – Erie
Alexander – Genesee
Alfred – Allegany
Allegany – Cattaraugus
Almond – Allegany
Andover – Allegany
Angelica – Allegany
Angola – Erie
Arcade – Wyoming
Attica – Wyoming
Barker – Niagara
Belmont – Allegany
Bemus Point – Chautauqua
Bergen – Genesee
Blasdell – Erie
Bolivar – Allegany
Brocton – Chautauqua
Canaseraga – Allegany
Cassadaga – Chautauqua
Castile – Wyoming
Cattaraugus – Cattaraugus
Celoron – Chautauqua
Cherry Creek – Chautauqua
Corfu – Genesee
Cuba – Allegany
Delevan – Cattaraugus
Depew – Erie
East Aurora – Erie
East Randolph – Cattaraugus
Elba – Genesee
Ellicottville – Cattaraugus
Falconer – Chautauqua
Farnham – Erie
Forestville – Chautauqua
Franklinville – Cattaraugus
Fredonia – Chautauqua
Gainesville – Wyoming
Gowanda – Erie/ Cattaraugus
Hamburg – Erie
Holley – Orleans
Kenmore – Erie
Lakewood – Chautauqua
Lancaster – Erie
LeRoy – Genesee
Lewiston – Niagara
Limestone – Cattaraugus
Lydonville – Orleans
Mayville – Chautauqua
Medina – Orleans
Middleport – Niagara
North Collins – Erie
Oakfield – Genesee
Orchard Park – Erie
Panama – Chautauqua
Perry – Wyoming
Perrysburg – Cattaraugus
Pike – Wyoming
Portville – Cattaraugus
Randolph – Cattaraugus
Richburg – Allegany
Sherman – Chautauqua
Silver Creek – Chautauqua
Silver Springs – Wyoming
Sinclairville – Chautauqua
Sloan – Erie
South Dayton – Cattaraugus
Springville – Erie
Warsaw – Wyoming
Wellsville – Allegany
Westfield – Chautauqua
Williamsville – Erie
Wilson – Niagara
Wyoming – Wyoming
Youngstown – Niagara

Appendix 5 : THE WESTERN NY REGION



THE WESTERN NEW YORK REGION

Pennsylvania, Lake Erie, Lake Ontario and the Province of Ontario, Canada border the Western New York Region (also known as the Buffalo Region) of New York State. The region consists of eight counties: Allegany, Cattaraugus, Chautauqua, Erie, Genesee, Niagara, Orleans and Wyoming with the 2000 Census population being reported at 1,591,708. The City of Buffalo, the second largest city in New York State, with a 2000 population of 292,648, and Niagara Falls with a 2000 population of 55,593, anchor a largely rural area dotted with smaller urban and suburban communities.

The region is home to several diverse populations. There are several Native American reservations including: Allegany, Cattaraugus, Oil Springs, Tonawanda, and Tuscarora Nation Reservations. There is also members of the Cayuga Nation living in the region being served by an office located in Cattaraugus County, and the Six Nation reservation is located 60 miles to the north of Buffalo, in Ontario, Canada. There is a significant Amish population predominately living in Allegany and Cattaraugus Counties. Seasonal immigrant and migrant farm workers are employed throughout various agricultural settings in numerous communities in the eight county region. Ten county correctional facilities and eleven state correctional facilities are located throughout the region. There are over 140,000 people attending over thirty institutions of higher education, ranging from large public universities to small private colleges.

Tourism is a major industry in Western New York with Niagara Falls attracting about 13 million annual visitors to the area. Other regional tourism activities include over 500 parks – including Allegany and Letchworth State Parks, over 100 golf courses, a dozen alpine and cross-country ski resorts, numerous lakes and rivers, several professional sports teams and numerous historical sites. Approval of casino gaming was granted in 2002 for the Seneca Nation to operate casinos on reservation and in the cities of Buffalo and Niagara Falls. There are four international bridge crossings into Ontario Canada and the City of Buffalo is within short driving proximity to several cities such as: Toronto, Ontario, Rochester, NY, and Cleveland, Ohio.

The Western New York region is often known for its reputation of “extreme” winters and is often blanketed with “lake-effect” snow, which can hinder winter travel. In common with other large geographic regions, long distance travel is often required to obtain a full range of care and supportive services. Public transportation is available, but limited, especially in the rural and suburban communities.

The racial makeup of the region (based on the eight county Census average) is 91.78% White, 4.76% African American, 0.80% Native American, 0.59% Asian, 0.02% Pacific Islander, 0.97% from other races, and 1.09% from two or more races. 2.38% of the population are Hispanic or Latino of any race. The median income for a household in the region (based on the eight county Census average) is \$39,760. In the region, 11.58% of the population and 8.34% of families are below the poverty line. Out of the total people living in poverty in the region, 15.60% are under the age of 18 and 7.30% are 65 or older.

THE COUNTIES OF WESTERN NEW YORK

Allegany County

Allegany County is located in the southeastern part of the Western New York Region of New York State, immediately north of the Pennsylvania border. The county has a total area of 1,034 square miles. Its county seat is Belmont.

The county is home to the Oil Springs Native American Reservation (Seneca) near Cuba. Higher education institutions include Alfred State College, The College of Technology at Alfred, Alfred University, and Houghton College. Hospitals located in the county include Cuba Memorial Hospital and Jones Memorial Hospital. There is one county correctional facility, The Allegany County Jail, located in Belmont.

As of 2000, there are 49,927 people, 18,009 households and 12,192 families residing in the county. The racial makeup of the county is 97.03% White, 0.72% African American, 0.28% Native American, 0.72% Asian, 0.00% /Pacific Islander, 0.37% from other races, and 0.88% from two or more races. 0.91% of the population are Hispanic or Latino of any race.

The median income for a household in the county is \$32,106. 15.50% of the population and 10.50% of families are below the poverty line. Out of the total people living in poverty, 19.20% are under the age of 18 and 7.50% are 65 or older.

Cattaraugus County

Cattaraugus County is located in the Allegheny Mountains in the south central part of the Western New York Region of New York State, immediately north of the Pennsylvania border. The county has a total area of 1,322 square miles. Its county seat is Little Valley.

The county is home to the Allegheny Reservation (Seneca) near the City of Salamanca, a portion of the Cattaraugus Reservation (Seneca Nation of Indians) near Gowanda, and an office of the Cayuga Nation in Gowanda. Higher education institutions include St Bonaventure University and Olean Business Institute. There is one hospital located in the county, Olean General Hospital. There is one county correctional facility, The Cattaraugus County Jail, located in Little Valley. There are three state correctional facilities in the county: Cattaraugus Residential Center (Limestone), Gowanda Correctional Facility (Gowanda) and Great Valley Residential Center (Great Valley).

As of 2000, there are 83,955 people, 32,023 households and 21,647 families residing in the county. The racial makeup of the county is 94.63% White, 1.06% African American, 2.60% Native American, 0.46% Asian, 0.02% Pacific Islander, 0.23% from other races, and 1.01% from two or more races. 0.94% of the population are Hispanic or Latino of any race.

The median income for a household in the county is \$33,404. 13.70% of the population and 10.00% of families are below the poverty line. Out of the total people living in poverty, 18.60% are under the age of 18 and 9.90% are 65 or older.

Chautauqua County

Chautauqua County is located in the southwestern part of the Western New York Region of New York State, along the east coast of Lake Erie and is the westernmost of the counties along the New York-Pennsylvania border. The county has a total area of 1,500 square miles. Its county seat is Mayville.

The county is home to a portion of the Cattaraugus Reservation (Seneca Nation of Indians) near Dunkirk, Fredonia and Silver Creek. Higher education institutions include Fredonia State College, Jamestown Community College and Jamestown Business College. Hospitals located in the county include Brooks Memorial Hospital, Lake Shore Health Care Center, WCA Healthcare System and Westfield Memorial Hospital. There is one county correctional facility, The Chautauqua County Jail, located in Mayville. There is one state correctional facility in the county, Lakeview Shock Incarceration Facility located in Brocton.

As of 2000, there are 139,750 people, 54,515 households and 35,979 families residing in the county. The racial makeup of the county is 94.04% White, 2.18% African American, 0.43% Native American, 0.36% Asian, 0.03% Pacific Islander, 1.73% from other races, and 1.23% from two or more races. 4.22% of the population are Hispanic or Latino of any race.

The median income for a household in the county is \$33,458. 13.80% of the population and 9.70% of families are below the poverty line. Out of the total people living in poverty, 19.30% are under the age of 18 and 8.20% are 65 or older.

Erie County

Erie County is in the east central part of the Western New York Region of New York State, bordering Lake Erie and the Niagara River. The county has a total area of 1,227 square miles. Its county seat is Buffalo, the second largest city in New York State.

The county is home to the Tonawanda Band of Seneca's Native American Reservation near Akron, a portion of the Cattaraugus Reservation (Seneca Nation of Indians) located near Angola and North Collins, and the Six Nation reservation is located 60 miles to the north, in Ontario Canada. The Peace Bridge, located in Buffalo, is an international border crossing into Fort Erie, Canada. Higher education institutions include The University at Buffalo, Buffalo State College, SUNY Empire State College, Erie Community College, Bryant and Stratton Business Institute, Canisius College, Christ the King Seminary, Cornell University-Industrial & Labor Relations, D'Youville College, Daemen College, Hilbert College, ITT Technical Institute, Medaille College, Trocaire College and Villa Maria College. Hospitals located in the county include Bertrand Chafee, Buffalo General, Buffalo Psychiatric Center, Children's Hospital at Buffalo, Erie County Medical Center, Kenmore Mercy, Mercy Hospital, Millard Fillmore, Our Lady of Victory, Roswell Park Cancer Institute, Sisters of Charity, St. Joseph's, Sheehan Memorial, Tri-County Memorial, and Veterans WNY Healthcare System. There are three county correctional facilities, The Erie County Correctional Facility located in Alden, Erie County Holding Center and Erie County Youth Services Detention Facility located in Buffalo. There are three state correctional facilities in the county: Buffalo Correctional Facility (Alden), Collins Correctional Facility (Collins), and Wende Correctional Facility (Alden).

As of 2000, there are 950,265 people, 380,873 households and 243,377 families residing in the county. The racial makeup of the county is 82.18% White, 13.00% African American, 0.61% Native American,

1.46% Asian, 0.02% Pacific Islander, 1.42% from other races, and 1.31% from two or more races. 3.27% of the population are Hispanic or Latino of any race.

The median income for a household in the county is \$38,567. 12.20% of the population and 9.20% of families are below the poverty line. Out of the total people living in poverty, 17.30% are under the age of 18 and 7.80% are 65 or older.

Genesee County

Genesee County is located in the central part of the Western New York Region of New York State, east of Buffalo and west of Rochester. The county has a total area of 495 square miles. Its county seat is Batavia.

The county is home to a portion of the Tonawanda Reservation (Seneca) near Akron. Higher education institutions include Genesee Community College. There is one hospital located in the county, United Memorial Medical Center. There is one county correctional facility, The Genesee County Correctional Facility, located in Batavia.

As of 2000, there are 60,370 people, 22,770 households and 15,825 families residing in the county. The racial makeup of the county is 94.69% White, 2.13% African American, 0.78% Native American, 0.48% Asian, 0.02% /Pacific Islander, 0.71% from other races, and 1.18% from two or more races. 1.50% of the population are Hispanic or Latino of any race.

The median income for a household in the county is \$40,542. 7.60% of the population and 5.60% of families are below the poverty line. Out of the total people living in poverty, 9.00% are under the age of 18 and 6.80% are 65 or older.

Niagara County

Niagara County is in the northwestern part of the Western New York Region of New York State, adjacent to Lake Ontario, the Niagara River, and Niagara Falls. The county has a total area of 1,140 square miles. Its county seat is Lockport.

The county is home to the Tuscarora Nation Reservation (Tuscarora Tribe) located near Sanborn and a portion of the Tonawanda Reservation (Seneca) near Akron. The Rainbow and Whirlpool Bridges located in Niagara Falls, and the Lewiston-Queenston Bridge located in Lewiston, are international border crossings into Ontario, Canada. Higher education institutions include Niagara County Community College and Niagara University. Hospitals located in the county include DeGraff Memorial, Inter-Community Memorial, Mount St. Mary's, and Niagara Falls Memorial Medical Center. There is one county correctional facility, The Niagara County Jail, located in Lockport.

As of 2000, there are 219,846 people, 87,846 households and 58,593 families residing in the county. The racial makeup of the county is 90.70% White, 6.15% African American, 0.94% Native American, 0.58% Asian, 0.02% Pacific Islander, 0.40% from other races, and 1.21% from two or more races. 1.33% of the population are Hispanic or Latino of any race.

The median income for a household in the county is \$38,136. 10.60% of the population and 8.20% of families are below the poverty line. Out of the total people living in poverty, 15.00% are under the age of 18 and 7.30% are 65 or older.

Orleans County

Orleans County is in the northeastern part of the Western New York Region of New York State, northeast of Buffalo and west of Rochester on the southern shore of Lake Ontario. The county has a total area of 817 square miles. Its county seat is Albion.

There is one hospital located in the county, Medina Memorial Hospital Health Care System. There is one county correctional facility, Orleans County Correctional Facility, located in Albion. There are two state correctional facilities Albion Correctional facility and Orleans Correctional Facility, both located in Albion.

As of 2000, there are 44,171 people, 15,363 households and 10,846 families residing in the county. The racial makeup of the county is 89.12% White, 7.31% African American, 0.46% Native American, 0.32% Asian, 0.03% Pacific Islander, 1.54% from other races, and 1.21% from two or more races. 3.89% of the population are Hispanic or Latino of any race.

The median income for a household in the county is \$37,972. 10.80% of the population and 7.70% of families are below the poverty line. Out of the total people living in poverty, 15.00% are under the age of 18 and 5.20% are 65 or older.

Wyoming County

Wyoming County is in the eastern central part of the Western New York Region of New York State, east of Buffalo and west of Rochester. The county has a total area of 1,545 square miles. Its county seat is Warsaw.

There is one hospital located in the county, Wyoming County Community Health System. There is one county correctional facility, The Wyoming County Jail, located in Warsaw. There are two state correctional facilities: Wyoming Correctional Facility and Attica Correctional Facility both located in Attica.

As of 2000, there are 43,424 people, 14,906 households and 10,717 families residing in the county. The racial makeup of the county is 91.84% White, 5.52% African American, 0.27% Native American, 0.37% Asian, 0.02% Pacific Islander, 1.32% from other races, and 0.67% from two or more races. 2.94% of the population are Hispanic or Latino of any race.

The median income for a household in the county is \$39,895. 8.40% of the population and 5.80% of families are below the poverty line. Out of the total people living in poverty, 11.60% are under the age of 18 and 5.80% are 65 or older.

**Appendix 6. AIDS Institute Contracts Serving Western New York
(Effective 11/02)**

**Action For A Better Community
(Subcontractor-Group Ministries)**
Funding: \$308,036

Centro Civico of Amsterdam
Funding: \$120,000

Hispanics United of Buffalo
Funding: \$155,000

AIDS Alliance of Western NY
Funding: \$108,000

Child & Family Services
Funding: \$55,575

Horizon Health Services
Funding: \$181,280

AIDS Community Services
Funding: \$1,794,178

Cicatelli & Associates
Funding: \$137,200

Kaleida Health
Funding: \$500,831

AIDS Network of Western NY
Funding: \$122,892

Community Health Network
Funding: \$304,357

Monroe County Dept. of Health
Funding: \$198,970

AIDS Rochester
Funding: \$199,521

Erie 1 BOCES
Funding: \$162,500

Men of Color Health Awareness
Funding: \$348,333

American Indian Community House
Funding: \$499,573

Erie County Bar Association
Funding: \$77,917

**National Black Leadership
Commission on AIDS**
Funding: \$694,047

**American Red Cross
Greater Buffalo Chapter**
Funding: \$411,000

Erie County Dept. of Health
Funding: \$115,000

Native American Comm. Services
Funding: \$102,679

Benedict House of Western NY
Funding: \$173,835

Erie County Medical Center
Funding: \$873,965

NY State Catholic Health Plan
Funding: \$482,946

Buffalo Prenatal Perinatal Network
Funding: \$233,449

Geneva B. Scruggs, CHCC
Funding: \$514,334

Niagara County Dept. of Health
Funding: \$49,125

Catholic Charities
Funding: \$200,000

Group Ministries, Inc.
Funding: \$368,111

Roswell Park Cancer Institute
Funding: \$168,000

Cattaraugus Community Action
Funding: \$162,500

Health Association
Funding: \$110,000

Rural Opportunities
Funding: \$357,232

Women's Prison Assoc & Home
Funding: \$126,011

Appendix 7. Service Directory

SERVICE PROVIDERS

AIDS Alliance of Western New York

367 Delaware Avenue
Buffalo, NY 14202
Telephone: (716) 852-6778
Fax: (716) 852-6791

AIDS Community Services

206 South Elmwood Avenue
Buffalo, NY 14201
Telephone: (716) 847-2441
Fax: (716) 847-0418

www.aidscommunityservices.com

AIDS Family Services

40 Gates Circle
Buffalo, NY 14209
Telephone: (716) 881-4612
Fax: (716) 881-4618

www.aidsfamilyservices.com

AIDS Network of Western New York

40 Gates Circle, Suite 100
Buffalo, NY 14209
Telephone: (716) 882-7840
Fax: (716) 882-2139

www.aidsnetwork.net

Allegany County Department of Health

7 Court Street
Belmont, NY 14813
Telephone: (585) 268-9250
Fax: (585) 268-9264

www.alleganyco.com/health

American Indian Community House

1005 Grant Street
Buffalo, NY 14207
Telephone: (716) 874-4460
Fax: (716) 874-1874

American Red Cross-Greater Buffalo

786 Delaware Avenue
Buffalo, NY 14209
Telephone: (716) 878-2394
Fax: (716) 878-2381

www.redcross.org/ny/buffalo

Benedict House of Western New York

2211 Main Street
Buffalo, NY 14214
Telephone: (716) 834-4940
Fax: (716) 878-2381
www.benedichouse.org

Buffalo Prenatal-Perinatal Network

625 Delaware Avenue – Suite 4410
Buffalo, New York 14202
Telephone: (716) 884-6711
Fax: (716) 884-0513

Cattaraugus County Dept. of Health

1701 Lincoln Avenue, Suite 4010
Olean, NY 14760
Telephone: (716) 373-8050
Fax: (716) 373-0942
www.co.cattaraugus.ny.us/doh/reproduction/

Center for Hospice & Palliative Care

225 Como Park Blvd.
Cheektowaga, NY 14227
Telephone: (716) 686-8050
Fax: (716) 686-8111
www.hospicebuffalo.org/kresge

Chautauqua County Dept. of Health

7 North Erie Street
Mayville, NY 14757
Telephone: (716) 753-4780
Fax: (716) 753-4794
www.chautauqua-ny.com

Chautauqua Opportunities

17 West Courtney Street
Dunkirk, NY 14048
Telephone: (716) 366-3333
Fax: (716) 366-7366
www.chautauquaopportunities.com

Child & Family Services

330 Delaware Avenue
Buffalo, NY 14222
Telephone: (716) 842-2750
Fax: (716) 842-0668
www.childfamily.org

Children's Hospital of Buffalo

239 Bryant Street
Buffalo, NY 14222
Telephone: (716) 878-7908
Fax: (716) 888-3868
www.kaleidahealth.org

Community Health Center of Buffalo

462 Grider Street
Buffalo, NY 14215
Telephone: (716) 898-5854
Fax: (716) 898-3051

Collins Correctional Facility

PO Box 490
Collins, NY 14034
Telephone: (716) 532-4588
Fax: (716) 532-4588, Ext. 209

Crisis Services

2969 Main Street
Buffalo, NY 14214
Telephone: (716) 834-3131
Fax: (716) 934-9881
www.crisisservices.org

**Episcopal Church Home
AIDS Home Health Care**

24 Rhode Island Street
Buffalo, NY 14213
Telephone: (716) 883-7917
Fax: (716) 884-2061
www.esha.org

Erie County Dept. of Health

95 Franklin Street
Buffalo, NY 14202
Telephone: (716) 858-7691
Fax: (716) 858-8701
www.erie.gov

Erie County Medical Center

462 Grider Street
Buffalo, NY 14215
Telephone: (716) 898-4119
Fax: (716) 898-3187
www.aidscenterecmc.org

Gay & Lesbian Youth Services

330 Delaware Avenue
Buffalo, NY 14202
Telephone: (716) 855-0221
Fax: (716) 855-0661
www.glyswny.com

Genesee County Dept. of Health

County Bldg. II, 3837 W. Main Street
Batavia, NY 14020
Telephone: (585) 344-8506
Fax: (585) 344-4713
www.co.genesee.ny.us

Geneva B. Scruggs, CHCC

1461 Main Street
Buffalo, NY 14209
Telephone: (716) 881-2361
Fax: (716) 816-0318
www.gbscruggs.com

Group Ministries

1333 Jefferson Avenue
Buffalo, NY 14208
Telephone: (716) 883-4367
Fax: (716) 883-4449

Hispanics United of Buffalo

254 Virginia Street
Buffalo, NY 14201
Telephone: (716) 856-7110
Fax: (716) 856-9617

Horizon Health Services

3020 Bailey Avenue
Buffalo, NY 14215
Telephone: (716) 831-1800
Fax: (716) 831-1818
www.horizon-health.org

Kaleida – Project Reach

3060 Bailey Avenue
Buffalo, NY 14215
Telephone: (716) 845-0172
Fax: (716) 845-0219
www.doingitsafe.com

Lakeshore Behavioral Health

951 Niagara Street
Buffalo, NY 14213
Telephone: (716) 842-0440
Fax: (716) 884-1758
www.lake-shore.org

Men of Color Health Awareness Project

531 Virginia Street
Buffalo, NY 14202
Telephone: (716) 852-1142
Fax: (716) 852-1518
www.mochaproject.org

Native American Community Services

1005 Grant Street
Buffalo, NY 14207
Telephone: (716) 874-4469
Fax: (716) 874-1874

Niagara County Dept. of Health

711 Pine Avenue
Buffalo, NY 14301
Telephone: (716) 285-5781
Fax: (716) 285-1687
www.healthyniagara.com

New York State Dept. of Health

584 Delaware Avenue
Buffalo, NY 14202
Telephone: (716) 847-4511
Fax: (716) 847-4327
www.health.state.ny.us

Orleans County Dept. of Health

14012 Route 31
Albion, NY 14411
Telephone: (585) 589-3162
Fax: (585) 589-6647
www.orleansny.com/health.htm

Planned Parenthood of Buffalo & Erie

2697 Main Street
Buffalo, NY 14214
Telephone: (716) 831-2200
Fax: (716) 831-1065
www.plannedparenthood.bfn.org

Planned Parenthood of Niagara

752 Portage Road
Niagara Falls, NY 14301
Telephone: (716) 282-2502
Fax: (716) 282-2558

Roswell Park Cancer Institute

Elm & Carlton Streets
Buffalo, NY 14263
Telephone: (716) 845-2300
www.roswellpark.org

Veteran's WNY Healthcare System

3495 Bailey Avenue

Buffalo, NY 14215

Telephone: (716) 862-8758

Fax: (716) 862-3221

www.va.gov/visns/visn02/buffalo.html

Volunteer Lawyers Project

700 Statler Tower

Buffalo, NY 14202

Telephone: (716) 847-0662

Fax: (716) 786-3537

Wyoming County Dept. of Health

338 North Main Street

Warsaw, NY 14569

Telephone: (585) 786-8890

Fax: (585) 786-3537

www.wyomingco.com/pubhlth.htm

COUNTY TASK FORCES

Allegany County AIDS Task Force

C/o Helen Evans

County Office Building – 7 Court Street

Belmont, NY 14813

Telephone: (585) 268-9250

Cattaraugus County AIDS Task Force

C/o Tony LeGalbo

P.O. Box 397

Olean, NY 14760

Telephone: (716) 375-2153

Chautauqua County AIDS Coalition

C/o Russell Tilaro

15 West Mosher Street

Falconer, NY 14733

Telephone: (716) 665-6948

Genesee County AIDS Task Force

C/o Mary Ellen Wilber

205 Liberty Street

Batavia, NY 14020

Telephone: (585) 343-1610

Niagara County AIDS Task Force

C/o Barbara Jesz

719 Ashland Avenue

Niagara Falls, NY 14302

Telephone: (716) 285-6938

Orleans County AIDS Task Force

C/o Nola Goodrich
14012 Route 31
Albion, NY 14411
Telephone: (585) 589-3162

Wyoming County AIDS Task Force

C/o LuAnne Meyer
338 North Main Street
Warsaw, NY 14569
Telephone: (585) 786-8890

HIV/AIDS HOTLINES

New York State

Tape Hotline: 1-800-541-AIDS
Tape Hotline (Spanish): 1-800-233-7432
Counseling Hotline: 1-800-872-2777
Deaf Hotline (TDD): 1-800-369-2437

ADDITIONAL SERVICE RESOURCES

www.aidsnetwork.net

SECTION IX. ACKNOWLEDGEMENTS AND THANKS

Network

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Bernice Burgos, Program Assistant

Pat Letourneau, Former Executive Director

Service Delivery Plan Committee: Helen Evans – Allegany County AIDS Task Force; Paul Kokoszka – Community Member; John Miller – AIDS Community Services; John Morgan – Men of Color Health Awareness Project; Mark Nowak – Community Member (Committee Chairperson); Anthony Perri – Geneva B. Scruggs; Babette Sullivan – Children’s Hospital of Buffalo; Kati Walsh – Erie County Medical Center; Mary Ellen Wilber – Genesee County AIDS Task Force, Erie County Department of Health.

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