Newark EMA

HIV Health Services Planning Council

NEEDS ASSESSMENT 2010 UPDATE

June 2010

NEWARK EMA HIV HEALTH SERVICES PLANNING COUNCIL
NEEDS ASSESSMENT - 2010 UPDATE

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LIST OF ABBREVIATIONS

The following abbreviations and acronyms are used in this Needs Assessment.

ADAP	AIDS Drug Assistance Program
ADDP	(New Jersey) AIDS Drug Distribution Program
AETC	AIDS Education and Training Center
ARV	Anti-Retroviral (therapies)
CBO	Community Based Organization
CHAMP	Comprehensive HIV/AIDS Management Program (the Newark EMA's Client Level Data Base)
CLD	Client Level Data (system)
Cmte	Committee
COC	Continuum of Care Committee of NEMA Planning Council
CQM	Clinical Quality Management
CPC	Comprehensive Planning Committee of NEMA Planning Council
CSAC	Community Service Advisory Committee of NEMA Planning Council
CTR	Counseling, Testing and Referral sites (for early identification of PLWHA)
DCFWB	Newark Department of Child and Family Well Being (Formerly, the Newark Department of Health and Human Services – DHHS)
DHAS	Division of HIV/AIDS Services (New Jersey)
EI	Early Identification (also shown as Early ID or EID)
EIS	Early Intervention Services
EMA	Eligible Metropolitan Area
FQHC	Federally Qualified Health Center
GLBTQ	Gay, Lesbian, Bisexual, Transgendered, Questioning
HAART	Highly Active Anti-Retroviral Therapy
HAB	HIV/AIDS Bureau (of HRSA)
HOPWA	Housing Opportunities for Persons With AIDS
HRSA	Health Resources and Services Administration (of the U.S. Department of Health and Human Services)
IDU	Injection Drug User
MAI	Minority AIDS Initiative (formerly Congressional Black Caucus – CBC)
MCM	Medical Case Management
MH	Mental Health
MNT	Medical Nutritional Therapy

MSM	Men who have Sex with Men
MSW	Morris, Sussex, Warren counties in the Newark EMA
MOA, MOU	Memorandum of Agreement, Memorandum of Understanding
NEMA	Newark Eligible Metropolitan Area
NJDHSS	N.J. Department of Health and Senior Services
PAAD	(New Jersey) Pharmaceutical Assistance to the Aged and Disabled Program
PHS	(U.S.) Public Health Service
PLWHA	People Living With HIV or AIDS
REC	Research and Evaluation Committee of NEMA Planning Council
RWTEA	Ryan White HIV/AIDS Treatment Extension Act of 2009
RWTMA	Ryan White HIV/AIDS Treatment Modernization Act of 2006
SA	Substance Abuse
SAMHSA	Substance Abuse and Mental Health Services Administration (of the U.S. Department of Health and Human Services)
SAMISS	Substance Abuse Mental Illness Screening Survey
UBHC	University Behavioral Health Care (of UMDNJ)
UMDNJ	University of Medicine and Dentistry of New Jersey
WICY	Women, Infants, Children and Youth
WSW	Women who have Sex with Women

INTRODUCTION

The information below was extracted from the Ryan White Part A Manual published by HRSA/HAB in 2009 on its website. It reflects requirements of the Ryan White HIV/AIDS Treatment Extension Act (RWTEA) of 2009, Public Law 111-87, October 30, 2009. The citations are referenced to the Public Health Service Act (42 U.S.C. 300ff-11).

Legislative Background

Section 2602(b)(4) requires the planning council to:[1]

A. "determine the size and demographics of the population of individuals with HIV/AIDS, **as well as the size and demographics of the estimated population of individuals with HIV/AIDS who are unaware of their HIV status''**;

B. "determine the needs of such population, with particular attention to:

   i. individuals with HIV/AIDS who know their HIV status and are not receiving HIV-related services;

   ii. disparities in access and services among affected subpopulations and historically underserved communities; and"

   iii. **individuals with HIV/AIDS who do not know their HIV status."**

2602(b)(4)(G) requires planning councils to "establish methods for obtaining input on community needs and priorities which may include public meetings, conducting focus groups, and convening ad-hoc panels."

Section 2602(b)(4)(F) calls for the planning council and grantee to "participate in the development of the statewide coordinated statement of need initiated by the State public health agency responsible for administering grants under Part B."

Section 2602(b)(4)(H) requires the planning council to "coordinate with Federal grantees that provide HIV-related services within the eligible area."

Needs assessment data are critical to conducting other planning tasks. Needs assessment results must be reflected in both the planning council's priority setting and resource allocations and in the EMA's/TGA's comprehensive plan. Planning councils are required to:

- Address coordination with programs for HIV prevention and the prevention and treatment of substance abuse

[1] HRSA. HIV/AIDS Bureau. http://hab.hrsa.gov/tools/parta/parta/ptAsec6chap1.htm#SecVIChap1a

- Include links with outreach and early intervention services
- Address capacity development needs
- Be closely linked with comprehensive planning and annual implementation plan development, as interconnected parts of an ongoing planning process.

Section 2603(b)(1) specifies that in seeking supplemental funding, the EMA/TGA is expected to include in its application for funding an array of information, including needs assessment data that demonstrate need.

Section 2603(b)(2)(B) specifies that, in making awards for **demonstrated need**, the Secretary may consider any or all of the following factors:

i. "The unmet need for such services, as determined under section 2602(b)(4) or other community input process as defined under section 2609(d)(1)(A).

ii. An increasing need for HIV/AIDS-related services, including relative rates of increase in the number of cases of HIV/AIDS.

iii. The relative rates of increase in the number of cases of HIV/AIDS within new or emerging subpopulations.

iv. The current prevalence of HIV/AIDS.

v. Relevant factors related to the cost and complexity of delivering health care to individuals with HIV/AIDS in the eligible area.

vi. The impact of co-morbid factors, including co-occurring conditions, determined relevant by the Secretary.

vii. The prevalence of homelessness.

viii. The prevalence of individuals described under section 2602(b)(2)(M).

ix. The relevant factors that limit access to health care, including geographic variation, adequacy of health insurance coverage, and language barriers."

HAB/DSS Expectations

Needs assessment is expected to generate information about:

- The size and demographics of the HIV/AIDS population within the service area, including those who are unaware of their HIV status (not tested), and

- The needs of PLWHA, with emphasis on individuals with HIV/AIDS who know their HIV status and are not receiving primary health care, and on disparities in access and services among affected subpopulations and historically underserved communities.

HAB/DSS expects Part A needs assessments to meet all legislative requirements and to provide a sound information base for planning and decision making.

RWTEA Amendments

In addition to expanding the scope of the needs assessment, the RWTEA added responsibilities regarding the comprehensive plan.

Section 2602(b)(4) requires the planning council to:

> (D) develop a comprehensive plan for the organization and delivery of health and support services described in section 2604 that-
>
> > **''(iv) includes a strategy, coordinated as appropriate with other community strategies and efforts, including discrete goals, a timetable, and appropriate funding, for identifying individuals with HIV/AIDS who do not know their HIV status, making such individuals aware of such status, and enabling such individuals to use the health and support services described in section 2604, with particular attention to reducing barriers to routine testing and disparities in access and services among affected subpopulations and historically underserved communities;''**

As required by HRSA HAB, the Newark EMA prepared a plan for FY 2010 for early identification of PLWHA. This plan is set forth in Appendix A.

PURPOSE AND METHODOLOGY

The purpose of the Needs Assessment - 2010 Update was to conduct an in-depth study of issues raised by HIV surveillance data and consumers in the 2008 Needs Assessment and 2009 Update – mental health among PLWHA and increasing need for specialty care - and to further investigate new responsibilities under the RWTEA regarding individuals "unaware" of their HIV status and early identification of PLWHA through testing and connection to medical care.

The goal of the 2010 Update to the Needs Assessment was to obtain as much input as possible from the community, while utilizing existing sources and work done by the Council. The Council utilized quantitative methods including a consumer survey and qualitative methods including key informants to obtain consumer input. Information was also obtained through public testimony, information discussions and reports, and new analysis of client level data (CLD) from the EMA's Comprehensive HIV/AIDS Management Program (CHAMP) system. The methodologies are discussed in each chapter.

Data on utilization of Part A services was obtained from the Newark EMA Grantee and the Comprehensive HIV/AIDS Management Program (CHAMP) system.

The Needs Assessment - 2010 Update incorporates directions from HRSA/HAB and reflects current policies and information including early identification of PLWHA.

PART 1: EPIDEMIOLOGICAL PROFILE

The Newark EMA Epidemiological Profile for the Needs Assessment - 2010 Update follows guidelines on epidemiological profiles issued by the U.S. Centers for Disease Control and Prevention (CDC). This section includes data on current PLWHA, counties/regions, trends 1999-6/2009 and prevalence. All surveillance data is from the **New Jersey Department of Health and Senior Services (NJDHSS), Division of HIV/AIDS Services (DHAS)**. See Appendix B for additional tables and figures.

1.1 The Current HIV/AIDS Epidemic

1.1.1 People Living with HIV/AIDS

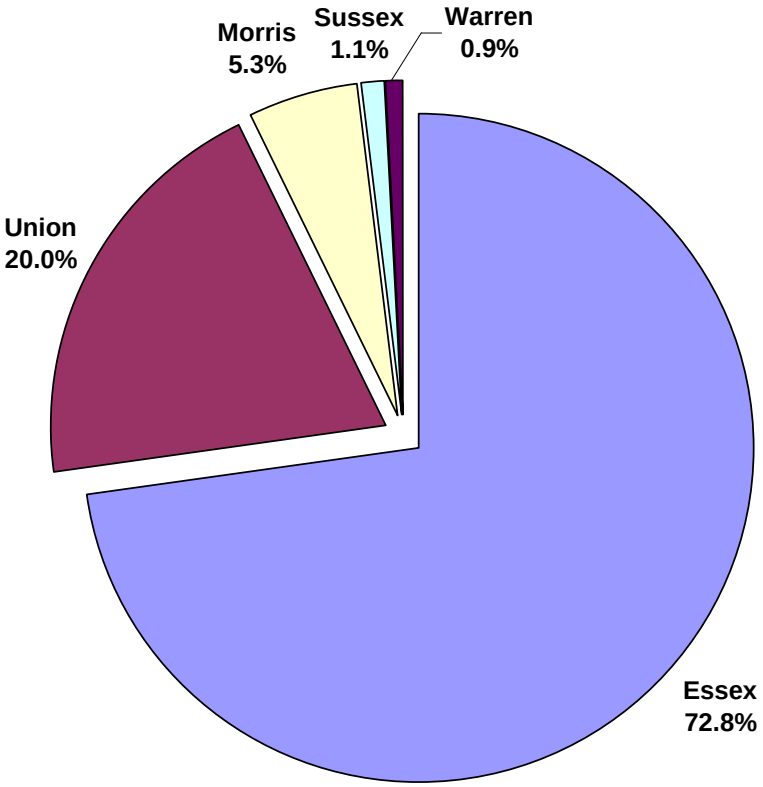
As of June 30, 2009, there were 13,109 people living with HIV/AIDS (PLWHA) residing in the Newark EMA. This is an decrease of 1% or -109 over the 13,218 as of December 31, 2008. Similarly, there were 34,712 PLWHA in New Jersey as of 2008, or a 1% decrease (-203) over the 34,915 in 2008. No information has been provided yet by NJDHSS regarding these declines The Newark EMA accounts for 38% of PLWHA in New Jersey. Table 1 and Figure A.

Table 1: People Living With HIV or AIDS as of June 30, 2009 - Newark EMA and New Jersey

	PLWHA			%		%	
County	**AIDS**	**HIV**	**Total**	**AIDS**	**HIV**	**NEMA**	**NJ**
Essex	4,672	4,867	9,539	49.0%	51.0%	72.8%	27.5%
Morris	372	322	694	53.6%	46.4%	5.3%	2.0%
Sussex	69	71	140	49.3%	50.7%	1.1%	0.4%
Union	1,483	1,135	2,618	56.6%	43.4%	20.0%	7.5%
Warren	57	61	118	48.3%	51.7%	0.9%	0.3%
Newark EMA	**6,653**	**6,456**	**13,109**	**50.8%**	**49.2%**	**100.0%**	**37.8%**
New Jersey	18,075	16,637	34,712	52.1%	47.9%		
Rest of NJ	10,876	10,080	20,956	51.9%	48.1%		
NEMA/NJ	**36.8%**	**38.8%**	**37.8%**				

Within the Newark EMA, most PLWHA (9,539 or 72.8%) reside in Essex County, followed by 2,618 (20.0%) in Union County. A total of 95 or 7.2% reside in the remaining three counties – 694 (5.3%) in Morris, 140 (1.1%) in Sussex, and 118 (0.9%) in Warren County.

Figure A: People Living With HIV/AIDS in Newark EMA by County – 6/30/09



PLWHA:	
Essex	9,539
Union	2,618
Morris	694
Sussex	140
Warren	118
TOTAL	13,109

Morris, Sussex, Warren region has 7.2% PLWHA.

Trends in HIV versus AIDS. HIV infection may or may not progress to AIDS. Comparing people living with HIV only versus AIDS gives an indication of the following: (1) New infections and diagnoses (people living with HIV) versus older infections/diagnoses (people living with AIDS). (2) A higher percent of people living with HIV may indicate that testing is more effective, because people are being diagnosed at earlier stages in the disease. (3) A higher percent of people living with HIV may indicate effectiveness of medical care – that more people are getting necessary and appropriate treatment and medications on a regular basis – such that HIV is not converting to AIDS.

The percent of "HIV versus AIDS" has implications for costs of medical care and related support services. Medical care costs (including inpatient care) for people living with AIDS are higher, with support services related to serious stages of the illness. Medical care costs for people living with HIV may not be as high (outpatient visits and medications) but types and levels of "quality of life" support services enabling consumers to remain healthy and in medical care may be more diverse and utilized at higher rates.

EMA-wide, the percent of people with AIDS has been decreasing and percent with HIV increasing to equal or exceed those with AIDS. Two exceptions are in 2002 when reporting definitions were changed and in 2008 due to a statistical anomaly. From 2002-2007 the percent of people with HIV (not AIDS) increased. We are awaiting additional data for 2009 to discern current trends. See Figure B.

By **county/region**, Union County and Morris/Sussex/Warren region have much higher percent of people with AIDS (57% and 52%) than Essex (49%). Figure C. They must assess their access to HIV medical care.

Figure B: Trends in HIV ands AIDS in Newark EMA – 1999 – 6/2009

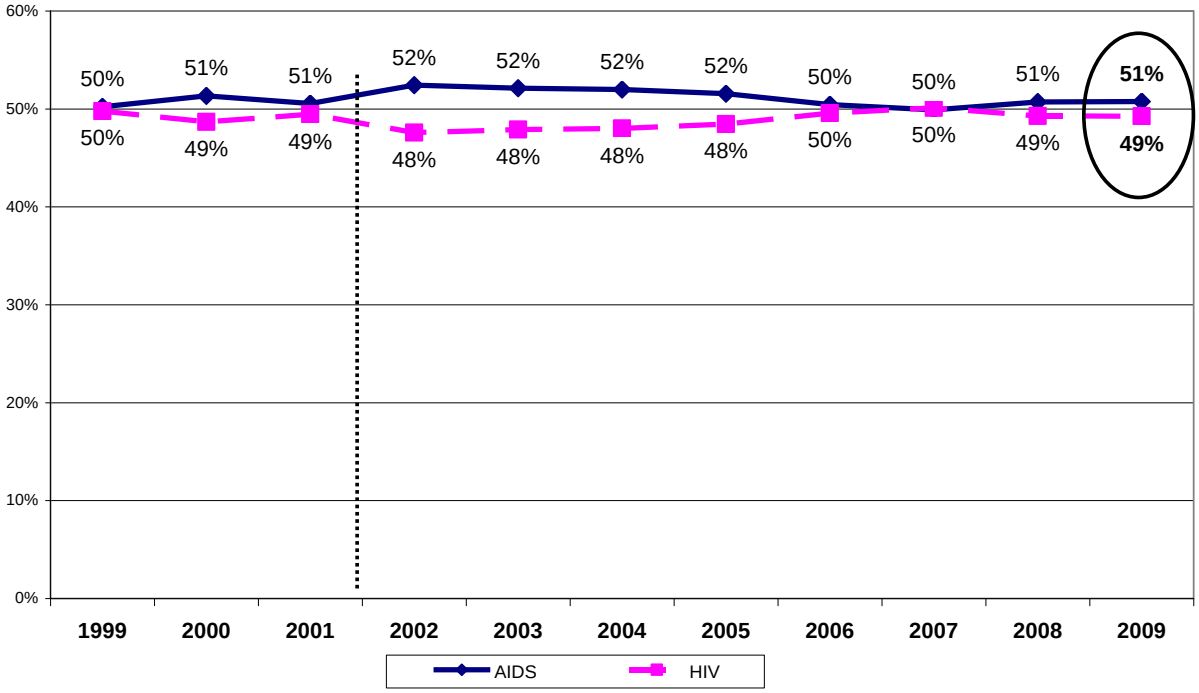
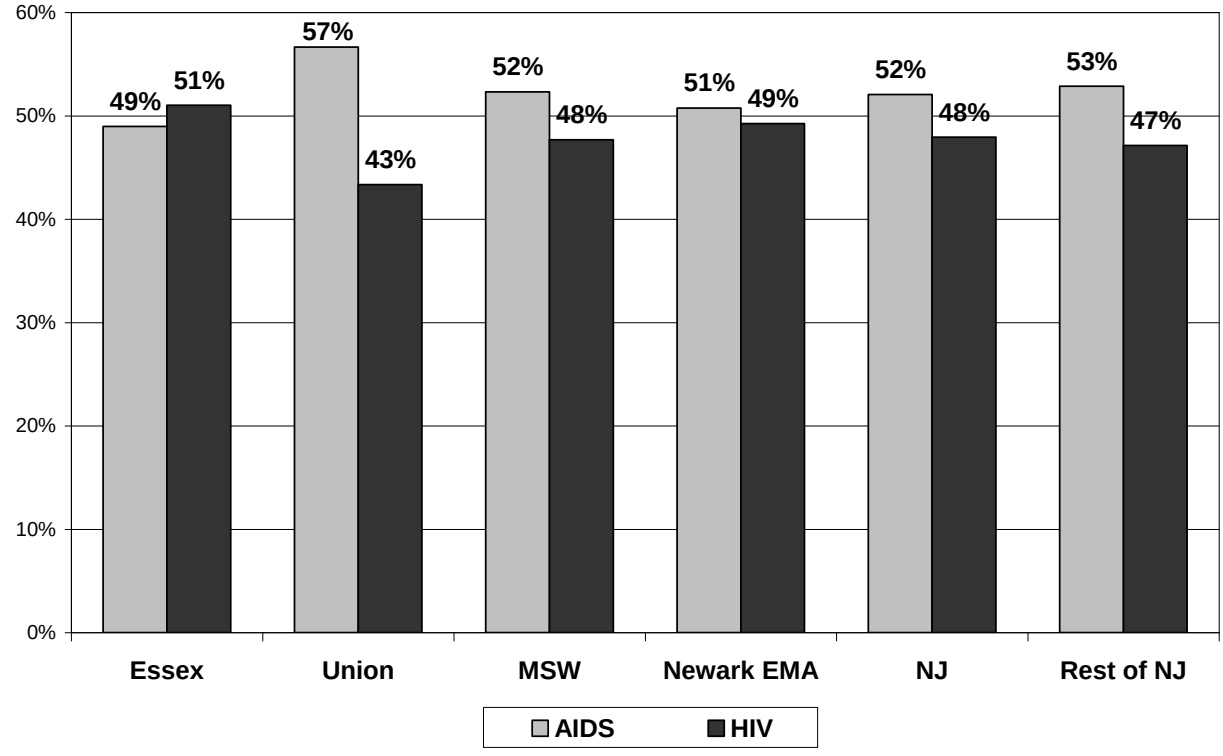


Figure C: HIV vs. AIDS in Counties, EMA, NJ – 6/2009



1.1.2 Gender

Of the total PLWHA, 60% or 7,903 were male and 40% or 5,206 were female. This reflects the same distribution as 2008. The epidemic among women in the Newark EMA directly affects the corresponding statewide epidemic. The percent of female PLWHA in New Jersey including the Newark EMA is 35.2%, but in the rest of New Jersey without the Newark EMA the percent of HIV+ women drops to 32.9% of cases. Within the Newark EMA, the highest percent of female PLWHA (41.7%) reside in Essex County, followed by Union County (35.6%) and Sussex County (35.0%). The lowest percent of female PLWHA reside in Warren County (31.4%) and Morris County (30.1%). See Table 2 and Figure D.

Table 2: PLWHA as of June 30, 2009 - Gender - Newark EMA & NJ

	Number			Percent		
County	**Male**	**Female**	**Total**	**Male**	**Female**	**Total**
Essex	5,561	3,978	9,539	58.3%	41.7%	100.0%
Morris	485	209	694	69.9%	30.1%	100.0%
Sussex	91	49	140	65.0%	35.0%	100.0%
Union	1,685	933	2,618	64.4%	35.6%	100.0%
Warren	81	37	118	68.6%	31.4%	100.0%
NEMA	**7,903**	**5,206**	**13,109**	60.3%	39.7%	**100.0%**
NJ	22,485	12,227	34,712	64.8%	35.2%	100.0%
Rest of NJ	14,058	6,898	20,956	67.1%	32.9%	100.0%
NEMA/NJ	**35.1%**	**42.6%**	**37.8%**			

The distribution of PLWHA by gender has been the same in the EMA since 1999 – 60% male and 40% female. See Figure E. However, the differences have remained by county/region. The EMA must consider these differences in planning for services to ensure geographic by all populations.

Figure D: PLWHA by Gender within County, Newark EMA, NJ – 6/30/09

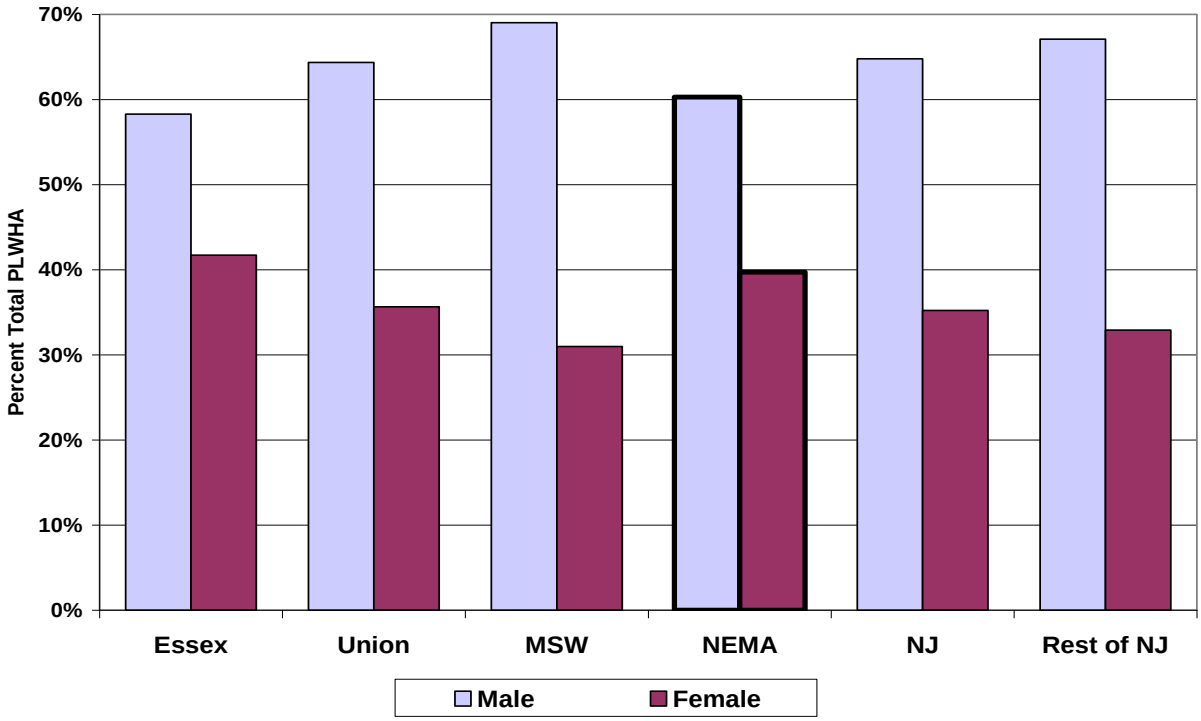
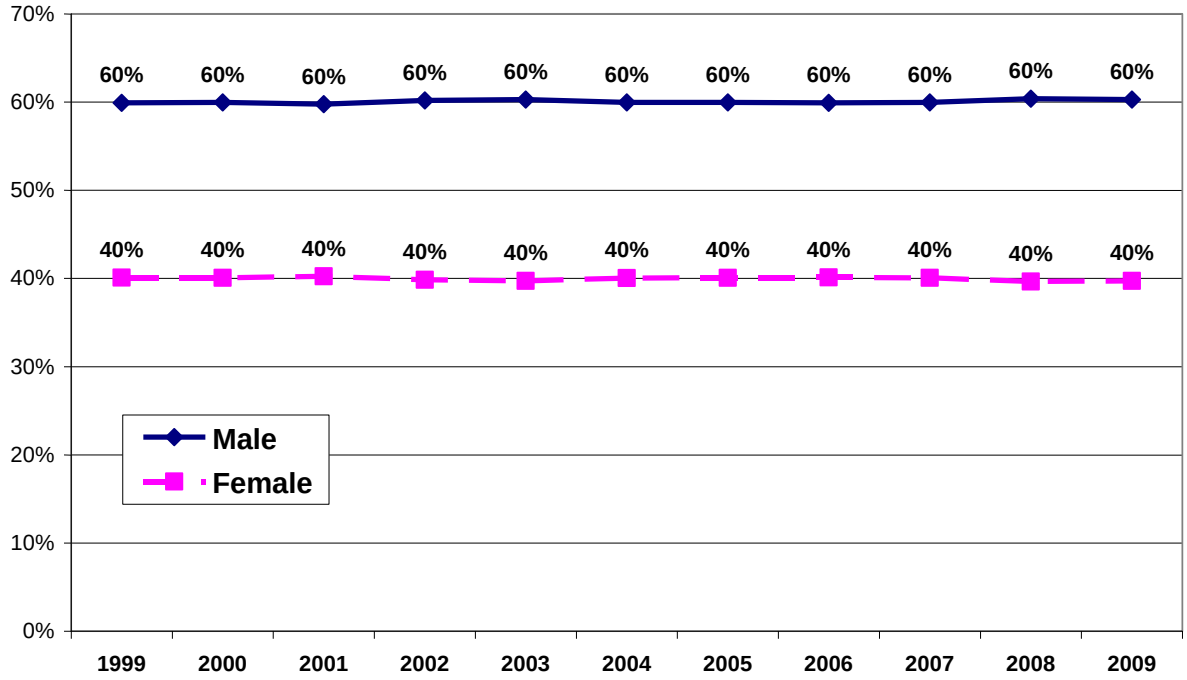


Figure E: Trends in PLWHA by Gender in Newark EMA, NJ – 1999 – 6/2009



1.1.3 Age

The highest number (4,988) and percent (38%) of PLWHA are age 45-54. The second highest age category is PLWHA age 35-44 (3,481 or 27%). The third highest category is individuals age 50 and older at 2,909 or 22%. PLWHA age 45 and older now comprise 60% of the HIV epidemic; this percentage is steadily increasing ever year. In contrast to the younger epidemic age 25-44 prior to development of antiretroviral therapy, now more people are being diagnosed later in life and are living longer with HIV disease due to life sustaining medications. They are "aging into" these older age categories following a diagnosis at a younger age. See Table 3 and Figure F.

County/Region. The distribution of PLWHA by age does not vary by county/region as seen in Figure G. This means that services throughout the EMA must address health needs of PLWHA of all ages, but particularly those age 45 and older. This means that Part A services throughout the EMA must address the needs of PLWHA regardless of age, or ensure access to these services.

Figure F: Distribution of PLWHA by Current Age in Newark EMA, 6/30/09

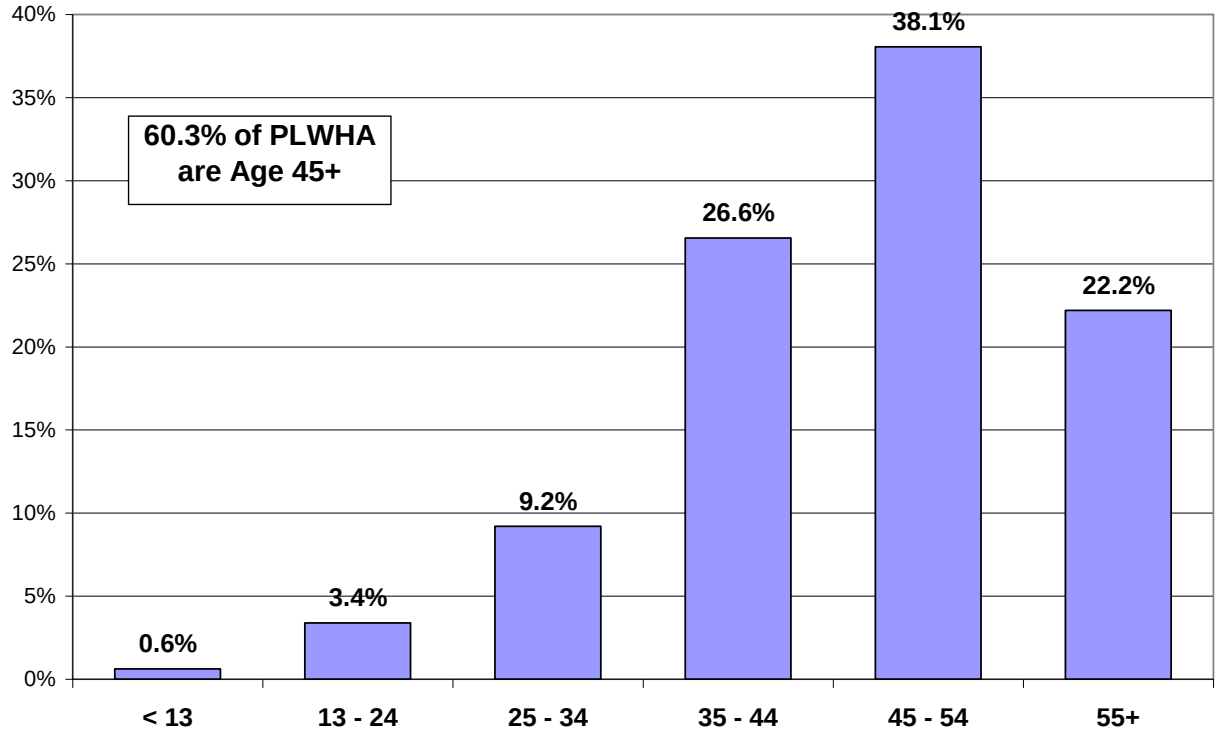
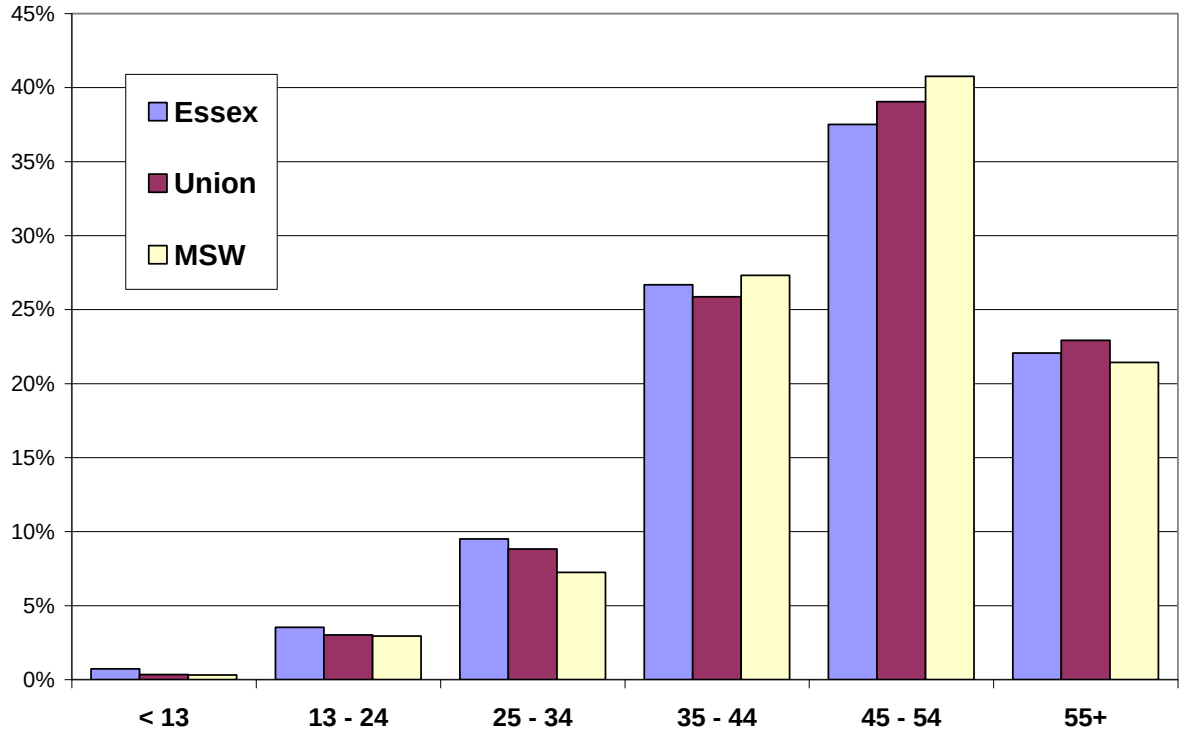


Figure G: PLWHA by Current Age by County/Region as of 6/30/09



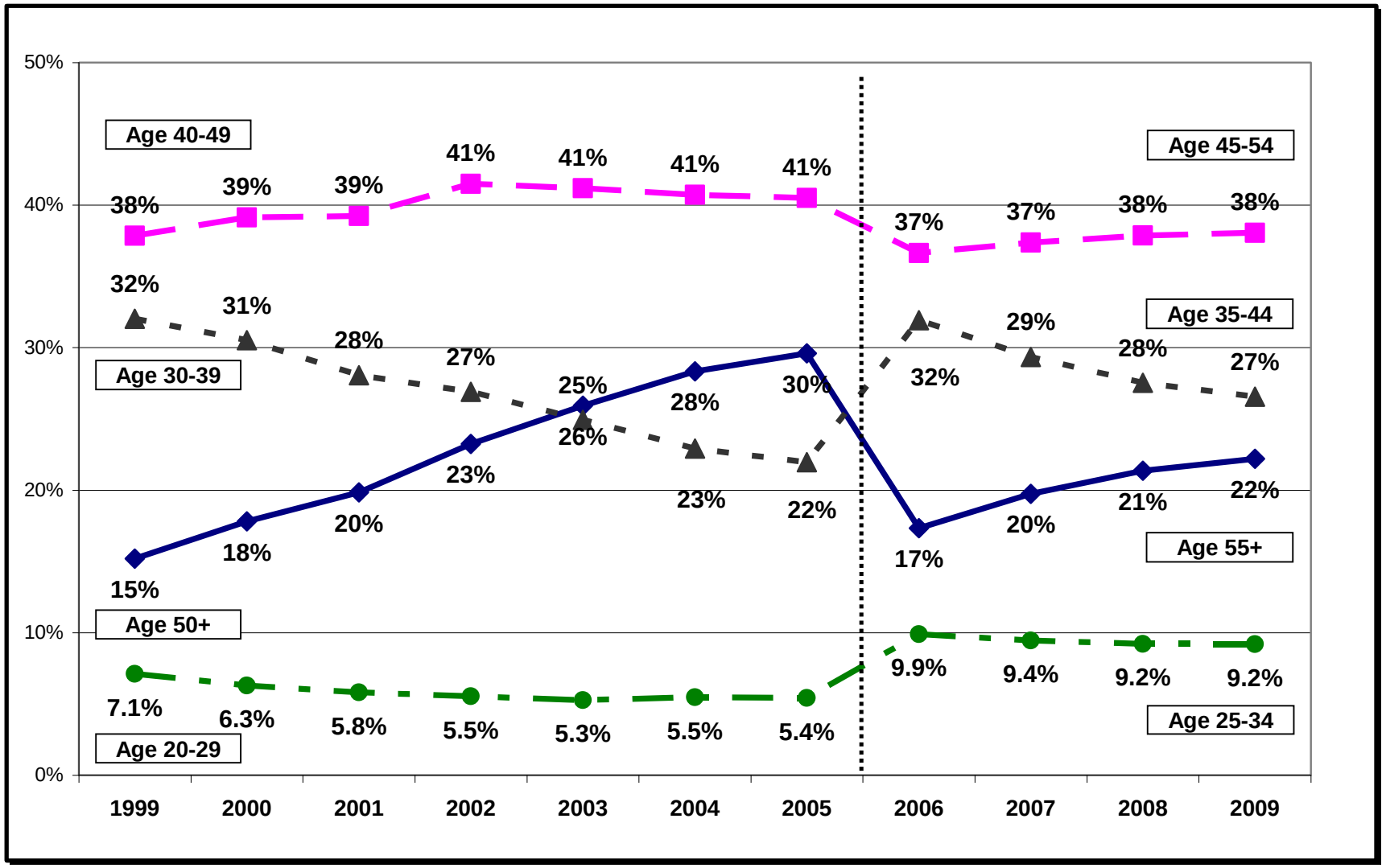
Trends in Age. Changes in the age of PLWHA over the past 10 years have been so dramatic that the age categories had to be redefined to reflect PLWHA living longer. See Figure H. People age 50 and older are the fastest growing population and doubled from 15% of PLWHA in 1999 to 31% of PLWHA in 2005. Those age 55 and older rose from 17% to 22% of PLWHA by 2009. Similarly, PLWHA age 40-49 and then 45-54 comprise 38% of PLWHA. Simultaneously, PLWHA age 30-39 and 35-44 have declined as a percent of total PLWHA. Less than 10% of PLWHA are age 25-34. The percent of PLWHA age 45 and older has risen from 54% in 2006 to 60% in mid-2009 with most increase occurring in the 55+ category.

Table 3: PLWHA by Age as of June 30, 2009 - Newark EMA & NJ

Age	Essex	Morris	Sussex	Union	Warren	NEMA	NJ	Rest of NJ	NEMA/NJ
< 13	69	1	1	9	1	81	160	141	50.6%
13-24	337	22	5	79	1	444	1,162	614	38.2%
25-34	906	47	8	231	14	1,206	3,206	1,971	37.6%
35-44	2,544	196	35	677	29	3,481	9,396	7,116	37.0%
45-54	3,578	277	64	1,022	47	4,988	13,647	7,952	36.6%
55+	2,105	151	27	600	26	2,909	7,141	3,162	40.7%
Total	**9,539**	**694**	**140**	**2,618**	**118**	**13,109**	**34,712**	**20,956**	**37.8%**
Age 45+	5,683	428	91	1,622	73	7,897	20,788	11,114	38.0%

Age	Essex	Morris	Sussex	Union	Warren	NEMA	NJ	Rest of NJ
< 13	0.7%	0.1%	0.7%	0.3%	0.8%	0.6%	0.5%	0.7%
13-24	3.5%	3.2%	3.6%	3.0%	0.8%	3.4%	3.3%	2.9%
25-34	9.5%	6.8%	5.7%	8.8%	11.9%	9.2%	9.2%	9.4%
35-44	26.7%	28.2%	25.0%	25.9%	24.6%	26.6%	27.1%	34.0%
45-54	37.5%	39.9%	45.7%	39.0%	39.8%	38.1%	39.3%	37.9%
55+	22.1%	21.8%	19.3%	22.9%	22.0%	22.2%	20.6%	15.1%
Total	**100.0%**	**100.0%**	**100.0%**	**100.0%**	**100.0%**	**100.0%**	**100.0%**	**100.0%**
Age 45+	59.6%	61.7%	65.0%	62.0%	61.9%	60.2%	59.9%	53.0%

Figure H: Trends in PLWHA Age Category in Newark EMA, 1999-6/2009



1.1.4 Race/Ethnicity

The EMA's HIV epidemic is comprised of mostly racial/ethnic minority populations (87%). Nearly three quarters of PLWHA (70% or 9,218) are Black/African American, Not Hispanic, 16% (2,085) are Hispanic/ Latino and 1% (162) other races. Only 13% (1,644) are White, Not Hispanic. By county/region, Essex PLWHA are predominantly African-American, Union County PLWHA are African American and Hispanic/Latino, and Morris/Sussex/Warren PLWHA are predominantly White Not Hispanic with pockets of HIV+ African Americans and Latinos. See Table 4 and Figure I.

The EMA's epidemic differs from the state which is 54% African American, 22% Hispanic, 22% White Not Hispanic and 2% Other. The rest of New Jersey outside the EMA is 45% African American, 28% White Not Hispanic, 26% Hispanic and 2% Other.

Nearly half (49%) of New Jersey's HIV+ African Americans reside in the Newark EMA, mostly in Essex County (40%). But the Newark EMA contains only 27% of the state's Hispanic/Latino PLWHA. Since 1999, African Americans have declined slightly as a percent of total PLWHA and Hispanics and Non-Hispanic Whites have increased slightly. See Figure J.

Table 4: PLWHA by Race/Ethnicity as of June 30, 2009 - Newark EMA and New Jersey

County	NonHispanic White	NonHispanic Black	Hispanic	Other	Total
	Number				
Essex	650	7,496	1,292	101	9,539
Morris	385	151	139	19	694
Sussex	103	22	13	2	140
Union	425	1,531	624	38	2,618
Warren	81	18	17	2	118
NEMA	**1,644**	**9,218**	**2,085**	**162**	**13,109**
NJ	7,643	18,890	7,616	563	34,712
Rest of NJ	5,871	9,430	5,271	384	20,956
NEMA/NJ	**21.5%**	**48.8%**	**27.4%**	**28.8%**	**37.8%**
	Percent Distribution within Area				
Essex	6.8%	78.6%	13.5%	1.1%	100.0%
Morris	55.5%	21.8%	20.0%	2.7%	100.0%
Sussex	73.6%	15.7%	9.3%	1.4%	100.0%
Union	16.2%	58.5%	23.8%	1.5%	100.0%
Warren	68.6%	15.3%	14.4%	1.7%	100.0%
NEMA	**12.5%**	**70.3%**	**15.9%**	**1.2%**	**100.0%**
NJ	22.0%	54.4%	21.9%	1.6%	100.0%
Rest of NJ	28.0%	45.0%	25.2%	1.8%	100.0%

Figure I: PLWHA by Race/Ethnicity by County, EMA, NJ – 6/30/09

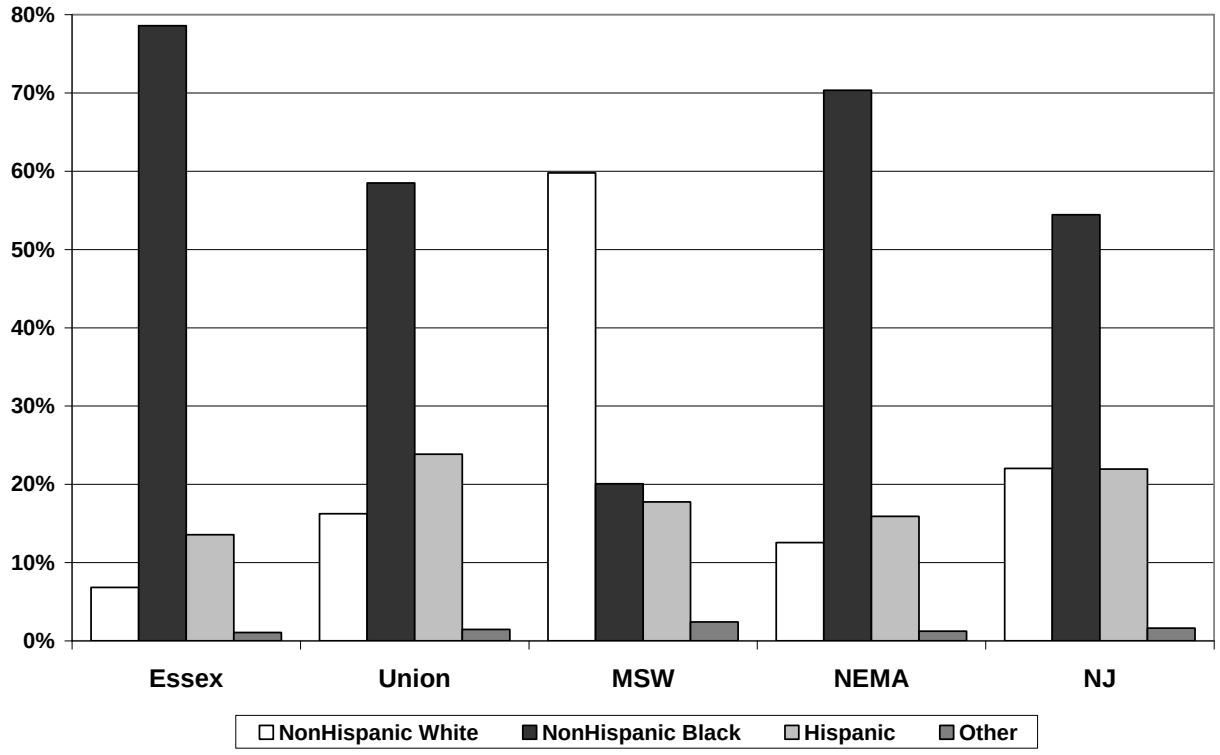
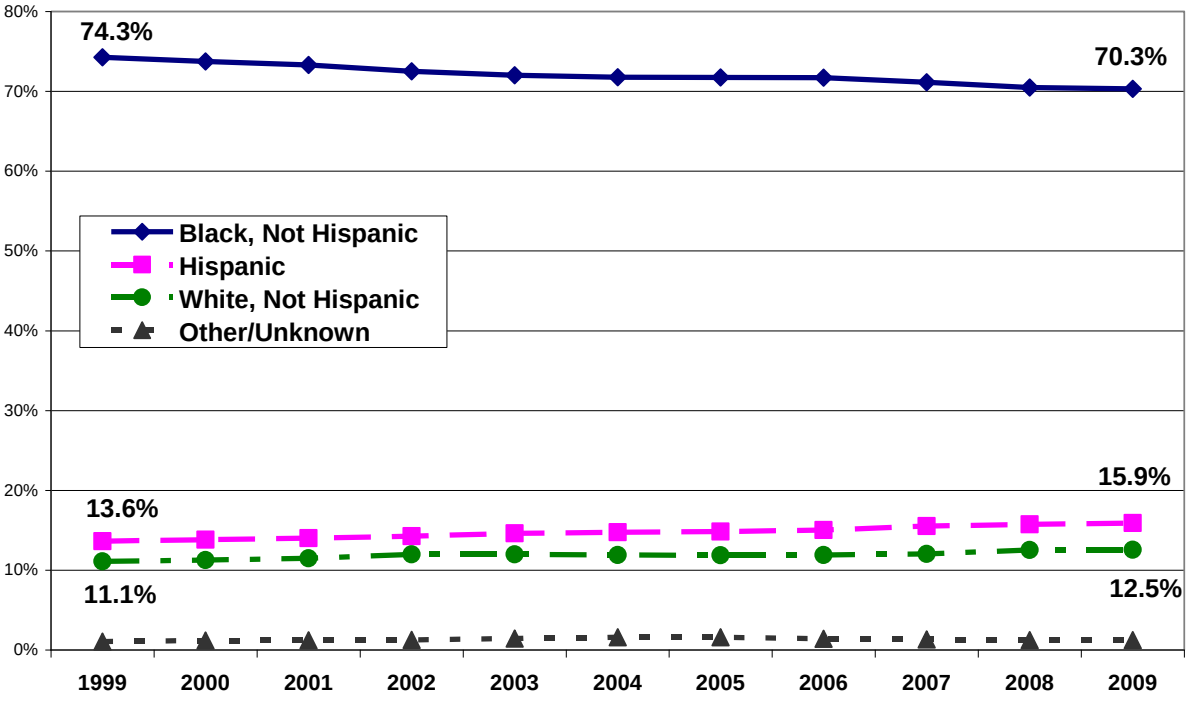


Figure J: Trends in PLWHA by Race/Ethnicity in Newark EMA, 1999- 6/30/09



1.1.5 Exposure/Transmission Category

Exposure category (also called mode of transmission) is presented for all PLWHA regardless of age (no separate Pediatric category). Effective for December 31, 2005, transmission categories were revised slightly by NJDHSS/DHAS, which resulted in changes to historical understanding of the EMA's epidemic. The most significant change was that Heterosexual contact replaced Injection Drug Use (IDU) as the leading transmission mode for HIV. IDU has been declining ever since, but this may be due to factors related to the drug trade and not classification.

As of June 30, 2009, Heterosexual transmission remains the leading cause of HIV infection in the Newark EMA, at 44% of PLWHA, followed by IDU at 24% and Men who have Sex with Men (MSM) at 16%. MSM/IDU is the fourth exposure category at 2% of all HIV infection. The "Other Risk or Unknown Risk" category reflects individuals who do not report the cause of their HIV infection, and accounts for 14% of PLWHA. See Table 5. Figure K shows trends in HIV exposure from 1999 through 2009 and the continuing decline of IDU as a mode of HIV transmission.

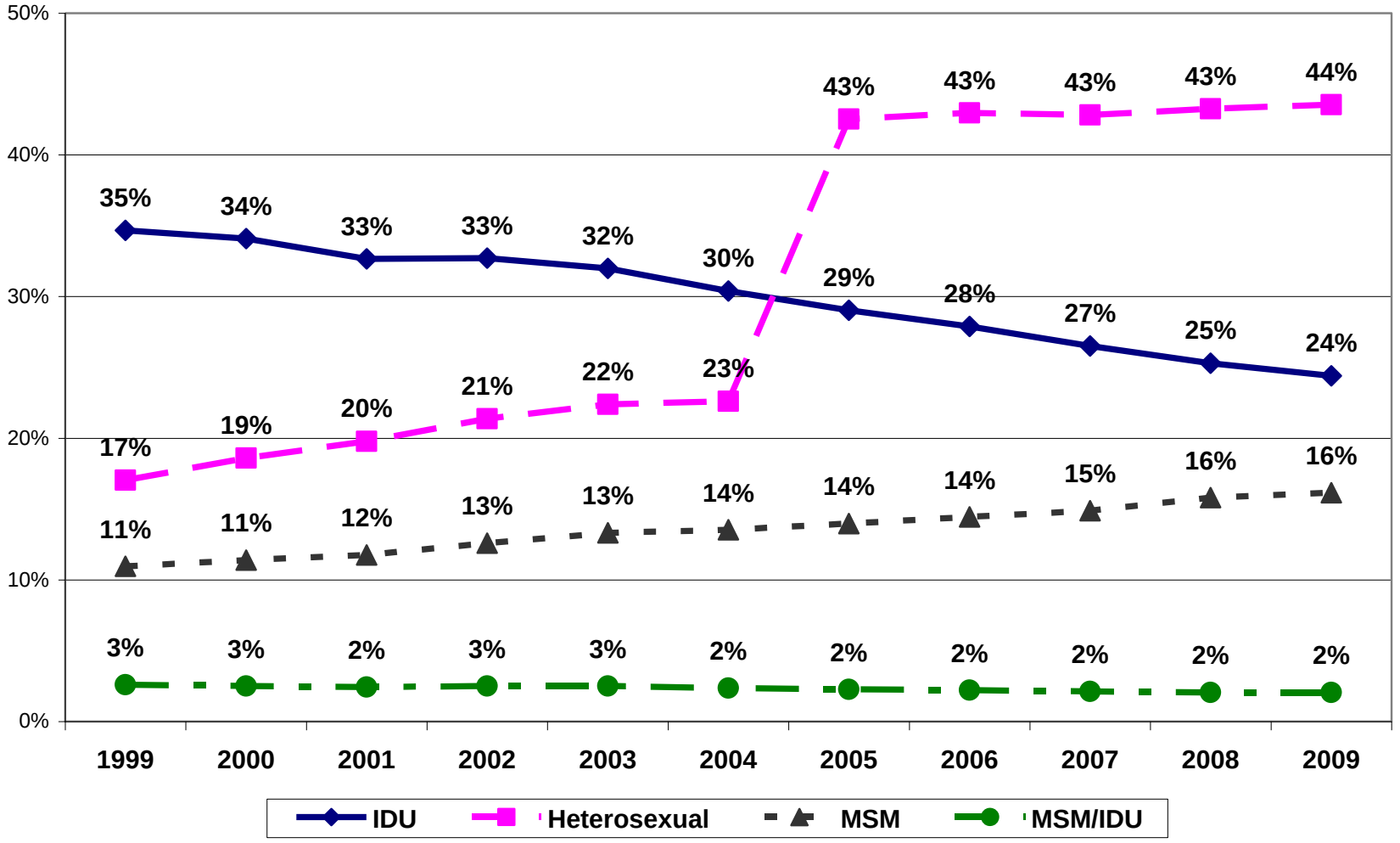
Heterosexual transmission is now the leading cause of HIV infection for the rest of New Jersey as well (37%), followed by IDU (28%) and MSM (23%). MSM/IDU is fourth at 3% of HIV.

Within New Jersey, the Newark EMA accounts for more than its proportionate share of heterosexual transmission (41% of NJ HIV), proportionate share of IDU (37%), but less than its proportionate share of MSM (29%).

Table 5: PLWHA by Exposure Category as of June 30, 2009–- Newark EMA & NJ

	Essex	Morris	Sussex	Union	Warren	NEMA	NJ	Rest of NJ	NEMA/NJ
Adult/Adolescent Exposure Categories									
	Number								
MSM	1,323	212	37	516	29	**2,117**	7,278	5,161	29.1%
IDU	2,458	139	20	552	29	**3,198**	8,585	5,387	37.3%
MSM/IDU	199	18	1	48	2	**268**	806	538	33.3%
Heterosexual	4,236	223	52	1,157	39	**5,707**	13,856	8,149	41.2%
Other/Unknown	1,323	102	30	345	19	**1,819**	4,187	2,368	43.4%
Total	**9,539**	**694**	**140**	**2,618**	**118**	**13,109**	**34,712**	**21,603**	**37.8%**
					Percent				
MSM	13.9%	30.5%	26.4%	19.7%	24.6%	16.1%	21.0%	23.9%	
IDU	25.8%	20.0%	14.3%	21.1%	24.6%	24.4%	24.7%	24.9%	
MSM/IDU	2.1%	2.6%	0.7%	1.8%	1.7%	2.0%	2.3%	2.5%	
Heterosexual	44.4%	32.1%	37.1%	44.2%	33.1%	43.5%	39.9%	37.7%	
Other/Unknown	13.9%	14.7%	21.4%	13.2%	16.1%	13.9%	12.1%	11.0%	
Total	**100.0%**	**100.0%**	**100.0%**	**100.0%**	**100.0%**	**100.0%**	**100.0%**	**100.0%**	

Figure K: Trends in PLWHA Exposure Category in Newark EMA, 1999-6/2009



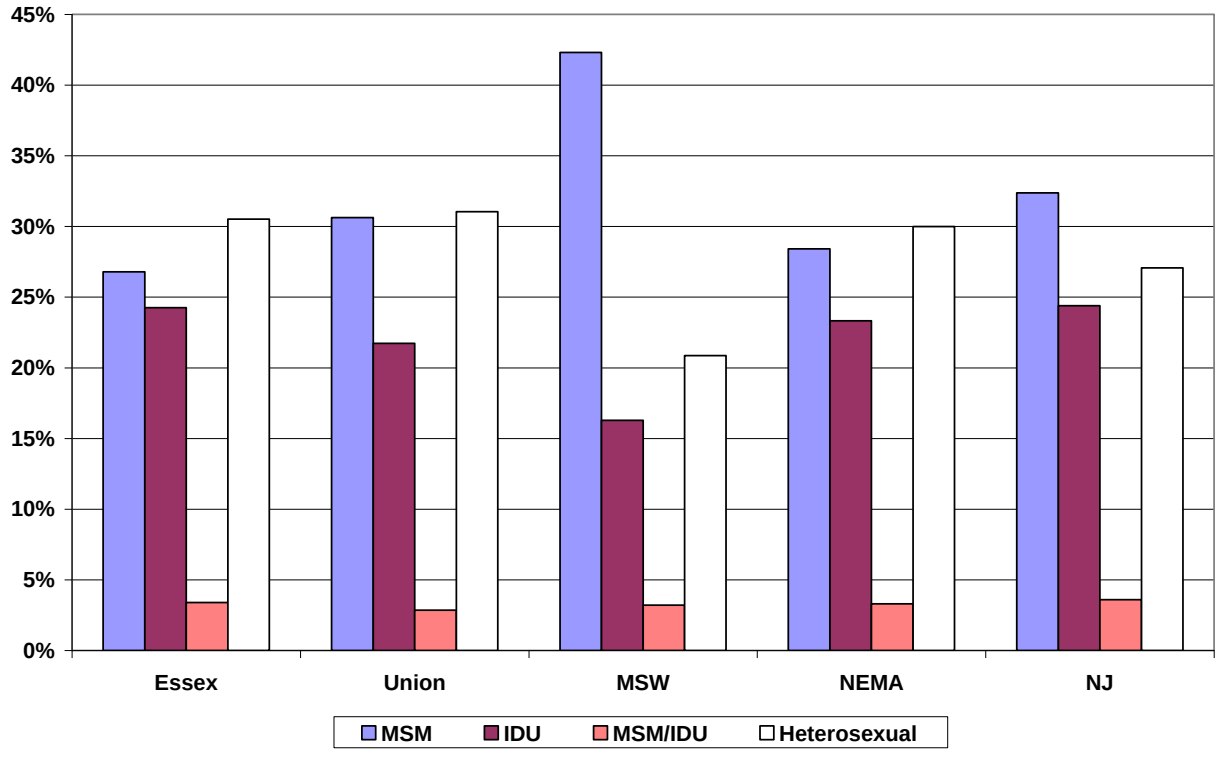
Exposure Category by Gender

Analysis of exposure category by gender shows differences within the EMA's counties, and the EMA compared to New Jersey.

Males. Among males, the leading exposure category for PLWHA as of 6/30/09 was heterosexual contact at 30% followed by MSM at 30% and IDU at 23% and MSM/IDU at 4%. MSM has been increasing over time as indicated in the Needs Assessment – 2009 Update. In the rest of New Jersey, MSM is the leading exposure category among males at 32%, followed by heterosexual contract at 27% and IDU at 24%. IDU is a declining cause of HIV transmission in the EMA and statewide. ("Other/Unreported" causes accounts for 13%-15% of male HIV disease.) See Figure L.

By county, male exposure differs. In Essex, heterosexual contact is the leading HIV exposure category at 31%, followed by MSM (27%) and IDU (24%). Union is similar but with heterosexual and MSM accounting for 31% each and IDU at 22%. In the Morris, Sussex, Warren (MSW) region, MSM is the leading cause (42%) followed by heterosexual (21%) and IDU (16%).

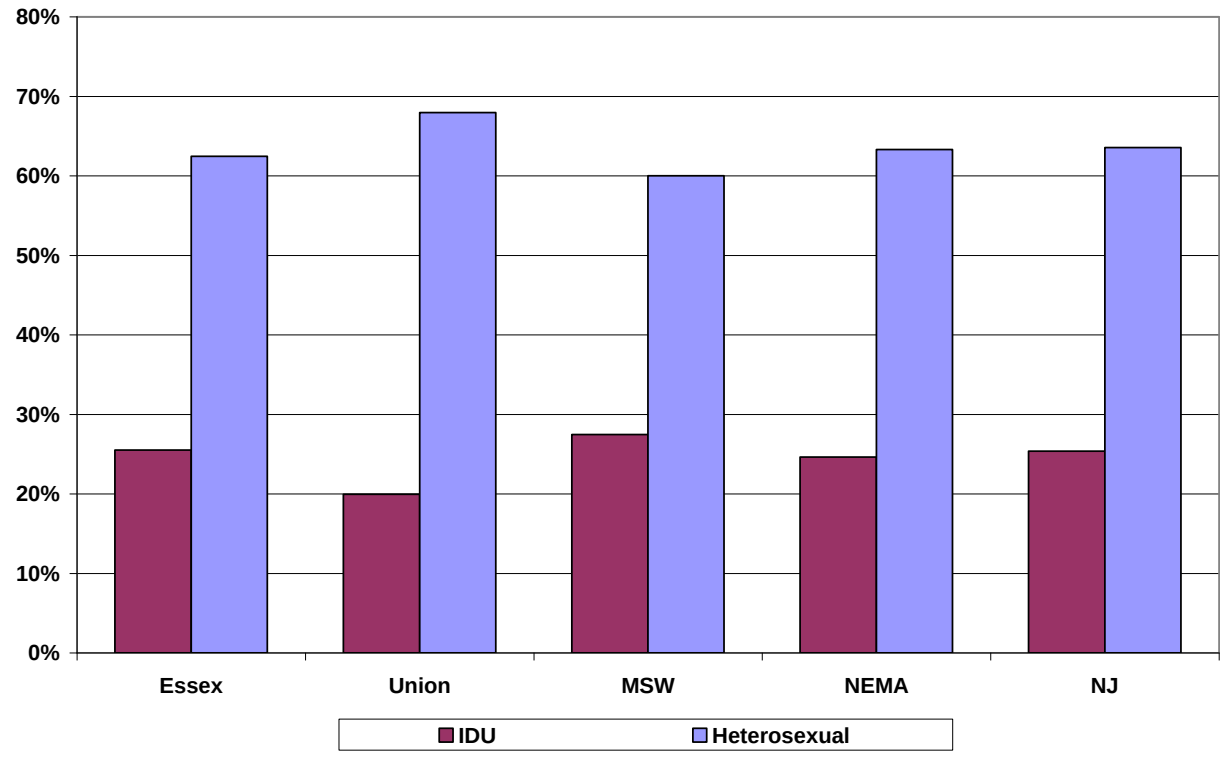
Figure L: Male PLWHA by Exposure Category (Excl Other) – Counties, Newark EMA, and NJ as of 6/30/09



Females. In contrast, exposure to HIV among females is the same in the EMA and the rest of New Jersey. Approximately 63% of HIV+ females in the Newark EMA were exposed by heterosexual contact and 25% by IDU (12% by "Not Reported/Other"). For the rest of New Jersey, the percents are 64% and 25%, respectively. See Figure M.

There are slight differences by county. In Essex and MSW region, 26%-27% of women reported IDU exposure compared to 20% in Union County.

Figure M: Female PLWHA by Exposure Category (Excl Other) – Counties, Newark EMA, NJ as of 6/30/09



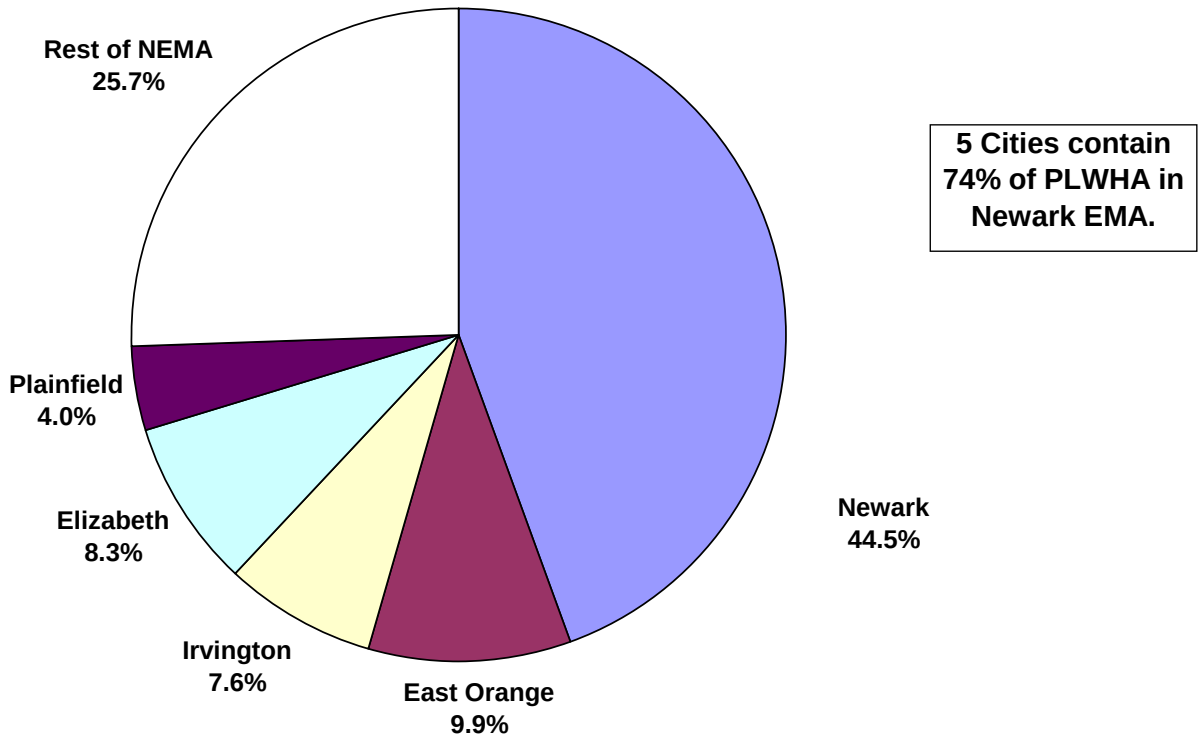
1.1.6 Geographical Distribution

In addition to county of residence, the Newark EMA HIV epidemic is further concentrated in its five largest cities – East Orange, Irvington and Newark in Essex County and Elizabeth and Plainfield in Union County. Three fourths of the EMA's PLWHA reside in these five cities. With 5,837 PLWHA, Newark accounts for 45% of PLWHA in the EMA and 17% of PLWHA in New Jersey. See Table 6 and Figure N.

Table 6: PLWHA as of June 30, 2009 - 5 Cities, Newark EMA and NJ

	#			%		Distn in	% 5 Cities of	
City	**AIDS**	**HIV**	**Total**	**AIDS**	**HIV**	**5 Cities**	**NEMA**	**NJ**
East Orange	666	638	1,304	51.1%	48.9%	13.4%	9.9%	3.8%
Elizabeth	618	475	1,093	56.5%	43.5%	11.2%	8.3%	3.1%
Irvington	470	521	991	47.4%	52.6%	10.2%	7.6%	2.9%
Newark	2,810	3,027	5,837	48.1%	51.9%	59.9%	44.5%	16.8%
Plainfield	305	213	518	58.9%	41.1%	5.3%	4.0%	1.5%
Total 5 Cities	**4,869**	**4,874**	**9,743**	**50.0%**	**50.0%**	**100.0%**	**74.3%**	**28.1%**
NEMA	**6,653**	**6,456**	**13,109**	50.8%	49.2%			
Rest of NEMA	1,784	1,582	**3,366**	53.0%	47.0%			
NJ	18,075	16,637	**34,712**	52.1%	47.9%			
Cities/NEMA	**73.2%**	**75.5%**	**74.3%**					

Figure N: PLWHA by 5 Cities in Newark EMA – 6/30/09



1.1.7 Disproportionate Impact

Disproportionate impact means that the HIV/AIDS epidemic affects the total population of the Newark EMA or subpopulations within the EMA at proportions or percent which are greater than the percent of the total general population. Disproportionate impact is important because it indicates where the HIV/AIDS epidemic is affecting residents more seriously.

The following areas indicate a disproportionate impact of HIV/AIDS in the Newark EMA.

- The entire Newark EMA is disproportionately impacted by the HIV epidemic – with 38% of the state's PLWHA, but only 24% of New Jersey's total residents.
    - Among counties in the EMA, Essex County is most impacted with 72% of PLWHA but only 39% of the EMA's general population.
    - All five cities are disproportionately impacted with 74% of PLWHA, but only 28% of the EMA's total residents. However, Newark bears the greatest burden with 45% of the EMA's PLWHA but only 13% of its population, and 17% of New Jersey's PLWHA but only 3% of the state's population.
- Women in the Newark EMA are most affected by HIV, at 40% of PLWHA. As of December 31, 2007 (most recent data available), the U.S. Centers for Disease Control and Prevention (CDC) reported that the Newark EMA contains the highest percent of women living with HIV/AIDS (37.11%) and second highest percent (40.96%) of women, infants, children and youth living with HIV/AIDS among the 56 EMAs/TGAs in the United States.[2]
    - Women represent a higher proportion of the HIV epidemic in urban areas – Essex County (42%) and three cities of Irvington (46%), East Orange (45%) and Newark (42%).
- HIV disproportionately affects African Americans in the Newark EMA. African Americans account for 22% of the EMA's general population but 70% of its HIV.
- Exposure to HIV via heterosexual contact continues to increase disproportionately in the EMA compared to the rest of New Jersey. The increase is concentrated in the five large cities within the EMA, and Irvington has the highest percent.
- Children in the Newark EMA continue to be disproportionately affected by HIV – the EMA accounts for 51% of New Jersey's PLWHA under age 13.

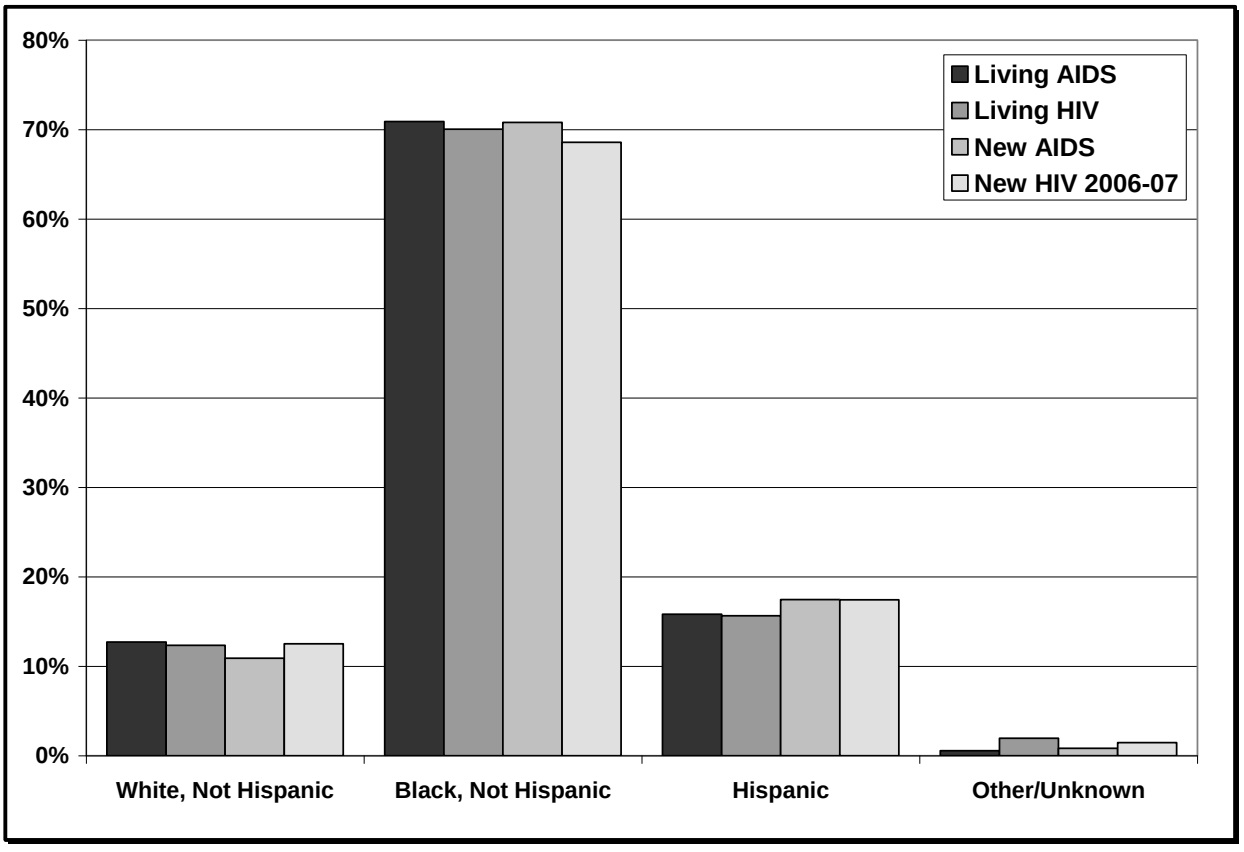
[2] Centers for Disease Control and Prevention. CDC. As of 12/31/07, the Newark EMA ranked #2 among the 56 EMAs/TGAs with 40.96% of WICY living with HIV/AIDS. (Data provided by HRSA/HAB for the FY 2010 Part A application.)

1.2 New Diagnoses - HIV versus AIDS

Examining new diagnoses of HIV disease – HIV (not AIDS) and AIDS - by gender, age, race/ethnicity and exposure category indicates if and where the disease is spreading and among which subpopulations. Diagnosis of HIV (not AIDS) indicates that the disease has been caught early, possibly due to effectiveness of prevention and early intervention efforts. In contrast, diagnoses of AIDS indicates later stages of the disease and a possible gap in counseling and testing and early intervention services. For purposes of this type of analysis, two years worth of surveillance data on new diagnoses are used to overcome lags in reporting of testing data, and to obtain higher numbers and a better picture of trends. Figure O through Figure S below compare people newly diagnosed with AIDS from January 1, 2007 through December 31, 2008 and HIV (not AIDS) from January 1, 2006 through December 31, 2007[3] with existing cases of HIV and AIDS (PLWHA) as of June 30, 2009.

Race/Ethnicity. Figure O shows that the percent of people living with AIDS and HIV by race/ethnicity is roughly equal, so no population lacks access to care. However, a higher percent of NonHispanic Blacks have been newly diagnosed with AIDS compared to HIV. Likewise, a lower percent of NonHispanic Whites have been newly diagnosed with AIDS. More efforts should be made to ensure that African Americans are tested for HIV.

Figure O: Distribution of PLWHA as of 6/30/09 and New-Diagnoses of AIDS during 2007-2008 and HIV (not AIDS) during 2006-2007 in the Newark EMA – by Race/Ethnicity

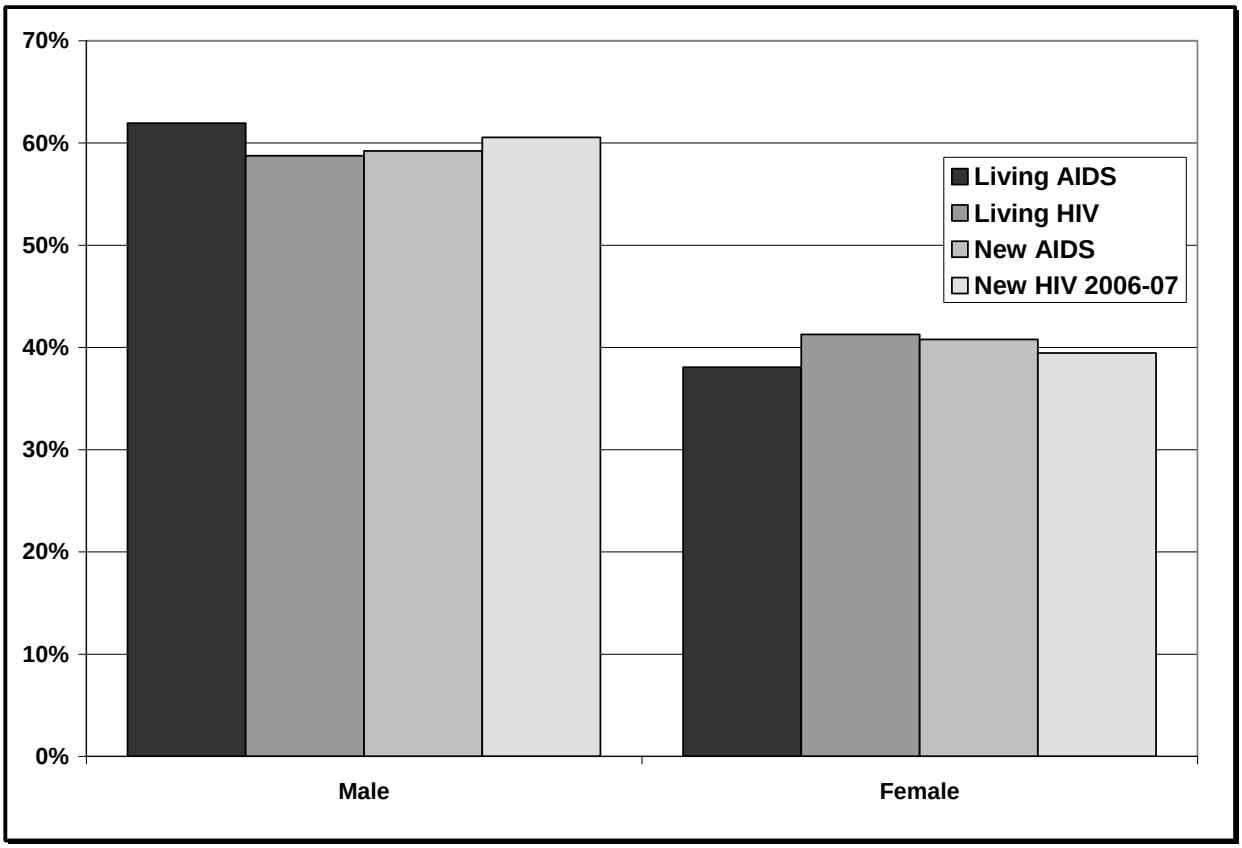


[3] Data for HIV incidence - new HIV (not AIDS) cases – covering the period January 1, 2007 through December 31, 2008 was not available from the NJDHSS, Division of HIV/AIDS Services.

1.2.1. Gender

Figure P shows that, by gender, a slightly higher percent of males are living with AIDS than HIV, so that a higher percent of females are living with HIV (not AIDS). Males and females are newly diagnosed with AIDS and HIV in the same proportions as their representation in the epidemic, indicating that both populations have access to early intervention services and HIV testing when they want to receive it.

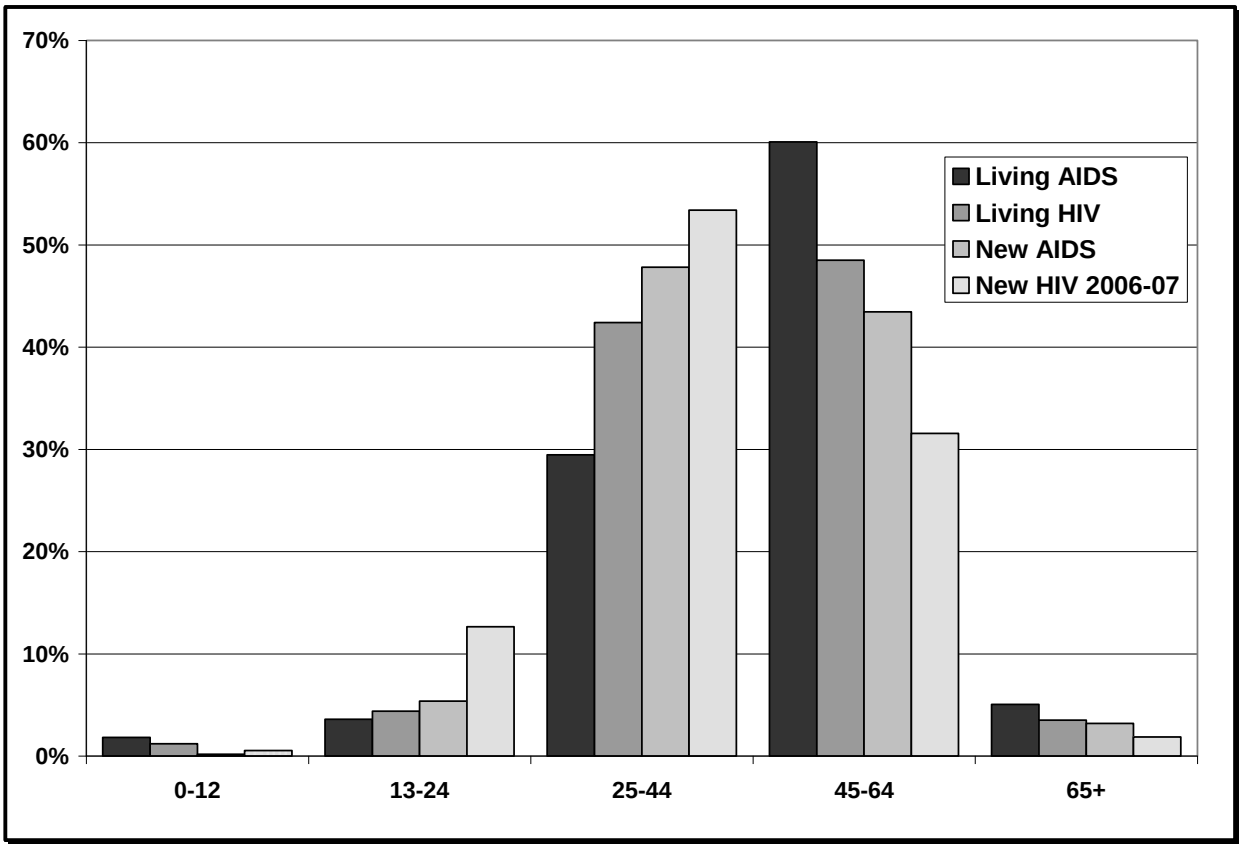
Figure P: Distribution of PLWHA as of 6/30/09 and New-Diagnoses of AIDS during 2007-2008 and HIV (not AIDS) during 2006-2007 in the Newark EMA – by Gender



1.2.2 Age

Figure Q shows differences by age among people living with HIV and AIDS and those newly diagnosed. Among individuals under age 24, twice as many are living with HIV than with AIDS. Among this group, a higher percent are diagnosed with HIV than with AIDS, indicating access to testing services. Among individuals age 25-44, a higher percent are living with HIV than AIDS. Individuals in this group are diagnosed equally as HIV (not AIDS) and AIDS. A higher percent of individuals age 45-64 are living with AIDS than HIV, indicating the course of the disease over time, presence of opportunistic infections, or drop in CD4. Consistent with PLWHA, more new diagnoses in this group are for AIDS than HIV. A slightly higher percent of individuals age 65 and older are living with AIDS versus HIV, continuing a trend seen in the previous age category and as people age into this category. New diagnoses are relatively equal between HIV and AIDS.

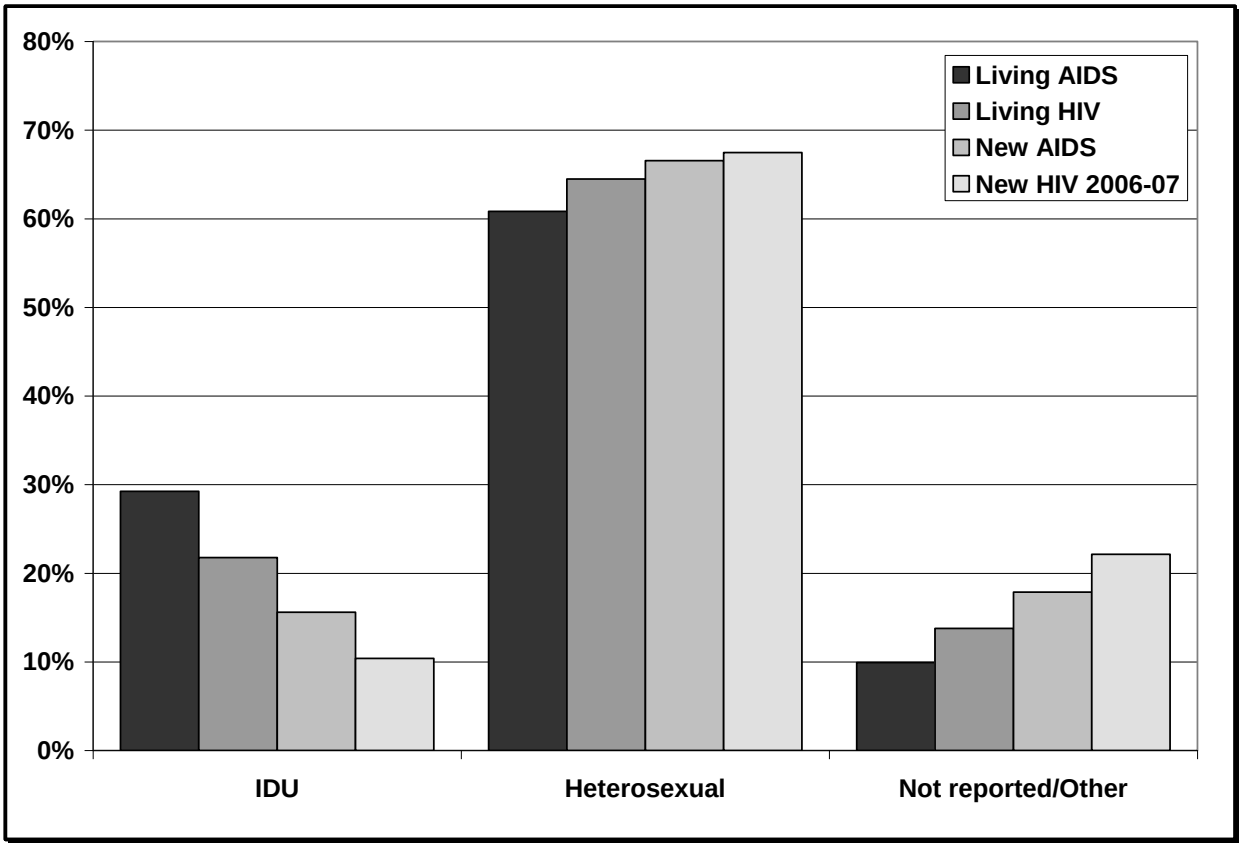
Figure Q: Distribution of PLWHA as of 6/30/09 and New-Diagnoses of AIDS during 2007-2008 and HIV (not AIDS) during 2006-2007 in the Newark EMA – by Current Age



1.2.3 Exposure Category - Female

Figure R shows how the epidemic is shifting, with a declining percent of females exposed to AIDS and HIV by injection drug use and an increasing percent exposed by heterosexual transmission. New diagnoses of AIDS among female IDUs are less then existing AIDS among females, and new diagnoses of HIV among female IDUs are even lower. Rates are increasing for heterosexual transmission.

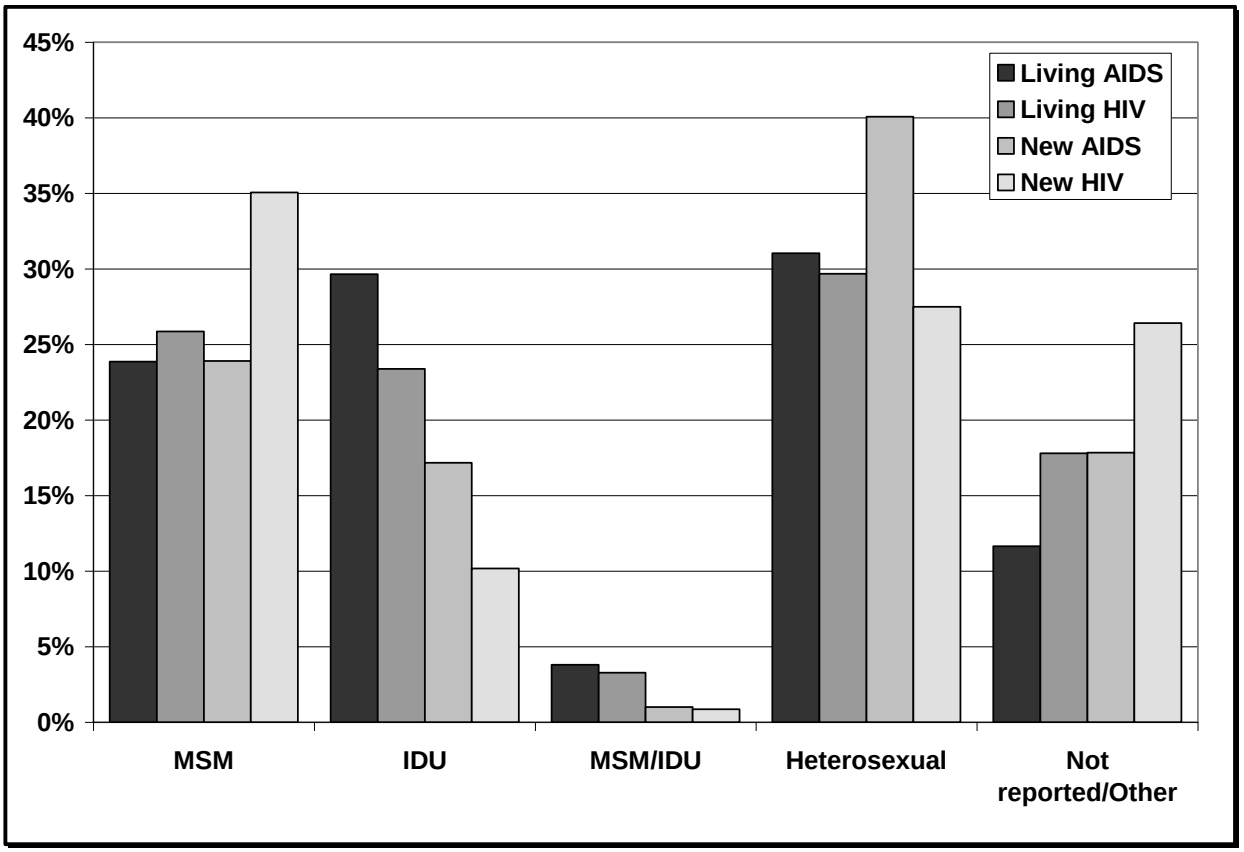
Figure R: Distribution of Female PLWHA as of 6/30/09 and New-Diagnoses of AIDS during 2007-2008 and HIV (not AIDS) during 2006-2007 in the Newark EMA – by Female Exposure Category



1.2.4 Exposure Category - Male

Figure S shows how the epidemic among males is caused by sexual transmission and is shifting back to MSM. The percent of men living with HIV or AIDS who were exposed by MSM is approximately 23%-25%, but MSM accounted for the most (35%) new diagnoses of HIV. Similarly, heterosexual transmission accounts for 30% of males living with HIV or AIDS, but 40% of new AIDS diagnoses among men. Likewise, IDU is declining as a source of HIV infection among men. New diagnoses of AIDS and HIV among male IDUs is much less than the percent of male PLWHA exposed by IDU. The declining impact of IDU is confirmed by new diagnoses among MSM/IDUs.

Figure S: Distribution of Male PLWHA as of 6/30/09 and New-Diagnoses of AIDS during 2007-2008 and HIV (not AIDS) during 2006-2007 in the Newark EMA – by Male Exposure Category



1.3 HIV/AIDS Prevalence

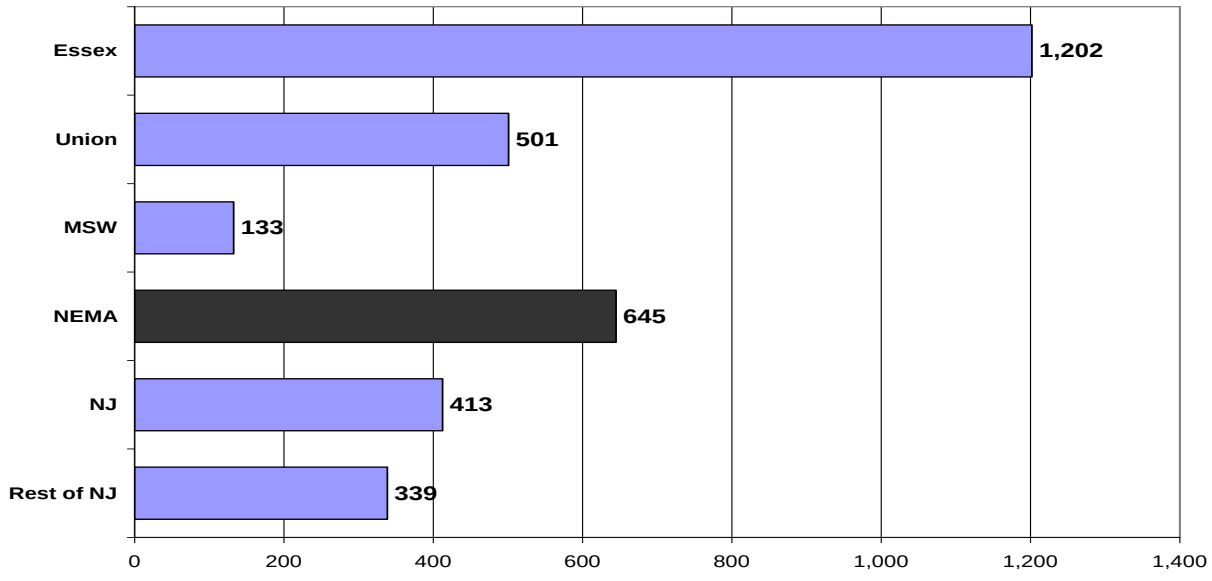
Prevalence of HIV disease, or number of PLWHA per 100,000 population, is another means of assessing the impact of HIV disease. It is computed by dividing PLWHA by the population, and can be adapted to total populations and populations within a geographical area. **Prevalence rates can be converted easily to percentages – prevalence of 1,000 per 100,000 means that 1% of population has HIV/AIDS.**

As of June 30, 2009, HIV prevalence in the Newark EMA is 645 PLWHA per 100,000 population, or nearly twice as high as the rest of New Jersey with a rate of 339 per 100,000 population. HIV prevalence is highest in Essex County, at 1,202 PLWHA per 100,000 population, nearly three times as high as the next county, Union at 501 PLWHA per 100,000 population. The remaining three counties have much lower HIV prevalence rates, with PLWHA spread out over larger geographical areas, which present additional challenges in ensuring access to medical care and other services. See Table 7 and Figure T.

Table 7: HIV/AIDS Prevalence as of 6/30/09 - Newark EMA and NJ

HIV/AIDS Prevalence Rates (per 100,000 population) as of 6/30/09					
	NonHispanic White	NonHispanic Black	Hispanic	Other	Total
Essex	213	2,283	1,056	266	1,202
Morris	99	1,194	380	60	148
Sussex	76	1,501	270	93	97
Union	148	1,422	606	160	501
Warren	85	953	453	124	115
NEMA	136	2,039	771	166	645
Rest of NJ	136	1,450	653	90	339
NJ	136	1,688	682	103	413

Figure T: HIV/AIDS Prevalence in Counties, Newark EMA, NJ as of June 30, 2009



1.3.1 Impact by Race/Ethnicity

African Americans are affected by HIV at extraordinary rates. Within the EMA, HIV prevalence of 2,039 NonHispanic Black PLWHA per 100,000 African American residents is three times greater than the EMA-wide rate for all residents. HIV prevalence among Blacks in Essex County is the highest, at 2,283 per 100,000, followed by Sussex County at 1,501 per 100,000 and Union at 1,422 per 100,000. Figure U.

Hispanics are also disproportionately affected by HIV in the EMA. The EMA-wide rate of 771 Hispanic PLWHA per 100,000 Hispanics/Latinos, is higher than the rest of New Jersey at 653 per 100,000. Essex County also has the highest HIV prevalence rates among Latinos at 1,056 per 100,000 followed by Union at 606 per 100,000 Hispanics/Latinos.

The EMA's NonHispanic Whites are affected by HIV at the same rates as the rest of New Jersey at 136 PLWHA per 100,000 population.

Within the EMA's five cities, the impact of HIV described above is more dramatic. HIV prevalence for the total of the five cities is 1,702 per 100,000 residents, nearly three times as high as the EMA-wide rate, and eight times as high as the rest of the EMA. HIV prevalence rates for all racial and ethnic categories in the five cities (total) exceed those of the rest of the EMA. Table 13 and Figure V.

Table 8: HIV/AIDS Prevalence as of 6/30/09 – Five Largest Cities in Newark EMA

HIV/AIDS Prevalence Rates (per 100,000 population) as of 6/30/09					
	NonHispanic White	NonHispanic Black	Hispanic	Other	Total
East Orange	1,491	1,976	1,066	719	1,868
Elizabeth	367	2,325	740	198	907
Irvington	605	1,859	963	344	1,633
Newark	571	3,190	1,287	303	2,134
Plainfield	1,011	1,355	515	641	1,083
Total 5 Cities	**543**	**2,492**	**1,012**	**350**	**1,702**
Rest of EMA	106	1,107	419	102	230
NEMA	136	2,039	771	166	645

1.3.2 Comparison of Newark EMA and Counties/Regions

Appendix B contains additional figures comparing epidemiological data of the Newark EMA with that of the three counties/regions – Essex County, Union County, Morris/Sussex/Warren county region. Topics include HIV versus AIDS, gender, race/ethnicity, age, and exposure category (total, male and female).

Figure U: HIV/AIDS Prevalence by Race/Ethnicity and County within Newark EMA as of June 30, 2009 (Percent)

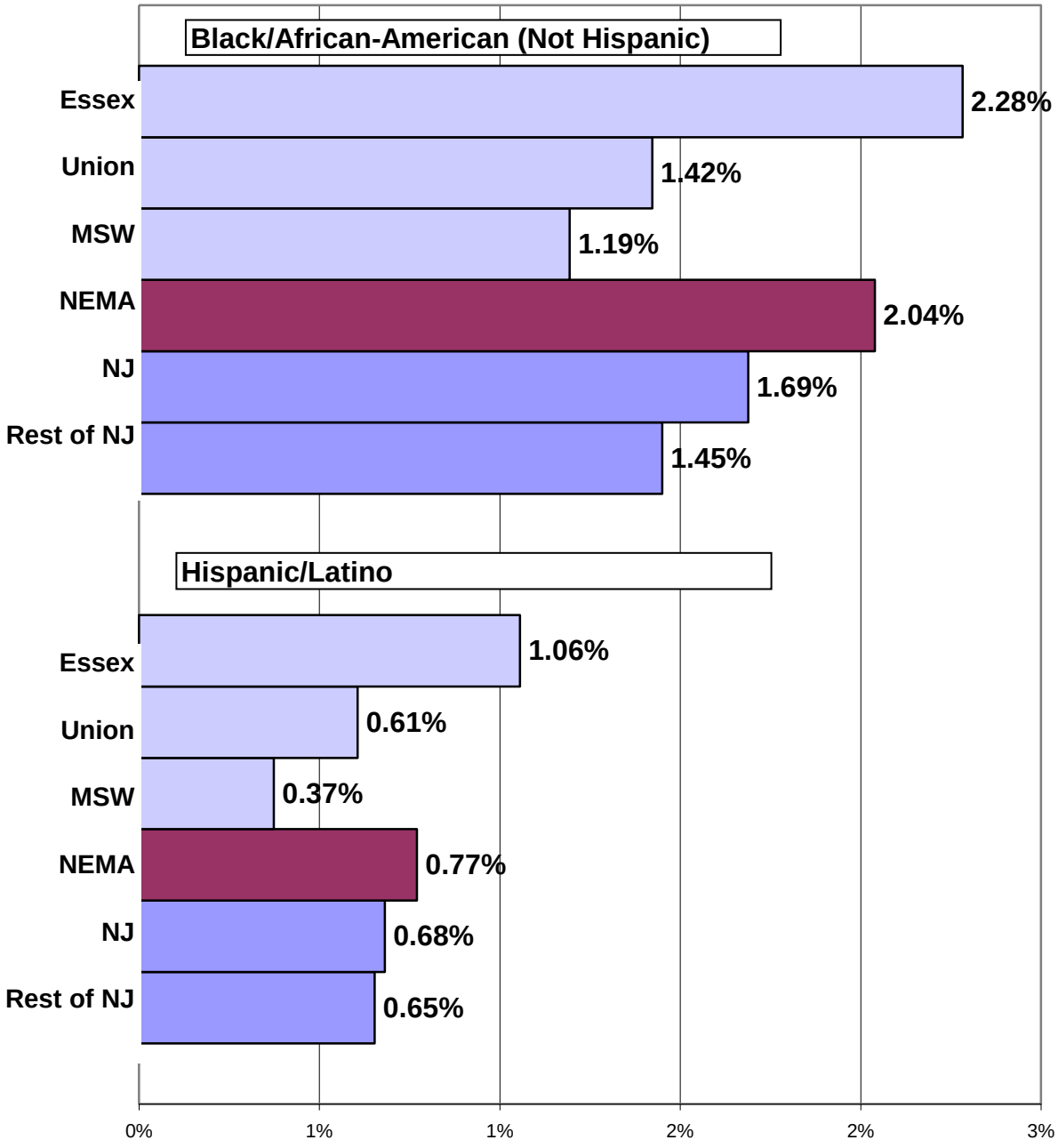
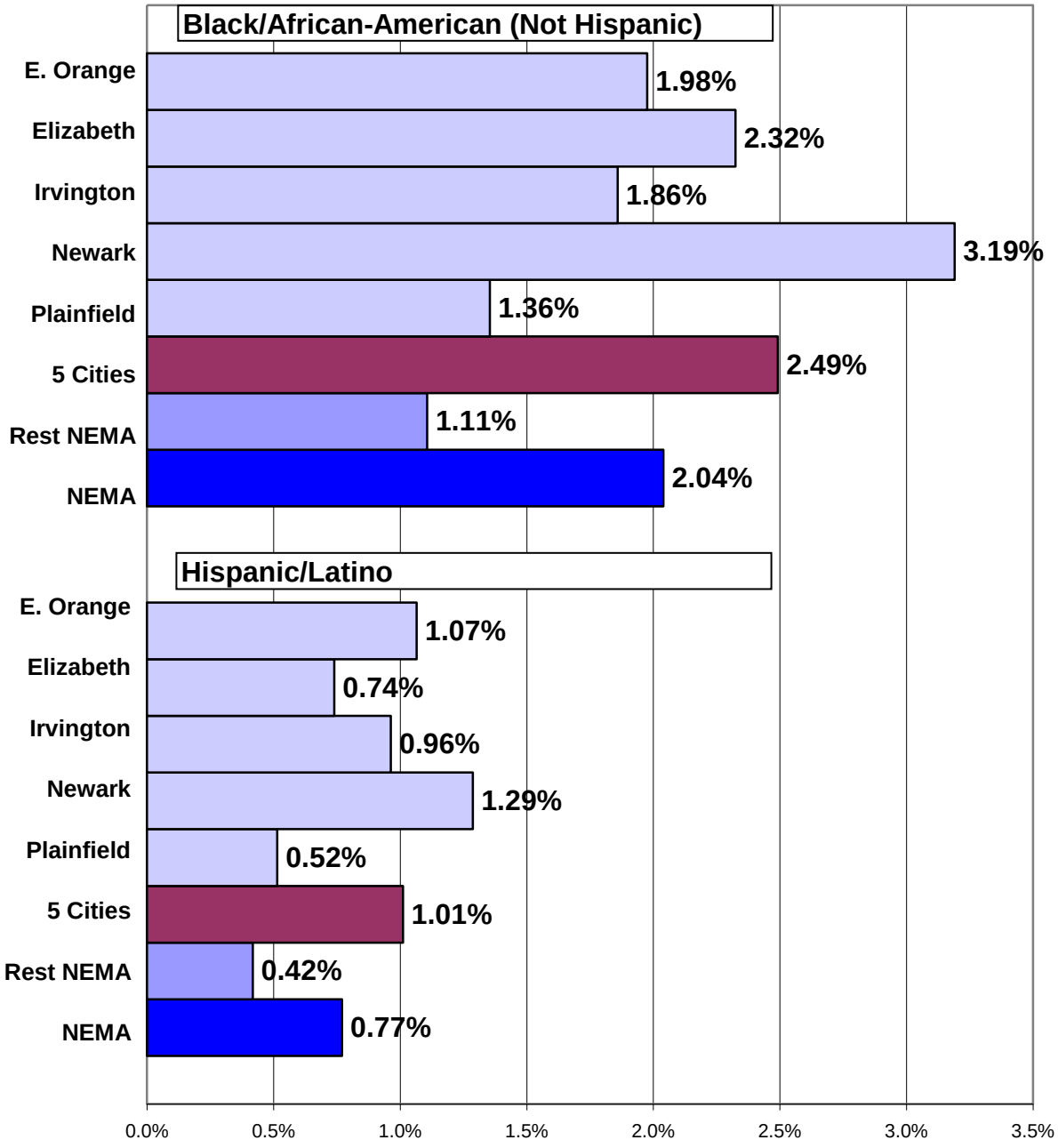


Figure V: HIV/AIDS Prevalence by Race/Ethnicity and City within Newark EMA as of June 30, 2009 (Percent)



PART 2: MENTAL HEALTH

2.1 Introduction

During 2008-2009 the Council and its committees recognized the impact of mental health problems on HIV medical care and treatment adherence to HIV medications and medical appointments. Consistent with the requirements of the federal Ryan White program, the Council decided to engage in an in-depth study of mental health issues facing PLWHA for the interim Needs Assessment – 2010 Update.

Research Question. The research question to be addressed is:

> **What is the extent of mental health problems among PLWHA in the Newark EMA, what services are needed to address these needs, what are the gaps in existing services, and do the Part A-funded services address those needs and gaps?**

2.2 Mental Health Issues and PLWHA

The issues related to mental health and people living with HIV/AIDS (PLWHA) were comprehensively reviewed in the May 2009 issue of HRSA CARE Action, "Mental Health Matters." [4] Excerpts from this newsletter have been copied into this section.

Substantial and consistent evidence has been found that chronic depression, stressful events, and trauma may negatively affect HIV disease progression. However, in approximately one-half of people living with HIV/AIDS who have depression, the depression is both undiagnosed and untreated. The HRSA Associate Administrator for HIV/AIDS underscored the need for mental health screening and treatment. "Tools such as the HRSA HAB Client Diagnostic Questionnaire (or SAMISS tool) can help detect potential signs of risk, such as social isolation and alcohol dependence. By closely monitoring patients at critical times, such as at the start of antiretroviral treatment, we can aid them at the onset of mental health issues. Because the sooner we see warning signs, the sooner we can act." However, "treatment regimens only go so far in treating mental illness—relationships matter, too. By providing support groups and strengthening patient– provider bonds, we can boost retention for people at risk, improving patients' bodies and minds in the process."

Diagnosis and treatment of mental health issues are essential to the physical health and quality of life of people living with HIV/AIDS (PLWHA). Psychiatric disorders are a barrier to medical care and adherence to medications, and several studies have found that depression, stress, and trauma can lead to disease progression and increased mortality. The power of mental health treatment to reduce depression and anxiety, improve adherence and HIV health outcomes and, in turn, reduce the likelihood of death from AIDS-related causes speaks to the vital role of mental health care in the web of HIV care.

[4] U.S. Department of Health and Human Services. Health Resources and Services Administration, HIV/AIDS Bureau. 5600 Fishers Lane, Room 7-05. Rockville, MD 20857. http://hab.hrsa.gov/publications/may2009/default.htm

The HIV Costs and Services Utilization Study (HCSUS) found that **nearly 50 percent of adults being treated for HIV also have symptoms of a psychiatric disorder—prevalence that is 4 to 8 times higher than in the general population.** Nineteen percent of patients studied showed signs of substance abuse, and 13 percent had co-occurring mental illness and substance abuse disorders.

A more recent study of more than 1,000 PLWHA in North Carolina found even higher rates: 60 percent of study participants reported symptoms of mental illness, 32 percent reported substance use problems, and nearly 25 percent identified both symptoms of mental illness and substance use problems.[5] High rates of depression and anxiety have been identified in PLWHA regardless of race, gender, or sexual orientation.

People with serious mental illness are particularly vulnerable to HIV infection as a result of the higher prevalence among this group of a variety of factors, including **poverty, homelessness, high risk sexual activities, drug abuse, sexual abuse, and social marginalization**.

Major depression is the most common mental health disorder among PLWHA; estimates are that about 60 percent of PLWHA will have a depressive episode at some time during their illness.[6] Strong evidence indicates that HIV infection is associated with greater risk of major depressive disorder, although a review of research also found that most PLWHA appear to be psychologically resilient.[7]

Finding People Who Need Support. Before PLWHA can be linked to the mental health care they need, those who have mental health issues must be identified. **Two screening tools developed specifically for PLWHA** are aimed at working efficiently in busy clinical or support service settings. These are

(1) The **HIV/AIDS Bureau's Client Diagnostic Questionnaire (CDQ)** developed through the Special Projects of National Significance (SPNS) Program for use in various service sites, including medical clinics, multiservice community organizations, and homeless shelters. The questionnaire, which takes 15 to 20 minutes to complete, can be administered by staff with no mental health training. It screens for depression, anxiety disorder, and psychosis as well as for alcohol and drug abuse or dependence. The tool yields a baseline assessment that indicates PLWHA who need either further assessment or direct referral to treatment by a clinician. Research on the CDQ's effectiveness found that it identified 90 percent of clients with clinically significant mental health needs.

(2) The **Substance Abuse and Mental Illness Symptoms Screener (SAMISS)**, a 16-question form which has proved its effectiveness as a **frontline screening tool**. The questions take less than 15

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[5] Whetten K, Reif S, Napravnik S, et al. Substance abuse and symptoms of mental illness among HIV-positive persons in the Southeast. *South Med J*. 2005;98:9–14.

[6] National Alliance of State and Territorial AIDS Directors. *Mental Health Issue Brief: HIV and mental health: the challenges of dual diagnosis*. July 2006. Available at: www.nastad.org/Docs/Public/ InFocus/200632_NASTAD_Mental_Health_final.pdf. Accessed June 19, 2010.

[7] Ciesla JA, Roberts JE. Meta-analysis of the relationship between HIV infection and risk for depressive disorders. *Am J Psychiatry*. 2001;158:725–30.

minutes to administer, so patients who screen positive are also advised to undergo a confirmatory psychiatric evaluation. It is available in English- and Spanish-language versions.

Data from the HCSUS also identified certain **characteristics** that may predict a greater likelihood of mental health issues. An analysis of a subsample from the HCSUS found that those most likely to screen positive for mental illness:

- Were under age 35,
- Lived alone or with a nonromantic partner,
- Were unemployed or disabled,
- Experienced more HIV-related symptoms, or
- Used illicit drugs other than marijuana.

Specific **triggers** that may lead to mental distress include the following:

- Learning of one's HIV-positive status;
- Disclosure of one's HIV status to family and friends;
- Introduction of medication;
- Occurrence of any physical illness;
- Recognition of new symptoms or progression of disease (e.g., a major drop in CD4 cells, an increase in viral load);
- Necessity of hospitalization (particularly the first hospitalization);
- Death of a significant other or anniversaries of loved ones' deaths;
- Holidays;
- Diagnosis of AIDS;
- Changes in major aspects of lifestyle (e.g., job loss, end of relationship, relocation);
- Need to make end-of-life and permanency planning decisions.

The **aging PLWHA population**, many of whom are long-term survivors, is a growing mental health concern. Age is closely linked to issues of isolation, which may be heightened by the loss of significant others and friends to HIV.

Recent research reflects the tremendous importance of identifying and treating depression in PLWHA. A retrospective study of more than 3,000 patients found strong evidence that **depression without treatment** using the class of antidepressant medications known as selective serotonin reuptake inhibitors (SSRIs) **decreased the odds of both achieving adherence to highly active antiretroviral therapy (HAART) and lowering viral load**.[8]

[8] Horberg MA, Silverberg MJ, Hurley LB, et al. Effects of depression and selective serotonin reuptake inhibitor use on adherence to highly active antiretroviral therapy on clinical outcomes in HIV infected patients. *J Acquir Immun Defic Syndr*. 2008;47:384–90.

Table 9: Psychiatric Disorders Commonly Associated with HIV and AIDS[9]

MOOD DISORDERS[10]	
Major depression	A disabling condition characterized by a persistent sad mood; a diminished sense of wellbeing; and feelings of guilt, anxiety, or self-loathing. Symptoms interfere with a person's ability to work, sleep, study, eat, and enjoy once-pleasurable activities, and they prevent normal functioning.
Dysthymia	Chronic, mild depression that can prevent normal functioning and persists for at least 2 years in adults or 1 year in children.
Bipolar disorder	Dramatic mood swings from overly "high," irritable, or both to sad and hopeless, and then back again, often with periods of normal mood in between. The periods of highs and lows are called episodes of mania and depression, respectively.
ANXIETY DISORDERS[11]	
Generalized anxiety Disorder	Chronic anxiety, exaggerated worry, and tension accompanied by a variety of physical symptoms.
Panic disorder	Unexpected and repeated episodes of intense fear accompanied by physical symptoms that may include chest pain, heart palpitations, shortness of breath, dizziness, or abdominal distress.
Posttraumatic stress disorder	Persistent frightening thoughts and memories of a terrifying event or ordeal in which grave physical harm occurred or was threatened. Symptoms include sleep problems and feelings of detachment or numbness.
OTHER	
Adjustment disorders	A psychological response from an identifiable stressor or group of stressors that causes significant emotional or behavioral symptoms, including anxiety and depressed mood, but does not meet criteria for more specific disorders.
HIV-associated dementia or AIDS dementia complex	Progressive illness that is the result of HIV's impact on the central nervous system. May affect behavior, cognition, mood, and motor skills. Patients may develop ambulation or gait problems, mania, panic, psychosis, social isolation, or anxiety.
Personality disorders	A group of mental disorders characterized by inflexibility, rigidity, and inability to respond to the changes and demands of life. People with personality disorders tend to have a narrow view of the world and find it difficult to participate in social activities.
Substance abuse	Abuse or dependence on anything that is ingested to produce a high, alter one's senses, or otherwise affect functioning.

[9] New York State Department of Health. *The role of the primary care practitioner in assessing and treating mental health in persons with HIV*. 2001 Available at: www.hivguidelines.org/GuideLine.aspx?pageI D=261&guideLineID=40&vType=text. Accessed November 3, 2008.

[10] National Institute of Mental Health. *Depression*. 2008. Available at: www.nimh.nih.gov/health/publications/depression/summary.shtml. (Accessed June 19, 2010.)

[11] National Institute of Mental Health. *Anxiety disorders*. 2009. Available at: www.nimh.nih.gov/health/publications/anxietydisorders/introduction.shtml. Accessed June 19, 2010.

Although the high prevalence of depression among PLWHA is well documented, clinicians at Johns Hopkins University's Moore Clinic describe an equally prevalent condition among their patients known as **demoralization**.[12] Common among people with physical and mental illness, demoralization is characterized by **existential despair, hopelessness, helplessness, and loss of meaning and purpose in life**.

Although it shares many of the symptoms of depression, demoralization has key differences that affect its symptoms and the course of treatment; correct diagnosis is made trickier because the two disorders can coexist. Unlike depression, demoralization is not a brain disease but an adjustment disorder caused by recent events or ongoing life circumstances.

Table 10: Depression versus Demoralization

Depressed	Demoralized
Persistent inability to experience pleasure from normally pleasurable life events	Characterized by a "welling up of grief"
Cannot be distracted by and enjoy pleasant activities	Can be distracted by and enjoy pleasant activities
Feel worst in the morning; mood improves during the day	Feel best in the morning; mood worsens during the day
Difficulty staying asleep	Difficulty falling asleep

According to the Hopkins team, clients with major depression respond well to antidepressants, whereas those with demoralization may not. Clients who are demoralized, however, do respond well to psychotherapy, support groups, encouragement, drop-in centers, education, and time.

2.3 Prevalence of Mental Health Issues among PLWHA in NEMA - Consumer Survey

The purpose of this survey of consumers was to determine the prevalence of mental health (and substance abuse) issues among consumers in the Newark EMA – and to see how the EMA compared to national prevalence estimates of 50% to 60% of PLWHA experiencing depression or other mental health problem at some time in their lives. The Research and Evaluation Committee and Planning Council made the decision to conduct this survey as part of the Needs Assessment – 2010 Update.

2.3.1 Survey Tool and Methodology

Survey Tool. The survey tool combined demographic and HIV-related questions used in previous NEMA consumer surveys and all questions from the **Substance Abuse and Mental Illness Symptoms Screener (SAMISS)** tool developed by the federal Substance Abuse and Mental Health Services Administration (SAMHSA). This tool was chosen because it consisted of only 16 questions making it easy for consumers to complete, questions and responses were correlated to specific indicators of mental health and

[12] Reisman GJ, Angelino AF, Hutton HE. Psychiatric issues in the management of patients with HIV infection. *JAMA*. 2001;286:2857–64.

substance abuse issues and the types of issues, and most importantly because it had been validated among other groups. When this tool is administered with a client, answers will result in follow up assessment as needed. For our purposes, the tool was used to indicate prevalence among consumers.

The use of SAMISS and other mental health/substance use screening and assessment tools, such as the **Client Diagnostic Questionnaire** developed by HRSA (which is has also been validated), is up to the individual agency. However, the Council and grantee are sharing these tools among providers who have expressed willingness to test or use them among their patients.

The SAMISS was incorporated into a **Consumer Health Survey** form developed by NEMA which includes client demographic information and HIV diagnosis. The survey tool is in Appendix C.

Survey Methodology. It was decided that the survey form would be administered by **all Ryan White providers** and not just those providing medical care or core medical services. The reason was that research has shown that often times the person using support services only is often facing mental health or substance abuse issues. These support services may be the only link for them to Ryan White. We wanted to see the prevalence of such issues among these clients as well. A total of 40 providers received surveys in April 2010 and 20 provided completed surveys to NEMA. Responses were received from a total of **465 consumers.** Detailed findings and tabulations are shown in Appendix D.

Limitations. The limitation of the survey was that it was **self-administered** without guidance or review by agency personnel, e.g., case manager, who could review the responses and possibly probe more. For this reason, response rates regarding the amount or level of substance use appear lower than what objective data show. However, once, the questions focused on feelings or experiences, response rates increased to rates equal to or greater than some national results.

The SAMISS tool itself is a **screening tool** and not an in-depth assessment of behavioral issues. The purpose is to indicate where further assessment is needed. Therefore, the results should be viewed as an indicator of the extent of need for such assessment which can then be used to determine the extent of treatment needs – short, medium or longer term.

Some subcategories yielded **small numbers of responses**. Examples include: age category under 13, some sexual identification categories, etc. Caution should be used when assessing results of cells/responses with small numbers.

2.3.2 Findings - Demographics of Participants

The demographics of survey respondents are shown below. See Appendix D for more detailed numbers and percentages.

- **Gender** = 61% male, 37% female, 2% transgendered or no answer.
- **Sexual Identity** = 69% heterosexual, 11% MSM, 3% WSW, 4% bisexual, 1% MSM + Bisexual, 12% no answer
- **Race/Ethnicity** = 53% African American, 17% Hispanic/Latino, 7% White, 4% Other NonHispanic, 19% unknown race/ethnicity
    - **Hispanic country of origin** (12%) = 39% Puerto Rico, 6% Peru, 3% each Trinidad[13] or Dominican Republic or Guatemala or Cuba, , 1% each Colombia or Mexico.
- **Age =** 1% Under age 13, 3% Age 13-24, 26% 25-44, 64% age 45 and older, 6% no answer.
- **County of residence** = 71% Essex, 13% Morris, 10% Union, 2% Sussex & Warren, 5% outside NEMA. 49% of respondents reside in Newark.
- **Year of HIV Diagnosis.** 7% were diagnosed within the past year, 11% 2-4 years ago, 21% 5-10 Years ago, 21% 11-15 years ago, 36% 15+ years ago, <1% at birth, and 5% did not answer.
- **Site of Diagnosis.** 5% were diagnosed in the hospital emergency department (ED), 38% in a hospital, 36% in a clinic, 17% in other venues, and 4% did not answer.
- **Receipt of Medical Care** = 88% are in medical care for their HIV, 8% said not in medical care, 4% gave no answer.
    - **Reasons for not in medical care (8% or 38 responses)** = I cannot afford the cost; I do not feel sick; My CD4 is OK; I do not trust the system; other reasons – am in VA care, I plan on getting into care, no need, and other with no reason given.

[13] Trinidad is not a Hispanic country but was listed by respondents nonetheless.

2.3.3 Findings – Substance Abuse Health Issues

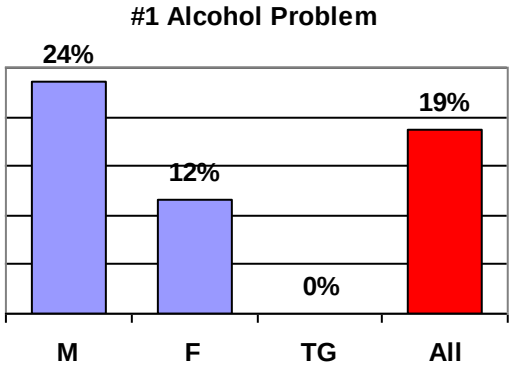
#1 Alcohol Problem

A possible alcohol problem was indicated by three questions regarding alcohol use - Question #11 on frequency of alcohol use, Question #12 on number of drinks per occasion, and Question #13 on 4+ drinks per occasion. A combined score of "5" or higher indicated a possible alcohol problem.

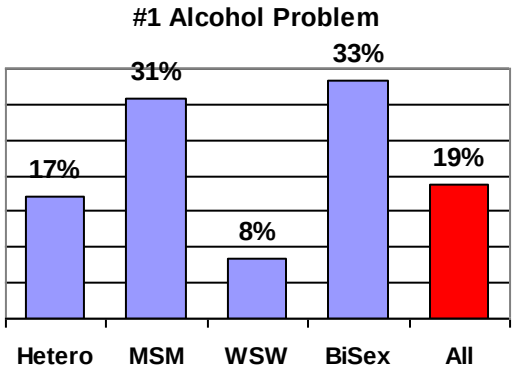
A total of **19% indicated a possible alcohol problem**. Results varied slightly by gender, sexual identification and race/ethnicity, but did not vary significantly by age or county of residence.

Figure W: Possible Alcohol Problem by Gender, Sexual Identification, Race/Ethnicity, Age and County of Residence

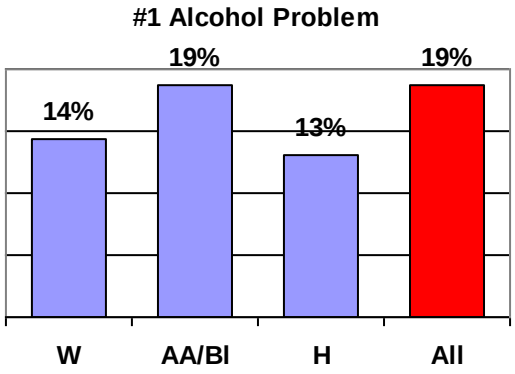
Gender	No Alcohol Problem	Alcohol Problem	Total
Male	218	67	285
Female	152	20	172
Transgendered	6	0	6
No Answer	2	0	2
Total	**378**	**87**	**465**



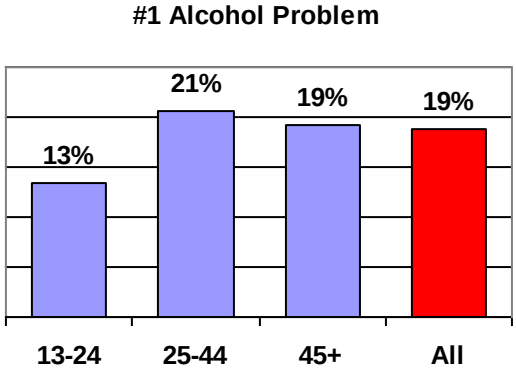
Sexual Identity	No Alcohol Problem	Alcohol Problem	Total
Heterosexual	267	55	322
MSM	36	16	52
WSW	11	1	12
Bisexual	12	6	18
MSM+Bisexual	1	2	3
No Answer	51	7	58
Total	**378**	**87**	**465**



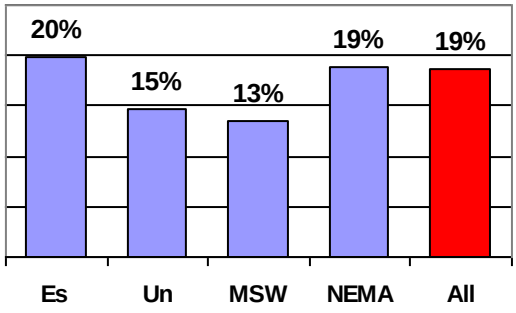
Race/Ethnicity	No Alcohol Problem	Alcohol Problem	Total
White Not Hispanic	30	5	35
Black/Afr Amer Not Hisp	199	46	245
Hispanic	67	10	77
Other Not Hispanic	16	5	21
Unknown Race/Ethn.	66	21	87
Total	**378**	**87**	**465**



Age Category	No Alcohol Problem	Alcohol Problem	Total
Under Age 13	2	1	3
Age 13-24	13	2	15
Age 25-44	96	25	121
Age 45+	241	57	298
No Answer	26	2	28
Total	**378**	**87**	**465**



County of Residence	No Alcohol Problem	Alcohol Problem	Total
Essex	263	65	328
Morris	52	9	61
Sussex	4	0	4
Union	36	9	45
Warren	2	0	2
NEMA TOTAL	**357**	**83**	**440**
Outside NEMA	20	4	24
Unknown	1	0	1
Total	**378**	**87**	**465**

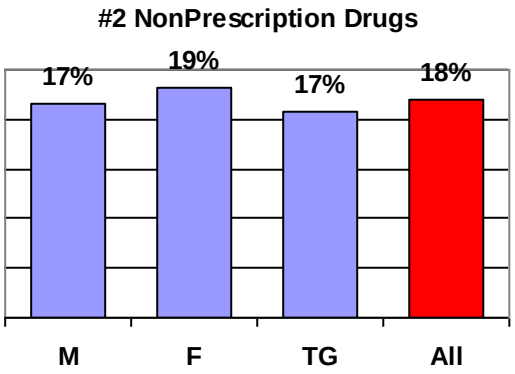


#2 NonPrescription Drug Use Issue

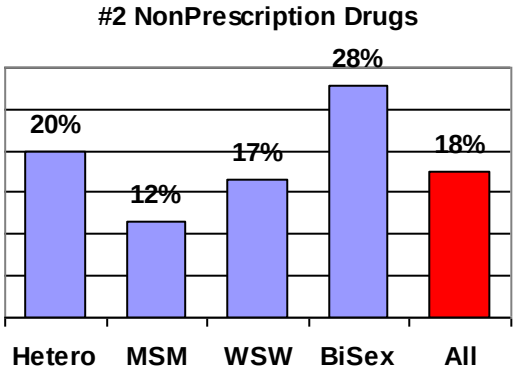
An issue regarding nonprescription drug abuse is indicated by Question #14 on frequency of use of nonprescription drugs to get high or change the way the respondent felt. A score of "3" or higher (weekly or more often) indicated a possible nonprescription drug use issue.

A total of **18% indicated a possible nonprescription drug use problem**. Results varied by sexual identification and race/ethnicity, but did not vary significantly by gender, age or county of residence.

Figure X: Possible NonPrescription Drug Use Issue by Gender, Sexual Identification, Race/Ethnicity, Age and County of Residence

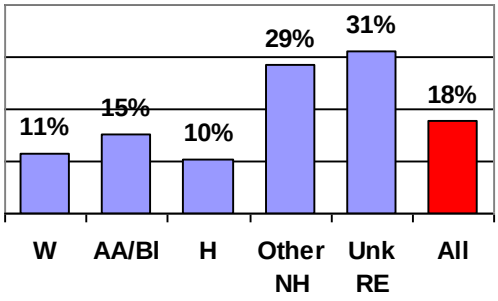


Gender	NonPrescription Drug Issue		
	No	Yes	Total
Male	236	49	285
Female	140	32	172
Transgendered	5	1	6
No Answer	2	0	2
Total	**383**	**82**	**465**



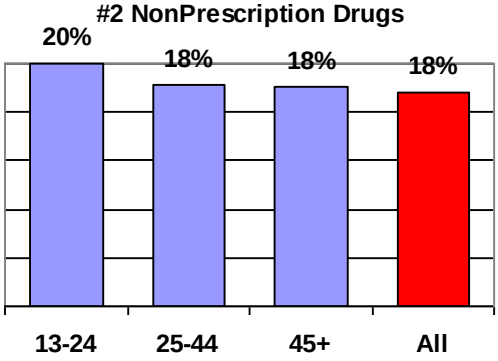
Sexual Identity	NonPrescription Drug Issue		
	No	Yes	Total
Heterosexual	258	64	322
MSM	46	6	52
WSW	10	2	12
Bisexual	13	5	18
MSM+Bisexual	2	1	3
No Answer	54	4	58
Total	**383**	**82**	**465**

#2 NonPrescription Drugs



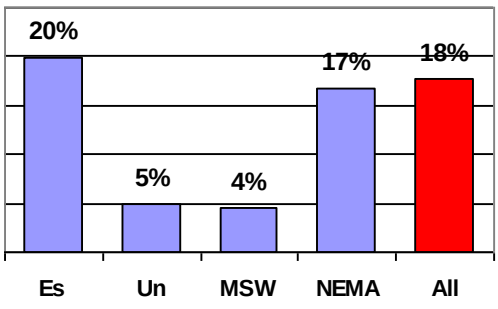
Race/Ethnicity	NonPrescription Drug Issue		
	No	Yes	Total
White Not Hispanic	31	4	35
Black/Afr Amer Not Hisp	208	37	245
Hispanic	69	8	77
Other Not Hispanic	15	6	21
Unknown Race/Ethnicity	60	27	87
Total	383	82	465

#2 NonPrescription Drugs



Age	NonPrescription Drug Issue		
	No	Yes	Total
Under Age 13	3	0	3
Age 13-24	12	3	15
Age 25-44	99	22	121
Age 45+	244	54	298
No Answer	25	3	28
Total	383	82	465

#2 NonPrescription Drugs



County of Residence	NonPrescription Drug Issue		
	No	Yes	Total
Essex	263	65	328
Morris	58	3	61
Sussex	4	0	4
Union	39	6	45
Warren	2	0	2
NEMA TOTAL	**366**	**74**	**440**
Outside NEMA	16	8	24
Unknown	1	0	1
Total	383	82	465

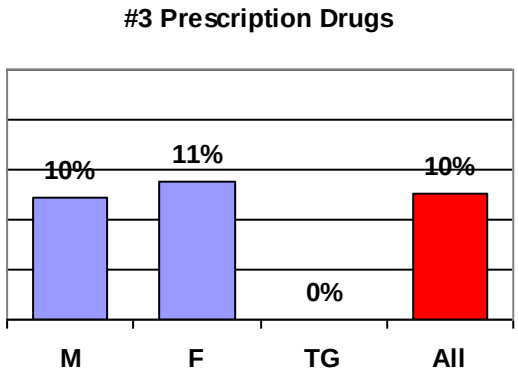
#3 Prescription Drug Use Issue

An issue regarding prescription drug abuse is indicated by Question #15 on frequency of use of drugs prescribed to the respondent or to someone else to get high or change the way the respondent felt. A score of "3" or higher (weekly or more often) indicated a possible nonprescription drug use issue.

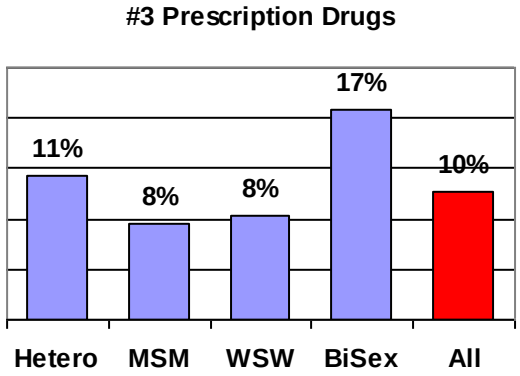
A total of **10% indicated a possible prescription drug use problem**. Results varied within sexual identification, race/ethnicity, age and county of residence, but did not vary significantly within gender.

Figure Y: Possible Prescription Drug Abuse Issue by Gender, Sexual Identification, Race/Ethnicity, Age and County of Residence

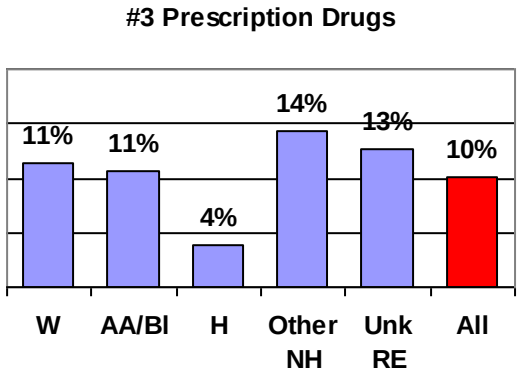
Gender	Prescription Drug Issue		
	No	Yes	Total
Male	257	28	285
Female	153	19	172
Transgendered	6	0	6
No Answer	2	0	2
Total	418	47	465



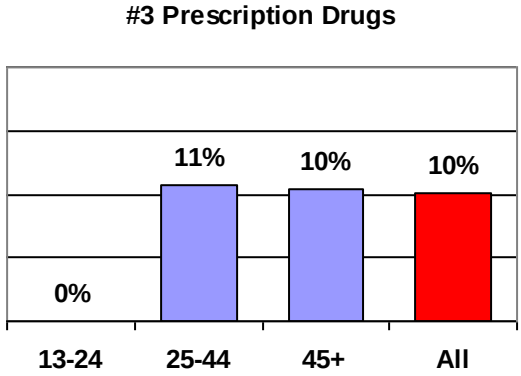
Sexual Identity	Prescription Drug Issue		
	No	Yes	Total
Heterosexual	285	37	322
MSM	48	4	52
WSW	11	1	12
Bisexual	15	3	18
MSM+Bisexual	2	1	3
No Answer	57	1	58
Total	418	47	465



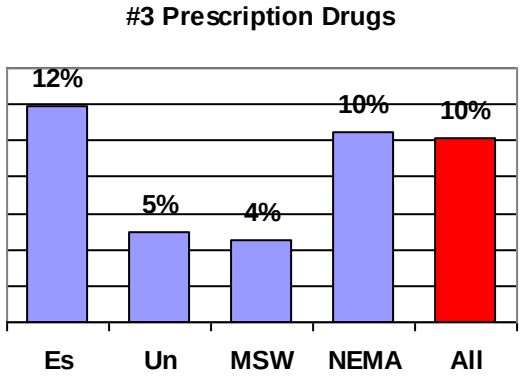
Race/Ethnicity	Prescription Drug Issue		
	No	Yes	Total
White Not Hispanic	31	4	35
Black/Afr Amer Not Hisp	219	26	245
Hispanic	74	3	77
Other Not Hispanic	18	3	21
Unknown Race/Ethn.	76	11	87
Total	**418**	**47**	**465**



Age Category	Prescription Drug Issue		
	No	Yes	Total
Under Age 13	3	0	3
Age 13-24	15	0	15
Age 25-44	108	13	121
Age 45+	267	31	298
No Answer	25	3	28
Total	**418**	**47**	**465**



County of Residence	Prescription Drug Issue		
	No	Yes	Total
Essex	289	39	328
Morris	58	3	61
Sussex	4	0	4
Union	41	4	45
Warren	2	0	2
NEMA TOTAL	**394**	**46**	**440**
Outside NEMA	23	1	24
Unknown	1	0	1
Total	418	47	465

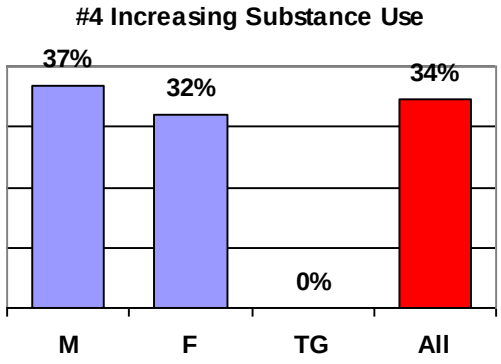


#4 Increasing Substance Use

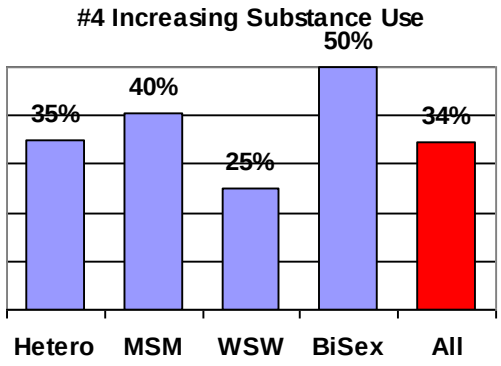
Increasing use of substances by Question #16 "in the past year, how often did you drink or use drugs more than you meant?". A score of "1" or higher (less than monthly or more often) indicated increasing need for or use of substances.

A total of **34% indicated increasing substance use – drinking/using drugs more than they meant to**. Results varied within all categories - gender, sexual identification, race/ethnicity, age and county of residence.

Figure Z: Increasing Substance Use by Gender, Sexual Identification, Race/Ethnicity, Age and County of Residence

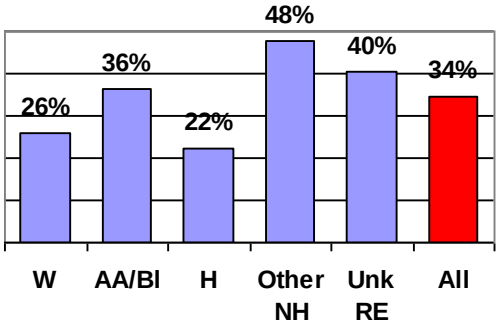


Gender	Increasing Substance Use Issue		
	No	Yes	Total
Male	180	105	285
Female	117	55	172
Transgendered	6	0	6
No Answer	2	0	2
Total	**305**	**160**	**465**



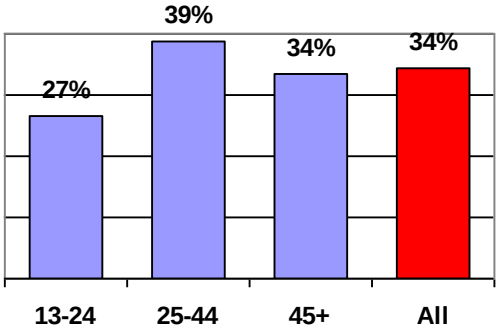
Sexual Identity	Increasing Substance Use Issue		
	No	Yes	Total
Heterosexual	210	112	322
MSM	31	21	52
WSW	9	3	12
Bisexual	9	9	18
MSM+Bisexual	1	2	3
No Answer	45	13	58
Total	**305**	**160**	**465**

#4 Increasing Substance Use



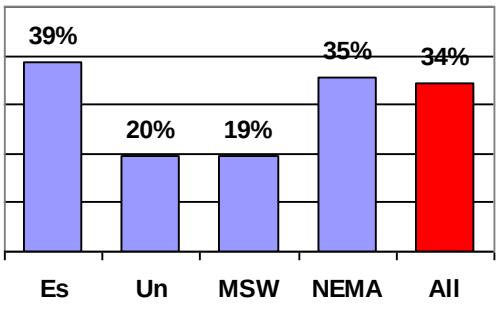
Race/Ethnicity	Increasing Substance Use		
	No	Yes	Total
White Not Hispanic	26	9	35
Black/Afr Amer Not Hisp	156	89	245
Hispanic	60	17	77
Other Not Hispanic	11	10	21
Unknown Race/Ethnicity	52	35	87
Total	**305**	**160**	**465**

#4 Increasing Substance Use



Age	Increasing Substance Use Issue		
	No	Yes	Total
Under Age 13	1	2	3
Age 13-24	11	4	15
Age 25-44	74	47	121
Age 45+	198	100	298
No Answer	21	7	28
Total	**305**	**160**	**465**

#4 Increasing Substance Use



County of Residence	Increasing Substance Use Issue		
	No	Yes	Total
Essex	201	127	328
Morris	49	12	61
Sussex	3	1	4
Union	29	16	45
Warren	2	0	2
NEMA TOTAL	**284**	**156**	**440**
Outside NEMA	20	4	24
Unknown	1	0	1
Total	305	160	465

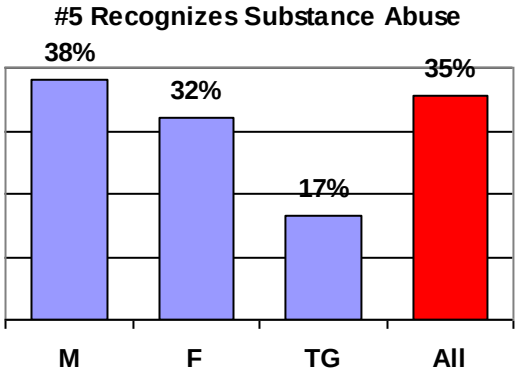
#5 Recognizes Substance Abuse

Awareness or recognition of one's substance abuse is indicated by Question #17 "How often did you feel you wanted or needed to cut down on your drinking or drug use in the past year, and were not able to?". A score of "1" or higher (less than monthly or more often) indicates a possible substance abuse issue.

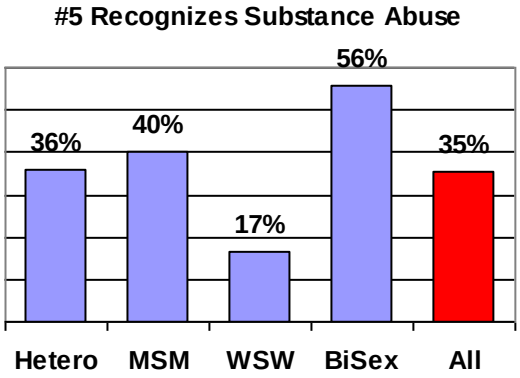
A total of **35% indicated recognition/awareness of their own substance abuse**. Results varied within all categories - gender, sexual identification, race/ethnicity, age and county of residence.

Figure AA: Recognition of Substance Abuse by Gender, Sexual Identification, Race/Ethnicity, Age and County of Residence

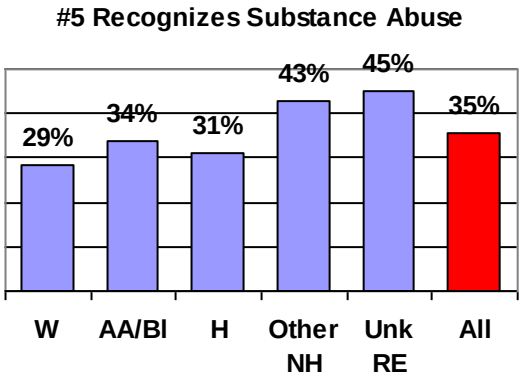
Gender	Recognizes Substance Abuse		
	No	Yes	Total
Male	176	109	285
Female	117	55	172
Transgendered	5	1	6
No Answer	2	0	2
Total	300	165	465



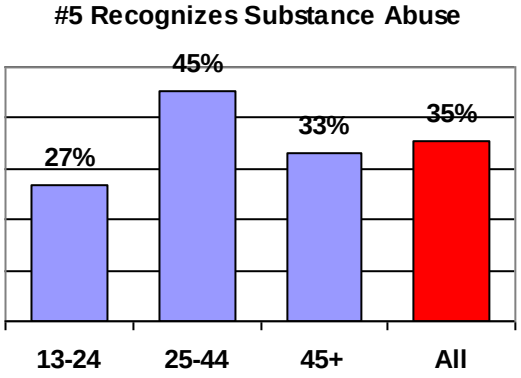
Sexual Identity	Recognizes Substance Abuse		
	No	Yes	Total
Heterosexual	207	115	322
MSM	31	21	52
WSW	10	2	12
Bisexual	8	10	18
MSM+Bisexual	1	2	3
No Answer	43	15	58
Total	300	165	465



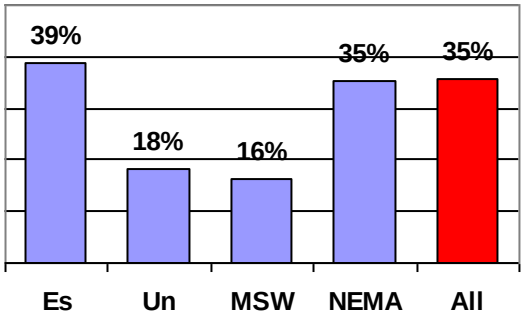
Race/Ethnicity	Recognizes Substance Abuse		
	No	Yes	Total
White Not Hispanic	25	10	35
Black/Afr Amer Not Hisp	162	83	245
Hispanic	53	24	77
Other Not Hispanic	12	9	21
Unknown Race/Ethn.	48	39	87
Total	**300**	**165**	**465**



Age Category	Recognizes Substance Abuse		
	No	Yes	Total
Under Age 13	2	1	3
Age 13-24	11	4	15
Age 25-44	66	55	121
Age 45+	199	99	298
No Answer	22	6	28
Total	**300**	**165**	**465**



County of Residence	Recognizes Substance Abuse		
	No	Yes	Total
Essex	201	127	328
Morris	50	11	61
Sussex	4	0	4
Union	27	18	45
Warren	2	0	2
NEMA TOTAL	**284**	**156**	**440**
Outside NEMA	15	9	24
Unknown	1	0	1
Total	300	165	465



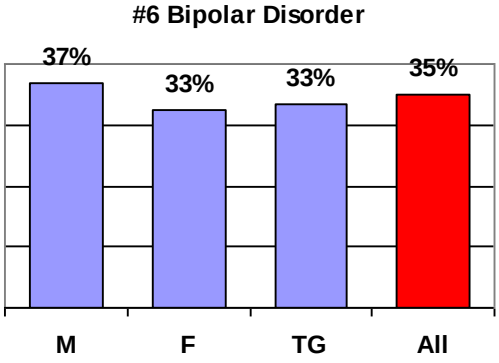
2.3.4 Findings – Mental Health Issues

#6 Possible Bipolar Disorder

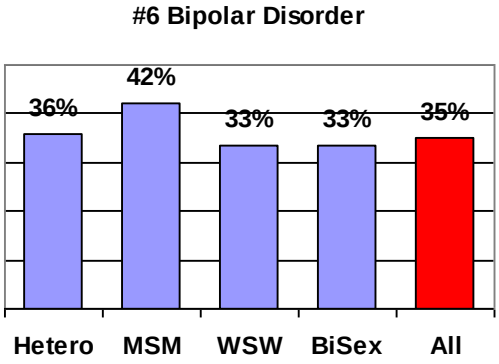
Possible bipolar disorder is indicated by Question #18 "in the past year, when not high or intoxicated, did you ever feel extremely energetic or irritable and more talkative than usual?". A positive response ("yes") may indicate the manic side of bipolar disorder.

A total of **35% indicated possible bipolar disorder**. Results varied within sexual identification, race/ethnicity, age and county of residence, but did not vary significantly within gender.

Figure BB: Possible Bipolar Disorder by Gender, Sexual Identification, Race/Ethnicity, Age and County of Residence

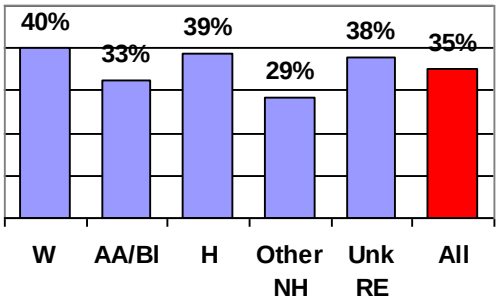


Gender	Possible Bipolar		
	No	Yes	Total
Male	180	105	285
Female	116	56	172
Transgendered	4	2	6
No Answer	2	0	2
Total	**302**	**163**	**465**



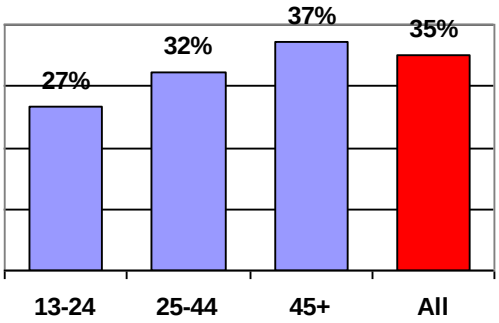
Sexual Identity	Possible Bipolar		
	No	Yes	Total
Heterosexual	207	115	322
MSM	30	22	52
WSW	8	4	12
Bisexual	12	6	18
MSM+Bisexual	1	2	3
No Answer	44	14	58
Total	**302**	**163**	**465**

#6 Bipolar Disorder



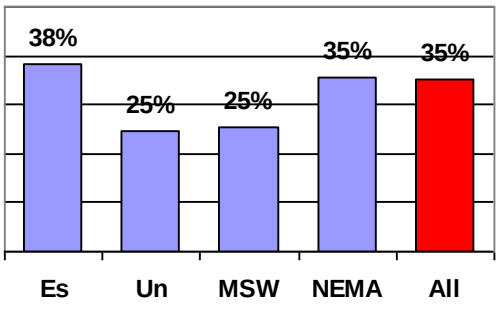
Race/Ethnicity	Possible Bipolar		
	No	Yes	Total
White Not Hispanic	21	14	35
Black/Afr Amer Not Hisp	165	80	245
Hispanic	47	30	77
Other Not Hispanic	15	6	21
Unknown Race/Ethnicity	54	33	87
Total	**302**	**163**	**465**

#6 Bipolar Disorder



Age	Possible Bipolar		
	No	Yes	Total
Under Age 13	1	2	3
Age 13-24	11	4	15
Age 25-44	82	39	121
Age 45+	187	111	298
No Answer	21	7	28
Total	**302**	**163**	**465**

#6 Bipolar Disorder



County of Residence	Possible Bipolar		
	No	Yes	Total
Essex	203	125	328
Morris	46	15	61
Sussex	3	1	4
Union	31	14	45
Warren	1	1	2
NEMA TOTAL	**284**	**156**	**440**
Outside NEMA	17	7	24
Unknown	1	0	1
Total	302	163	465

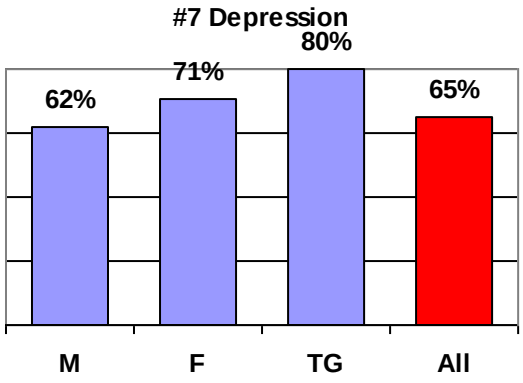
#7 Depression

Possible depression was indicated by three questions concerning the experience in the past year - Question #19 "were you ever on medication or antidepressants for depression or nerve problems?", Question #20 "was there ever a time when you felt sad, blue, or depressed for more than 2 weeks in a row?, and Question #21 "was there ever a time lasting more than 2 weeks when you lost interest in most things like hobbies, work, or activities that usually give you pleasure?". A positive response ("yes") to any of the three questions indicates possible depression.

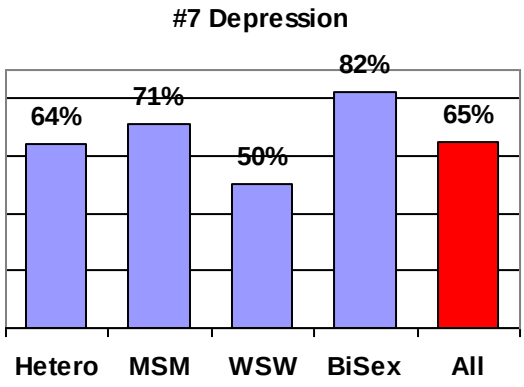
A total of **65% indicated possible depression**. Of these, **17% had one indicator, 20% had two indicators, and 29% had three indicators**. Results varied within gender, sexual identification, race/ethnicity and age, but did not vary significantly within county of residence.

Figure CC: Possible Depression by Gender, Sexual Identification, Race/Ethnicity, Age and County of Residence

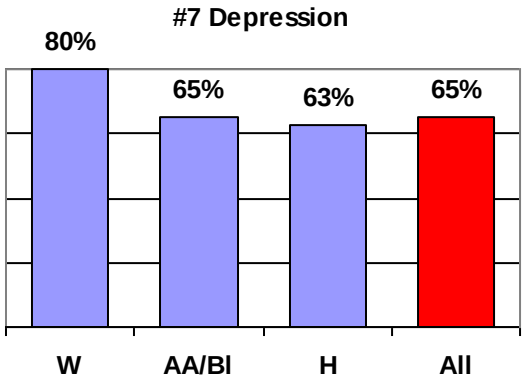
Gender	Depression		
	No	Yes	Total
Male	107	**174**	281
Female	50	**121**	171
Transgendered	1	**4**	5
No Answer	2	**0**	2
Total	160	**299**	459



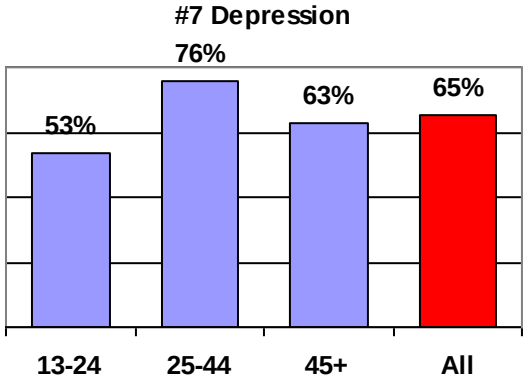
Sexual Identity	Depression		
	No	Yes	Total
Heterosexual	114	**204**	318
MSM	15	**37**	52
WSW	6	**6**	12
Bisexual	3	**14**	17
MSM+Bisexual	0	**3**	3
No Answer	22	**35**	57
Total	160	**299**	459



Race/Ethnicity	Depression		
	No	Yes	Total
White Not Hispanic	7	**28**	35
Black/Afr Amer Not Hisp	85	**158**	243
Hispanic	28	**47**	75
Other Not Hispanic	10	**10**	20
Unknown Race/Ethn.	30	**56**	86
Total	160	**299**	459



Age Category	Depression		
	No	Yes	Total
Under Age 13	1	**2**	3
Age 13-24	7	**8**	15
Age 25-44	29	**91**	120
Age 45+	110	**184**	294
No Answer	13	**14**	27
Total	160	**299**	459



County of Residence	Depression		
	No	Yes	Total
Essex	113	**212**	325
Morris	24	**37**	61
Sussex	1	**3**	4
Union	14	**29**	43
Warren	0	**2**	2
NEMA TOTAL	**152**	**283**	**435**
Outside NEMA	8	**15**	23
Unknown	0	**1**	1
Total	160	**299**	459

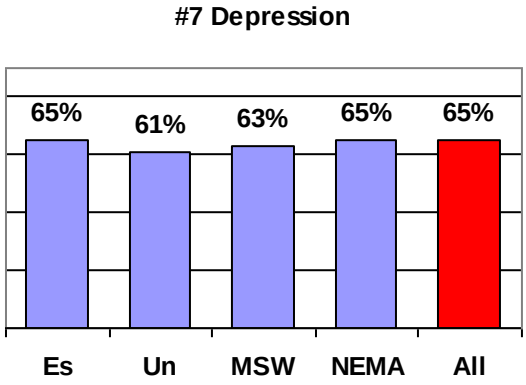
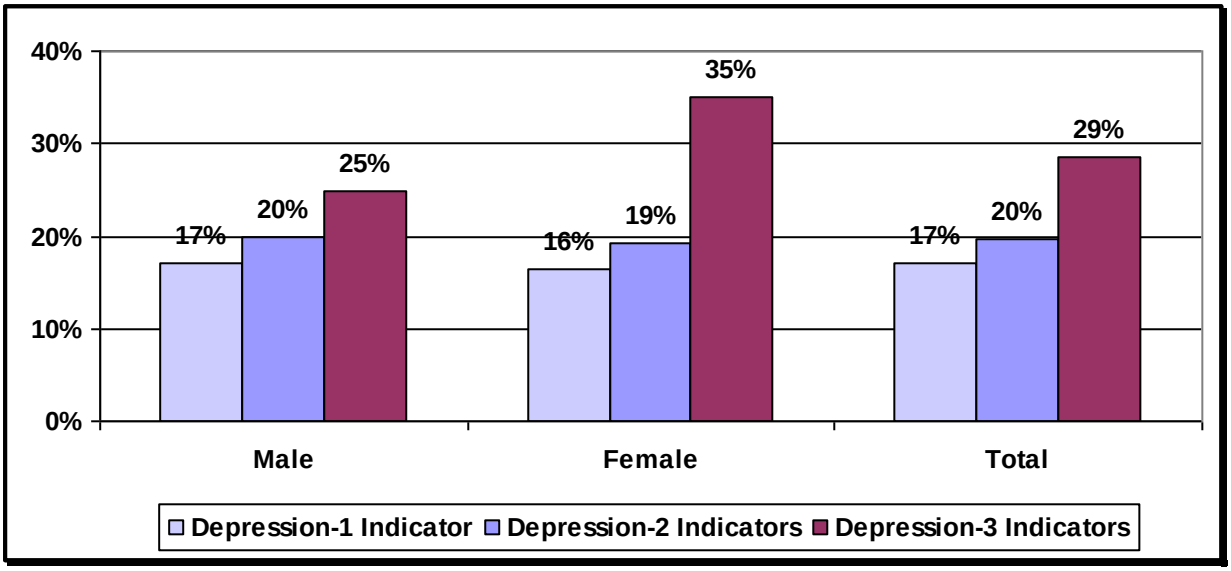


Figure DD: Possible Depression by Severity (1-3 Indicators) by Gender

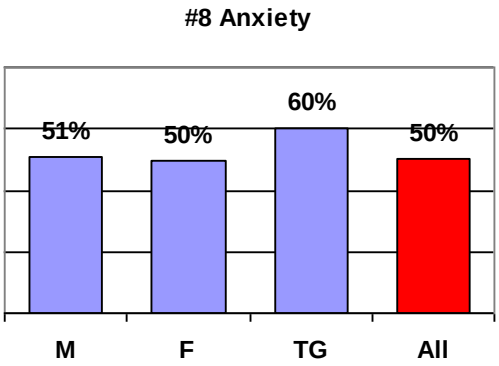


#8 Possible Anxiety Disorder

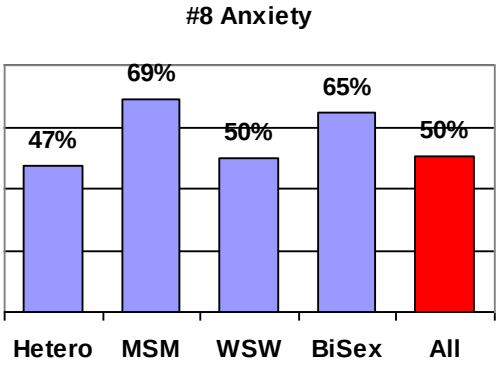
Possible anxiety was also indicated by three questions concerning the experience in the past year - Question #22 "did you ever have a period lasting more than 1 month when most of the time you felt worried and anxious?", Question #23 "did you have a spell or an attack when all of a sudden you felt frightened, anxious, or very uneasy when most people would not be afraid or anxious?", and Question #24 "did you ever have a spell or an attack when for no reason your heart suddenly started to race, you felt faint, or you couldn't catch your breath?". Question #24A allowed respondents to explain this answer; results are in **section 2.4.1**. A positive response ("yes") to any of the three questions indicates possible anxiety.

A total of **50% indicated possible anxiety disorder**. Of these, **19% had one indicator, 14% had two indicators, and 17% had three indicators**. Results varied within sexual identification, race/ethnicity, and age, but did not vary significantly within gender or county of residence.

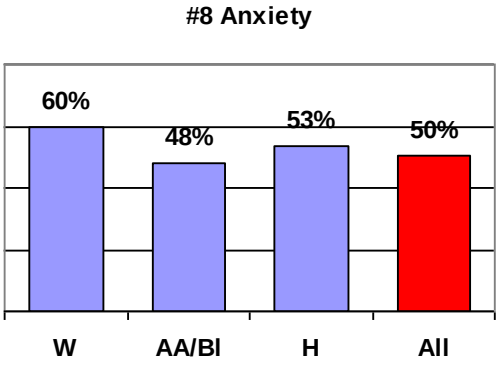
Figure EE: Possible Anxiety by Gender, Sexual Identification, Race/Ethnicity, Age and County of Residence



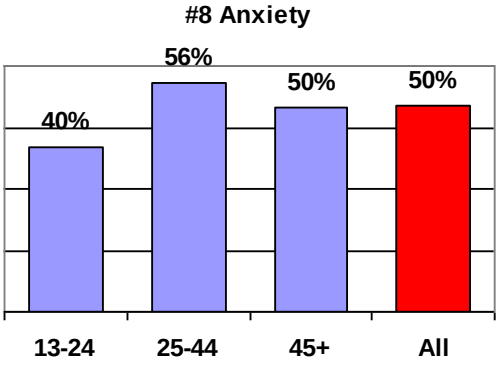
Gender	Anxiety		
	No	Yes	Total
Male	138	**143**	281
Female	86	**85**	171
Transgendered	2	**3**	5
No Answer	2	**0**	2
Total	228	**231**	459



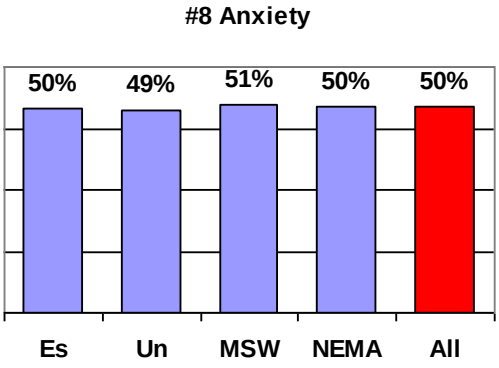
Sexual Identity	Anxiety		
	No	Yes	Total
Heterosexual	167	**151**	318
MSM	16	**36**	52
WSW	6	**6**	12
Bisexual	6	**11**	17
MSM+Bisexual	0	**3**	3
No Answer	33	**24**	57
Total	228	**231**	459



Race/Ethnicity	Anxiety		
	No	Yes	Total
White Not Hispanic	14	**21**	35
Black/Afr Amer Not Hisp	127	**116**	243
Hispanic	35	**40**	75
Other Not Hispanic	10	**10**	20
Unknown Race/Ethnicity	42	**44**	86
Total	228	**231**	459

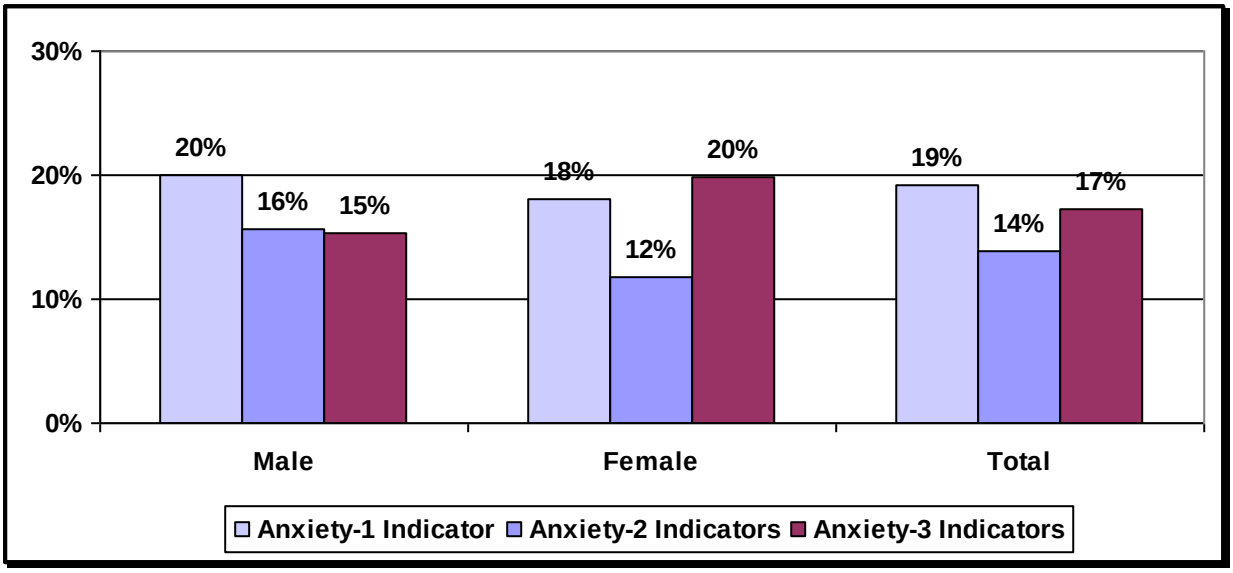


Age	Anxiety		
	No	Yes	Total
Under Age 13	2	**1**	3
Age 13-24	9	**6**	15
Age 25-44	53	**67**	120
Age 45+	148	**146**	294
No Answer	16	**11**	27
Total	228	**231**	459



County of Residence	Anxiety		
	No	Yes	Total
Essex	163	**162**	325
Morris	31	**30**	61
Sussex	1	**3**	4
Union	20	**23**	43
Warren	1	**1**	2
NEMA TOTAL	**216**	**219**	**435**
Outside NEMA	12	**11**	23
Unknown	0	**1**	1
Total	228	**231**	459

Figure FF: Possible Anxiety by Severity (1-3 Indicators) by Gender



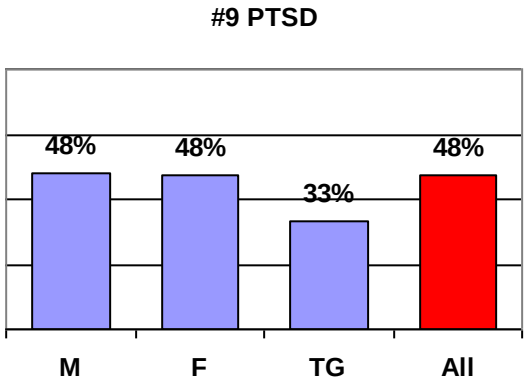
#9 Post Traumatic Stress Disorder (PTSD)

Possible Post-Traumatic Stress Disorder (PTSD) was indicated Question #25 "During your lifetime, as a child or adult, have you experienced or witnessed traumatic event(s) that involved harm to yourself or to others?". If the respondent answered "yes", Question 25A asked "If yes: In the past year, have you been troubled by flashbacks, nightmares, or thoughts of the trauma?". A positive response ("yes") to #25 indicates possible PTSD depression and #25A indicates that this is continuing.

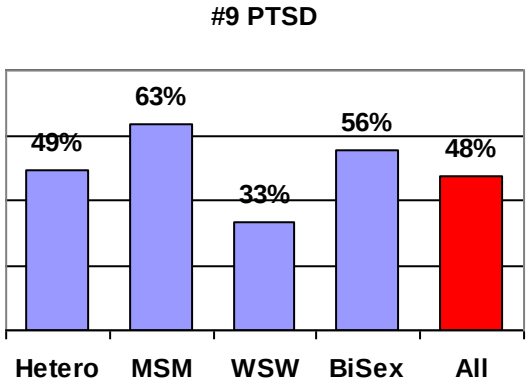
A total of **48% indicated possible PTSD**. Of these, **23% (nearly half) had flashbacks, nightmares or thoughts of the trauma within the past year.** Results regarding PTSD varied within sexual identification, race/ethnicity and age, but did not vary significantly within gender or county of residence.

Figure GG: Possible PTSD by Gender, Sexual Identification, Race/Ethnicity, Age and County of Residence

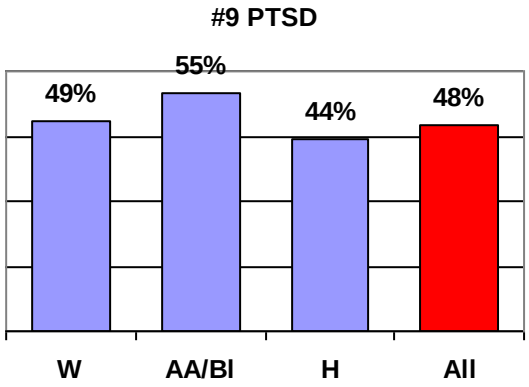
Gender	Possible PTSD		
	No	Yes	Total
Male	149	136	285
Female	90	82	172
Transgendered	4	2	6
No Answer	1	1	2
Total	**244**	**221**	**465**



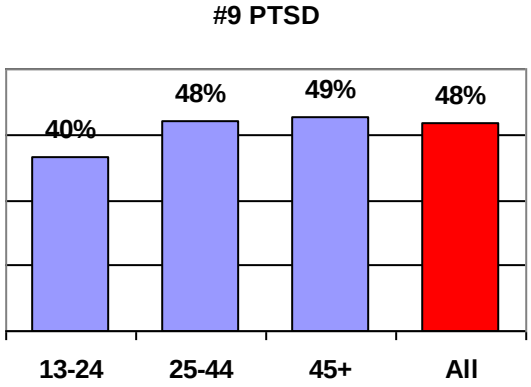
Sexual Identity	Possible PTSD		
	No	Yes	Total
Heterosexual	163	159	322
MSM	19	33	52
WSW	8	4	12
Bisexual	8	10	18
MSM+Bisexual	0	3	3
No Answer	46	12	58
Total	**244**	**221**	**465**



Race/Ethnicity	Possible PTSD		
	No	Yes	Total
White Not Hispanic	18	17	35
Black/Afr Amer Not Hisp	111	134	245
Hispanic	43	34	77
Other Not Hispanic	10	11	21
Unknown Race/Ethn.	62	25	87
Total	**244**	**221**	**465**



Age Category	Possible PTSD		
	No	Yes	Total
Under Age 13	0	3	3
Age 13-24	9	6	15
Age 25-44	63	58	121
Age 45+	152	146	298
No Answer	20	8	28
Total	**244**	**221**	**465**



County of Residence	Possible PTSD		
	No	Yes	Total
Essex	171	157	328
Morris	28	33	61
Sussex	2	2	4
Union	24	21	45
Warren	2	0	2
NEMA TOTAL	**227**	**213**	**440**
Outside NEMA	16	8	24
Unknown	1	0	1
Total	244	221	465

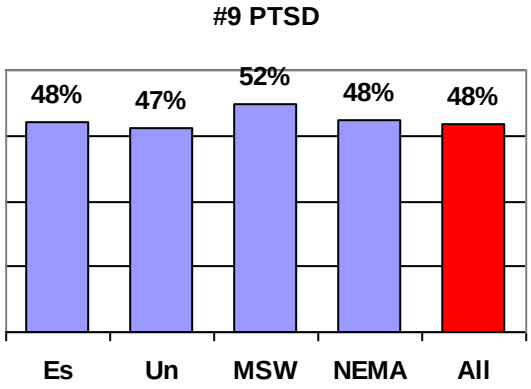
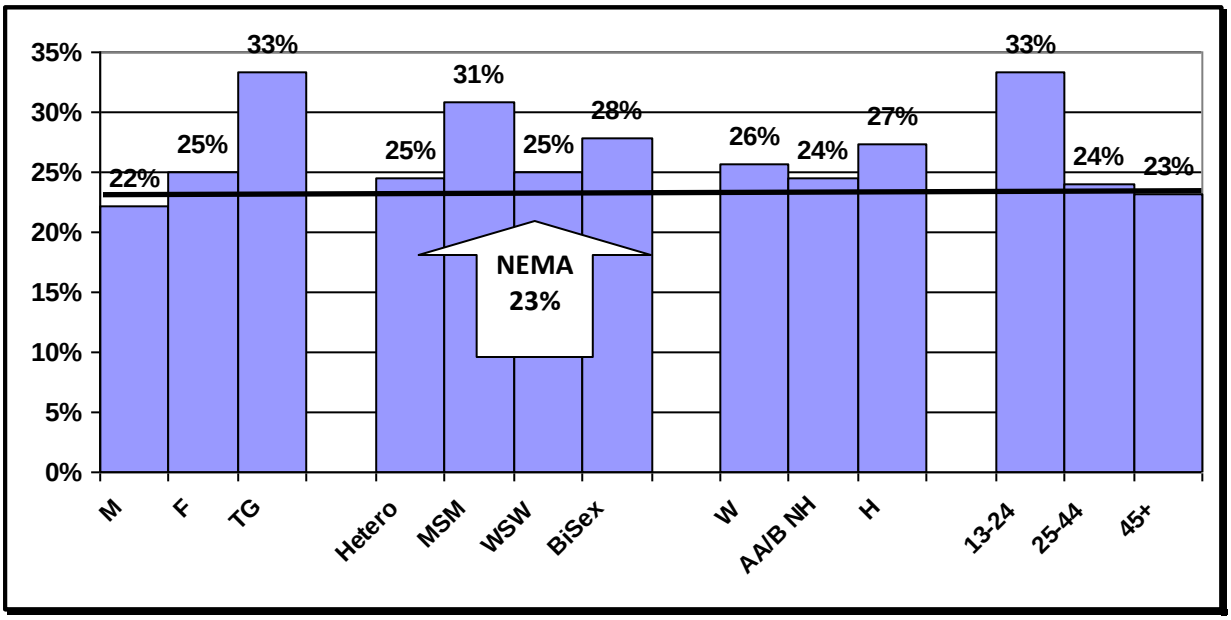


Figure HH: Percent Experiencing Recent PTSD Flashbacks by Gender, Sexual Identification, Race/Ethnicity and Age

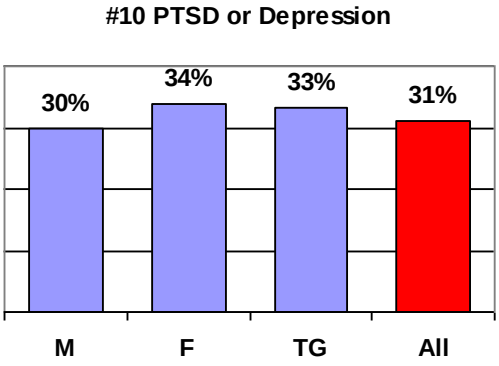


#10 Post Traumatic Stress Disorder (PTSD) and/or Depression

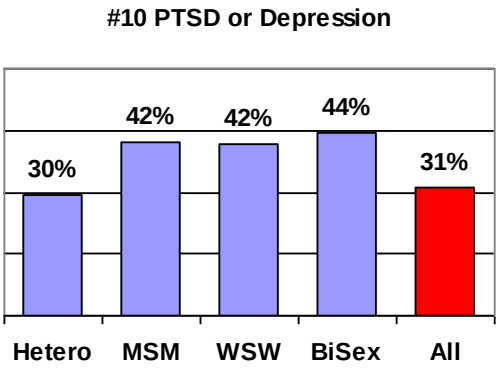
Additional recent effects of PTSD and/or Depression were indicated by Question #26 "In the past 3 months, have you experienced any event(s) or received information that was so upsetting it affected how you cope with everyday life?". A positive response ("yes") indicates possible PTSD or depression.

A total of **31% indicated possible recent effects of PTSD or depression**. Results varied within sexual identification and age, but did not vary significantly within gender, race/ethnicity or county of residence.

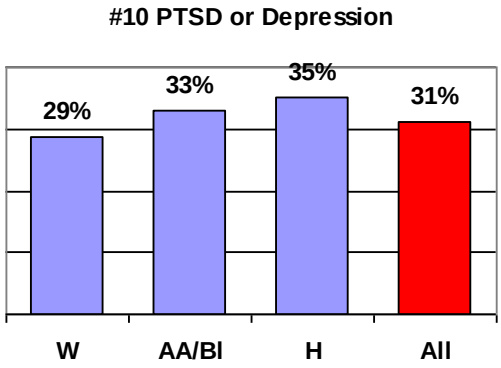
Figure II: Possible Recent PTSD or Depression by Gender, Sexual Identification, Race/Ethnicity, Age and County of Residence



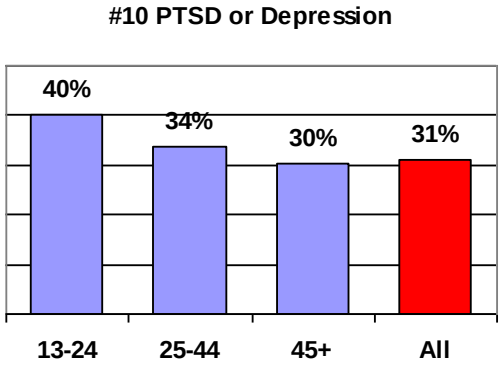
Gender	PTSD or Depression		
	No	Yes	Total
Male	200	85	285
Female	114	58	172
Transgendered	4	2	6
No Answer	2	0	2
Total	**320**	**145**	**465**



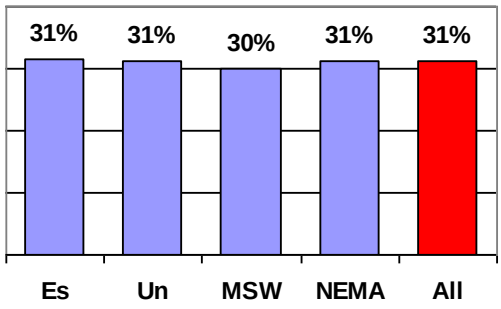
Sexual Identity	PTSD or Depression		
	No	Yes	Total
Heterosexual	227	**95**	322
MSM	30	**22**	52
WSW	7	**5**	12
Bisexual	10	**8**	18
MSM+Bisexual	0	**3**	3
No Answer	46	**12**	58
Total	**320**	**145**	**465**



Race/Ethnicity	PTSD or Depression		
	No	Yes	Total
White Not Hispanic	25	**10**	35
Black/Afr Amer Not Hisp	164	**81**	245
Hispanic	50	**27**	77
Other Not Hispanic	15	**6**	21
Unknown Race/Ethnicity	66	**21**	87
Total	320	**145**	465



Age	PTSD or Depression		
	No	Yes	Total
Under Age 13	3	**0**	3
Age 13-24	9	**6**	15
Age 25-44	80	**41**	121
Age 45+	208	**90**	298
No Answer	20	**8**	28
Total	320	**145**	465



County of Residence	PTSD or Depression		
	No	Yes	Total
Essex	225	103	328
Morris	44	17	61
Sussex	3	1	4
Union	31	14	45
Warren	0	2	2
NEMA TOTAL	**303**	**137**	**440**
Outside NEMA	16	8	24
Unknown	1	0	1
Total	320	145	465

Total Depression and Anxiety

A cross tabulation of respondents indicated that **69% experienced either or both depression and anxiety.** Thirty one percent (31%) indicated that they did not experience either anxiety or depression.

Total PTSD

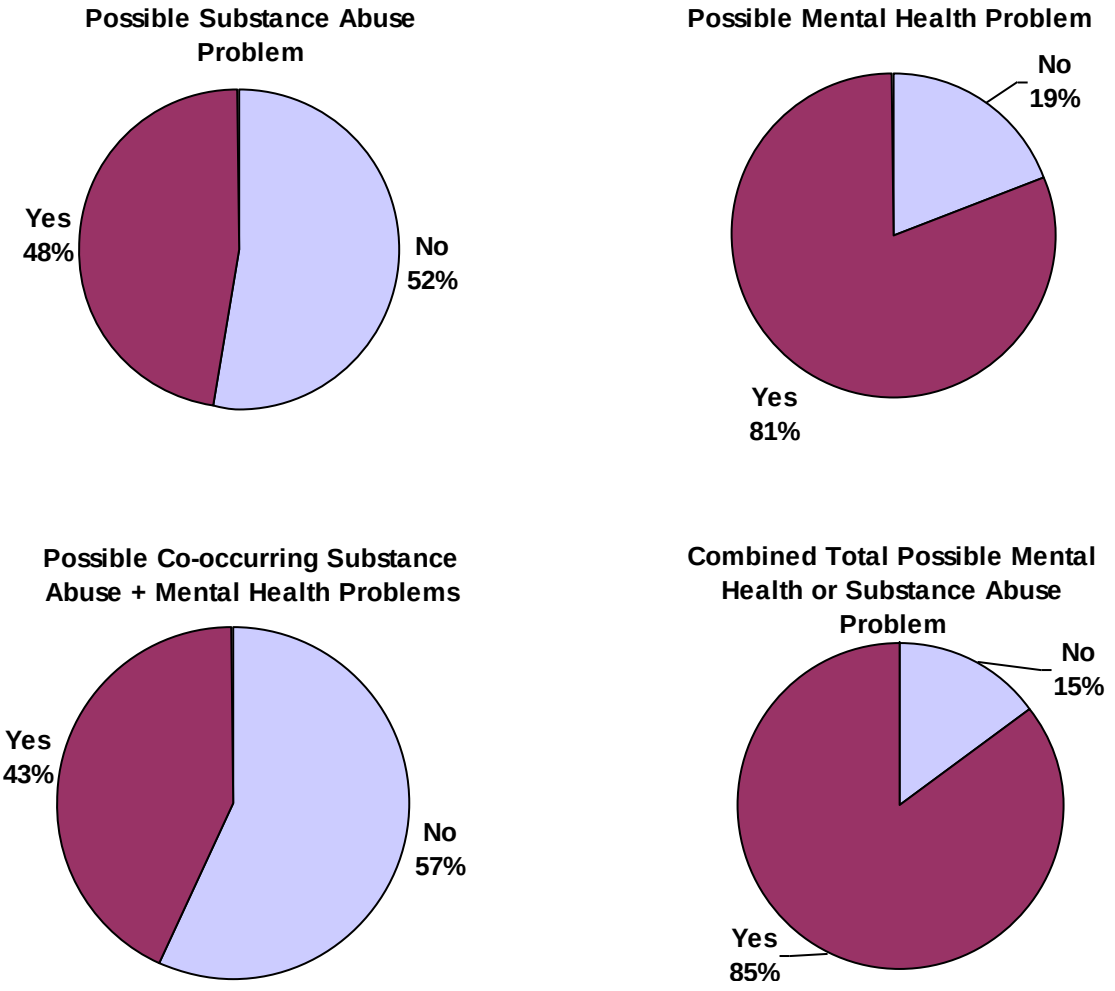
A cross tabulation of respondents to Questions #25 and #26 indicated that **56% experienced PTSD (including PTSD + depression)**. Forty four percent (44%) did not.

2.3.5 Findings – Total Substance Use and Mental Health Issues

Data were tabulated across all participants for all variables to determine the total percent of respondents with possible substance abuse or mental health problems.

Figure JJ shows that a total of **48% of respondents indicated a possible substance abuse problem, 81% indicated a possible mental health problem, for a combined total of 85% of respondents with a possible behavioral issue. 43% had possible co-occurring disorders of substance abuse and mental health problems.**

Figure JJ: Summary of Percent of Respondents with Substance Abuse or Mental Health Problem, Co-Occurring and Combined Total



2.4 Comments from Consumers

2.4.1 Comments related to Anxiety

A total of 64 respondents or 28% of those indicating anxiety provided further comments about their experience, in response to Question #24A. They are shown below and add further insight into experiences of respondents in addition to their living with HIV disease.

Response	#
Suffer from anxiety, anxiety attacks	4
anxiety-entire life	1
Anxiety, just broke up with my seven years partner.	1
Anxious, Heart races	1
anxious, depression	1
Feeling Anxious	1
Very Anxious	1
I suffer from Panic Attacks	6
Asthma	2
Because I was not high on drugs.	1
Breathing difficulty	1
chest pain slow heart rate	1
chest pain & upper left arm	1
Cholesterol	1
Depression	2
Drug use- High BP	1
Extreme sweat attacks	1
Financial worries of homelessness, lack of money	1
I felt confuse and lost while shopping in D.T.	1
I have anxious attach to the meds.	1
I have serious depression issues	1
I smoke cigarettes/that might be the cause of short of wind.	1
I think about death and all of the sudden it starts racing.	1
I was very tired and I began worrying about my health.	1
I'm sorry I just can't explain it.	1
It just felt good	1
It's not anymore but like 3 times a week for a month.	1
mental chatter, worry, obsessing	1
My heart starts to race sometime	1
Not knowing the outcome of the meds.	1
Overwhelmed with life situations, long-term breakup and ho	1
PASS OUT	1
Pressure in my chest.	1
Running for a bus	1
Seizures	3
seizures/strokes	1
Shortness of breath	2

Response	#
Stroke	1
Sugar attack	2
Too, much cocaine	1
Walking around and doing shopping	1
When anxious I usually have sweat attacks.	1
When he was angry.	1
When I can't find thing or have financial problems or things	1
When I found out my daughter was having a baby.	1
When I get anxious my heart races fast	1
When not drinking	1
When not taking my medications (skipped).	1
When upset	1
When using weed	1
Total	**64**

2.4.2 General Comments

A total of 38 respondents provided additional comments in response to Question #27 asking for comments. These also provide insight about the experiences of respondents living with HIV.

Aside from the slight wheezing and congestion in my lungs I feel terrific.
I have been drug free for 18 months as of April 3 2010
I need more fruits; oranges.
I need more info about this HIV disease
I still have depression problems some times but I'm in treatment in the UMDNJ.
I want to get my own place
I wish there was more information about health care
I worry about my daughter and where she taking her life and with who
I would appreciate a gym and a public computer facility for HIV infected
I'm not into drugs or alcohol; and on the question (sexual ID), it should be (GAY) instead of "man who have sex with men".
In life on thing is for sure, we all have a choice
It is a good survey.
It wants help with sexual, mental and physical abuse. More information on how to cope with the HIV disease
Make it possible for our governor or political officials to acknowledge how severe this disease can be!!
Medicine is important
Most times things work out
My baby sister died, but I did not use.
My health has been declining in the last past 6 months, need to go to the Doctor as scheduled and no alcohol or drug use
Really trying to get my life together
Received information that was upsetting but was able to process and accept.
Some who work in the field are very judgmental which stigmatizes and prevent services
Sometimes I think about how I am supposed to be also how things suppose to be in my life.
Sometimes, because lost of fingers in a car accident.
Thank God, I feel good (Changer)
Thank you so much for everything

The E.P.T. clinic has been a life saver for me.
The visibility of workers & peers are not noticeable in the West Ward as it should be.
There needs to be more financial help for patients not on Medicare/Medicaid who have no health ins. Or cant afford it
There should be a scholarship opportunity for who are passive with HIV
This is a very good survey
This past year I've been hospitalized four times cause of depression.
Try and not be judgmental, which tend to over extend into stigmatizing clients.
Very close friend who died, it was very traumatic and hard to cope with
Very depressed
Well I was on dialysis, and have high blood pressure
Yeah, what is it for
Yes but it would take a lot of time doing so or explaining on paper
Yes, I have been through so much as a black man; I wish that life was a little bit EASIER on me. THANK you! I don't think it is my color but it's me

2.4 Resources Available for Mental Health Issues in the Newark EMA

There are significant non-Ryan White funded resources available within the Newark EMA to screen and treat mental health problems. See Appendix E.

In 2009 the Newark EMA Planning Council worked with the grantee and CHAMP client level data (CLD) program to ensure that the service categories and subcategories correctly identified the treatments needed and provided for PLWHA. The CHAMP service subcategories were revised to reflect current treatment methodologies and New Jersey mental health standards. These revisions were effective for FY 2010, March 1, 2010.

2.5 Conclusions and Recommendations

There is a very high prevalence (up to 85%) of behavioral issues – substance abuse but particularly mental health – among PLWHA in the Newark EMA. It is necessary to identify affected Ryan White clients, assess the extent of behavioral problems particularly as they impact treatment adherence (medical care and medication regimens), and to provide appropriate care for those needing it.

- **Screening.** All Ryan White program clients should be screened for behavioral issues – substance abuse and mental health. The HRSA HAB Core Clinical Performance Indicators recommend that this screening be conducted for **new clients.** The Newark EMA should screen both for new clients and for all existing clients, particularly those who have not been screened to date.
- **The screening for both substance abuse and mental health should be recorded in CHAMP.** It is recommended that CHAMP incorporate the SAMISS tool questions for this purpose, and that these questions become required fields.

- The medical case manager or case manager must be required to conduct the initial screening.
- **Behavioral Assessment.** For all clients indicating a possible behavioral issue – an **estimated 85% of total PLWHA** – a behavioral assessment should be conducted. **The behavioral assessment should be required for all new Ryan White clients** and periodically thereafter, at intervals to be determined by the Council and Grantee.
    - All medical providers should routinely utilize a **standard behavioral assessment tool** or use the **HRSA HAB Client Diagnostic Questionnaire** for this purpose**.**
    - **Part A and Part F funding allocations should ensure that the initial behavioral assessments can be conducted.**
- The Council should do a further review of the level of non-Ryan White mental health services available in its annual **Funding Stream Analysis.**
    - **Part A and Part F funding allocations should ensure that service gaps are addressed for clients needing treatment for behavioral problems.**
- The Grantee should do an assessment of the effectiveness of the new CHAMP mental health and substance abuse service definitions.

PART 3: EARLY IDENTIFICATION OF PLWHA

3.1 Introduction

Since the Ryan White CARE Act amendments of 2000, Part A program funds may be used for a service category of "early intervention services (EIS)." "***Early intervention services*** for Parts A and B include counseling individuals with respect to HIV/AIDS; testing (including tests to confirm the presence of the disease, to diagnose the extent of immune deficiency, and to provide information on appropriate therapeutic measures); referrals; other clinical and diagnostic services regarding HIV/AIDS; periodic medical evaluations for individuals with HIV/AIDS; and provision of therapeutic measures."[14] Annually thereafter, the Newark EMA assessed the need for EIS, found that non-Part A resources in the EMA were sufficient, and therefore did not allocate Part A resources to this service category.

The Ryan White Treatment Extension Act (RWTEA) of 2009 significantly expanded planning councils' responsibilities with respect to EIS and early identification of PLWHA. Specifically,

> "(4) DUTIES.-The planning council established or designated under paragraph (1) shall-
> (A) determine the size and demographics of the population of individuals with HIV disease; **as well as the size and demographics of the estimated population of individuals with HIV/AIDS who are unaware of their HIV status;**
> (B) determine the needs of such population, with particular attention to-
> (i) individuals with HIV disease who know their HIV status and are not receiving HIV-related services; ~~**and**~~
> (ii) disparities in access and services among affected subpopulations and historically underserved communities; "**and**
> **(iii) individuals with HIV/AIDS who do not know their HIV status;''**
>
> "(D) develop a comprehensive plan for the organization and delivery of health and support services described in section 2604 that-
> (i) includes a strategy for identifying individuals who know their HIV status and are not receiving such services and for informing the individuals of and enabling the individuals to utilize the services, giving particular attention to eliminating disparities in access and services among affected subpopulations and historically underserved communities, and including discrete goals, a timetable, and an appropriate allocation of funds;
> (ii) includes a strategy to coordinate the provision of such services with programs for HIV prevention (including outreach and early intervention) and for the prevention and treatment of substance abuse (including programs that provide comprehensive treatment services for such abuse); ~~and~~

[14] Ryan White HIV/AIDS Program Services Report Instruction Manual Version 2.0. HIV/AIDS Bureau Division of Science and Epidemiology Health Resources and Services Administration U.S. Department of Health and Human Services 5600 Fishers Lane, Room 7-90 Rockville, MD 20857

> (iii) is compatible with any State or local plan for the provision of services to individuals with HIV disease; **and**
> **"(iv) includes a strategy, coordinated as appropriate with other community strategies and efforts, including discrete goals, a timetable, and appropriate funding, for identifying individuals with HIV/AIDS who do not know their HIV status, making such individuals aware of such status, and enabling such individuals to use the health and support services described in section 2604, with particular attention to reducing barriers to routine testing and disparities in access and services among affected subpopulations and historically underserved communities;"**

The EMA's FY 2010 Part A Supplemental Application included a plan for the first year of early identification of PLWHA. The plan was developed within the short timeframe allowed by HRSA HAB. This section of the Needs Assessment – Update 2010 explores the information about the EMA's EIS services in more detail to assess if Part A funding should be allocated for EIS for FY 2011.

Research Question. The research question to be addressed by this section is:

> **What systems are in place in the EMA for early identification of HIV+ individuals, for connecting HIV+ individuals to care, what are the gaps, and what are ways to improve those connections particularly among those unaware of their HIV+ status.**

3.2 Existing Infrastructure in Newark EMA for Early Identification of PLWHA

3.2.1 Estimated Number of Unaware Individuals

The CDC estimates that 21% of PLWHA are unaware of their HIV status (*New Estimates of U.S. HIV Prevalence, 2006* published by the CDC in October 2008 at http://www.cdc.gov/hiv/topics/surveillance/resources/factsheets/pdf/prevalence.pdf). This is down from an estimated 25% unaware in 2003. Applying this percent to the EMA's 13,218 PLWHA as of 12/31/08 yields an estimated **3,520 individuals** in the EMA who are unaware of their HIV status, for a total of **16,738 individuals living with HIV disease as of 12/31/08.**

3.2.2. Early Identification Sites and Geographical Coverage

The NJDHSS provided a list of early identification sites, that is, counselling, testing and referral (CTR) sites, number of individuals tested, number diagnosed as HIV+, for the most recent program year of June 1, 2008 – May 31, 2009. There are a total of 208 sites within the EMA – including stationary CTR sites, mobile units (MUs), hospital Emergency Department (ED) testing, rapid - rapid testing, and others. Many of the CTR sites are Part A providers, including medical care, other core medical services, medical case management and support services. This list of CTR sites is in Appendix F.

There are CTR sites in every county in the EMA: Essex - 114, Morris - 20, Sussex –11, Union – 52, and Warren - 11. This shows that there is geographical coverage of CTR sites for early identification of PLWHA throughout the EMA.

Testing. For the year June 1, 2008-May 31, 2009 a total of 35,955 individuals were tested for HIV at 208 sites in the Newark EMA. Of these, 388 individuals or 1.1% were HIV positive. The number of testing sites and individuals tested in the EMA is proportional to the EMA's HIV epidemic of 13,218 individuals - 38% of the state's PLWHA. However, the EMA accounts for a greater percent (57%) of the state's individuals testing positive for HIV. Nearly half (47%) of the state's newly diagnosed PLWHA are from Essex County testing sites.

Table 11: Number of Individuals Tested, HIV+, Total PLWHA in Newark EMA and New Jersey

Area	6/1/08 – 5/31/09				PLWHA 12/31/08
	# Sites	# Tested	Positive		
			#	%	
Essex County	114	21,436	322	1.5%	9,629
Morris County	20	2,961	12	0.4%	704
Sussex County	11	446	1	0.2%	143
Union County	52	10,920	52	0.5%	2,623
Warren County	11	192	1	0.5%	119
Newark EMA	**208**	**35,955**	**388**	**1.1%**	**13,218**
NJ	535	91,385	686	0.8%	34,915
Percent					
Essex/NJ	21%	23%	**47%**		28%
Newark EMA/NJ	39%	39%	**57%**		38%

Source: NJ Dept. Health and Senior Services (NJDHSS). Division of HIV/AIDS Services (DHAS)

3.2.3 Existing Funding for Early Identification of PLWHA

The annual **Newark EMA Funding Stream Analysis**, prepared by the Newark EMA Planning Council as part of the annual priority setting and resource allocation process, collects and presents current data on funding resources available for early identification of PLWHA - prevention education and counseling and testing services.

The 2009 Funding Stream Analysis, the most recent data available, indicates that a total of $7,663,736 is available from federal and state sources for early identification of PLWHA in the Newark EMA. This includes $2,323,447 for prevention education, $3,699,465 for counseling and testing and $2,008,863 combined prevention/counseling and testing. Federal funding is awarded to five providers directly by the CDC and to nine providers through NJDHSS. State funding (100%) is awarded by NJDHSS directly to 16 providers. A total of 20 agencies receive funding, and 14 (70%) also are funded by Ryan White Part A to provide medical care, other core medical services and support services. Table 12 shows the total funding for early identification, types of providers, and amount going to Part A providers.

Table 12: Existing Funding in Newark EMA for Early Identification of PLWHA

Funding Source & Type of Provider	Prevention & Education	Counseling and Testing	Total Early ID	Early ID Funding to Ryan White Part A Agencies		
	$	$	$	# Provs	$	% Total EI $
Federal CDC & Part B Thru NJDHSS						
Medical Care	$697,225	721,456	$1,418,681	4	$1,337,035	94%
Support Services	$705,086	$0	$705,086	2	$386,250	55%
Total	***$1,402,311***	***$721,456***	***$2,123,767***	***6***	***$1,723,285***	***81%***
Federal CDC Directly to Providers						
Medical Care	$0	$368,039	$1,633,175*	4	$1,633,175	100%
Support Services	$0	$0	$375,688**	1	$375,688	100%
Total	***$0***	***$368,039***	***$2,008,863***	***5***	***$2,008,863***	***100%***
State NJDHSS						
Medical Care	$411,933	$2,254,463	$2,666,396	8	$1,855,852	76%
Core Medical	$155,003	$146,329	$301,322	2	$301,322	100%
Support Services	$354,200	$209,1078	$563,378	2	$409,178	73%
Total	***$921,136***	***$2,609,970***	***$3,531,106***	***12***	***$2,357,184***	***73%***
Total Early ID						
Medical Care	$1,109,158	$3,343,958	$5,718,252	10	$4,826,062	84%
Core Medical	$155,003	$0	$301,332	2	$301,332	100%
Support Services	$1,059,286	$355,507	$1,644,152	3	$1,171,116	71%
Total	***$2,323,447***	***$3,699,465***	***$7,663,736***	***14***	***$6,298,510***	***82%***
Total Federal	$1,402,311	$1,089,495	$4,132,630		$3,732,148	90%
Total State	$921,136	$2,609,970	$3,531,106		$2,566,362	73%
% Federal	60%	29%	54%		59%	
% State	40%	71%	46%		41%	

* Includes combined Prevention & Education and Counseling and Testing of $1,265,136.
** Combined Prevention & Education and Counseling and Testing.

3.2.4 Linkages between CTR Sites and Medical Care

There are a number of linkages between CTR sites and Part A medical care within the EMA.

The first is **Memoranda of Understanding (MOUs)** between every Part A provider and a CTR site. Since FY 2001 the grantee has required <u>all</u> Part A providers (including nonmedical and support services) to execute written referral agreements with HIV CTRs, so that newly diagnosed PLWHA can be linked to the Part A continuum and medical care. These mandatory agreements serve as the infrastructure of connection with medical care, and have replaced outreach as the EMA's primary method for reaching new clients. <u>For FY 2010 the Grantee will require all providers to obtain from their CTR current data on the number of individuals tested and those who are HIV+, to increase awareness of new PLWHA and strengthen these relationships.</u>

The second is **colocation of CTR and medical sites**. This ensures immediate entry or linkage with Part A medical care upon positive HIV diagnosis. The EMA Part A program has given priority funding to colocation of services since 2000. Colocation includes within (1) same clinic or medical office, (2) within the same building, or (3) within the same institution, such as a hospital ED and Part A Clinic. Eleven EI providers are collocated with HIV medical clinics.

The third linkage mechanism includes **special testing initiatives** which target special providers, populations or testing methods to increase HIV diagnoses among high risk, vulnerable or historically underserved populations. These include:

- **Continued HIV Testing in Hospital Emergency Departments (EDs)**, including hospital protocols ensure that individuals testing positive are linked immediately with their HIV clinics for medical care.
- **Expansion of Rapid-Rapid Testing Pilot** beyond three community sites in the Newark EMA, whereby a positive HIV rapid test is confirmed with a second rapid test, and the new HIV+ client is immediately linked to medical care**.**
- **Continued Opt Out Testing in Correctional Facilities and HIV Discharge Planning** to link incarcerated individuals newly diagnosed with HIV with medical care upon their release and to provide ongoing support for 3 to 6 months**.**
- **Continued mandatory testing of pregnant women** required by NJ law, and connection with medical care upon delivery.
- **Testing adolescents for HIV**, per NJ law passed in 2006 allowing an individual age 13 and older to be tested for HIV without consent of parent or guardian, youth outreach and connection with adolescent/young adult-specific HIV medical services.
- **Social Networking to Connect Youth to HIV Testing and Care** through Project WOW! (Web Outreach Works) is reaching lesbian, gay, bisexual and transgender (LGBT) youth, especially young men of color who have sex with men (YMCSM) at high risk of acquiring HIV/STDs.
- **(New in 2010) "Status is Everything"** initiative encouraging youth in Newark to get tested for HIV, particularly LGBT.
- **Immediate linkage of HIV+ Individuals tested at Newark STD Clinic by escort** within Newark Department of Child and Family Well Being (DCFWB) to its Homeless Health Care (HCH) HIV Clinic for medical care, particularly for high risk and transient populations.
- **Continued Participation in Statewide and Regional/Local Prevention Activities** by the Executive Director of the Newark EMA HIV Health Services Planning Council, who is the Chair of the Community Committee of the N.J. HIV Planning Group (NJHPG), to help ensure flow of relevant information between prevention and the Part A care and treatment program.

3.2.5 Patterns of Entry into [Part A] Medical Care

This section reviews current and historical CHAMP data regarding care patterns and entry into medical care including CHAMP reports and statistical analysis showing the (1) Length of time between the earlier of date of HIV and AIDS diagnosis (both dates are federally-required for the RDR/RSR CLD reporting) and initial entry into Part A medical care and (2) source of referral to Part A medical care, e.g., from HIV testing site, hospital discharge, and other sources. These activities and findings are being coordinated with the EMA's Clinical Quality Management Plan and CQM Committee as needed.

3.2.5.1 Length of Time between HIV/AIDS Diagnosis and Entry into Part A Medical Care

Figure KK shows the length of time between HIV/AIDS diagnosis and entry into Part A Medical are for FY 2009 (March 1, 2009 – February 28, 2010). Of the 507 individuals residing in the Newark EMA who are new Part A medical clients in FY 2009 (never received a Part A service before), nearly half (49%) or 249 were diagnosed within the year. In other words, **currently there is an immediate link between HIV diagnosis and entry into medical care which accounts for half of new Part A medical clients.** Another 8% entered care one year after diagnosis.

This linkage to care has been improving over time.

Figure LL shows that the percent of new Part A medical clients entering medical care immediately following HIV diagnosis (under one year) has increased from 28% of new clients in FY 2006 to 49% of new clients in FY 2009.

Figure KK: Distribution of FY 2009 New Part A Medical Clients by Length of Time between HIV/AIDS Diagnosis and Start of Medical Care (N=507 EMA Residents)

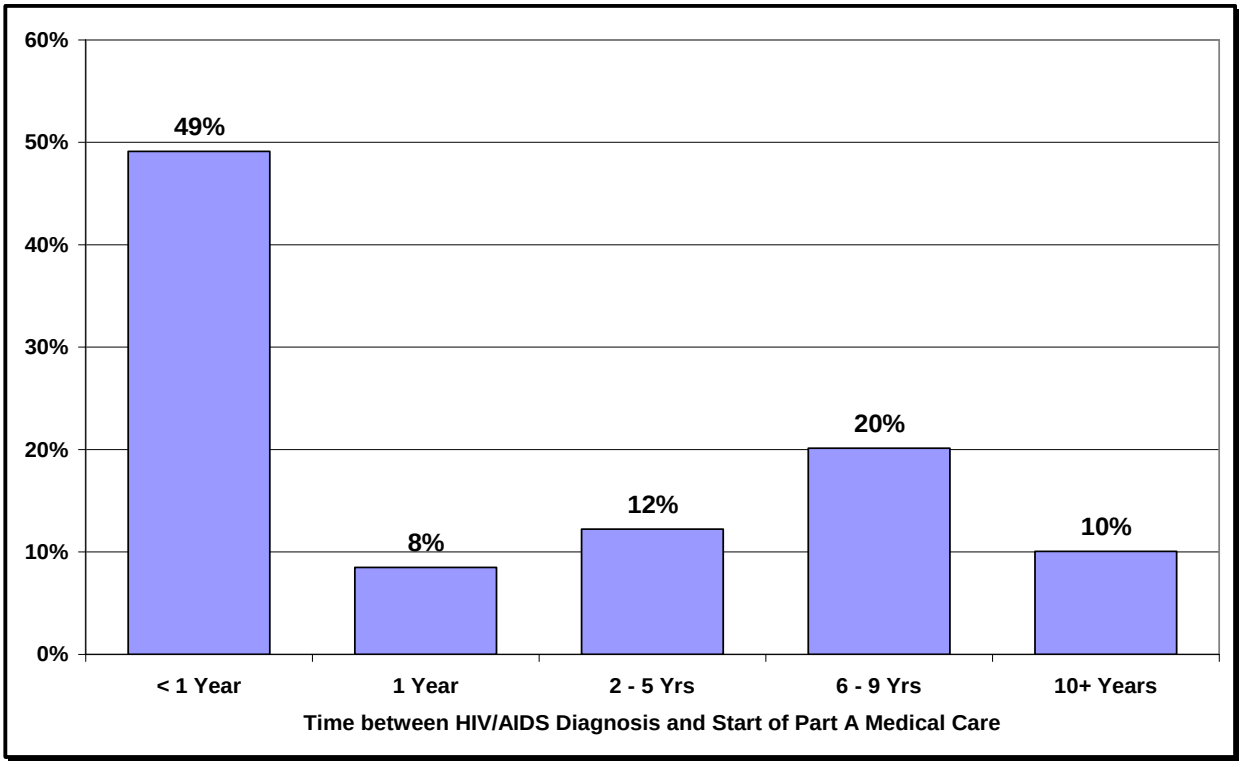
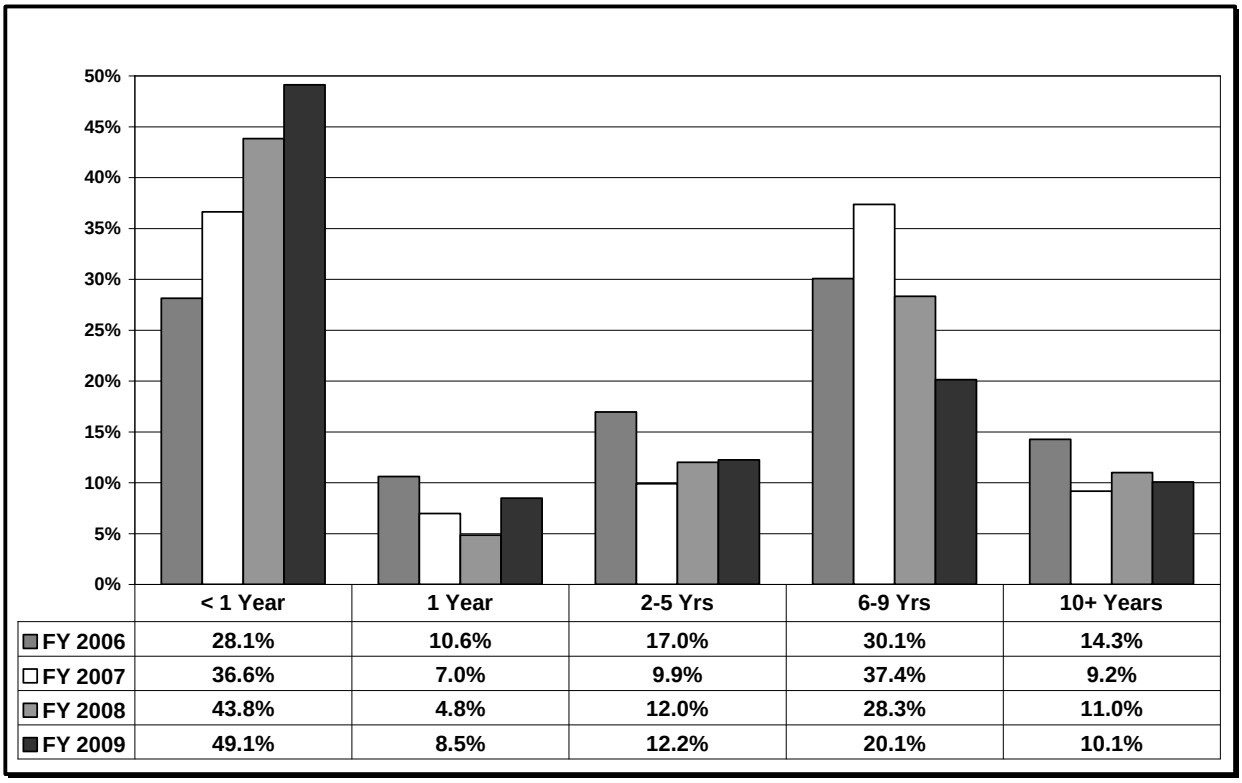


Figure LL: Trends in Length of Time between HIV/AIDS Diagnosis and Start of Medical Care for New Part A Clients (FY 2006 – FY 2009)



	< 1 Year	1 Year	2-5 Yrs	6-9 Yrs	10+ Years
FY 2006	28.1%	10.6%	17.0%	30.1%	14.3%
FY 2007	36.6%	7.0%	9.9%	37.4%	9.2%
FY 2008	43.8%	4.8%	12.0%	28.3%	11.0%
FY 2009	49.1%	8.5%	12.2%	20.1%	10.1%

3.2.5.1 Source of Referral to Part A Medical Care

The purpose of identifying the source of referral to Part A Medical Care is to help the EMA identify current practices and sources which connect PLWHA with medical care as "new clients" – including (1) the newly-diagnosed, (2) those who know their status and are not in care, and (3) those who do not know that they are HIV+ (never returned for test results). Based on this information, the EMA can assess the effectiveness of these sources and determine if changes may be needed to increase referrals – warranting changes in service priorities and/or resource allocation.

Sources of referral to medical care which are recorded in CHAMP include:

- Case Management (CM) Agency
- Hospital Discharge
- Primary Care Physician
- Self
- Test Site
- Other

Table 13 and Figure MM show the source of referral of new clients to Part A medical care.

Table 13: New Part A Medical Clients in FY 2009* – Time Between HIV Diagnosis and Start of Part A Medical Care by Source of Referral to Medical Care

Source of Referral	Time Between HIV Diagnosis & Start of Part A Medical Care					Total
	< 1 Year	1 Year	2 - 5 Yrs	6 - 9 Yrs	10+ Years	
# New Part A Medical Clients in FY09						
Case Mgt (CM) Agency	48	7	18	22	17	112
Hospital Discharge	44	2	6	7	3	62
Primary Care Physician	40	15	5	16	8	84
Self	49	15	21	30	13	128
Test Site	46	1	4	6	2	59
Other	22	3	8	21	8	62
Total	**249**	**43**	**62**	**102**	**51**	**507**
% Dist. by Interval	**49%**	**8%**	**12%**	**20%**	**10%**	**100%**
% Distribution by Referral Source						
Case Mgt (CM) Agency	19.3%	16.3%	29.0%	21.6%	33.3%	22.1%
Hospital Discharge	17.7%	4.7%	9.7%	6.9%	5.9%	12.2%
Primary Care Physician	16.1%	34.9%	8.1%	15.7%	15.7%	16.6%
Self	19.7%	34.9%	33.9%	29.4%	25.5%	25.2%
Test Site	18.5%	2.3%	6.5%	5.9%	3.9%	11.6%
Other	8.8%	7.0%	12.9%	20.6%	15.7%	12.2%
Total	**100.0%**	**100.0%**	**100.0%**	**100.0%**	**100.0%**	**100.0%**

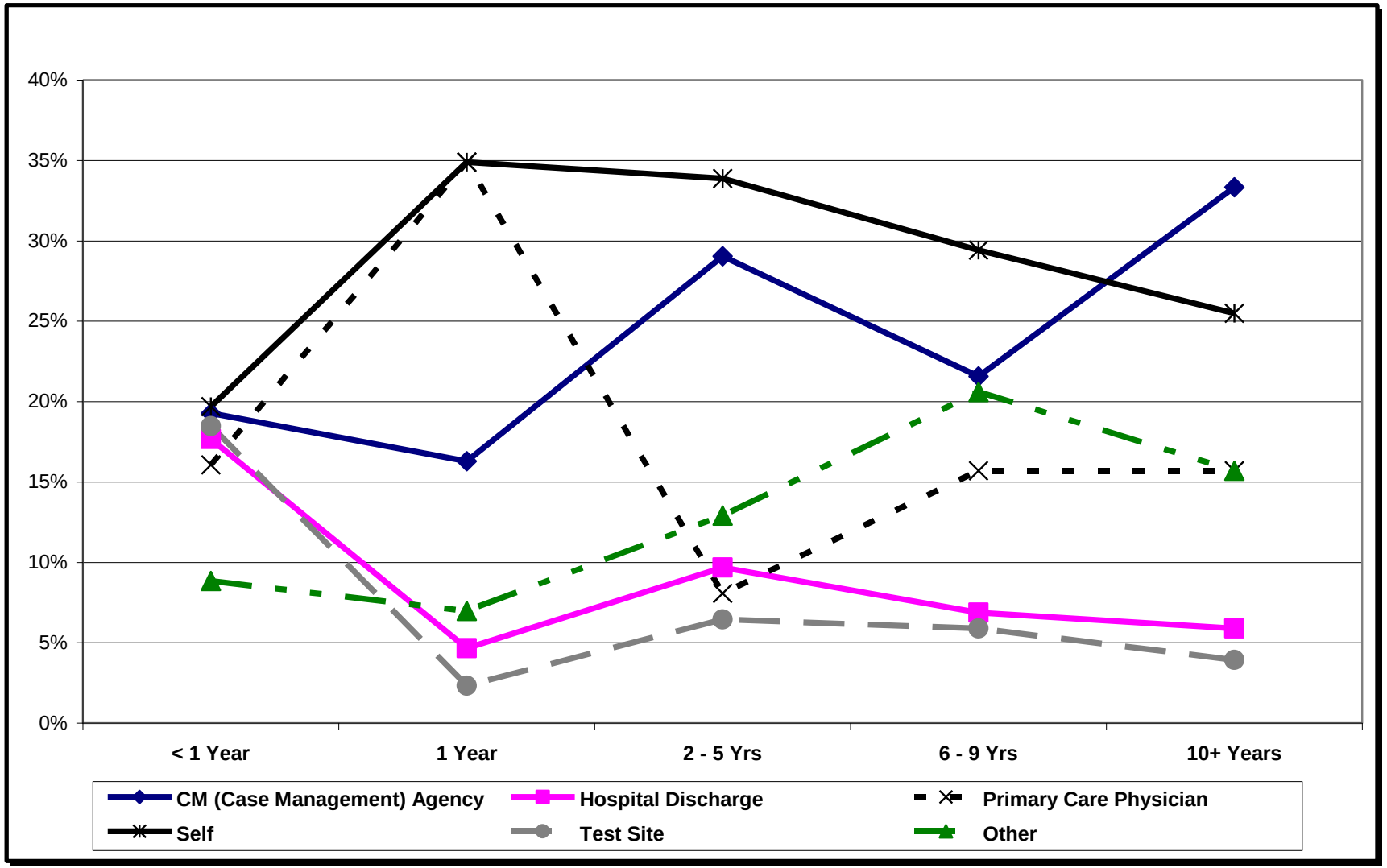
*Residing in the EMA's 5 counties

Immediate Entry into Medical Care. Table 13 shows that all methods of referral at time of HIV testing – case management agency, hospital, primary care physician, testing site, and self-referral – each contribute 16% to 19% of new Part A medical clients. **Thus all referral sources appear to be equally effective in getting people immediately into medical care following HIV/AIDS diagnosis**.

Delayed Entry into Medical Care. If a person waits to enter medical care, then the effectiveness of referral sources changes regarding their ability to get PLWHA into medical care. The physician is important within the first year, but afterwards, a case management agency may be important as well as other sources, e.g., family or friends. But the most important person at this point is the individual himself or herself, probably because they are sick or starting to feel the effects of untreated HIV infection.

Conclusion. It does not appear that it is necessary to allocate Part A resources to counseling and testing under the service category of Early Identification Services, since CTR is no more effective than other sites in connecting newly diagnosed to medical care. Existing funding sources appear to be sufficient.

Figure MM: FY 2009 Part A Medical Clients in Newark EMA by Time Between HIV Diagnosis & Start of Part A Medical Care and Source of Referral to Medical Care



3.2.6 Assessment of Existing System in Newark EMA for Early Identification of PLWHA

This section includes an assessment of all existing systems connecting counseling, testing and referral (CTR) sites with Part A systems, particularly Part A medical care. These systems include an updated assessment by the Council's Continuum of Care (COC) and Comprehensive Planning Committees (CPC) to identify the best venues for assessing referral to medical care, as well as statewide prevention planning groups such as the NJ HIV Planning Group (NJHPG) through membership of the Council's Executive Director and NJDHSS Part B representative to the Planning Council.

A review of existing resources within the Newark EMA – funding and providers – indicates that there are sufficient resources for early identification of people who do not know their HIV status as well as reaching unknown PLWHA through mobile units.

- **Geographical coverage.** A total of 15 mobile units travel to 150 sites by zip code areas in the EMA. All zip code areas in Essex and Union Counties are covered by the mobile units.
- **Connection between CTR and Part A.** Of the 20 CTR providers, 14 or 70% receive Part A funding. This means that there is a direct link between CTR and the Part A system of care.
- **Funding.** The prevention/education and CTR funding in the Newark EMA of $7.7 million is double the expenditures for Part A medical care of $3.7 million in FY 2009.

3.3 Gaps in Connection between HIV Testing and [Part A] Medical Care

Even though there are resources (funding), mandated linkages between CTR and medical care, new initiatives, and planning across prevention/testing and medical care, there are still gaps or problems in connecting PLWHA from testing to medical care. These operational issues have arisen over time as well as recently in response to CTR program changes.

Existing Systems. At the Continuum of Care (COC) meeting of June 10, 2010, the committee members who all have experience in CTR and medical care, discussed some of the issues regarding the EI initiative. They identified the following gaps or barriers between CTR and medical care. The Consumer Services Advisory Committee (CSAC) provided additional input at its June 10th meeting as well.

On the HIV Testing Side

- **Advertisements and PSAs** all emphasize HIV testing "Know Your Status" but do not emphasize getting medical care. We need education telling people to get into medical care.
- **Perception of the Mobile Unit (MUs).** Some high risk groups, e.g., young adults, do not feel that results from the "testing vans" are legitimate or valid, because it is only a van. They will go to a clinic or other stationary facility.

  - Some clients come into a stationary site, e.g., hospital CTR, for retesting even after receiving a HIV+ test from a mobile unit. "I got this result, what does in mean?"

- **Incentives.** CTR agencies are permitted to give consumers incentives, e.g., grocery store gift certificates or vouchers, to come in for testing. This has increased the number of people being tested. These incentives are not available for keeping a medical appointment.

Patient Behavior

- **Patient denial** is still a factor. One provider noted that at least 50% are in denial about their HIV status and will not take the next step - go into medical care, etc.
- **Stigma** about HIV is still an issue. Patients do not want people to know they are HIV+. Even in a closed setting, e.g., jail, one patient who tested HIV+ by rapid test did not want a second confirmatory test because of the stigma and fear that people would learn the patient's status. The October 2009 issue of POZ magazine reported that PLWHA do not get into medical care due to stigma. In the original study by UCLA of 202 low income HIV+ patients, 33% reported high levels of stigma, and as a result, most (77%) reported poor access to medical care.[15]
- **Readiness.** Patients may not be "ready" to start medical care. Even if they come to the clinic on their own volition, and go through medical case management, nurse, etc., they may drop out.
  - Even if they are diagnosed at a hospital-based CTR site and are escorted to the medical clinic, they may still drop out after the first visit.

On the Part A Medical Care Side

- **Connection between CTR and Medical Care varies.** Effectiveness of linkages often depends on CTR and clinic locations. There are different results in linking newly-diagnosed to medical care depending on the location of the CTR and Part A site and the procedures for entry into medical care.
  - If in the same building, linkage is easier. Some persons are brought directly from the testing clinic into the medical clinic to see the HIV physician. Others have a longer process.
  - If in different locations, e.g., mobile unit and stationary medical clinic, the process is more challenging.
- **Patient Navigators.** The Patient Navigator links the newly diagnosed person with medical care and provides support during the initial 3-6 months of medical care. This has met with mixed success. In one instance, once the patient navigation support services ended after 6 months of medical care, the patient dropped out of care.

[15] Sayles J. MD, MPH, Wong M. MD, PhD, Kinsler J. PhD, Martins D. MD. Cunningham W. MD, MPH. The Association of Stigma with Self-Reported Access to Medical Care and Antiretroviral Therapy Adherence in Persons Living with HIV/AIDS. Division of General Internal Medicine and Health Services Research, David Geffen School of Medicine at University of California, Los Angeles, CA, USA; Charles R. Drew University of Medicine and Science, Los Angeles, CA, USA; Department of Health Services, UCLA School of Public Health, Los Angeles, CA, USA.

Communication between CTR sites and Part A Medical Care

- **New state CTR program instructions** may not completely address linkages to medical care. For example, new CTR initiatives include going out into the community to perform "outreach testing" and to test individuals during nontraditional hours such as evenings and weekends. However, once the person is diagnosed they cannot be connected to medical care immediately because the Part A medical providers may not be open or have office hours at these times.
- **CTR agencies may not have not historically shared best practices or lessons learned with newer combined CTR/Part A agencies** which would make counseling and testing activities more effective for newly funded CTR agencies. For example, one agency had to learn by experience, that there were convenient and inconvenient times for conducting testing in non-traditional hours to at-risk and hard-to-reach individuals. They had to learn by agency trial and error what were the best hours, venues and types of staff who could do the testing best to reach the most people.
- **State CTR program instructions may inadvertently create "silos" and gaps between CTR and medical care.** CTR providers reported that state CTR instructions did not allow then to co-locate with medical clinics and make immediate connection to medical care because the clinics are funded to "do routine testing." This may be a misunderstanding of Part A clinics or possibly an actual gap.
    - Although **Part A clinics** do routine HIV testing for those already diagnosed, they cannot use Part A funding for testing the general population, unless the Planning Council approves the service category of **Early Intervention Services (EIS)** which includes counseling and testing regardless of HIV status and **the Chief elected official certifies that Federal, State, or local funds are otherwise inadequate and if funds expended for EIS will supplement and not supplant other funds available to the entity for EIS for the fiscal year**. The Newark EMA has never made this certification or allocated Part A funding for EIS because funding and locations were sufficient, as described above.
    - **Testing gap.** In 2006 the CDC recommended that all medical sites (not HIV only) perform routine testing for HIV regardless of patient risk. NJDHSS recommended this practice to NJ medical sites, and offers to provide rapid testing supplies but no staff. This placed the onus for HIV testing on private medical staff, and many did not follow the recommendation despite availability of supplies at no cost to the provider. Simultaneously, NJDHSS policy was that publicly funded CTR sites should not collocate with these non-HIV medical sites charged with routine testing, which would have been duplication of services.

Locating the Unaware. We need to identify where the "unaware" PLWHA are – that is, undiagnosed PLWHA. Consumers attending Council's committees provide anecdotal information regarding locations frequented by two patient groups – (1) undiagnosed persons or (2) diagnosed-not-in-care persons. The question is: where do these individuals hang out? And, are these locations accessed by existing CTR mobile units? If not, how can the "early identification system" be improved to reach these new locations? This will require work with the CTR agencies, NJDHSS, NJ HIV Planning Group (NJHPG) as well as the Council's Consumer Services Advisory Committee (CSAC) and consumers on all Council committees.

Strategies to Address these Barriers/Gaps. As part of planning for the FY 2011 Part A grant application, the Planning Council, grantee and providers will be developing strategies to help address these barriers and gaps. The goal will be to improve connection to care for those unaware of their status. (Method to be finalized during project.) More guidance on the federal expectations for FY 2011 will be available from HRSA HAB during the summer by Technical Assistance teleconference.

3.4 Conclusions and Recommendations

The Newark EMA has a comprehensive infrastructure of early intervention services – prevention education and counseling/testing/referral (CTR) – which is strongly linked to the Part A system with 70% of CTR providers also providing Part A services and particularly Part A medical care. CTR services in the Newark EMA are very effective, resulting in 57% of the state's new HIV diagnoses which exceeds our proportion of PLWHA (38%). Funding of $7.7 million in CTR including $4.1 million of federal monies is sufficient to continue early identification services in the Newark EMA without the need for additional allocation from Part A EIS.

- Based on these findings, it is recommended that the Council carefully assess the most recent information on the current and future CTR funding situation before allocating Part A services to EIS for CTR for FY 2011.

Notwithstanding the strong infrastructure, there are still gaps in the early identification continuum. The following recommendations will address some of those gaps:

- Advertising for HIV testing and education should also include a recommendation to get medical care and treatment for HIV disease.
- Part A should look at services or methods which would incentivize PLWHA keep their medical appointments and provide support to remain in care. These strategies should be incorporated into a provider's medical program.
- Part A should work with existing CTR services to better understand both systems and to improve connections from diagnosis to care, possibly through a **joint meeting of all CTR and Part A providers in the Newark EMA.** Topics should include the following:
    - Most recent CTR program goals, objectives, policies and instructions, and desired outcomes, particularly regarding testing venues and strategies;
    - Clarification of Part A roles and responsibilities with respect to counseling, testing and medical care;
    - Effectiveness of existing CTR venues, including mobile units, in reaching undiagnosed. Are there perception problems or other factors which may be barriers to testing;
    - Networking between Part A and CTR providers with MOUs to understand referral systems and make improvements where needed;
    - Strategies to locate the unaware population in the EMA, particularly areas of high HIV prevalence, and new sites for outreach;
    - Strategies for ongoing communication to update new locations and provide feedback on joint performance.
- Evaluation of performance of early identification services by Council, through its Research and Evaluation Committee.

PART 4: SPECIALTY CARE

4.1 Introduction

During 2009 and a review of the EMA's HIV continuum of care with respect to demographics of the current HIV+ population, medical providers noted an increasing need for specialty medical care services beyond HIV primary medical care. These needs are arising because (1) patients are living longer and, as HIV disease evolves over time, the longer term impacts are manifesting themselves, and (2) HIV+ individuals are aging and experiencing the same health care issues facing all adults age 50 and older.

The issue is important because of the cost of and payment for specialty care. If patients are receiving Ryan White Part A and Part F funded medical care, they are in fact uninsured lacking health insurance. The question becomes who pays for specialty care, and if charity care is available, there may be a long wait for this care at a hospital.

The federal Ryan White program references specialty care in its definition of outpatient/ambulatory medical care.

> ***"Outpatient/ambulatory medical care*** includes the provision of professional diagnostic and therapeutic services rendered by a physician, physician's assistant, clinical nurse specialist, nurse practitioner, or other health care professional who is certified in his or her jurisdiction to prescribe antiretroviral (ARV) therapy in an outpatient setting. These settings include clinics, medical offices, and mobile vans where clients generally do not stay overnight. Emergency room services are not considered outpatient settings. Services include diagnostic testing, early intervention and risk assessment, preventive care and screening, practitioner examination, medical history taking, diagnosis and treatment of common physical and mental conditions, prescribing and managing medication therapy, education and counseling on health issues, well-baby care, continuing care and management of chronic conditions, and **referral to and provision of specialty care (includes all medical subspecialties)**. Primary medical care for the treatment of HIV infection includes the provision of care that is consistent with the PHS's guidelines. Such care must include access to ARV and other drug therapies, including prophylaxis and treatment of opportunistic infections and combination ARV therapies."[16]

Research Question. The research question to be addressed is:

> **What is the extent of need for specialty care among PLWHA, the availability of those services, and gaps?**

[16] Ryan White HIV/AIDS Program Services Report Instruction Manual Version 2.0. HIV/AIDS Bureau Division of Science and Epidemiology Health Resources and Services Administration U.S. Department of Health and Human Services 5600 Fishers Lane, Room 7-90 Rockville, MD 20857

This section provides detail about the various types of "specialty care" needed and will assist the Planning Council in understanding this issue and needs of PLWHA when prioritizing services and allocating resources.

4.2 Definition of Specialty Care

The first step was to define "specialty care". The Council's committees provided guidance. The definition started with the National Board of Internal Medicine listing of board-certified subspecialties. The Research and Evaluation Committee (REC) reviewed the list and recommended appropriate categories for Part A. The REC compared the list with the Newark EMA HIV Primary Medical Care Standards of Care[17] and found that all recommended specialties were included in the standards. The Continuum of Care (COC), Comprehensive Planning (CPC) and Council's Executive Committees reviewed the REC list and provided additional guidance and recommendations. The list of specialty care was finalized and is shown in Table 14 below.

Table 14: List of Specialty Care Medical Subspecialties

	Type of Medicine
1.	Allergy and immunology
2.	Cardiovascular disease
3.	Endocrinology, diabetes, and metabolism
4.	Gastroenterology
5.	Geriatric medicine
6.	Hematology
7.	Infectious disease (1)
8.	Medical oncology (2)
9.	Nephrology
10.	Pulmonary disease
11.	Rheumatology
12.	Neurology
13.	Dermatology
14.	Ophthalmology

Comments and Notes:
(1) Some Ryan White physicians are not Infectious Disease (ID) specialists so this has to be listed as a separate specialty.
(2) Medical oncology includes follow up to abnormal Pap and cervical cancer.

[17] Newark EMA. http://www.newarkema.org/content/pdf/2008_needs/Primary_Medical_Care_Standards_2008.pdf

The Newark EMA standards of care reflect specialty care as follows:

"3.2 ACCESS, CARE AND PROVIDER CONTINUITY

j. Are there care services which include (or arranged by referral):

- Laboratory
- Radiological studies/imaging
- Pharmacy
- Developmentally specific mental health services
- Gastroenterology/Hepatology
- Hematology
- Neurology
- Psychiatry
- Ophthalmology
- Dermatology
- Outpatient surgery
- Obstetrics and gynecology
- Pediatrics, adolescent medicine and pediatric sub-specialties
- Pulmonary
- Oncology
- Dentistry
- Case Management
- Physical therapy
- Nutritional counseling
- Substance Abuse treatment
- Developmentally specific and appropriate behavioral health counseling
- Antiretroviral counseling/therapy for pregnant women
- Information for persons with inherited coagulopathies and referral to the local federally funded hemophilia treatment center
- Pain management/palliative care

4.3 Specialty Care Needs

The Council has not assessed the quantitative need for specialty care as defined above. However, the extent of specialty screening and care is comprehensively discussed in the June 2009 issue of New Jersey AIDS Line, "What is Good Practice? HIV Care Beyond ART."[18] Examples include but are not limited to:

- **Screening for Other Infectious Diseases:** Sexually Transmitted Infections (STIs) including Chlamydia and Gonorrhea, Lymphogranuloma venereum (LGV) outbreaks, caused by Chlamydia trachomatis, Syphilis, Herpes simplex as well as Hepatitis: A, B, and C:,
- **Cardiac issues – monitoring of lipid profiles,** coronary artery disease noting age, perimenopause and postmenopausal women, comorbid substance use;
- **Pulmonary issues** – asthma screening, chronic obstructive pulmonary disease (COPD), lung cancer.
- **Gastrointestinal** – colon cancer, stomach (dyspepsia and diarrhea), nausea and vomiting, abdominal pain;
- **Cancer screenings** - head and neck, breast, prostate, rectal, liver.
- **Renal or Kidney Disease**

[18] Kloser, P and Nakata, K. What is Good Practice? HIV Care Beyond ART. New Jersey AIDSLine. June 2009. UMDNJ. Center for Continuing and Outreach Education. Newark, NJ. http://ccoe.umdnj.edu/catalog/aids/pdf/AIDSLine_June2009.pdf

- **Liver Disease** – hepatitis is most common
- **Allergy and Immunology**
- **Endocrine –** diabetes, erectile dysfunction, need for hormone replacement therapy.

4.4 Availability of Specialty Care

The Ryan White program is the payer of last resort. Providers must exhaust all non-Ryan White sources for provision of specialty care. This includes actively assessing patients for eligibility for Medicaid and Social Security Disability.

Specialty care can be provided by Part A if the provider applies for and receives Part A medical care. A Part A medical provider can subcontract with another medical provider to deliver specialty care, within the Part A provider's contracted medical care allocation. The Part A provider is responsible for paying the specialty provider, with a unit cost the same as the primary medical care unit cost. No additional funding is available separately for specialty care.

Every Part A medical provider must negotiate this arrangement with the Grantee.