Cleveland/Lorain/Elyria TGA

2009 Out of Care PLWHA
Needs Assessment
Report of Findings

Cuyahoga Regional HIV Services
Planning Council

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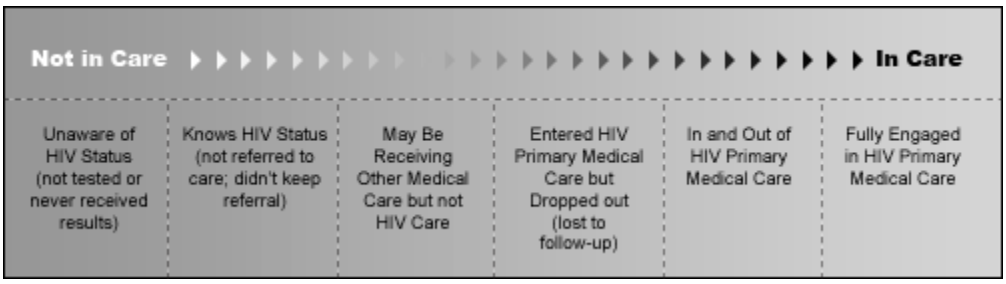
Overview of the Cleveland TGA

The Cleveland TGA consists of six counties in Northeastern Ohio. The region is characterized by an historic industrial economy, with recent economic deterioration resulting in out-migration of population from the area, particularly from the City of Cleveland. General demographics of the area show a higher percentage of African Americans than Ohio, smaller fraction of Anglos, and slightly smaller Latino population than the state. The PLWHA community is disproportionately composed of African American, with disparities for PLWHA of color. The PLWHA community has a high percentage of 'aged'. Concerns exist about barriers to care access related to the broad geographic region, cost of transportation, and centralized provision of primary medical care in Cuyahoga County. In addition, needs assessments conducted from 2003 to the present cite affordable housing as a barrier, and a lack of aggressive referral to medical care entry for care of HIV disease following confirmatory diagnosis.

Relevance of the 2009 "Out of Care" Needs Assessment Study



(Source: HRSA CARE Action Newsletter, 2007)

Overview of Out of Care Needs Assessment Findings

CHAPTER 1. INTRODUCTION TO THE CLEVELAND TGA

The Cleveland TGA consists of six counties in three distinct regions bordering Lake Erie in the State of Ohio. The general population of this six-county area is estimated to be 2,216,858 persons in 2006 or 19.3% of the entire population of the State of Ohio. Population size varies dramatically by county. Cuyahoga County comprises 59.3% of the six-county area, with 34% of the population of Cuyahoga County residing within the City of Cleveland. Ashtabula, Geauga and Lake Counties comprise the *Eastern* Region and Lorain County, the *Western* Region. Cuyahoga and Medina Counties define the TGA's *Central* Region. Cuyahoga County comprises the bulk of the general population as well as the HIV infected.

FIGURE 1: MAP OF 6 COUNTIES OF CLEVELAND TGA IN NORTHEASTERN OHIO

TABLE 1. GENERAL POPULATION ESTIMATE IN 6-COUNTY TGA, 2008

County	Estimated General Population - 2008	% of 6-County TGA
Ashtabula	100,648	4.6%
Cuyahoga	1,283,925	58.7%
Geauga	94,753	4.3%
Lake	234,030	10.7%
Lorain	304,373	13.9%
Medina	171,210	7.8%
Cleveland TGA	**2,188,939**	**100.0%**

(Source: U.S. Census Bureau, 2008Population Estimate of Ohio by County)

General Demographics of the TGA: The racial/ethnic profile of the Cleveland TGA varies greatly by county. Cuyahoga and Lorain Counties are the only counties with an Anglo population of less than 90%. Almost 30% of Cuyahoga County's residents are African American, while Lorain County has an African American population of 9% and the largest

Latino population in the TGA, at 7.2%. Only Cuyahoga County has a significant Asian population, at 2% of residents. These figures compare to 85% Anglo, 11.5% African American and 1.9% Latino in the state of Ohio. The United States is made up of 75.1% Anglo, 12.3% African American and 12.5% Latino. Therefore, the TGA has a smaller Anglo population, larger African American and *smaller* Latino population than Ohio, with the only variance from the United States profile being a *smaller* percentage of Latinos.

TABLE 2. RACE/ETHNIC GROUP BY COUNTY & REGION, 2008*

Race/Ethnicity	TGA	Ashtabula	Geauga	Lake	Eastern Region	Cuyahoga	Medina	Central Region	Lorain/ Western Region
Anglo	**77.7%**	94.8%	97.0%	94.8	**95.3%**	66.9%	96.6%	**71.0%**	**88.0%**
African	**19.1%**	3.3%	1.6%	2.9%	**2.7%**	29.3%	1.5%	**27.0%**	**9.0%**
Latino	***4.0%***	*3.0%*	*0.8%*	*2.9%*	***2.5%***	*4.1%*	*1.3%*	***4.0%***	***7.0%***
Asian	**1.7%**	0.4%	0.6%	1.2%	**0.9%**	2.3%	0.1%	**1.0%**	**1.0%**
Native American	**0.2%**	0.2%	0.1%	0.1%	**0.1%**	0.2%	0.1%	**0.2%**	**0.3%**
Multi race	**1.1%**	1.3%	0.7%	0.9%	**0.9%**	1.2%	0.8%	**1.0%**	**0.7%**

(Source: U.S. Census Bureau, 2008 Population Estimate of Ohio by County) * *Latino* may be of any race.

As evidenced in Table 2 above, the demographic profile of each region in the TGA is distinct:
1) The Eastern region has a **dominant Anglo** population (95%) with 3% African American and 2.5% Latino residents (steadily increasing since 2000).
2) The Central region also has a majority Anglo population (71%), with the **largest subgroup (27%) of African Americans, and 4% Latino.**
3) The Western region also has an Anglo majority (88%) but with **9% African American and the largest Latino subgroup at 7%.**

Age breakdowns show variation in age brackets in the general population for the TGA and within the individual regions and counties. The Central region has the youngest age groups when compared to the TGA; the **Eastern region has the highest percentage of those over 45 years of age (39%),** followed by the Western (36%), and then Central (30%) regions. All subgroups have a gender split between male and female close to the 48% male: 52% female proportion of the six-county TGA, as seen in Table 3. The Central Region is the furthest from that ratio due to Cuyahoga County's higher number of female residents.

TABLE 3. GENDER COMPOSITION BY REGION, 2008

Gender	TGA	Eastern	Central	Lorain
Male	**48%**	49%	47%	49%
Female	**52%**	51%	53%	51%

(Source: U.S. Census Bureau, 20086 Population Estimate of Ohio by County)

This overview demonstrates that the three regions exhibit varied racial, age and gender compositions. This variation impacts the needs of PLWHA and is considered by the grantee and Planning Council when allocating Part A resources to ensure parity.

HIV/AID Incidence and Prevalence in the TGA

Data provided by the Ohio Department of Health (ODH) for the time period ending December 31, 2007, illustrates the impact of the epidemic on various populations in the Cleveland TGA. The TGA's minority populations are disproportionately impacted by the HIV/AIDS epidemic, since African Americans are 20% of the general population in the TGA, but comprise 54% of the affected population; Latinos are 4% of the population but 9% of PLWHA in the TGA. The combined minority comparison is 24% of the TGA population bearing 63% of the existing HIV disease burden. The ODH 2007 AIDS Surveillance Report shows the following estimates of persons reported living with HIV/AIDS in the TGA by county. The six counties comprising the Cleveland TGA account for 26% of all cases reported in Ohio. The majority of cases (82%) in the TGA are in Cuyahoga County and the Central Region, followed by the Western Region, with Lorain County accounting for 13% of cases. The Eastern Region represents 5% of cases in the Cleveland TGA.

TABLE 4. CLEVELAND TGA: COUNTY LEVEL DATA, PLWHA, ODH, 2007

County	Number	Percentage of TGA
Ashtabula	56	1%
Cuyahoga	3,401	81.5%
Geauga	19	1%
Lake	104	3%
Lorain	559	13%
Medina	36	0.5%
TOTAL	**4,175**	**100%**

(Source: Ohio Department of Health, HIV/AIDS Surveillance Program. Data as of December 31, 2007).

HIV/AIDS Cases by Demographic Characteristics and Exposure Categories: Examination of the infected community between the years of 2005-2007 focuses on the TGA's three major racial subgroups along with age, gender and mode of transmission. Contrast is made separately for newly diagnosed AIDS cases (AIDS incidence), and people living with the disease (AIDS prevalence and HIV prevalence).

Race/Ethnic Groups:

TABLE 5. TREND LINE OF RACE/ETHNIC GROUP COMPOSITION IN CLEVELAND TGA, 2005-2007

	2007			2006			2005		
RACE/ ETHNIC GROUP	**Newly Diagnosed AIDS**	**PLWA**	**PLWH**	**Newly Diagnosed AIDS**	**PLWA**	**PLWH**	**Newly Diagnosed AIDS**	**PLWA**	**PLWH**
White	34%	38%	33%	31%	37%	35%	29%	38%	34%
Black	55%	52%	56%	58%	52%	57%	59%	52%	56%
Latino	9%	9%	8%	10%	10%	7%	12%	9%	9%
Asian						1%		.3%	.3%
Amer. Indian								.3%	.3%
Multiracial	2%	1%	1%	1%		1%		.3%	.3%
TOTAL	**100**	**100**	**100**	**100**	**100**	**100**	**100**	**100**	**100**

(Source: Ohio Department of Health, HIV/AIDS Surveillance Program. Data as of December 31, 2007).

As illustrated, the percentage of cases of PLWH and PLWA by race/ethnicity has remained constant among Whites, Blacks and Latinos over the three year period. There has been a slow decline in the percentage of new AIDS cases among people of color from 59% to 55% among Blacks and from 12% to 9% among Latinos, and a **significant increase from 29% to 34% among Whites.**

Race/Ethnic Group Disparities:

TABLE 6. 2007 AIDS INCIDENCE, PREVALENCE AND HIV PREVALENCE BY RACE/ETHNICITY

Race/ Ethnicity	TGA (Gen. Pop)	Newly Diagnosed AIDS	Newly Diagnosed HIV	PLWA	PLWH	Delta New AIDS	Delta New HIV	Delta PLWA	Delta PLWH
Anglo	**78%**	34%	34%	38%	33%	*NO DISPARITY*	*NO DISPARITY*	*NO DISPARITY*	*NO DISPARITY*
African	**20%**	55%	58%	52%	56%	**35%**	**38%**	**32%**	**36%**
Latino	**4%**	9%	8%	9%	8%	**5%**	**4%**	**5%**	**4%**

(Source: Ohio Department of Health, HIV/AIDS Surveillance Program. Data as of December 31, 2007).

Comparison of the 2007 HIV/AIDS statistics to the general population demonstrates that **disparities in HIV disease** are present for People of Color for all indicators—new HIV and AIDS cases, PLWA and PLWH. Latinos also have disparities for all indicators, but to a lesser degree than African Americans. Rephrased, African Americans have over 3 times the rate of HIV disease than their proportion in the general population while Latino/a have twice the rate.

Age:

TABLE 7. AGE GROUP AMONG INFECTED COMMUNITY IN CLEVELAND TGA, 2005-2007

	2007			2006			2005		
AGE AT DIAGNOSIS	Newly Diagnosed AIDS	PLWA	PLWH	Newly Diagnosed AIDS	PLWA	PLWH	Newly Diagnosed AIDS	PLWA	PLWH
<13 years		1%	2%		1%	1%		1%	1%
13-19 years	3%	3%	3%	1%	1%	6%	5%	1%	1%
20- 44 years	62%	80%	80%	69%	79%	75%	69%	55%	58%
45 + years	35%	16%	15%	29%	19%	19%	26%	43%	36%
TOTAL	**100**	**100**	**100**	**100**	**100**	**100**	**100**	**100**	**100**

(Source: Ohio Department of Health, HIV/AIDS Surveillance Program.)

Age group comparisons of new AIDS cases to existing AIDS and/or HIV prevalence show emerging patterns of the disease and indicate where risk behaviors are moving the epidemic. ***The Cleveland TGA evidences a bimodal age emergence, with young (ages 15-24 years) minority MSM being diagnosed at late stages of the disease (AIDS incidence).***

The group with the second highest number of new AIDS diagnoses is the 45 and older age band, now comprising 35% of new AIDS cases. The large 20-44 year age band appears to be slowly decreasing in numbers of new cases. The percentage of PLWH among those 20-44 years of age has risen from 58% in 2005 to 80% in 2007 and the percentage of PLWA 20-44 has risen from 55% to 80% during that same three-year period.

During the same period the percentage of PLWH among those 45 years of age and older has decreased from 36% to 15% and the percentage of PLWA over 45 has decreased from 43% of the cases to 16%. This is due to both the inevitable actual death rates among the older population group as well as a one-time data purge accounting for the removal of a significant number of cases previously included in the surveillance data for this age group.

HIV/AIDS incidence among youth in Cuyahoga County increased 57% to 80 cases reported in 2006-2007 compared to 2004-2005. On average, four youth males are diagnosed with HIV to every one youth female. Youth represent about 30% of all incident diagnoses annually.

Gender:

TABLE 8. GENDER AMONG INFECTED COMMUNITY IN CLEVELAND TGA, 2005-2007

	2007			2006			2005		
GENDER	**Newly Diagnosed AIDS**	**PLWA**	**PLWH**	**Newly Diagnosed AIDS**	**PLWA**	**PLWH**	**Newly Diagnosed AIDS**	**PLWA**	**PLWH**
Male	75%	80%	79%	74%	80%	81%	77%	81%	77%
Female	25%	20%	21%	26%	20%	19%	23%	19%	23%

(Source: Ohio Department of Health, HIV/AIDS Surveillance Program).

Comparison of the TGA's HIV/AIDS statistics to the proportion of males to females in the general population demonstrates disparities for males in all three indicators—new AIDS cases, PLWA and PLWH.

Exposure/Transmission Category:

TABLE 9. TRANSMISSION AMONG INFECTED COMMUNITY IN CLEVELAND TGA, 2005-2007

	2007			2006			2005		
EXPOSURE. TRANSMISSION	**Newly Diagnosed AIDS**	**PLWA**	**PLWH**	**Newly Diagnosed AIDS**	**PLWA**	**PLWH**	**Newly Diagnosed AIDS**	**PLWA**	**PLWH**
MSM	40%	51%	37%	39%	50%	37%	41%	49%	34%
IDU	9%	11%	9%	8%	12%	4%	7%	13%	10%
MSM: IDU	7%	6%	3%	4%	6%	4%	3%	6%	3%
Heterosexual	35%	13%	12%	15%	14%	8%	11%	12%	10%
Other/Unknown	8%	19%	39%	34%	18%	47%	37%	20%	42%
TOTAL	**100**	**100**	**100**	**100**	**100**	**100**	**100**	**100**	**100**

(Source: Ohio Department of Health, HIV/AIDS Surveillance Program).

Transmission groups show a decrease in MSM exposure from 2005 to 2007 for **newly diagnosed AIDS cases.** IDU experienced a dramatic decrease from 2003 to 2004, with a slight rise in 2005 -2007. Heterosexual transmission is erratic due to the large 'Other Unknown' percentage. **PLWA** continue to be largely represented by MSM, although in 2005, the percentage dipped below 50% of the entire group for the first time. IDU activity-- whether IDU or MSM/IDU, is decreasing slightly.

A large unknown/other fraction represents an obstacle to determining causation. **PLWH** show decreases in all categories with interpretation hampered by the 42% other/unknown percentage.

TABLE 10. NEWLY DIAGNOSED AIDS

NEW AIDS 2007	E. REGION	CENTRAL	WEST	TGA
Anglo	57%	33%	34%	**34%**
African American	21%	58%	54%	**55%**
Latino	21%	8%	12%	**9%**
Other	1%	1%	2%	**2%**

TABLE 11. NEWLY DIAGNOSED HIV

NEW HIV 2007	E. REGION	CENTRAL	WEST	TGA
Anglo	53%	33%	35%	**34%**
African American	27%	59%	56%	**57%**
Latino	20%	7%	10%	**8%**
Other		1%		**1%**

TABLE 12. PEOPLE LIVING WITH AIDS

PLWA 2007	E. REGION	CENTRAL	WEST	TGA
Anglo	75%	35%	38%	38%
African American	15%	55%	48%	52%
Latino	9%	9%	14%	9%
Other	1%	1%	1%	1%

TABLE 13. PEOPLE LIVING WITH HIV

PLWH 2007	E. REGION	CENTRAL	WEST	TGA
Anglo	70%	32%	31%	33%
African American	17%	58%	54%	56%
Latino	7%	7%	14%	8%
Other	6%	3%	1%	3%

(Source for all tables: Ohio Department of Health, HIV/AIDS Surveillance Program. Data as of Dec 31, 2007).

Summary of Regional Differences. By race/ethnic group, distinct differences between the three regions are apparent—the Central Region (Cuyahoga and Medina counties) has the most PLWA who are African American, the Western Region (Lorain) has the highest percentage of Latino PLWA, and the Eastern region (Ashtabula, Geauga and Lake counties) have the highest proportion of Anglo PLWA.

Gender is almost identical with the exception of Lorain County, which has a higher percentage (29%) of female PLWA. Age group shows the Western region to have the only notable percentage of young (13-19) PLWA, with the Eastern region having the oldest or 'aged' PLWA (47%) close to that of the Central Region (46%).

By exposure category, the Eastern and Central regions are predominantly MSM. The Western region has the highest IDU exposure, followed by non-reported risk, then heterosexual transmission. Future projection of HIV/AIDS cases based on newly diagnosed AIDS cases shows that some trends continue—the highest proportion of MSM is in the Eastern region and the highest proportion of IDU remains in the Western region. Differing trends are the proportion of heterosexuals with the Central region slightly leading the Western region (12% versus 10%), a negative trend not evident in the PLWH and PLWA trend lines.

Disproportionate Impact by Race/Ethnic Group. The group most disproportionately affected are African Americans. They consistently comprise 55% or more of newly diagnosed cases and 52% of People Living With AIDS and 56% People Living With HIV. The 50% or greater figure compares to their 20% representation in the overall population of the TGA, with 27% in Cuyahoga County. Sixty percent (60%) of all newly diagnosed AIDS cases occur in the Central region, dominated by Cuyahoga County. This trend does not appear to be diminishing based on the three-year analysis. Blacks in the Cleveland TGA are diagnosed with AIDS 7.6 times higher than their representation in the general population. They live with AIDS at a rate 6.9 times higher, and live with HIV at a rate 7.1 times greater than their proportion in the overall population. It's notable that among MSM in the Cleveland TGA, transmission rates are highest among African Americans. Likewise, rates of infection among the "aged" population occur most frequently among African Americans.

Hispanics contract AIDS at a 3.5 times higher rate than expected, are living with AIDS at 4.2 times and HIV at 3.5 times higher than their percentage in the general population. Latinos are the next most disproportionately affected, representing 9% of all newly diagnosed AIDS cases in the Cleveland TGA. The Western region accounts for 10% of these cases, closely followed by the Central region with 9%.

Disproportionate Impact by Gender. 75% of newly diagnosed AIDS cases are male and 25% female. This figure is rising for newly diagnosed HIV cases, but not for AIDS cases. This may represent an earlier stage diagnosis for females, or a worsening trend for MSM in the Cleveland TGA. The region with the most newly diagnosed AIDS cases for females is the Central region. The region with the greatest number of female PLWH is the Western region. Minority women are most heavily impacted, with heterosexual contact with IDUs and bisexual MSM being the most prevalent transmission category.

Disproportionate Impact by Age Group. The 20-44 age group is 2.5 times 'over-represented' for being diagnosed with AIDS, 1.9 times more likely to live with AIDS and 2.2 times more likely to have HIV than expected. The only 'disparity' for another age group is among 45 and older PLWA (People Living With AIDS) who live with AIDS 1.16 times greater than their percentage in the general population.

Unlike the HIV and AIDS prevalence figures, the Western region does not display any adolescent cases for newly diagnosed AIDS. The Western region is also the 'oldest' region to present with 43% of newly diagnosed AIDS cases that are 'aged' (45 years+). This is a newer development, as it contrasts with the HIV and AIDS prevalence figures that show the Eastern region to be the most 'aged'. This development is interpreted to be due to two factors—the

stability of the MSM population in the Eastern region (not presenting with escalating new cases of AIDS) and the deterioration of the IDU subgroup in the Western region. The Central region follows the Western region with 24% of 'aged' (45+) newly diagnosed AIDS cases', then the Eastern region with 14%.

Comparison to National Epidemic

An estimated 47% of the persons living with HIV in the United States as of December 31, 2006 were black, 34% were white, and 17% were Hispanic. Asians/Pacific Islanders and American Indians/Alaska Natives each represented roughly 1% of the HIV-infected population.

Males accounted for 74% of the population living with HIV.

The largest population living with HIV (45%) comprised men who have sex with men (MSM), followed by persons infected through high-risk heterosexual contact (27%), those infected through injection drug use (22%), and those who were exposed through both male-to-male sexual contact and injection drug use (5%).

Researchers believe that these estimates point to an increased need for HIV testing, prevention, and treatment services to slow the US epidemic. As persons with HIV are now living longer than ever before, a growing population of HIV-infected men and women must be reached with testing and prevention services to help them protect others from infection. Additionally, increasing HIV prevalence means increased opportunities for transmission to HIV-negative persons who engage in risky behaviors. Efforts to reduce the number of new infections must therefore meet the needs of populations that are infected and populations that are not infected.

HIV prevalence differs from HIV incidence: incidence reflects the number of new HIV infections each year. CDC recently announced the first national system for determining HIV incidence on the basis of direct measurement of new HIV infections. This new technology distinguishes recent HIV infections from long-standing infections and provides critical information in tracking the US epidemic. In addition, it provides the clearest picture to date of HIV infections in the United States and over time and will benefit the populations at highest risk by better focusing HIV prevention efforts and helping to measure progress. In 2006, 56,300 individuals were infected with HIV [2].

Estimated Number of New HIV Diagnoses, 2006

CDC's analysis of HIV diagnoses includes all new HIV diagnoses, with or without an AIDS diagnosis, in the 33 states that have long-standing confidential, name-based HIV infection reporting systems.*

HIV diagnoses do not necessarily represent new infections: some persons with a new HIV diagnosis were infected recently; others were infected long ago, but their infection was detected only recently. Additionally, although the inclusion of New York State data since 2001 provides a sample of diagnoses that is more representative than the sample from earlier analyses, several high-morbidity areas (including California and Illinois) lack longstanding, name-based reporting and are still not included in this analysis.

An analysis of persons with a diagnosis of HIV infection, by race/ethnicity and risk factor, underscores the disproportionate impact of HIV among communities of color and MSM of all races:

- By race/ethnicity, nearly half (49%) were black, although blacks made up only 13% of the population of the 33 states [3]. Whites accounted for 30% of diagnoses, and Hispanics accounted for 18%. Asians/Pacific Islanders and American Indians/Alaska Natives each accounted for 1% or less of diagnoses.
- By age, more than half (57%) were aged 25–44. Children younger than 13 years accounted for less than 1% of diagnoses.
- Among adults and adolescents:
    - By transmission category, MSM continued to account for the largest number of diagnoses overall, followed by males and females exposed through high-risk heterosexual contact and injection drug use.
    - By sex, males accounted for 73% of all new HIV diagnoses in 2006.
    - Among males, most diagnoses were for MSM. Although past analyses indicate this is true regardless of race, high-risk heterosexual contact also accounts for a considerable proportion of new HIV diagnoses among men of minority races/ ethnicities [4, 5]
    - Among females, most diagnoses were for those exposed through high-risk heterosexual contact.

Estimated Rates of HIV Diagnosis, 2006

Disparities among Races/Ethnicities Persist

In 2006, the overall rate of HIV diagnosis (the number of diagnoses per 100,000 population) in the 33 states was 18.5 per 100,000 [3]. The rate for blacks was roughly 8 times the rate for whites (67.7 per 100,000 vs 8.2 per 100,000).

African American males continue to bear the greatest burden of HIV infection. In 2006, the HIV diagnosis rate for all black males in 33 states (119.1 per 100,000 population) was the highest of any group— more than 7 times that for white males (16.7), more than twice the rate for Hispanic males (50.9), and more than twice the rate for black females (56.2). The diagnosis rate for Hispanic males was approximately 3 times that for white males.

African American females are also severely and disproportionately affected by HIV infection. In 2006, the HIV diagnosis rate for black females (56.2) was more than 19 times the rate for white females (2.9). The rate for Hispanic women was 15.1, more than 5 times that for white females.

Among American Indians/Alaska Natives, the rate of HIV diagnosis for males (17.7) was slightly higher than the rate for white males, and the rate for females (4.6) was nearly twice the rate for white females. Among Asians/Pacific Islanders, the rate of HIV diagnosis for males was 13.5, and the rate for females was 3.2.

Multiple Challenges Place African Americans and Hispanics/Latinos at Increased Risk

Race and ethnicity are not, by themselves, risk factors for HIV infection. But studies show that African Americans and Hispanics/Latinos are more likely than their white counterparts to face multiple challenges associated with risk for HIV infection. These challenges include high rates of sexually transmitted diseases, which can facilitate HIV transmission [6, 7]; substance abuse, which may increase the risk for HIV infection through sexual or drug-related transmission [8]; and socioeconomic factors, such as limited access to high-quality health care [9]. Studies have also suggested that poverty may place African American women at increased risk because of the power imbalance created by financial dependence on men [10]. Among MSM of minority races/ethnicities, cultural barriers that may impede the acknowledgment of risk behaviors and the ability to access prevention services may result in increased risk [11–15]. For Hispanics/Latinos, language barriers may also affect the quality of care [16]. Additionally, because many Hispanics/Latinos or their parents have emigrated from diverse countries or regions, there is no single culture for persons of Spanish origin in the United States. Research shows that Hispanics/Latinos born in different countries have different behavioral risk factors for HIV [3, 17].

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CHAPTER 2. CLEVELAND TGA UNMET NEED

According to the Ohio Department of Health HIV/AIDS surveillance data report, the number of PLWH in the TGA as of December 31, 2007, was 2,031 and the total number of PLWA in the TGA as of December 31, 2007 was 2,144 for a total of 4,175 cases of HIV/AIDS. An unduplicated total of 1,410 PLWA and 1,477 PLWH met the definition of "In-Care" during the specified time period (calendar year 2007.)

This translates to a total of 621 (31%) Persons with AIDS and 667 (31%) with HIV that are "Out of Care" according to the HRSA definition for calculating unmet need or 1,288 PLWHA.

TABLE 14. UNMET NEED FRAMEWORK, 2008

Column 1	Column 2	Column 3	Column 4	Column 5
Population Sizes		**Value**		**Data Source(s)**
Row A.	Number of persons living with AIDS (PLWA), for the period of [01/01/2007-12/31/2007)]	**2,031**		Ohio Department of Public Health
Row B.	Number of persons living with HIV (PLWH)/non-AIDS/aware, for the period of [01/01/2007-12/31/2007)	**2,144**		Ohio Department of Public Health
Row C.	Total number of HIV+/aware for the period of [01/01/2007-12/31/2007)]	**4,175**		Ohio Department of Public Health
Care Patterns		**Value**		**Data Source(s)**
Row D.	Number of PLWA who received the specified HIV primary medical care during the 12-month period [01/01/2007-12/31/2007)	**1,410**		Unmet Need provider database for January-December, 2007 from Ryan White Part A and C providers
Row E.	Number of PLWH/non-AIDS/aware who received the specified HIV primary medical care during the 12-month period [01/01/2007-12/31/2007)	**1,477**		Unmet Need provider database for January December, 2007 from Ryan White Part A and
Row F.	Total number of HIV+/aware who received the specified HIV primary medical care during the 12-month period [01/01/2007-12/31/2007)	**2,887**		Unmet Need provider database for January December, 2007 from Ryan White Part A and C providers
Calculated Results		**Value**	**Percent**	**Calculation**
Row G.	Number of PLWA who did not receive the specified HIV primary medical care	**621**	**31%**	Value: Row A-Row D
Row H.	Number of PLWH/non-AIDS/aware who did not receive the specified HIV primary medical care	**667**	**31%**	Value: Row B-Row E
Row I.	Total HIV+/aware not receiving the specified HIV primary medical care (quantified estimate of unmet need)	**1,288**	**31%**	Value: Row G +Row H

Populations representing the 'Out of Care' fraction include Males (89%), those living with HIV-not AIDS (88%), the 40-49 years of age (56%) subgroup, and African Americans (56%). This data was collected from Ryan White Part A and C providers of ambulatory outpatient medical care, using the HRSA definition of 'In Care' to determine Care Status.

TABLE 15. CHARACTERISTICS OF OUT OF CARE POPULATION IN CLEVELAND TGA

	% IN CARE	*% OUT OF CARE*	*EPI (PLWHA)*
GENDER			
Male	*70%*	***89%***	*75%*
Female	*29%*	***11%***	*25%*
Transgender	*1%*		
HIV STATUS			
HIV+	*78%*	***88%***	*51%*
AIDS	*22%*	***12%***	*49%*
AGE GROUP			
20-29	*13%*	***6%***	
30-39	*35%*	***33%***	
40-49	*42%*	***56%***	
50-59	*10%*	***5%***	
RACE/ETHNICITY			
AA	*56%*	***56%***	*54%*
WHITE	*32%*	***29%***	*35%*
HISPANIC	*8%*	***11%***	*9%*
Multi-Race	*4%*	***4%***	*2%*

(Source: Ryan White Office Unmet Need Data Tables provided by Part A and Part C PMC providers, 2008)

2009 Ohio SCSN Service Gaps

The Statewide Coordinated Statement of Need (SCSN) process in 2009 resulted in a productive collaborative 'All Parts' discussion emphasizing the coordination of mutual unmet needs and barriers, with the major focus of that discussion on reducing disparities.

TABLE 16. 2009 SCSN UNMET NEEDS/SERVICE GAPS OF TGA PLWHA

UNMET NEEDS	REASONS FOR UNMET NEEDS
CORE MEDICAL SERVICES	
1. Primary Medical care	1. Inability to afford care; No transportation; Inability to find Provider; Concerns with Providers*
2.Medications	2. No way to pay for HIV meds; No way to pay for non-HIV meds; Need assistance filling out applications for various prescription assistance programs; No transportation to pick up meds
3. Oral Health Services	3. Can't afford dental care; Concerns with Dental providers; Inability to get appointments; Lack of Dentists in geographic area of residence
4. Home Care Services	4.Need help with errands, getting home health aide/homemaker services, home nursing care

UNMET NEEDS	REASONS FOR UNMET NEEDS
SUPPORT SERVICES	
5. Transportation	5. Need vouchers and tokens for public transportation, especially among African Americans; Need help with car-related expenses
6. Food	6. Need food vouchers, public assistance, food banks; Hard to obtain meats, fruits and vegetables
7. Social Support	7.Need professional counseling, buddy services, support groups: Not comfortable asking for help; Not eligible; Not able to find services; Concerns w/service providers

(Source: Ohio Statewide Coordinated Statement of Need, 2009)

Additional problems with providers reported by participating PLWHA included:

1. Medical care provider not sensitive to needs or not culturally sensitive;
2. Fear of provider telling others about their HIV status; and
3. Provider lacked knowledge about HIV/AIDS treatment.

Based upon the Unmet Need Framework, the Cuyahoga Regional HIV Services Planning Council undertook a rapid needs assessment process in order to begin to address the following four items, including any plans for cross-Part collaboration in these areas:

1. *Describe the demographics and location of persons who know their status and are NOT in care;*
2. *Assess the service needs, gaps and barriers to care, including disparities in access and services among affected subpopulations and historically underserved communities;*
3. *Describe plans to find people NOT in care and get them into care; and*
4. *Describe how the results of the Unmet Need Framework were used in planning and decision-making about priorities, resource allocations and the system of care.*

This Unmet Need Report is organized around addressing Items 1 and 2 above.

Relevance of an Unmet Need/Out of Care Study

The latest estimates indicate that at the end of 2003, HIV prevalence— the total number of persons with HIV—was roughly 1 million (estimated range between 1,039,000–1,185,000)[1]. Approximately one-fourth (24% –27%) of HIV-infected persons are believed to be unaware of their infection, underscoring the need to expand opportunities for HIV testing. Reasons for being Out of Care differ, but occur and re-occur at points along the Continuum of Care.

Four (4) subgroups exist among the 'Out of Care', two of whom do not technically adhere to the HRSA definition of at least one year not accessing primary medical care, but do shed insight into the 'Out of Care' issue. The four (4) groups are: 1) Newly diagnosed (risk of 'ever' attaching to care); 2) Those at 'risk of going Out of Care' (over 6 months not accessing primary medical care, display warning signs of non-compliance with treatment regimens); 3) the 'Technically Out of Care' (over 12 months not accessing primary care); and, 4) the Never in Care.

[1] Glynn M, et al. Estimated HIV prevalence in the United States at the end of 2003. National HIV Prevention Conference; June 12–15, 2005; Atlanta. Abstract T1-B1101

The initial and significant burden is attaching persons to care immediately upon a positive HIV diagnosis. This juncture is one that many PLWHA recount as 'shock', 'disbelief', 'denial' and often, if co-afflicted with mental health and/or substance abuse issues, regress to numb themselves from the diagnosis. Recent advances in HIV treatment, especially Highly Active Antiretroviral Therapy (HAART) have resulted in person's newly diagnosed taking the news lightly under the misguided assumption that HIV medications can quickly relieve any sickness. These individuals tend to not enter care until they 'feel sick'. In cultures that tend to not disclose or accept illness, particularly ones that are sexually transmitted or incurred due to injection drug use, this pattern exerts a dual deterrent to entering care. The 'late to care' pattern as evidenced by seroconversion to an AIDS diagnosis within a year of being diagnosed HIV-positive is most pronounced among African-Americans, Hispanics, Injection Drug Users, Other Substance Users and the Incarcerated/Recently Released.

Upon entry to primary medical care, the reasons for detachment include inability or unwillingness to maintain a rigorous treatment regimen (one in which adherence should be 94% or more to attain optimal benefit), side effects of HIV medications, the high cost of drugs or the co-payment related to HIV medications, and the pressure of other subsistence needs such as employment, housing and transportation to either access primary medical care or in lieu of paying for primary medical care.

Key points along the Continuum of Care assessed in a study specific to the 'Out of Care' confirm risk flags for PLWHA considering abandoning their care regimen. Flags include erratic appointment compliance (missing three or more appointments), tendency to not disclose issues, and repeated concerns about medication regimens and drug resistance that may be flags for non-compliance with medication regimens. Questioning PLWHA that are 'Out of Care' about their decision to abandon primary medical care will better highlight these risk points.

The Never in Care are one of the most troubling and least known subgroups. This group evidences resistance issues related to initial attachment to care upon positive HIV diagnosis. Subgroups exist within the 'Never in Care' including PLWHA who self-manage (majority are long-term survivors and wary of HIV medications from the first generation of HIV drugs such as AZT), the 'unconnected' which includes undocumented citizens, the Incarcerated/Recently Released, Injection Drug Users and some Substance Abusers. The Never in Care do not wish to expose themselves to any legal ramifications nor change their current patterns of behavior. Entering medical care is perceived as an exposure risk.

Project Design

Collaborative Research surveyed PLWHA who are 'Out of Care'. Strategies for reaching these individuals included :

- *Working with Primary Care Clinics to identify individuals who are out of care or in danger of going out of care;*
- *Working with local support services agencies to identify individuals who are accessing support services (food bank) and not primary medical care; and*
- *Working with Counseling and Testing providers to survey newly diagnosed.*

Collaborative Research offered $20 incentives (Gift Card) using both a toll-free 1-800 number for survey respondents to take the survey and facilitating on-site surveys. The proposed sample size for the Unmet Need/Out of Care survey was 130 PLWHA and a total of 124 surveys were actually completed. Table 17 shows the breakdown of the Unmet Need/Out of Care survey

respondents by race, gender and mode of transmission. Collaborative Research conducted the 2009 needs assessment in collaboration with the Cleveland TGA. Out of Care surveys were completed in April and May of 2009 and administered by telephone through an 800 number. The same individual conducted all interviews. Survey recruitment was done in the following ways:

- *Out of Care clients were identified through various AIDS service organizations*
- *Flyers were widely posted and distributed throughout the TGA to promote self-referrals*.

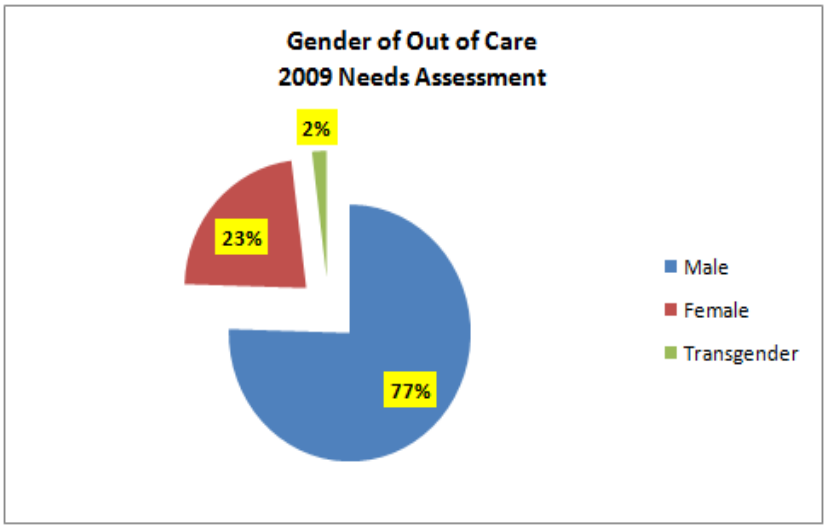
Table 17. Composition of Out of Care Survey Respondents, Cleveland TGA, 2009

HIV Disease Status	#	%		Year HIV Diagnosis	#	%
AIDS	54	44%		2009		
HIV	60	48%		2008	1	1%
Unknown or Would Not Disclose	9	7%		2007	4	3%
Race				2006	6	5%
White	9	7%		2005	7	6%
Black	85	69%		2004	8	6%
Hispanic	9	7%		2003	1	1%
Multi Race	21	16%		2002	7	6%
Gender				2001	6	5%
Male	96	77%		2000	5	4%
Female	25	20%		1999	4	3%
Transgender	3	2%		1998	6	5%
Mode				1997	7	6%
MSM	57	46%		1996	9	7%
IDU	26	21%		1995	8	6%
MSM/IDU	2	1%		1994	5	4%
Blood				1993	7	6%
Heterosexual	38	31%		1992	2	2%
Perinatal	1	1%		1991	3	2%
Undetermined				1990	7	6%
	124	100%		1989	5	4%
				1988	1	1%
				1987	5	4%
				1986	2	2%
				1985	5	4%
				1984 or earlier	3	2%

Data is also displayed using a 'Consumer Tracker' approach, in which an ongoing description of the Out of Care population is displayed. Four (4) Out of Care studies have been performed in the Cleveland TGA—in 2003 using a focus group methodology, in 2004 using a full survey approach similar to this 2009 study, in 2005 using a survey methodology limited to PLWHA 45 years of age and older and this 2009 update.

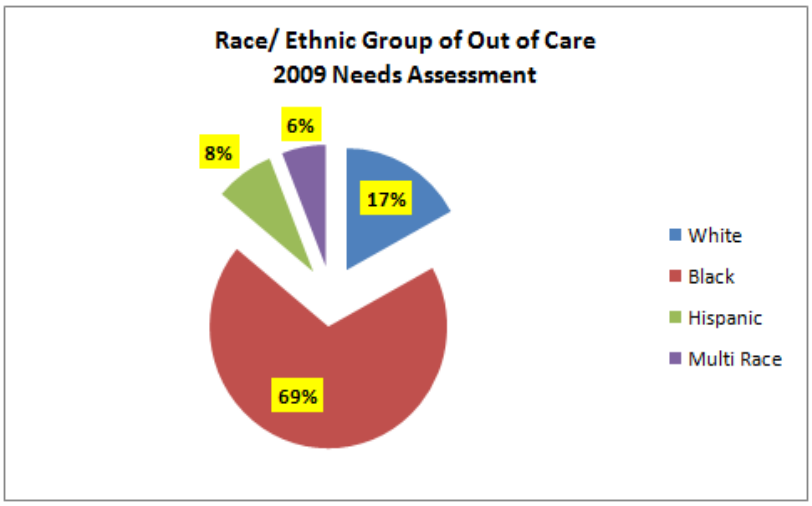
This trend line allows the Cleveland TGA, specifically the Cuyahoga HIV Regional Services Planning Council, to track the composition of the hard-to-reach Out of Care population. This tracking, with detailed query of responses to rationale for not accessing primary medical care for their HIV and incentives/reasons to enter or return to care, is valuable information for reducing unmet need and providing information to decrease secondary transmission of the disease.

Gender



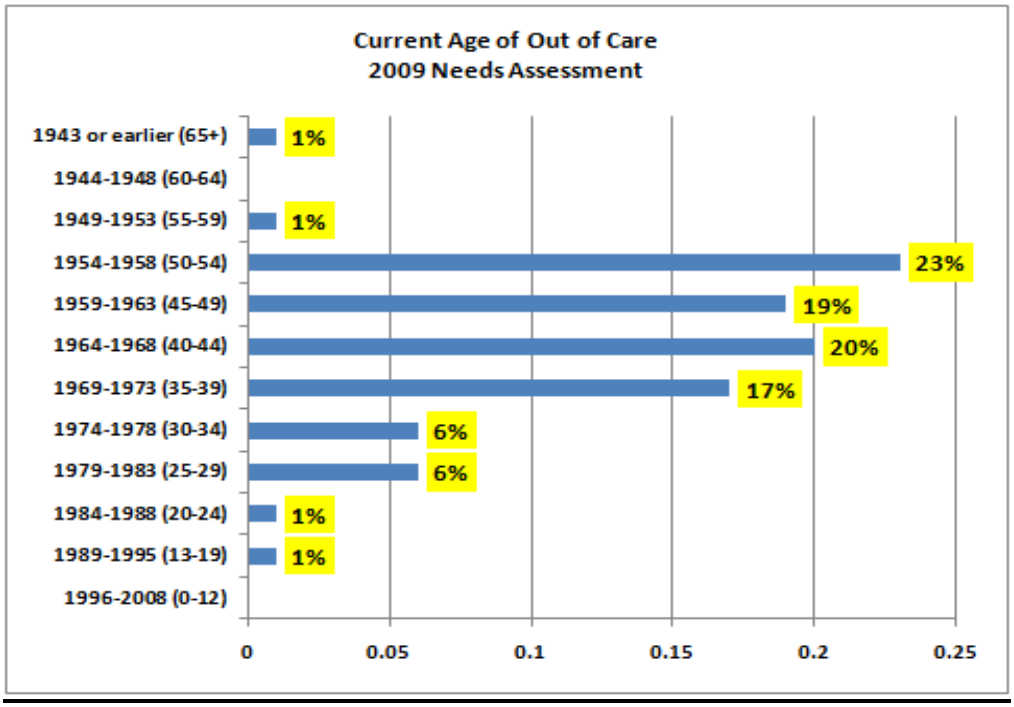
GENDER	2009	2005	2004	2003
Male	77%	65%	67%	68%
Female	23%	35%	33%	32%
Transgender	*2%*			*1%*

Race/Ethnic Group



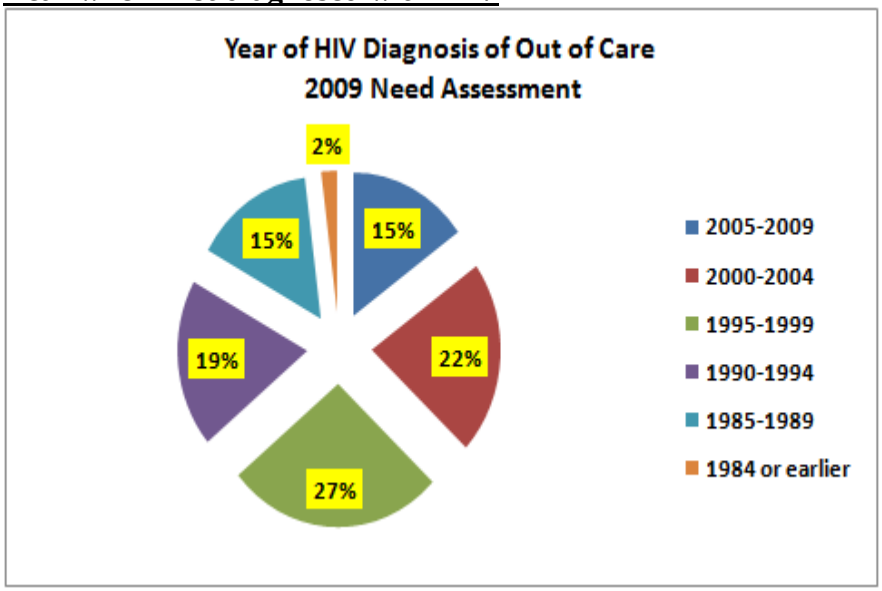
RACE/ ETHNIC	2009	2005	2004	2003
White	17%	22%	25%	24%
Black	69%	40%	64%	46%
Hispanic	8%	20%	11%	30%
Multi Race	6%	18%		

Age (Current)



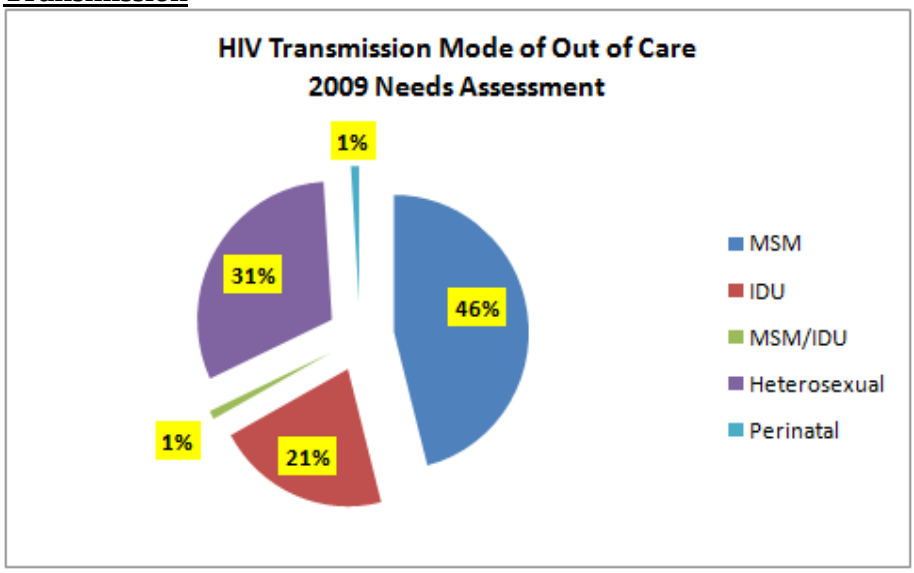
Current Age	2009	2005	2004	2003
1996-2008 (0-12)				
1989-1995 (13-19)	1%		2%	2%
1984-1988 (20-24)	1%		55	6%
1979-1983 (25-29)	6%		7%	8%
1974-1978 (30-34)	6%		19%	19%
1969-1973 (35-39)	17%		22%	22%
1964-1968 (40-44)	20%		9%	10%
1959-1963 (45-49)	19%	30%	15%	15%
1954-1958 (50-54)	23%	20%	11%	11%
1949-1953 (55-59)	1%	15%	4%	4%
1944-1948 (60-64)		10%	5%	3%
1943 or earlier	1%	25%	2%	

Year when first diagnosed with HIV



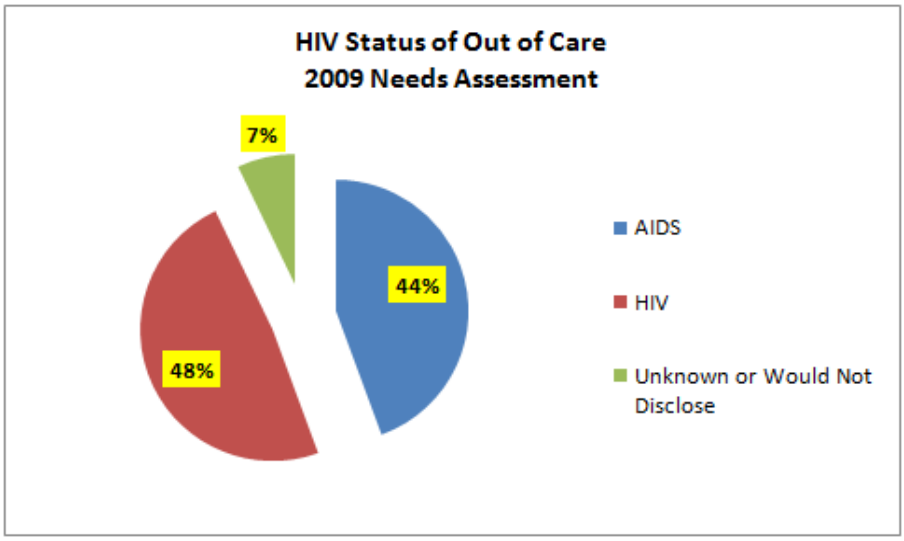
YEAR FIRST DIAGNOSED	2009	2005	2004	2003
2005-2009	15%	1%		
2000-2004	22%	35%	49%	48%
1995-1999	27%	26%	21%	25%
1990-1994	19%	23%	15%	18%
1985-1989	15%	13%	8%	7%
1984 or earlier	2%	3%	6%	1%

Transmission



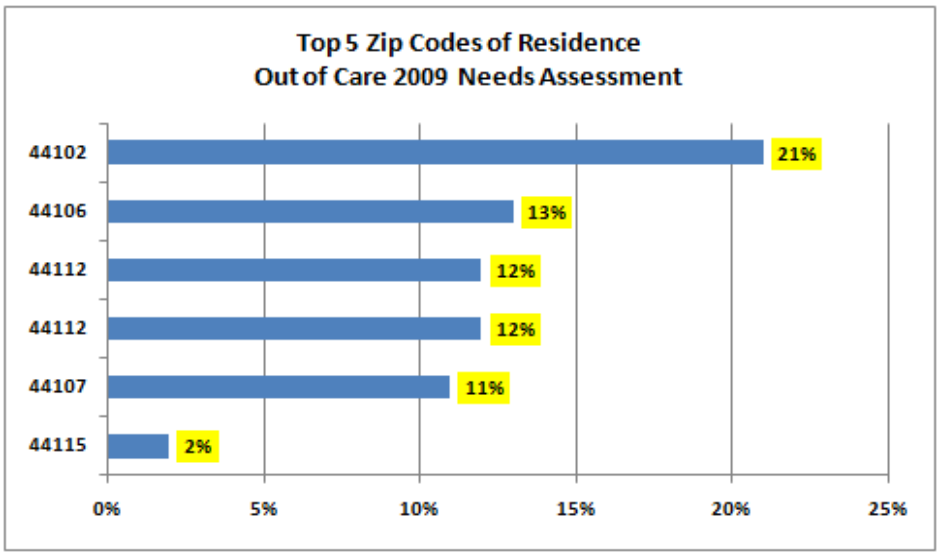
TRANSMISSION	2009	2005	2004	2003
MSM	46%	38%	38%	38%
IDU	21%	25%	25%	25%
MSM/IDU	1%	8%	6%	5%
Heterosexual	31%	30%	31%	32%
Perinatal	1%			

HIV Status

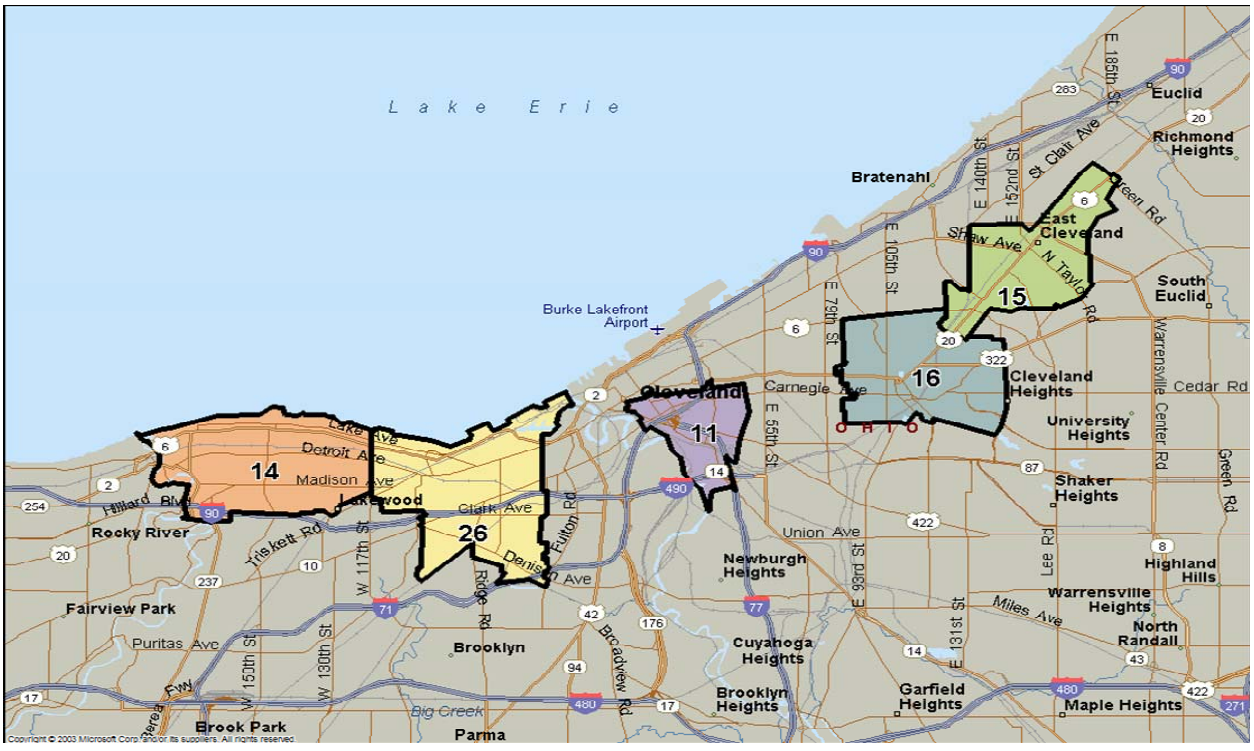


HIV STATUS	2009	2005	2004	2003
AIDS	44%	58%	62%	37%
HIV	48%	43%	38%	63%
Unknown /Would Not Disclose	7%			

Geography



TOP ZIPS	2009	2005	2004	2003
44102	21%	23%	23%	29%
44106	13%	3%	5%	8%
44112	12%	9%	7%	2%
44107	11%	17%	16%	12%
44115	11%	20%	18%	23%



CHAPTER 3. 'UNMET NEED' STUDY FINDINGS

Based upon the Unmet Need Framework, the Cleveland TGA undertook a needs assessment process in order to address the following four items:

1. Describe the demographics and location of persons who know their status and are NOT in care;

2. Assess the service needs, gaps and barriers to care, including disparities in access and services among affected subpopulations and historically underserved communities;

3. Describe plans to find people NOT in care and get them into care; and

4. Describe how the results of the Unmet Need Framework were used in planning and decision-making about priorities, resource allocations and the system of care.

The Unmet Need Study findings addresses Items 1 and 2 above in the following narrative.

A. Describe the demographics and location of persons who know their status and are NOT in care

1. What subpopulations are most likely to be 'Out of Care'?

Based upon the Cleveland TGA estimate of unmet need and the demographics of those living with HIV versus those living with AIDS who are NOT in care, the following table delineates the Out of Care (OOC) populations by race, and compares their percent in the total PLWHA population in the service area and the percent of the total OOC population, in order to determine what subpopulations are most likely to be 'Out of Care' in the Planning Area.

Table 18: Unmet Need Population Comparisons to Total PLWHA and Total OOC

DEMOGRAPHICS	UNMET NEED (Ryan White Office)	OUT OF CARE (2009 Needs Assessment)	TOTAL PLWHA (Epidemiology)
GENDER			
Male	89%	79.8%	75%
Female	11%	20.2%	25%
RACE/ETHNIC			
Anglo	29%	17%	35%
African American	11%	69%	9%
Latino	4%	8%	2%
Asian	29%		35%
Native American	11%		9%
Multi race	4%	6%	2%
TRANSMISSION			
MSM	56%	46%	54%
IDU	29%	21%	35%
MSM/IDU	11%	1%	9%
Heterosexual	4%	31%	2%
Perinatal	56%	1%	54%

DEMOGRAPHICS	UNMET NEED (Ryan White Office)	OUT OF CARE (2009 Needs Assessment)	TOTAL PLWHA (Epidemiology)
CURRENT AGE			
1996-2008 (0-12)			
1989-1995 (13-19)		1%	3.2%
1979-1983(20-29)	13%	7%	
1973-1978 (30-34)	35%	23%	**40-44** 81.4%
1959-1968 (40-49)	42%	40%	
1949-1958 (50-59)	10%	24%	45+ 15.4%
1944-1948 (60-64)			
1943 or earlier (65+)		1%	
Would Not Disclose Age		4%	

2. Characteristics of PLWHA Not in Care

HIV Status

HIV STATUS	2009
AIDS	44%
HIV	48%
Unknown /Would Not Disclose	7%

Year First Diagnosed

YEAR FIRST DIAGNOSED	2009
2005-2009	15%
2000-2004	22%
1995-1999	27%
1990-1994	19%
1985-1989	15%
1984 or earlier	2%

Sexual Orientation

SEXUAL ORIENTATION	#	%
Heterosexual/straight	50	40.3%
Homosexual - gay man	44	35.5%
Homosexual - lesbian	0	0.0%
Bisexual	25	20.2%
Other:	5	4.0%

Highest Level of Education

Answer Options	Response Count	Response Frequency
Grade school or less	3	2.4%
Some high school	22	17.7%
High school graduate/GED	48	39.0%
Technical or Trade School	4	3.3%
Some college	39	31.7%
Graduated college	5	4.1%
Graduate School	3	2.4%
TOTAL		
answered question		124

Relationship status

Relationship status:			
Answer			
Answer Options	**Yes**	**No**	**Response Count**
Single	81	0	81
Legally Married	7	0	7
Common Law	9	0	9
Partnered	12	0	12
Separated	5	0	5
Divorced	4	0	4
Widow/Partner died	4	0	4

Is/was this person HIV+?			
Answer Options	**Yes**	**No**	**Response Count**
Single	0	0	0
Legally Married	0	1	1
Common Law	0	0	0
Partnered	1	0	1
Separated	0	2	2
Divorced	0	0	0
Widow/Partner died	1	0	1
		answered question	122
		skipped question	2

Housing

Do you currently live:		
Answer Options	**Response Frequency**	**Response Count**
In my own apartment/house	65.3%	81
At my parent's/relative's apartment/house	10.5%	13
Someone else's apartment/house	16.1%	20
In a rooming or boarding house	3.2%	4
In a "supportive living" facility (Assisted Living Facility)	1.6%	2
In a group home or residence	0.8%	1
In a half-way house, transitional housing or treatment facility (drug or psychiatric)	0.8%	1
Skilled Nursing Home	0.0%	0
Homeless (on the street/in car)	0.0%	0
Homeless shelter	0.8%	1
Women's shelter	0.0%	0
Men's shelter	0.0%	0
Jail or correctional facility	0.0%	0
Other housing provided by the city or state	0.8%	1
Residential Hospice facility	0.0%	0
Other:	0.0%	0
	answered question	**124**

Co-morbidities

Please indicate if you have ever been diagnosed with any of the communicable diseases listed below by completing the following table:						
Answer						
Answer Options	**Yes**	**No**	**Don't know**	**Prefer not to answer**	**Response Count**	**% (Y/Responses)**
Chlamydia	17	103	0	0	120	14%
Genital warts	9	108	0	0	117	8%
Gonorrhea	35	84	1	0	120	29%
Hepatitis (A, B, or C)	21	98	1	0	120	18%
Herpes (genital)	16	102	0	0	118	14%
Syphilis	20	99	0	0	119	17%
Yeast infections	16	57	0	0	73	22%
Tuberculosis	10	97	0	0	107	9%
				answered question	**123**	
				skipped question	**1**	

Active Substance Use

Do you use alcohol or other substances?		
Answer Options	**Response Frequency**	**Response Count**
Yes	33.1%	41
No	66.9%	83
	answered question	**124**

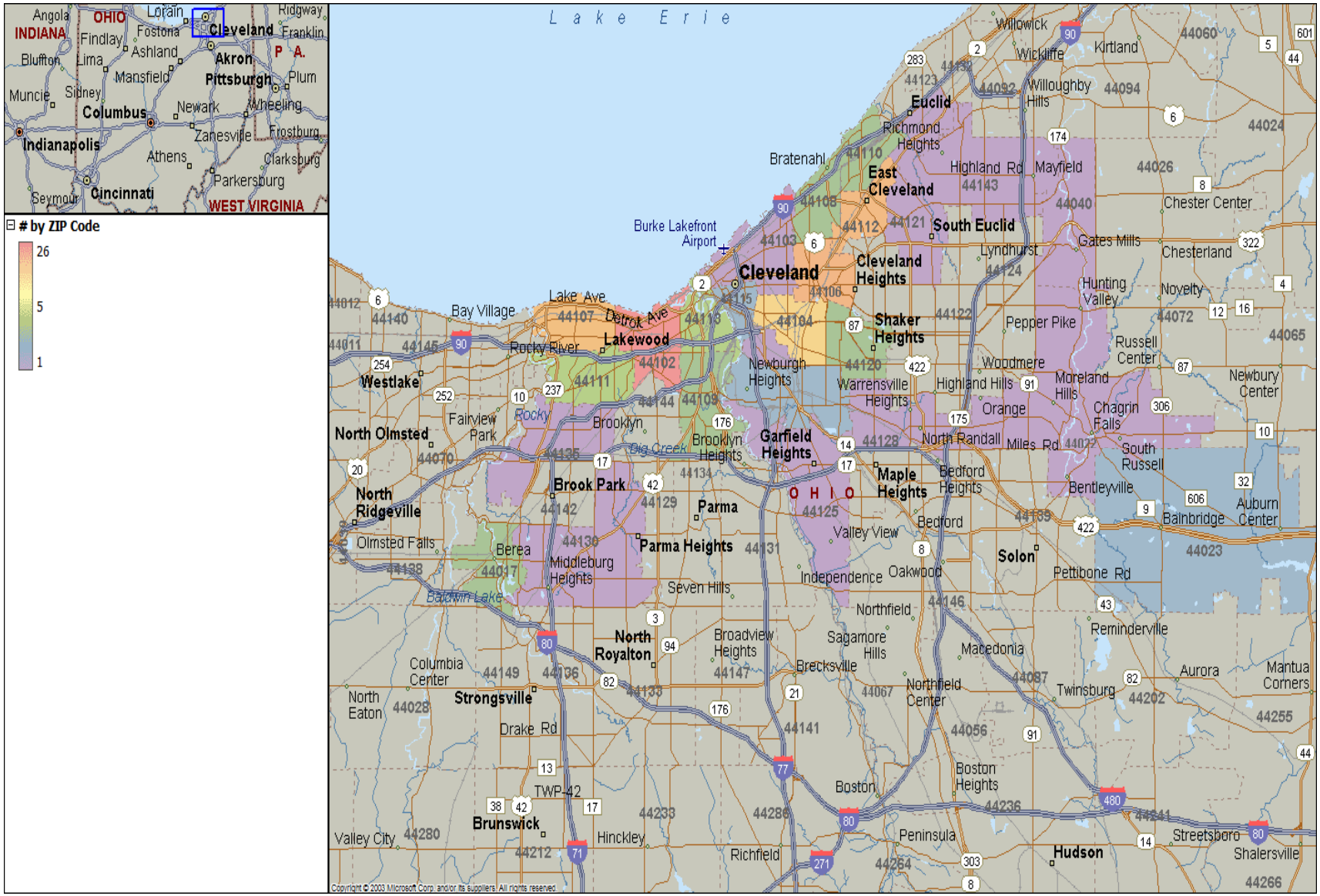
During the past 12 months, how often have you used any of the following substances?						
Frequency used						
Answer Options	**Not at all**	**Daily**	**Weekly**	**Monthly**	**Prefer not to answer**	**Response Count**
Alcohol	4	15	9	7	0	35
Cocaine	23	0	2	1	0	26
Crack	20	4	3	1	0	28
Crystal Meth /Methamphetamines	24	0	0	1	0	25
Heroin	24	2	0	1	0	27
Marijuana or hash	18	5	5	1	0	29
Speedball	24	0	0	0	0	24
Tobacco	14	15	1	0	0	30
Other (1)	0	0	0	0	0	0
Other (2)	0	0	0	0	0	0
					answered question	**41**
					skipped question	**83**

Have you ever used injecting drugs?		
Answer Options	**Response Frequency**	**Response Count**
Yes	17.0%	8
No	83.0%	39
	answered question	**47**
	skipped question	**77**

Are you currently injecting drugs?		
Answer Options	**Response Frequency**	**Response Count**
Yes	7.3%	3
No	92.7%	38
	answered question	**41**
	skipped question	**83**

If you are currently injecting substances, how often do you share needles or works?		
Answer Options	**Response Frequency**	**Response Count**
Not applicable, I am not currently injecting	83.3%	10
Never	16.7%	2
	answered question	**12**
	skipped question	**112**

3. Location of PLWHA with Unmet Need in the TGA



5. ***Additional Out of Care Characteristics from the 'Out of Care' Needs Assessment Study***

Bisexuality. Over one fifth (20.2%) of Out of Care respondents reported bisexuality, all of them males, with 92% (23/25) reporting African American heritage, 1 (4%) reporting Latino ethnicity and 1 (4%) reporting Caucasian heritage.

Transgender. Three (3) individuals reported transgender orientation, with significant issues related to this status. Issues included lack of reimbursement through health insurance for hormone therapy, ostracization and stigma resulting in fear and reluctance to seek medical care. Underemployment was also an issue related to their status.

B. Assess the service needs, gaps and barriers to care, including disparities in access and services among affected subpopulations and historically underserved communities

A service need and accessibility/barriers ranking and gap (perceived unavailability ranking) was developed for ALL Out of Care respondents and as well as by Severe Need Group. Eight (8) severe need groups were analyzed including (1) African American Heterosexuals (2) African American MSM (3) Aged (45 years of age and older) (4) Hispanic (5) Injection Drug Users/Substance Abusers (IDU/SA) (6) Rural (7) Women and (8) Youth.

Q9. "How soon after you found out about being HIV+ did you get medical care? "		
Answer Options	**Response Frequency**	**Response Count**
I have never received care for HIV	0.0%	0
Within 3 months	62.1%	77
Within 6 months	16.1%	20
Within 1 year	8.1%	10
Longer than 1 year	10.5%	13
Other:	3.2%	4
	answered question	**124**

Six (6) questions inquired about Out of Care status, related service needs, barriers ('need service and have trouble getting') and gaps ('need service and can't get'). These inquiries were posed using different approaches.

Q10. "If you did not seek medical care from a doctor or a nurse within one (1) year of finding out you were HIV positive, please indicate the reasons why."		
Answer Options	**Response Frequency**	**Response Count**
Couldn't afford it	29.4%	5
Didn't need medical care	0.0%	0
Couldn't get transportation	0.0%	0
Didn't know where to go to get medical care	5.9%	1
Don't trust doctors	17.6%	3
Didn't think I needed it	11.8%	2
I was depressed	29.4%	5
Didn't like the way I was treated	5.9%	1
I feel good/healthy	17.6%	3
Other:	41.2%	7
	answered question	**17**

Q11. "If you haven't received medical care in the last 6 months, which of the following things would help you to get to a doctor."		
Answer Options	**Response Frequency**	**Response Count**
Transportation	62.9%	78
If I get really sick	45.2%	56
Free medical care	39.5%	49
Insurance to pay for doctor and meds	51.6%	64
Better quality of services	17.7%	22
Referrals or advice from someone I trust	37.9%	47
More information about services	46.8%	58
Better trained doctors and nurses	14.5%	18
Employment opportunities	25.8%	32
Substance abuse treatment	20.2%	25
More outreach services	33.9%	42
More government services	34.7%	43
If I know friends go there.	29.0%	36
Not having to wait so long for appointments	41.1%	51
Nothing	1.6%	2
Other:	10.5%	13
answered question		**124**

Q12. "What could be done to get you to see a doctor?"		
Answer Options	**Response Frequency**	**Response Count**
Referrals and advise	50.0%	62
Outreach services	31.5%	39
Lower cost of medical care.	37.9%	47
Housing	24.2%	30
Transportation	65.3%	81
Substance use treatment	17.7%	22
Someone to go with me	25.0%	31
Other:	24.2%	30
answered question		**124**

Q13. Why do you think people don't get medical care for HIV?		
Answer Options	**Response Frequency**	**Response Count**
Worried that other people will find out/ Fear of telling someone else	84.7%	105
Cannot speak English very well	16.9%	21
Feel healthy	51.6%	64
Can't afford it.	46.8%	58
Don't have transportation.	46.0%	57
Couldn't get an appointment.	21.8%	27
Drugs	45.2%	56
Don't want to take HIV medications.	50.0%	62
Don't believe they are HIV+	60.5%	75
Other:	21.0%	26
	answered question	**124**

Q 28. "What might help to link you to medical care?"		
Answer Options	**Response Frequency**	**Response Count**
Referrals and advice	40.3%	50
More information about the services for me.	50.8%	63
Outreach services	31.5%	39
Lower cost of medical care/medicines.	37.9%	47
Housing	25.0%	31
Transportation	54.8%	68
Substance use treatment	19.4%	24
Financial concerns	51.6%	64
Peer support/someone to help me understand	46.8%	58
Other:	12.9%	16
	answered question	**124**

Q 29. "If you have not had medical care in more than 6 months for your HIV, please tell us why:"		
Answer Options	**Response Frequency**	**Response Count**
My doctor or nurse told me that I do not need medical care right now	1.7%	2
I do not think that I need medical care now because I am not sick	24.0%	29
I do not think that medical care would do me any good	10.7%	13
I have not found a doctor or nurse who I want to treat me	24.0%	29
I have not found a place that I feel comfortable going.	32.2%	39
I don't have transportation to get to medical care appointments	45.5%	55
I don't have child care when I go for medical care	1.7%	2
I do not know where to go for medical care	5.0%	6
I do not want to receive medical care	6.6%	8
I use alternative treatments	6.6%	8
I can't afford medical care now	41.3%	50
I get anxious about going to a doctor or nurse about HIV	36.4%	44
I don't want anyone to know	33.9%	41
I don't have the money for parking/lunch	53.7%	65
Other:	27.3%	33
	answered question	**121**

SERVICE NEEDS

Q11. "If you haven't received medical care in the last 6 months, which of the following things would help you to get to a doctor."

Answer Options	ALL OOC Frequency	ALL OOC Count	AA HETERO	AA MSM	AGED	HIS	IDU/SA	RURAL	WOMEN	YOUTH
Transportation	78	62.9%	65.6%	57.1%	63.1%	22.2%	53.7%	0.0%	76.0%	100.0%
If I get really sick	56	45.2%	46.9%	38.8%	46.2%	33.3%	51.2%	0.0%	32.0%	0.0%
Free medical care	49	39.5%	53.1%	26.5%	38.5%	22.2%	48.8%	0.0%	36.0%	0.0%
Insurance to pay for doctor and meds	64	51.6%	71.9%	40.8%	43.1%	22.2%	48.8%	0.0%	52.0%	0.0%
Better quality of services	22	17.7%	18.8%	16.3%	18.5%	44.4%	12.2%	0.0%	12.0%	0.0%
Referrals or advice from someone I trust	47	37.9%	46.9%	30.6%	36.9%	33.3%	26.8%	0.0%	40.0%	0.0%
More information about services	58	46.8%	50.0%	38.8%	41.5%	11.1%	43.9%	0.0%	40.0%	0.0%
Better trained doctors and nurses	18	14.5%	12.5%	12.2%	13.8%	11.1%	9.8%	0.0%	16.0%	0.0%
Employment opportunities	32	25.8%	43.8%	14.3%	27.7%	22.2%	26.8%	0.0%	16.0%	0.0%
Substance abuse treatment	25	20.2%	40.6%	14.3%	20.0%	22.2%	31.7%	100.0%	24.0%	0.0%
More outreach services	42	33.9%	37.5%	30.6%	30.8%	11.1%	24.4%	0.0%	24.0%	0.0%
More government services	43	34.7%	40.6%	36.7%	33.8%	11.1%	29.3%	0.0%	32.0%	0.0%
If I know friends go there.	36	29.0%	40.6%	26.5%	29.2%	33.3%	26.8%	0.0%	24.0%	0.0%
Not having to wait so long for appointments	51	41.1%	37.5%	40.8%	46.2%	0.0%	29.3%	0.0%	40.0%	0.0%
Nothing	2	1.6%	0.0%	2.0%	1.5%	22.2%	2.4%	0.0%	0.0%	0.0%
Other:	13	10.5%	0.0%	12.2%	9.2%	22.2%	7.3%	100.0%	8.0%	0.0%
answered question		**124**	**32**	**49**	**65**	**9**	**41**	**1**	**25**	**1**

BARRIERS to Service NEEDS

Common barriers to care include lack of information, lack of transportation, not feeling sick enough and/or ready for care, stigma, and other mental health and/or substance abuse issues (Mosaica Unmet Need TA Center of the TAC, 2006). Some of the reasons given for the perceived service barriers to the top 12 ranking needs of the Sacramento EMA OOC population are common barriers to care. The specific reasons offered by the Sacramento OOC population yield potentially useful information for planners and providers, alike. (No barrier reasons were offered by the OOC respondents for services with lower than a 12th place ranking.)

Several of the service categories received barrier reasons that are readily amenable to intervention. For example, lack of information regarding the location of the service may be addressed in consumer handbooks describing available services with directions on how to physically locate the agency or program and how to readily access each service. Additionally, regular meetings and/or communications about services available in the TGA may be shared among and communicated to all Case Managers and other 'point of entry' staff.

Lack of available transportation, particularly medical transportation assistance to physician appointments, is a frequently cited barrier. A perceived lack of access to insurance assistance is another fairly frequently cited access barrier to services in the TGA.

BARRIERS to Service NEEDS by SNG

Q10. "If you did not seek medical care from a doctor or a nurse within one (1) year of finding out you were HIV positive, please indicate the reasons why."										
Answer Options	ALL OOC > 1 YEAR	ALL OOC > 1 YEAR	AA HETERO	AA MSM	AGED	HIS	IDU/SA	RURAL	WOMEN	YOUTH
Couldn't afford it	5	29.4%	0.0%	44.4%	27.3%	0.0%	20.0%	0.0%	0.0%	0.0%
Didn't need medical care	0	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%
Couldn't get transportation	0	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%
Didn't know where to go to get medical care	1	5.9%	0.0%	0.0%	9.1%	0.0%	0.0%	0.0%	50.0%	0.0%
Don't trust doctors	3	17.6%	100.0%	11.1%	18.2%	0.0%	20.0%	0.0%	0.0%	0.0%
Didn't think I needed it	2	11.8%	0.0%	11.1%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%
I was depressed	5	29.4%	100.0%	33.3%	18.2%	50.0%	40.0%	0.0%	0.0%	0.0%
Didn't like the way I was treated	1	5.9%	0.0%	11.1%	9.1%	0.0%	20.0%	0.0%	0.0%	0.0%
I feel good/healthy	3	17.6%	0.0%	22.2%	9.1%	0.0%	0.0%	0.0%	0.0%	0.0%
Other:	7	41.2%	0.0%	55.6%	45.5%	50.0%	60.0%	100.0%	50.0%	0.0%
answered question		17	1	9	11	2	5	1	25	1

Q13. Why do you think people don't get medical care for HIV?										
Answer Options	ALL OOC	ALL OOC	AA HETERO	AA MSM	AGED	HIS	IDU/SA	RURAL	WOMEN	YOUTH
Worried that other people will find out/ Fear of telling someone else	105	84.7%	93.8%	79.6%	83.1%	77.8%	87.8%	15.4%	92.0%	0.0%
Cannot speak English very well	21	16.9%	21.9%	12.2%	13.8%	22.2%	17.1%	30.8%	12.0%	0.0%
Feel healthy	64	51.6%	56.3%	49.0%	52.3%	33.3%	46.3%	15.4%	44.0%	0.0%
Can't afford it.	58	46.8%	50.0%	38.8%	43.1%	33.3%	48.8%	7.7%	36.0%	0.0%
Don't have transportation.	57	46.0%	56.3%	40.8%	47.7%	33.3%	46.3%	53.8%	56.0%	100.0%
Couldn't get an appointment.	27	21.8%	25.0%	14.3%	23.1%	22.2%	22.0%	7.7%	24.0%	0.0%
Drugs	56	45.2%	62.5%	34.7%	41.5%	44.4%	56.1%	23.1%	40.0%	0.0%
Don't want to take HIV medications.	62	50.0%	50.0%	55.1%	56.9%	22.2%	46.3%	23.1%	44.0%	0.0%
Don't believe they are HIV+	75	60.5%	68.8%	55.1%	61.5%	22.2%	56.1%	15.4%	48.0%	0.0%
Other:	26	21.0%	15.6%	20.4%	18.5%	66.7%	19.5%	30.8%	24.0%	0.0%
answered question		124	32	49	65	9	41	13	25	1

Service Gaps and Reasons for Gaps by Severe Need Group (SNG)

Q 29. "If you have not had medical care in more than 6 months for your HIV, please tell us why:"										
Answer Options	ALL OOC	ALL OOC	AA HETERO	AA MSM	AGED	HIS	IDU/SA	RURAL	WOMEN	YOUTH
My doctor or nurse told me that I do not need medical care right now	2	1.7%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%
I do not think that I need medical care now because I am not sick	29	24.0%	3.1%	0.0%	1.6%	0.0%	0.0%	8.3%	4.3%	0.0%
I do not think that medical care would do me any good	13	10.7%	28.1%	20.4%	20.3%	12.5%	25.6%	8.3%	17.4%	0.0%
I have not found a doctor or nurse who I want to treat me	29	24.0%	9.4%	10.2%	9.4%	12.5%	12.8%	0.0%	8.7%	0.0%
I have not found a place that I feel comfortable going.	39	32.2%	28.1%	16.3%	14.1%	25.0%	23.1%	8.3%	13.0%	0.0%
I don't have transportation to get to medical care appointments	55	45.5%	40.6%	24.5%	21.9%	37.5%	23.1%	8.3%	30.4%	0.0%
I don't have child care when I go for medical care	2	1.7%	50.0%	42.9%	39.1%	25.0%	35.9%	50.0%	47.8%	100.0%
I do not know where to go for medical care	6	5.0%	3.1%	0.0%	0.0%	0.0%	0.0%	0.0%	4.3%	0.0%
I do not want to receive medical care	8	6.6%	6.3%	2.0%	0.0%	12.5%	2.6%	0.0%	0.0%	0.0%
I use alternative treatments	8	6.6%	6.3%	2.0%	3.1%	12.5%	5.1%	8.3%	8.7%	0.0%
I can't afford medical care now	50	41.3%	3.1%	4.1%	4.7%	0.0%	5.1%	0.0%	4.3%	0.0%
I get anxious about going to a doctor or nurse about HIV	44	36.4%	43.8%	42.9%	34.4%	25.0%	41.0%	16.7%	34.8%	0.0%
I don't want anyone to know	41	33.9%	46.9%	26.5%	34.4%	12.5%	38.5%	25.0%	43.5%	0.0%
I don't have the money for parking/lunch	65	53.7%	37.5%	30.6%	29.7%	50.0%	28.2%	25.0%	30.4%	0.0%
Other:	33	27.3%	71.9%	36.7%	46.9%	25.0%	51.3%	41.7%	78.3%	100.0%
answered question		121	32	49	65	9	41	13	25	1

POSSIBLE RESOLUTION/INCENTIVES TO ENTER OR RE-ENTER CARE by SNG

Q 28. "What might help to link you to medical care?"										
Answer Options	ALL OOC	ALL OOC	AA HETERO	AA MSM	AGED	HIS	IDU/SA	RURAL	WOMEN	YOUTH
Referrals and advice	50	40.3%	37.5%	34.7%	36.9%	66.7%	29.3%	30.8%	44.0%	0.0%
More information about the services for me.	63	50.8%	50.0%	49.0%	49.2%	33.3%	43.9%	38.5%	48.0%	0.0%
Outreach services	39	31.5%	40.6%	26.5%	30.8%	22.2%	24.4%	23.1%	24.0%	0.0%
Lower cost of medical care/medicines.	47	37.9%	53.1%	28.6%	38.5%	33.3%	26.8%	7.7%	28.0%	0.0%
Housing	31	25.0%	34.4%	22.4%	21.5%	11.1%	22.0%	30.8%	8.0%	0.0%
Transportation	68	54.8%	56.3%	51.0%	52.3%	33.3%	48.8%	38.5%	40.0%	100.0%
Substance use treatment	24	19.4%	34.4%	16.3%	20.0%	22.2%	29.3%	7.7%	12.0%	0.0%
Financial concerns	64	51.6%	43.8%	49.0%	49.2%	33.3%	43.9%	38.5%	44.0%	0.0%
Peer support/someone to help me understand	58	46.8%	59.4%	40.8%	44.6%	22.2%	43.9%	30.8%	36.0%	0.0%
Other:	16	12.9%	6.3%	14.3%	16.9%	33.3%	22.0%	38.5%	12.0%	0.0%
answered question		124	32	49	65	9	41	13	25	1

Q12. "What could be done to get you to see a doctor?"										
Answer Options	ALL OOC	ALL OOC	AA HETERO	AA MSM	AGED	HIS	IDU/SA	RURAL	WOMEN	YOUTH
Referrals and advice	62	50.0%	50.0%	51.0%	53.8%	33.3%	43.9%	53.8%	52.0%	0.0%
Outreach services	39	31.5%	40.6%	20.4%	27.7%	22.2%	36.6%	23.1%	32.0%	0.0%
Lower cost of medical care.	47	37.9%	40.6%	38.8%	35.4%	33.3%	31.7%	15.4%	28.0%	0.0%
Housing	30	24.2%	34.4%	20.4%	24.6%	22.2%	19.5%	23.1%	16.0%	0.0%
Transportation	81	65.3%	68.8%	65.3%	67.7%	55.6%	61.0%	0.0%	64.0%	100.0%
Substance use treatment	22	17.7%	31.3%	12.2%	16.9%	22.2%	22.0%	7.7%	16.0%	0.0%
Someone to go with me	31	25.0%	25.0%	28.6%	24.6%	11.1%	17.1%	15.4%	20.0%	0.0%
Other:	30	24.2%	18.8%	18.4%	24.6%	33.3%	26.8%	0.0%	36.0%	0.0%
answered question		124	32	49	65	9	41	13	25	1

C. Describe Plans to Find People NOT in Care and Get Them into Care

Addressing the 'Unmet Need' is the most important aspect of the Unmet Need Framework and process. The strategies developed and implemented to address Unmet Need should:

1. Ensure equitable access to care regardless of OOC population characteristics or location within the service area;
2. Effectively help the OOC into care;
3. Effectively retain them in care;
4. Ensure that supportive services contribute to primary care entry and retention in care. (Mosaica Unmet Need TA Center of the TAC, June 2006 Meeting with Part A and Part B Programs)

Different strategies will be necessary for different sub-groups of PLWHA. For example, different strategies will be necessary for the Newly diagnosed, for PLWHA receiving medical and supportive services other than primary HIV medical care, for those PLWHA who have either 'erratically' been in care or who have dropped out of care, and for those PLWHA who have NEVER been in care.

Additionally, it is important to delineate specific continuum of care plans for each of the major Severe Need Groups in the TGA. This Unmet Needs Study provides detailed information about the Service Needs and Barriers as perceived by the entire OOC population and for each individual Severe Need Group. The report describes the services perceived as unavailable (Service Gaps), and some Reasons for the perceived Gaps as identified by the entire group of OOC respondents.

The chosen intervention strategies must effectively reduce the identified barriers to needed services and may require some changes to the existing continuum of care in the TGA.

Suggested Strategies for Newly Diagnosed PLWHA:

Improved links between prevention and care, such as:

1. *Locating HIV Testing programs in HIV primary clinics, with aggressive offers of testing to the Patients' sexual and drug-using partners, spouses, and*
2. *Use of rapid testing in clinical and outreach testing settings*
3. *Use of peer outreach testing specialists to locate and test other high risk individuals within their own unique social networks*
4. *Implementing same day referrals into primary medical care upon testing positive*
5. *Use of peer mentors to ease transition into care and assist with navigation of care systems*

Suggested Strategies for PLWHA Receiving Some Services But NOT Primary HIV Medical Care

Improved Linkages Between Supportive and Primary Care Services

1. *Case Managers and other Support staff who provide services should inquire about and encourage entry/re-entry into primary medical care*

2. *Case Managers and Therapists should ensure that the necessary supportive services are provided to stabilize the person's life situation (i.e, stable housing, food, safety) and then help ensure that these services are extended to facilitate entry into and retention in care, as indicated*
3. *Use of active referrals into primary medical care with documented confirmations of Intake appointments/Re-Establish appointments*

Suggested Strategies for PLWHA Who Have Dropped Out of Care

Improved Provider-Patient Partnerships and Collaborations with Peers

1. *Primary Care providers should make appointment reminder calls; facilitate transportation assistance; and implement/maintain "no-show" tracking and follow-up protocols*
2. *At least biannually, Primary Medical providers should examine patient lists to determine who has not returned for care and initiate telephone and/or letter contact to make appointments and encourage re-entry into care*
3. *Use of peer advocates to get PLWHA back into care*
4. *Focus on reducing known barriers to care and resolving gaps in continuum of care*

Suggested Strategies for PLWHA NEVER in Care

Peer-facilitated Linkages Between Points of Entry/Testing/Counseling & Primary Care

1. Active follow-up by Testing/Counseling agency to maintain contact and confirm entry into care

2. Peer Outreach to specific populations and locations, including homeless shelters, etc

3. Regular marketing of primary care services' availability and directions on making referrals with all points of entry staff and agencies

4. Social marketing efforts regarding benefits of care and treatment