

2007
‘Unmet Need’
Needs Assessment Report

Ryan White Part A
New Haven-Fairfield Counties
Transitional Grant Area

Prepared for

The New Haven-Fairfield Ryan White
HIV Health Services Planning Council

Prepared by:


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2007 Unmet Needs Assessment

New Haven-Fairfield HIV Health Services Planning Council August 2007

I. Introduction

A. Background

Annual Needs Assessments are studies conducted to canvass the HIV/AIDS client base and determine service gaps and barriers in the continuum of care for Persons Living with HIV/AIDS (PLWH/A). Results of this client-centered activity are used to establish service priorities, document the need for specific services, determine barriers to accessing care, provide baseline data for comprehensive planning, including capacity building, and help providers improve the access and quality of service, especially to Severe Need Groups (SNGs)¹. Severe Need Groups are demographic/exposure subsets of the community who are disproportionately impacted by the epidemic.

A recent focus of the Annual Needs Assessment process is to survey PLWH/A who are “Aware and Not in Care”² and determine their unmet needs. PLWH/A failing to access primary medical care for a period of time exceeding one year are deemed ‘Out of Care’. Primary Medical Care is technically defined as the receipt of one or more of three forms of service—use of (1) antiretroviral drugs (2) CD4 lab tests and (3) Viral Load lab test.³ The New Haven-Fairfield TGA considers an individual with HIV or AIDS to have an unmet need for care (or to be ‘Out of Care’) when there is no evidence that the person received any of the above forms of service during a defined 12 month time frame.

In Spring 2007, the New Haven-Fairfield HIV Health Services Planning Council contracted with Collaborative Research to conduct an ‘Out of Care’ needs assessment to further assess unmet need among targeted individuals living with HIV/AIDS who are ‘Out of Care’ in the Transitional Grant Area. “Unmet Need” specifically refers to the need for HIV-related primary health care. The need for other services is referred to as “Service Gaps”.

¹ Severe Need Groups: 1) Anglo MSM; 2) African American MSM; 3) Intravenous Drug Users; 4) Substance Abusers; 4) Women of Childbearing Age; 5) Incarcerated/Recently Released; 6) Youth ages 13-24. In addition we included High Risk Heterosexuals, and Foreign-Born.

² OOC & Aware: CDC estimate of 850-900,000 currently HIV positive, 2/3 or 670,000 know they are infected. Of this, 1/3 or 233,000 do not receive HIV-related primary health care (CDC, February 2002)

³ 1) CD4 – CD4 (T4) or CD4 + CELLS. HIV’s preferred targets are cells that have a docking molecule called “cluster designation 4 (CD4) on their surfaces. Cells with this molecule are known as CD4-positive (or CD4+) cells. Destruction of CD4+ lymphocytes is the major cause of the immunodeficiency observed in AIDS, and decreasing CD4+ lymphocyte levels appear to be the best indicator for developing opportunistic infections.
2) VIRAL LOAD TEST - Test that measures the quantity of HIV RNA in the blood. Results are expressed as the number of copies per milliliter of blood plasma. Research indicates that viral load is a better predictor of the risk of HIV disease progression than the CD4 count. The lower the viral load, the longer the time to AIDS diagnosis and the longer the survival time. Viral load testing is used to determine when to initiate and/or change therapy.
3) ANTIRETROVIRAL DRUGS - Substances used to kill or inhibit the multiplication of retroviruses such as HIV.

The Ryan White HIV/AIDS Treatment Modernization Act of 2006 requires Part A and Part B Grantees and planning bodies to determine how many people in their service area know they are HIV positive but are not receiving regular HIV-related primary medical care. The ultimate goal of the unmet need process is to facilitate re-entry and retention in care for the 'Out of Care', and to reduce the overall level of unmet need in the service area. The three major process steps for addressing unmet need include:

1. Estimating the number of people in each service area who know they are HIV-positive but not receiving HIV-related medical care: the number NOT "in care".
2. Assessing the service needs and barriers to care for such people, including finding out who they are and where they live.
3. Addressing unmet needs by finding these individuals and getting them into care. (HRSA/Mosaica Unmet Need TA Center, 2006)

Based upon the Unmet Need Framework, the New Haven-Fairfield TGA undertook a rapid needs assessment process in order to begin to address the following four items, including any plans for cross-Title 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 primarily organized around addressing Item 2 above.

B. Relevance of an Unmet Need/Out of Care Study

Approximately one-third of PLWH/A in the United States are aware that they are HIV-positive but do not access primary medical care as defined by the triad of antiretroviral therapy, CD4 and Viral Load laboratory monitoring tests at least every 12 months. The Centers for Disease Control (CDC) estimate that approximately 233,000 of 670,000 Americans who know their HIV status are not regularly receiving HIV primary medical care. (CDC: Ninth Conference on Retroviruses and Opportunistic Infections, Seattle, Washington, February 2002) 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 'erratically in care' and 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.

The initial and significant burden is attaching persons to care immediately upon a positive HIV diagnosis. This juncture is one that many PLWH/A 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. Curiously, the recent advances in HIV treatment, especially Antiretroviral Therapy (ART) 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 advancement 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 can be assessed in a study specific to the ‘Out of Care’ to confirm that these are the risk flags for PLWH/A considering abandoning their care regimen. Flags include erratic appointment compliance (missing three or more appointments), tendency to not disclose issues, 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 PLWH/A 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.

C. Project Design

Collaborative Research proposed to survey 160-180 PLWH/A that are ‘Out of Care’. Strategies for reaching these individuals included but were not limited to:

- *Working with Primary Care Clinics and other core medical service providers 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 access support services (e.g. food bank) and not primary medical care; and*
- *Working with outreach services to survey hard to reach populations that inform populations who are out of care.*

Incentives (\$20 Gift Card) were provided to survey respondents that completed the survey.

II. Unmet Need/Out of Care Framework and Survey Methodology

Table 1. Unmet Need Estimate

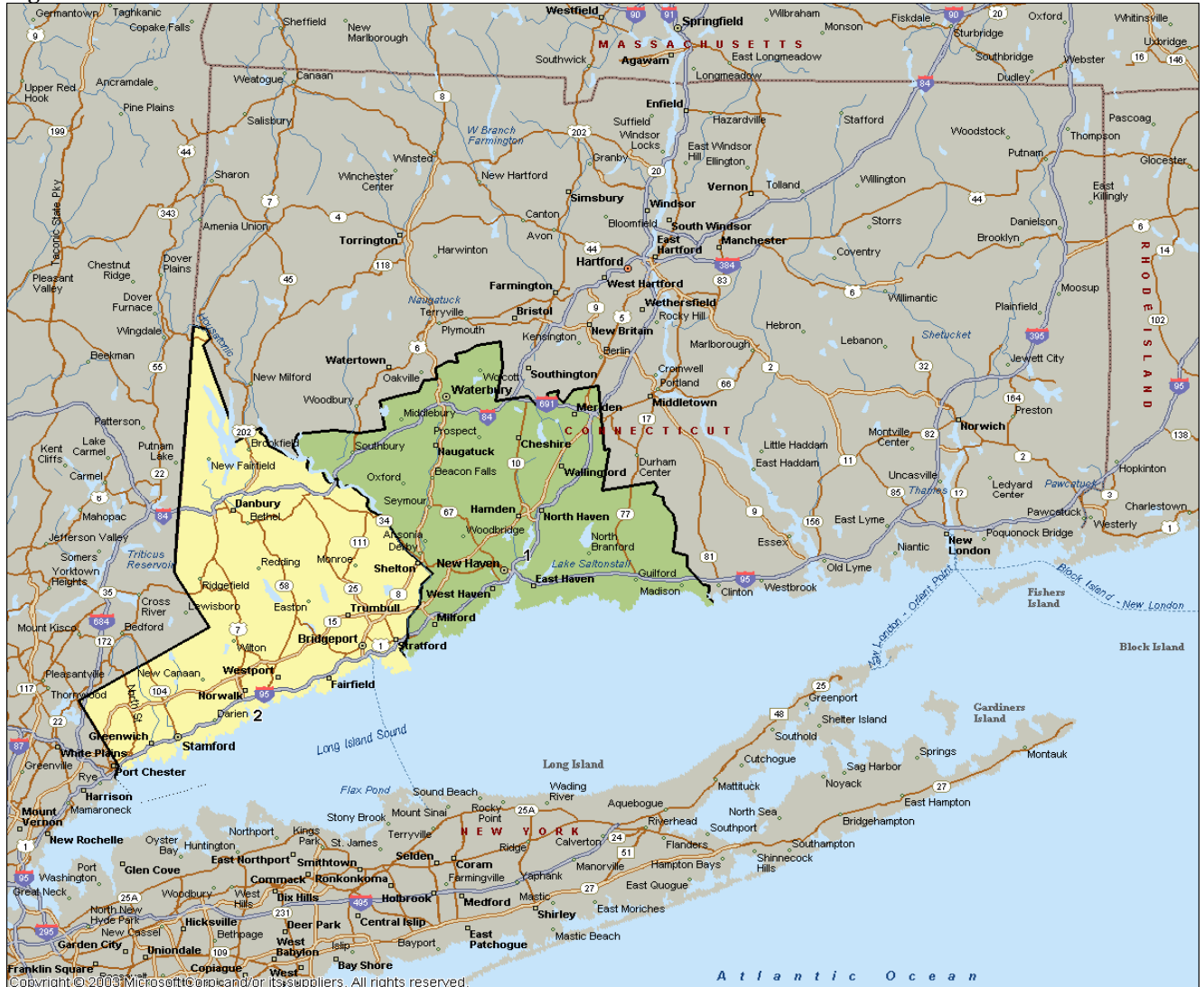
Column 1	Column 2	Column 3	Column 4	Column 5
Population Sizes		Value	Value	Data Source(s)
Row A.	Number of persons living with AIDS (PLWA), for the period of [01/01/2005-12/31/2005]	3,981		Connecticut Department of Health
Row B.	Number of persons living with HIV (PLWH)/non-AIDS/aware, for the period of [01/01/2005-12/31/2005)	4,866		Connecticut Department of Health
Row C.	Total number of HIV+/aware for the period of [01/01/2005-12/31/2005]	8,847		Connecticut Department of Health
Care Patterns		Value		
Row D.	Number of PLWA who received the specified HIV primary medical care during the 12-month period [01/01/2005-12/31/2005)	2,866		1) Ryan White Title I and III providers 2) Non-Ryan White Providers 3) Insurance Tables 4) 2006 Site Visits conducted in July/August 2006
Row E.	Number of PLWH/non-AIDS/aware who received the specified HIV primary medical care during the 12-month period [01/01/2005-12/31/2005)	3,078	1) Ryan White Title I and III providers 2) Non-Ryan White Providers 3) Insurance Tables 4) 2006 Site Visits conducted in July/August 2006.	
Row F.	Total number of HIV+/aware who received the specified HIV primary medical care during the 12-month period [01/01/2005-12/31/2005)	5,944	1) Ryan White Title I and III providers 2) Non-Ryan White Providers 3) Insurance Tables 4) 2006 Site Visits conducted in July/August 2006.	
Calculated Results		Value	Value	Percent
Row G.	Number of PLWA who did not receive the specified HIV primary medical care	1,115	28%	Total PLWA from 01/01/05-12/31/2005 - # of PLWA who received HIV primary medical care/100
Row H.	Number of PLWH/non-AIDS/aware who did not receive the specified HIV primary medical care	1,788	37%	Total PLWH from 01/01/05-12/31/2005 - # of PLWH who received HIV primary medical care/100
Row I.	Total HIV+/aware not receiving the specified HIV primary medical care (quantified estimate of unmet need)	2,903	33%	Total PLWH/A from 01/01/05-12/31/2005 - # of PLWH/A who received HIV primary medical care/100

Unmet Need Narrative

I. Introduction and Background for 2007 Study

The New Haven-Fairfield Counties' TGA consists of two (2) counties in Southeastern Connecticut—New Haven and Fairfield Counties. Five (5) distinct regions are further described, with different epidemic profiles characterized by region. Region 1 is New Haven, Region 2 is Waterbury-Naugatuck-Meriden, Region 3 is Bridgeport, Region 4 is Stamford/Norwalk and Region 5 is Danbury.

Figure 1. New Haven-Fairfield TGA – Two counties in Southeastern Connecticut



CURRENT EPIDEMIOLOGIC PREDICAMENT

CAVEAT: The epidemiologic profile for 2005 and 2006 for both the New Haven and Hartford TGAs are currently disputed by those jurisdictions, with significant attention paid to discrepancies noted in the 2005 Epidemiologic Profile used in the FY 2007 grant. Concurrent reduction in total reported prevalent (living with HIV/AIDS) and incident (new cases) A brief prologue addressing these concerns precedes an overview of the historic and emerging special populations at risk of being Out of Care.

CONTEXT:

(1) A computer system designed to collect laboratory blood values indicative of HIV disease (CD4, Viral Loads) was determined to be flawed, resulting in the need for manual entry of data on computer diskettes.

(2) Due to late realization of the issues with the automated information system, data on the CD's is approximately 1-1/2 years behind. As of the end of December 2006, data from 2005 was not yet fully entered (estimated at 2/3 of the year).

(3) While efforts have been made to update this lag, as of the mid-point of 2007 (June 30, 2007); all of 2006 has not yet been fully entered for inclusion and report to the CDC for the Calendar Year of 2006 needed as the foundation for formula grant funding.

(4) To our knowledge, the lateness with the data has not allowed for sufficient data integrity checks, with a consistent 20% difference factor in any single category prior to 2005 and the issues being dramatically felt by Connecticut.

(5) Given this set of circumstances, at least three (3) significant remedies/valiant efforts were conducted in 2007:

a) A full population study was conducted in 2007 by the Grantee to determine if any disparities exist in access to care – this study is now being conducted by the same consultant for the Hartford TGA. This data shows higher population in care than reported by the Epidemiologic Profile for either TGA. Case findings by chart reviews potentially yield the most accurate picture of the breadth and depth of the epidemic among Connecticut Ryan White Part A recipients.

b) One-time relief to repair the funding deficit experienced by both TGAs due to the flawed Epidemiologic Profile occurred, with receipt anticipated in November/December 2007. Immense gratitude is given to our highly esteemed politicians for realizing the value of our services and the extent of this crack in our infrastructure.

c) A formal request for a comprehensive audit of the State of Connecticut's Department of Public Health HIV/AIDS Surveillance Unit has been made to the CDC by the mayoral bodies represented by the New Haven and Hartford TGAs. An inadequate response was followed by a second request to examine this issue.

(6) Poor risk factor data, large group of unidentified risk (believed to be either IDU or MSM)

(7) No enforcement of existing HIV/AIDS reporting laws

Comparison of Connecticut Epidemiologic Profile to Historic Data

Statement regarding New Haven-Fairfield TGA Epidemiology Profile for PLWHA since 2005	CT Epidemiology Statement	Historic data supported by Center for Disease Control & Prevention (CDC)
% of State in New Haven-Fairfield Counties' TGA	56.8%	56% (60% PLWA, 45% PLWH)
Total Estimated PLWA in New Haven-Fairfield TGA	3,977	3,981
Total Estimated PLWH in New Haven-Fairfield TGA	1,050	4,866
Total Estimated PLWHA in New Haven-Fairfield TGA	5,027	8,847
Total Estimated new cases of AIDS in 2004 and 2005 in New Haven-Fairfield Counties' TGA	363 + 313 = 676	686

Summary:

Given these caveats, the data presented following this context has obvious flaws. In addition to the overall inaccurate picture of the size and scope of the epidemic, the ratio of HIV to AIDS cases is understated (should be more people living with HIV than reported), there are clearly people in care living with HIV that are over 45 years of age, and the percent of IDU, while still among the highest in the U.S., is understated.

Newly Diagnosed HIV/AIDS

Newly diagnosed cases increased slightly (4.7%) from 2005 to 2006. The increase was experienced more in newly diagnosed HIV cases (10% increase) versus AIDS cases (2%).

Populations experiencing an increase in HIV cases were Black (up 8%), Female (up 2%), in the 40-49 (up 7%) and over 49 years of age group (2% increase) and with No Risk Identified or Reported (18% increase).

Populations experiencing increases in newly diagnosed AIDS were Hispanic (up 12%), with slight increases in the 5-12 and 13-19 age groups and a 5% increase in the 30-39 age group. High-risk heterosexuals experienced a 4% increase in newly diagnosed AIDS, and a similar significant fraction of 17% increase in No Risk Identified or Reported.

2006 Epidemiologic Profile

NEWLY DIAGNOSED HIV/AIDS

RACE/ETHNICITY	NEWLY DIAGNOSED AIDS CASES (2006)	NEWLY DIAGNOSED HIV CASES (2006)	NEWLY DIAGNOSED HIV/AIDS (2005)
White, not Hispanic	82 (27%)	50 (29%)	132 (27%)
Black, not Hispanic	105 (34%)	57 (33%)	162 (34%)
Hispanic	121 (39%)	67 (38%)	188 (38%)
Asian/Pacific Islander		1 (1%)	1 (1%)
American Indian			
Multi-race			
TOTAL	308	175	483
GENDER			
Male	201 (65%)	110 (63%)	311 (64%)
Female	107 (35%)	65 (37%)	172 (36%)
TOTAL	308	175	483
AGE AT DIAGNOSIS (YEARS)			
Under 5			
5-12	1 (0.3%)		1 ((0.2%)
13-19	4 (1%)	1 (0.6%)	5 (1%)
20-29	29 (9%)	44 (25%)	73 (15%)
30-39	95 (31%)	50 (29%)	145 (30%)
40-49	108 (35%)	57 (33%)	165 (34%)
Over 49	71 (23%)	23 (13%)	94 (19%)
TOTAL	308	175	483
RISK/EXPOSURE			
Men who have sex with men	51 (17%)	37 (21%)	88 (18%)
Injection drug users	91 (30%)	33 (19%)	124 (26%)
Men who have sex with men and inject drugs	4 (1%)	1 (1%)	5 (1%)
Hemophilia/coagulation Disorder			
Heterosexual contact	68 (22%)	29 (17%)	97 (20%)
Receipt of blood transfusion, blood components, or tissue			
Risk not reported or identified	91 (30%)	75 (43%)	166 (34%)
TOTAL	308	175	483

RACE/ETHNICITY	NEWLY DIAGNOSED AIDS CASES (2005)	NEWLY DIAGNOSED HIV CASES (2005)	NEWLY DIAGNOSED HIV/AIDS (2005)
White, not Hispanic	101 (33%)	52 (33%)	153 (33%)
Black, not Hispanic	116 (38%)	40 (25%)	156 (34%)
Hispanic	83 (27%)	66 (42%)	149 (32%)
Asian/Pacific Islander		1 (1%)	1 (0.2%)
American Indian	1 (1%)		1 (0.2%)
Multi-race	1 (1%)		1 (0.2%)
TOTAL	302	159	461
GENDER			
Male	197 (65%)	103 (65%)	300 (65%)
Female	105 (35%)	56 (35%)	161 (35%)
TOTAL	302	159	461
AGE AT DIAGNOSIS (YEARS)			
Under 5	2 (1%)	2 (1%)	4 (1%)
5-12	2 (1%)	3 (2%)	5 (1%)
13-19		2 (1%)	2 (0.4%)
20-29	26 (9%)	47 (30%)	73 (16%)
30-39	78 (26%)	47 (30%)	125 (27%)
40-49	120 (40%)	41 (26%)	161 (35%)
Over 49	74 (25%)	17 (11%)	91 (20%)
TOTAL	302	159	461
RISK/EXPOSURE			
Men who have sex with men	55 (19%)	36 (23%)	91 (20%)
Injection drug users	123 (41%)	47 (31%)	170 (37%)
Men who have sex with men and inject drugs	5 (2%)	2 (1%)	7 (2%)
Hemophilia/coagulation Disorder			
Heterosexual contact	76 (26%)	32 (21%)	108 (23%)
Mother with/at risk for HIV infection	5 (2%)	2 (1%)	7 (2%)
Risk not reported or identified	38 (13%)	40 (25%)	78 (17%)
TOTAL	302	159	461

Prevalent HIV/AIDS

RACE/ETHNICITY	PEOPLE LIVING WITH AIDS (2006)	PEOPLE LIVING WITH HIV (2006)	PLWHA (06)
White, not Hispanic	1,442 (35%)	568 (33%)	2,010 (34%)
Black, not Hispanic	1,570 (38%)	555 (32%)	2,125 (36%)
Hispanic	1,126 (27%)	572 (33%)	1,698 (29%)
Asian/Pacific Islander	0	10 (0.6%)	10 (0.2%)
American Indian/Alaska Native	0	1 (0.05%)	1 (.02%)
Multi-race	17 (0.4%)	5 (0.3%)	22 (0.4%)
Total	4,155	1,711	5,866
GENDER			
Male	2,778 (68%)	1,034 (60%)	3,812 (65%)
Female	1,337 (32%)	677 (40%)	2,054 (35%)
TOTAL	4,155	1,711	5,866
AGE AT DIAGNOSIS (YEARS)			
Under 5 years	43 (1%)	5 (0.3%)	48 (0.8%)
5-12	14 (0.3%)	5 (0.3%)	19 (0.3%)
13-19	20 (0.5%)	10 (1%)	30 (0.5%)
20- 29	510 (2%)	452 (26%)	952 (16%)
30-39	1,705 (41%)	612 (36%)	2,317 (39%)
40-49	1,353 (33%)	452 (26%)	1,805 (31%)
Over 49	510 (12%)	175 (10%)	685 (12%)
TOTAL	4,155	1,711	5,866
RISK/EXPOSURE			
Men who have sex with men	872 (21%)	336 (20%)	1,208 (21%)
Injection drug users	1,758 (43%)	561 (33%)	2,319 (40%)
Men who have sex with men and inject drugs	84 (2%)	17 (1%)	101 (2%)
Hemophilia/coagulation Disorder	8 (0.2%)	2 (0.1%)	10 (0.2%)
Heterosexuals	1,005 (24%)	370 (22%)	1,375 (23%)
Receipt of blood transfusion, blood components, or tissue	8 (0.2%)	1 (0.06%)	9 (0.2%)
Risk not reported or identified	358 (8%)	424 (25%)	782 (13%)
TOTAL	4,155	1,711	5,866

2006 Epidemiologic Profile

HIV/AIDS demographics The number of new AIDS cases among TGA residents reported to the CDC during 2005 and 2006 was 610 (Connecticut Department of Health, HIV/AIDS Annual Report). In the New Haven-Fairfield Counties' TGA, there are 5,866 PLWH/A reported living in the TGA as of December 2006, representing 60% of total AIDS prevalence, 45% of HIV prevalence and 56% of new AIDS cases reported in the state.

- Newly diagnosed AIDS are almost equally divided among non-Latino Whites (30%), African Americans (36%) and Latinos (34%). Newly diagnosed HIV cases are dominated by Blacks (44%), then White (32%) then Latinos (25%).
- PLWA are comprised of Blacks (38%), followed by White (35%) then Latinos (27%). PLWH are equally divided among all three major race/ethnic groups slightly led by Latinos (33%), then Whites (33%) then Blacks (32%).
- People of color as a group, including African Americans and Latinos represent two-thirds of PLWHA in the TGA. The fraction of PLWH is slightly higher (66.8%) than PLWA (65.3%).
- IDU represent the largest proportion of PLWH/A at 40%, with 43% of PLWA and 33% of PLWH. 41% of new AIDS cases and 33% of new HIV cases. This is followed equally by Heterosexual Sex (24% PLWA, 22% PLWH, 26% new AIDS cases and 21% new HIV cases) and MSM (21% PLWA, 20% PLWH, 17% new AIDS cases and 20% of new HIV cases).
- Gender composition demonstrates spread to females with 35.23% new AIDS cases, 37 % of new HIV cases and 32% PLWA and 40% PLWH
- Roughly one-third of IDUs are female, with females over 70% of those infected through heterosexual contact
- The foreign born population comprising 15-20% of the TGA is 78% Latino and 22% African with countries represented including Haiti, Mexico, Nicaragua, Ecuador, Colombia and Brazil. African expatriates hail from the Congo, Tanzania, Ethiopia and the Sudan.
- Haiti immigrants equally claim Latino and African descent, with half speaking French and the other half Spanish.
- Nearly 55% of PLWH/A reside in New Haven County, 45% live in Fairfield County.
- Spanish is the primary language for 35% of the 'In Care' population. About 15% are monolingual.
- Age groups are significantly older than the general population or the national profile for PLWH/A with 36% of new AIDS cases and 25% of PLWA over 45 at time of diagnosis. The PLWH group is younger, with 10% of PLWH and over 45 years of age comprising 17% of newly diagnosed HIV cases.
- Chronic under-reporting of risk or exposure status continues at the state level with a significant 'not identified or reported' fraction of 13% of new AIDS cases, 23% of new HIV cases, 8% of PLWA and 25% of PLWH. State epidemiologists believe that these undisclosed cases equally divide between Injection Drug Users and MSM. These percentages have significantly decreased from 2004-2005.

Race/Ethnic Group. The highest proportion of African Americans within the TGA is in New Haven at almost 44% of the infected. For Whites, Danbury leads the TGA in almost 60% White composition; Waterbury is highest for Latino concentration followed by Bridgeport; and Stamford claims the highest ‘other’, composed mostly of foreign born who declared multi-racial ethnicity.

Table 2. Race/Ethnic Group of TGA by Regional Planning Service Area, 2005

Race/ Ethnic Group	New Haven Fairfield TGA	1-New Haven	2- Waterbury	3- Bridgeport	4-Stamford/ Norwalk	5- Danbury
AA	37.4%	43.6%	20.7%	39.1%	44.4%	15.0%
WHITE	25.3%	34.4%	41.1%	26.3%	37.6%	57.5%
LATINO	26.8%	21.5%	38.1%	34.1%	17.0%	26.3%
OTHER	0.5%	0.5%	0.1%	0.4%	1.7%	1.1%

Exposure. Stamford/Norwalk had the highest proportion of MSM; New Haven the most IDU; and Bridgeport the most MSM/IDU (primarily among African Americans and Latinos). Heterosexual contact as the risk exposure group was highest in Danbury; Other/Unknown (again believed to be equally split between MSM and IDU) highest in Bridgeport; and Pediatric transmission highest in New Haven.

Table 3. Exposure Group by Regional Planning Service Area, 2005

Exposure	New Haven Fairfield TGA	1-New Haven	2- Waterbury	3- Bridgeport	4-Stamford/ Norwalk	5- Danbury
MSM	19.4%	18.6%	18.1%	14.0%	27.7%	26.8%
IDU	39.9%	43.8%	40.7%	40.0%	31.1%	33.0%
MSM/ IDU	2.1%	2.2%	1.9%	2.5%	1.3%	2.2%
HET SEX	20.3%	20.0%	19.7%	20.7%	20.7%	22.3%
UNKNOWN	17.0%	13.6%	18.0%	21.9%	17.6%	15.1%
PEDIATRIC	1.5%	1.9%	1.5%	0.8%	1.7%	0.6%

(Source: Connecticut Department of Public Health, HIV/AIDS Surveillance, 2005)

Disproportionate impact on certain populations: Historically underserved populations in the New Haven-Fairfield TGA include Injection Drug Users (IDU), African Americans, Latinos and older PLWH/A (45 years+). Emerging populations are MSM, Foreign Born and Latinas. Trends of emergent HIV infection among all racial ethnic groups reflect general demographic trends. The HIV epidemic continues to be driven primarily by infection within the population of Injection Drug Users (IDU) with recent upward incidence among women of color and an upsurge among MSM, many of whom are of older age groups.

- IDU represent the largest proportion of PLWH/A at 40%, with 43% of PLWA and 33% of PLWH. 41% of new AIDS cases and 33% of new HIV cases. The New Haven-Fairfield TGA has the 3rd highest percent of IDUs among all Part A recipients and is 1st in the continental United States. Connecticut ‘leads’ the nation in percent of HIV/AIDS transmitted through injection drug use at 49%.
- People of color as a group, including African Americans and Latinos represent two-thirds of PLWHA in the TGA. The fraction of PLWH is slightly higher (66.8%) than PLWA (65.3%)
- Aged’ PLWH/A and Newly diagnosed—over 45 years of age. Age groups are significantly older than the general population or the national profile for PLWH/A with 36% of new AIDS cases and 25% of PLWA over 45 at time of diagnosis.

The PLWH group is younger, with 10% of PLWH and over 45 years of age comprising 17% of newly diagnosed HIV cases.

Populations of PLWH/A that are underrepresented in Ryan White funded medical care system. To estimate the distribution of PLWH/A within the Ryan White care system in 2006, data was collected using an in-depth chart review approach that abstracted care patterns from all 24 contracted providers of the six HRSA core funded services.

Historical:

- IDU enter primary medical care latest of any severe need group or historically underserved population. Over half (58%) of charts reviewed for the six (6) core services displayed a late to care pattern (as defined by the CDC—as an initial AIDS diagnosis or advancement from initial HIV diagnosis to AIDS within one year of initial HIV confirmation.) This pattern is further exacerbated for IDU with severe mental illness and/or with a history of over one year of homelessness. In the same provider study, it was determined that 11% of the ‘In Care’ PLWH/A in the TGA had ‘ever’ experienced homelessness; 7% or 260 were currently homeless or have experienced an episode of homelessness within the past year; and 5% or 183 had combined homelessness and severe mental illness.
- MSM (Men who have Sex with Men) are represented most often by African American and White males, with a recent increase in Latino males.

Emerging:

- ‘Aged’ PLWHA and Newly diagnosed—over 45 years of age. The age groups in the New Haven-Fairfield Counties TGA are significantly older than the general population or national profile with 36% of new AIDS cases and 25% of PLWA over 45 years of age at time of diagnosis. The PLWH group is much younger, with 10% of PLWH and over 45 years of age comprising 17% of newly diagnosed HIV cases.
- Foreign born accounted for 10% of PLWH/A population in 2000, increasing to 18.5% by 2005. Almost eighty percent (78%) of the foreign born are Latino and 22% African. Significant representation was from Haiti, and Central and South America for Latinos; and substantial numbers of Africans were also from Haiti and Continental Africa including Tanzania, Nigeria, the Sudan and other areas experiencing political strife.
- Spanish is the primary language for 35% of the ‘In Care’ population. About 15% of this 35% are monolingual.
- Female composition (all races/ethnicities) was 35% of new AIDS cases, 37% of new HIV cases, 35% PLWA and 40% PLWH. *Of all* female PLWH/A, women of color make up 82% of the new AIDS cases, 78% of PLWA and 87% of PLWH.
- African Americans and Latinos represent 65% of PLWH/A within the TGA, 70% of newly diagnosed AIDS and 69 of newly diagnose HIV cases in 2006..
- MSM had bimodal representation from young (15-24) and aged (over 45 years of age). This pattern is displayed most prominently in African American and Latino MSM for ‘young’ (under 20), with the over 45 group consisting of primarily White MSM.

A. Existing Unmet Need Data

Provider utilization figures were obtained for Ryan White and non-Ryan White providers caring for PLWH/A in the New Haven/Fairfield Counties’ TGA. Non-Ryan White funded providers consist of four (4) private practices associated with large hospitals, one skilled nursing facility dedicated to the care of HIV/AIDS patients, two private practices and the West Haven Veterans Administration client base. These 2,881 patients represent the non-Ryan White funded HIV/AIDS delivery system in the two-county TGA.

Using health insurance and information supplied in aggregate by the Connecticut Department of Social Services, unmet need was derived by payer source. The result indicated insurance coverage for 2,881 PLWH/A by payers other than Ryan White Part A or C for primary medical care. Given that 3,271 PLWH/A are covered by Ryan White Part A and C and 2,881 by other payers, the remaining Out of Care fraction is 2,695 PLWH/A or 30.5% (31% out of care).

Table 4. Provider estimate of ‘In Care’ Ryan White Part A and C

<u>Provider</u>	<u>1. IN CARE RW</u>	<u>2. IN CARE NON RW</u>	<u>OOO</u>
<i>Total</i>	<i>3,271</i>	<i>2,881</i>	<i>2,695</i>
	<i>37%</i>	<i>32%</i>	<i>31%</i>
<i>New Haven Total PLWHA*</i>	<i>8,847</i>		

[Sources: 1. In Care – Ryan White: a. Part A – Ryan White Part A Utilization figures, 2005
 b. Part C – Ryan White Part C CADR 2. In Care – non-Ryan White (private) providers, 2005 client base).

Approximately thirty one percent (31%) of the PLWH/A living in the TGA are ‘Out of Care’ according to the unmet need estimate.

B. New Haven-Fairfield Unmet Need Survey Methodology

The Department of Public Health does not currently collect viral load or CD4 information (other than AIDS cases with tests less than a count of 200 or 14%). Furthermore, the short tenure of the State’s HIV reporting system (using a name or code system, beginning in 2002) does not yield sufficient surveillance data to yet create a demographic-specific analysis of unmet need.

Therefore, the Strategic Planning and Assessment Committee decided to create a process to implement a survey-based model to estimate unmet need for primary care services. *The proposed sample size for the Unmet Need/Out of Care survey was 150 PLWH/A and a total of 204 surveys were actually completed. The tables below show the breakdown of the Unmet Need/Out of Care survey respondents by region, gender, race, and risk category.*

Collaborative Research conducted the 2007 needs assessment in collaboration with the New Haven-Fairfield TGA. Out of Care surveys were completed in May and June of 2007 and administered by TGA funded providers and CR Staff. Out of Care clients were primarily recruited through various core medical service provider organizations within each of the TGA’s Planning Regions.

III. ‘Unmet Need’ Study Findings

Based upon the Unmet Need Framework, the TGA undertook a rapid needs assessment process in order to address the following four items, including any plans for cross-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.

The Unmet Need Study findings will primarily address Item 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’?

Table 5. Comparison of Epidemiology Profile to Service Utilization, by Race/Ethnic Group, 2006

GROUP	Newly diagnosed AIDS	PLWA	PLWH	% RW ‘In Care’	Utilization
African American	34.0%	38.0%	30.6%	43%	47%
Latina/o	29.6%	25.6%	37.9%	28%	29%
White	36.3%	38.0%	30.1%	29%	24%

(Source: Epidemiology Profile (2005) and Utilization data (2006))

As evidenced in the table above, the utilization rates for Whites are lowest, followed by Latinos, with African Americans most highly represented in care, though their RW ‘In care’ status is less than desirable at less than 50% for the group. The 2006 Out of Care study included survey respondents from the following racial/ethnic groups: 65% African American; 17.5% Latina/o; and 17.5% White

2. Characteristics of PLWH/A Not in Care Inferred from Studies of ‘Erratically in Care’

Table 6. Medical Co-morbidities:

Co-Morbidity	Intake	Erratic	In Care	In Care White	In Care AA	In Care Latino
Hepatitis C	43.8%	24.5%	12.7%	14.7%	12.6%	10.9%
Hypertension	14.8%	4.6%	2.2%	2.5%	2.3%	1.8%
Hepatitis B	13.8%	4.9%	3.4%	2.8 %	3.2%	3.9%
Diabetes	12.0%	11.8%	18.1%	17.5%	21.6%	18.1%
Hepatitis A	10.4%	2.4%	1.2%	--	0.8%	1.1%
Asthma	8.4%	4.5%	1.1%	0.9%	1.1%	1.0%
Cancer	4.8%	3.9%	1.1%	1.4%	1.2%	0.7%

(Source: Chart audits conducted in July-August 2006 from ‘In Care’ provider base)

As evidenced above, those patients who are ‘erratically’ in and out of HIV primary medical care all have co-morbidities in rates much higher than any of the ‘In Care’ groups, regardless of race, (subsequent to initial

entry into care), except for Diabetes, which is present at higher rates among all ‘In Care’ groups. The high rate of Hepatitis C infection among those erratically in care most likely indicates that these individuals also have a history of injection drug use (IDU).

Table 7, on the following page highlights the prevalence of opportunistic infections (OIs) among those ‘erratically’ in care, evidencing higher rates of preventable and/or treatable OIs than for all racial groups who are maintaining an ‘In care’ status.

Table 7. Opportunistic Infections

Opportunistic Infections	Intake	Erratic	In Care	In Care White	In Care AA	In Care Latino
Toxoplasmosis	25%	7.6%	2.4%	2%	3%	1%
Pneumocystis jiroveci	20	11.7	0.5	0.5%	--	0.5%
Cachexia	4.4	4.3	0.8	0.8	--	0.5%
Tuberculosis	2.8	1.8	0.9	--	--	1%

(Source: Chart Audits conducted in July-August 2006 of all clients served by Ryan White Part A)

Of no surprise is the fact that those patients experiencing greater challenges in maintaining an ‘In care’ status (those ‘erratically’ in care) also have higher rates of serious mental health disorders than all of the ‘In Care’ groups. It is noteworthy that nearly half of the individuals characterized by erratic utilization of primary HIV medical care also suffer major depression.

Table 8. Mental Health Disorders

Mental Health Disorder	Intake	Erratic	In Care	In Care White	In Care AA	In Care Latino
Major Depression	62.9%	45.0%	31.7%	29.7%	32%	30%
Psychosis	11.8%	10.8%	6%	8%	5%	3%
Bipolar disorder	14.6%	16.7%	11.8%	9%	11%	10%
Schizo-affective disorder	13.8%	12.2%	4.5%	4%	4%	5%
Post-Traumatic Stress Disorder	9.8%	12.3%	3.2%	4%	5%	3%
Suicidal ideation	8.7%	8.7%	2.8%	4%	2%	3%
Anxiety disorder	12.6%	5.0%	3.1%	5%	5%	6%

(Source: Chart audits conducted in July-August, 2006 of all clients served by Ryan White Part A)

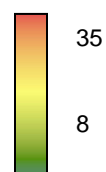
3. Location of PLWHA with Unmet Need in the TGA

At the time of this report, there was no current location information (i.e. zip code or county of residence) available for the entire OOC population. However, the zip code of current residence of OOC survey respondents is available and inference may be drawn from this data for planning purposes.

Zip Code of Residence for OOC Respondents

Almost one-half (48%) of the OOC respondents report their residence in one of seven major zip codes, including 06511, 06905, 06401, 06708, 06606, 06704 and 06904. The remainder of the respondents identified their current residence in numerous other zip codes within the TGA. (See Table 9 following map below. The map legend is displayed, with ‘warmer’ colors indicating higher amounts of OOC citing these areas as their residence, and ‘cooler’ colors with fewer OOC residents.

Number by ZIP Code



ZIP	Town	Number	Percent
06511	New Haven	33	16%
06905	Stamford	16	8%
06401	Ansonia	12	6%
06708	Waterbury	10	5%
06606	Bridgeport	9	5%
06704	Bridgeport	9	5%
06904	Stamford	9	5%

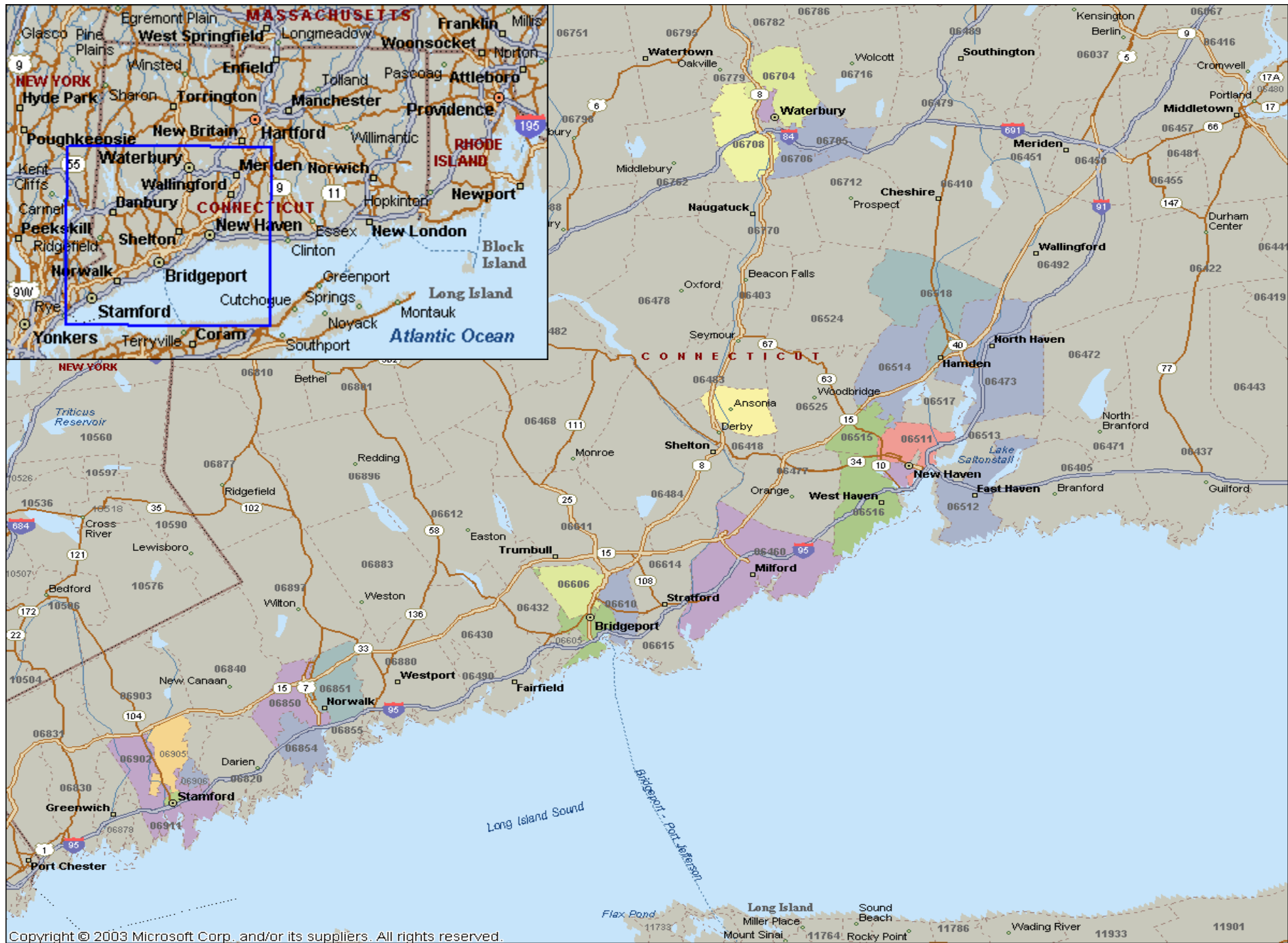


Table 9: Residential Zip Codes of OOC Respondents

ZIP	Town	Number	Percent
06511	New Haven	33	16%
06905	Stamford	16	8%
unknown		12	6%
06401	Ansonia	12	6%
06708	Waterbury	10	5%
06606	Bridgeport	9	5%
06704	Waterbury	9	5%
06904	Stamford	9	5%
06901	Stamford	7	3%
06908	Stamford	7	3%
06515	New Haven	6	3%
06516	New Haven	6	3%
06604	Bridgeport	6	3%
06608	Bridgeport	6	3%
06518	Hamden	4	2%
06851	Norwalk	4	2%
06473	North Haven	3	1%
06505	New Haven	3	1%
06512	East Haven	3	1%
06514	Hamden	3	1%
06607	Bridgeport	3	1%
06610	Bridgeport	3	1%
06705	Waterbury	3	1%
06706	Waterbury	3	1%
06790	Waterbury/Torri ngton	3	1%
06854	Norwalk	3	1%
06906	Stamford	3	1%
06911	Stamford	3	1%
06460	Milford	2	1%
06519	New Haven	2	1%
06710	Waterbury	2	1%
06850	Norwalk	2	1%
06902	Stamford	2	<1%
06909	Stamford	2	<1%
GRAND TOTAL		204	100%

Grouping Out of Care survey respondents by region, with exclusion of the 12 or 6% that either did not state a residence or are completely transitory, results in the following Region breakdown:

Residence	New Haven Fairfield TGA	1-New Haven	2-Waterbury/ Ansonia	3- Bridgeport	4-Stamford/ Norwalk	5- Danbury
#	192	65	42	27	58	--
%	100%	32%	21%	13%	28%	0%

4. Additional Characteristics Inferred from the 2007 'Out of Care' Needs Assessment Study

The Out of Care PLWHA who participated in the unmet need study included 114 Males (56% of the sample) and 90 Females (44% of sample) and no Transgender.

Table 10: Gender of OOC Respondents

Gender	New Haven Fairfield TGA	1-New Haven	2- Waterbury	3- Bridgeport	4-Stamford/ Norwalk	5- Danbury
Male	114	42	21	21	30	0
Female	90	36	24	18	15	0
Transgender	0	0	0	0	0	0
TOTAL	204	78	45	39	45	0

As evidenced in Table 11 below, the majority of survey respondents were African American/Black, followed by Latino/a, with less than 15% of the respondents' reporting their race as White.

Table 11: Race/Ethnicity of OOC Respondents

Race	New Haven Fairfield TGA	1-New Haven	2- Waterbury	3- Bridgeport	4-Stamford/ Norwalk	5- Danbury
African American/ Black	96	39	12	18	27	0
Latina/o	78	27	27	18	6	0
White	30	12	3	3	12	0
Other	0	0	0	0	0	0
TOTAL	204	78	42	39	45	0

The transmission risks reported by the OOC respondents include 21 MSM; 12 MSM/IDU; 102 IDU and 69 HET, as evidenced in Table 12. (Some respondents reported more than one risk category). The reported age ranges of the OOC survey participants primarily fall within the ranges of 35-54 years, as evidenced in Table 13 on the following page.

Table 12: Risk Exposure Category of OOC Respondents

Exposure	New Haven Fairfield TGA	1-New Haven	2- Waterbury	3- Bridgeport	4-Stamford/ Norwalk	5- Danbury
MSM	21	12	0	6	3	-
IDU	102	30	12	27	33	-
MSM/ IDU	12	3	3	0	6	-
HET SEX	69	27	33	6	3	-
UNKNOWN	6	6	0	0	0	-
I/RR*	8	4	4	0	0	-
Perinatal	1	0	1	0	0	-
Transfusion	1	1	0	0	0	-
TOTAL	220	83	53	39	45	

*I/RR risk is a combined risk with IDU & to a lesser degree, HET; and IDU is frequently a combined risk with HET, reflective of multiple risks; therefore risk numbers are higher than number of survey respondents

Table 13: Age Ranges of ALL OOC Survey Participants

Age Range	#	%
0-13	0	0%
13-24	9	4%
25-34	12	6%
35-44	57	28%
45-54	93	46%
55-64	12	6%
65-74	0	0%
UNKNOWN	21	10%
TOTAL	204	100%

The reported ages of the OOC respondents reflect the age ranges of PLWH/A within the local epidemic, and evidence a slightly aging population. Respondents reported a fairly wide range of highest grade completed in a formal education setting. The group as a whole is not well educated with almost half (40%) reporting only some high school education or grade school. Over one third (37%) of the survey participants report completing high school, and 16% report some college level courses. Only 5% completed college, and slightly more than 1% have completed some graduate level coursework.

Table 14: Educational Background of ALL OOC Survey Participants

EDUCATION	#	%
Grade school or less	12	6%
Some high school	71	35%
High school grad/GED	75	37%
Some College	32	16%
Completed college	11	5%
Graduate level	3	1%
TOTAL	204	100%

Significantly, ninety-five OOC respondents (or 46%) report that they are currently homeless, or have been homeless at some time in the recent past. A similar proportion of the OOC participants (42%) report being ‘temporarily housed’, either staying at a parent/relative’s house, or staying at someone else’s apartment or house. Twenty-five percent (25%) of respondents report currently or previously staying at a residential drug treatment facility.

Table 15: Current and Previous Residences of OOC Survey Participants

Residence	Live Now		Lived in Past 12-24+ mos	
	#	%	#	%
In apartment/house I own	104	51%	-	-
At my parent's/relative's house	63	31%	-	-
Someone else's apartment/house	27	13%	-	-
In a rooming or boarding house	6	3%	-	-
Residential Drug Treatment Facility	12	5%	43	21%
In a halfway house, transitional housing or treatment facility	0	0%		
Homeless	8	4%	87	43%
Jail or correctional facility	0	0%	8	4%
TOTAL	204	100%		100%

Time Span Since HIV Diagnosis

Forty-eight (48) OOC survey participants (almost one quarter) first learned their HIV status between 1985 and 1999 and 126 of the survey respondents (62%) report recently learning they were HIV positive, in the span of years between 2000 and 2007. Twenty-four (24) respondents did not supply an answer. Only 60 (30%) of the OOC respondents report an AIDS diagnosis. All survey participants report their state of residence at diagnosis as Connecticut, Haiti or Puerto Rico. All but 15 report themselves to be U.S. citizens.

Time Period between Diagnosis and Initial Entry into HIV Primary Medical Care

One of the most striking findings of this needs assessment is the fact that 70% (N=143) of the entire OOC survey sample reports meeting the CDC standard for initially entering HIV primary medical care within three months or less of diagnosis. Fifteen additional PLWH/A entered care within the first year of learning their sero-status, and 40 persons report NEVER having entered primary HIV medical care.

Table 16. Time between Testing HIV Positive and Initial Entry into HIV Medical Care by Region

Time Frame	New Haven Fairfield TGA	1-New Haven	2- Waterbury	3- Bridgeport	4-Stamford/ Norwalk	5- Danbury
3 months	143	60	30	24	29	-
6 months	3	0	0	0	3	-
7-12 months	12	3	3	6	0	-
> 1 year	6	3	0	0	3	-
> 2 years	0	0	0	0	0	-
Never in Care	40	12	9	9	10	-
TOTAL	204	78	42	39	45	-

Most Recent Primary Medical Care Visit

The OOC respondents, overall, report lengthy periods of time since their receipt of some form of primary medical care (PMC). A minority (9 respondents) report receipt of HIV PMC as recently as six months ago and 25 others within the past 7-12 months (erratically in care). Sixty-one (61) PLWH/A report receipt of PMC greater than one year ago (technically out of care) and 69 PLWH/A report last PMC as greater than two to four or more years ago (significant out of care status). A substantial minority of the OOC respondents (40 PLWH/A) report they have yet to enter care (NEVER entered care). The majority of the OOC sample report recent re-entry into care, within the past three months (where many of the respondents were surveyed).

One hundred thirty (130) of the OOC respondents (or 65%) evidence being ‘technically’ out of care over a period of greater than one to two years. An additional 25 OOC respondents (or 12%) report ‘erratically’ receiving care, over the last 6 to 12 months. **Forty PLWH/A (or approximately 20%) report a ‘Never in care’ status.**

Table 17: Time Period Since Last Report of Medical Care

Time Frame	New Haven Fairfield TGA	1-New Haven	2-Waterbury	3-Bridgeport	4-Stamford/Norwalk	5-Danbury
6 months	9	6	3	0	0	-
7-12 months	25	6	6	9	4	-
> 1 year	61	30	9	12	10	-
> 2 years	69	24	15	9	21	-
Never in Care	40	12	9	9	10	-
TOTAL	204	78	42	39	45	-

Most Recent Report of Antiretroviral Therapy and Receipt of Laboratory Monitoring Services

Similarly, when the OOC respondents were asked ‘how long it had been since they took antiretroviral medications for their HIV disease’, (prior to their recent re-entry into care), the respondents reported even longer relative periods since taking medication and/or receiving laboratory monitoring services (as evidenced in the table below). Eighty PLWHA, or 39% of the OOC respondents report having NEVER taken HAART. Seventy PLWH/A report last taking HAART over one year ago; 12 of these respondents cite drug rehabilitation as the reason for no ART during this time period.

Table 18: Time Since Last Report of ART/Last Laboratory Services

Most Recent Medical Services	Antiretroviral therapy		Laboratory Services	
Year	#	%	#	%
Never	80	39%	6	3%
Last 3 months	10	5%	3	1%
4-6 months ago	12	6%	32	16%
7-12 months ago	32	16%	36	18%
> 1 year	70	34%	127	62%
Total	204	100%	204	100%

HIV Testing Circumstances

Only 25% of all the OOC respondents' report first learning their HIV status upon a voluntary request for testing. Almost one quarter (48) of the OOC respondents (24%) learned their HIV status upon an ER or hospital visit for the treatment of another condition, or part of a routine physical exam or pregnancy exam. Nine PLWH/A (4%) learned they were HIV-positive as a result of blood donation and 4% first learned their sero-status upon entry into prison. Twenty four of the OOC respondents (12%) report testing upon the request of their partner and/or because their partner tested positive.

Table 19: HIV Testing Circumstances

Sero-status Discovery Method	#	%
Received testing when asked a health provider to test you for HIV	51	25%
Tested as part of Rehab/SA	28	13%
Tested when went to hospital/ER for something else	24	12%
Tested because partner tested positive or partner suggested testing	24	12%
Tested because "Ill"	18	9%
Tested when tried to donate blood/plasma	9	8%
Tested as part of a routine physical exam	15	8%
Tested as part of an outreach clinic or street outreach program that offered HIV testing	12	6%
Tested as part of pregnancy exam	9	4%
Tested in prison	8	4%
Tested because of immigration	6	3%
TOTAL	204	100%

Rates of Referral into Care and Delay from Testing Positive to Entering Care

Fully 75% (or 150) of the OOC respondents report having been referred into HIV primary medical care upon diagnosis, and **70% successfully entered care following initial diagnosis**. Forty-five PLWH/A (or 22%) of all OOC respondents report NO referral for any services whatsoever upon diagnosis. (See Table 20).

Table 20: Initial Primary Care and other Referral Rates

Referral Rates for Primary Care and Other Services	Total	
	#	%
Referred for medical care (from a doctor or nurse) related to being HIV positive	150	75%
Referred for case management services	44	22%
I was NOT referred for any services	45	22%
Referred for substance abuse counseling/treatment	24	12%
I was referred for dental care services	15	7%
Referred for mental health services (other than substance use)	6	3%
Referred for medical care for a condition other than HIV	4	2%
TOTAL	*>204	>100%

*Number of referral types is greater than number of respondents, as several PLWH/A reported multiple referrals upon testing positive

The majority of the OOC respondents (70%) report timely initial entry (within three months) into care following initial diagnosis. Six percent (6%) of the OOC respondents report a delay of six to 12 months, and 3% report initially delaying entry into care for more than one year. Twenty percent (20%), or 40 PLWH/A have NEVER entered care.

Table 22 below evidences the reasons offered by the OOC respondents for their delay into care. The respondents who delayed their entry into care offered multiple reasons for this decision, including 10% who believed they “didn’t need medical care”; 9% who were “using drugs/needed substance abuse treatment”; 7% who “don’t trust doctors”; 7% ‘can’t afford it or have no insurance”; 6% who were dealing with other illnesses/other issues”; and 4% admitted depression was the reason for their delay into care.

Table 21: Time Between Testing and Initial Entry Into Care

Time to receive medical care	Total	
	#	%
Within 3 months	143	70%
Within 6 months	3	1%
Within a year	12	6%
Longer than 1 year	6	3%
NEVER	40	20%
TOTAL	204	100%

Table 22: Reasons for Delay into HIV Primary Medical Care

Reasons for delay > 1 year of medical care	Total	
	#	%
Don't need medical care/didn't feel sick	21	10%
Drug use/needed substance abuse treatment	18	9%
Can't afford it/no insurance	15	7%
Don't trust doctors	15	7%
Dealing with other illnesses/issues	13	6%
Depressed	9	4%
Don't know where to go to get medical care	6	3%
Other: Jail; Travel to care for ill relative in Puerto Rico/caretaker forgot/confused	6	2%
Can't get transportation	3	1%
TOTAL	106	100%

* Number of responses is greater than those delaying care (61), with a multiple of 1.7 reasons per respondent delaying care since more than one response could be checked.

Table 23: Reasons Why PLWHA Do Not Seek HIV Medical Care

Reasons	#	%
Worried that others will find out/Privacy	36	18%
Other Basic needs not met/other health issues/Got job/Stable hours	27	13%
Fear of telling someone else	33	11%
Feel healthy	33	11%
Distrust/Stigma	15	7%
Can't afford it	12	6%
Don't have transportation	12	6%
Don't want to take HIV medications	12	6%
Communication difficulties	12	6%
Cultural issues	9	4%
Couldn't get an appointment	3	1%
Material/ instructions are confusing	3	1%
Denial	3	1%
Hate Doctors	3	1%
Undocumented alien	3	1%
TOTAL	>204	>100%

Other	#	%
Drug use	19	14%
Depression	8	4%
Total	27	13%

The OOC respondents who supplied reasons to the question “why PLWH/A do not seek HIV medical care” offered “worried about privacy”, “dealing with other health/life issues”, “fear of telling others”, and “feel healthy” most often as the reasons. Communication and cultural issues were cited by 21 PLWH/A, (10%) and drug use/depression was cited by 27 PLWH/A (13%).

Recommendations by PLWH/A to Ease Re-Entry Into/Maintenance in Care

The OOC PLWH/A who answered this question supplied several motivators. The most frequently cited ‘motivators’ included “substance abuse treatment”, “acute illness”, “free medical care”, “transportation”, followed by “insurance” and “more outreach services” as prompts to re-enter care and/or remain in care. *A significant minority (11%) cited the need for medical and mental health providers who speak Spanish and better linkage/integration of rehabilitation services with primary medical care services.*

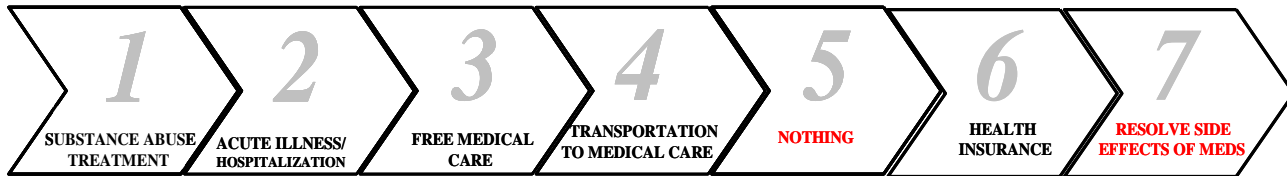
Seven (7%) cited ‘nothing’, reflecting the anti-authoritarian component of the NEVER IN CARE population (15/40 Never in Care or 38%) that are determined to avoid primary medical care.

Table 24: Motivators to Ease Re-Entry into HIV Medical Care

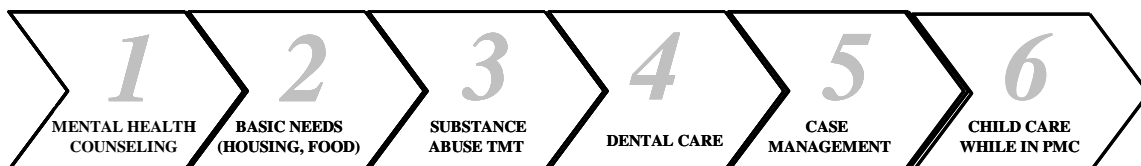
Motivators to Ease Re-Entry	#	%
Substance abuse treatment	36	18%
Acute illness	33	16%
Free medical care	24	12%
Transportation	21	10%
Nothing	15	7%
Insurance	12	6%
More outreach services	12	6%
Better quality of services	9	4%
More information about services	9	4%
Peer Counselor	9	4%
Mental Health Counseling	7	3%
Referrals or advice	6	3%
Employment opportunities	6	3%
Better trained doctors and nurses	6	3%
More government services	3	1%
Became citizen	3	1%
Total	>204	100%

Comparison of Paths into Care for Newly Diagnosed vs. Out of Care

The pathway into care for newly diagnosed individuals entering primary medical care is significantly different than that outlined in Table 24 for those re-entering care and dramatically different than the ‘Never in Care’. Never in Care are the only group that cites ‘NOTHING’ (see #5 above) and also reference ‘resolve side effects of HIV medications’.



Within subgroups of the newly diagnosed, minor differences reflect the needs of subpopulations. Women rank ‘child care’ while attending primary medical care appointments as one of their top 5 priorities while this does not appear in any other category and incarcerated/recently released rank basic needs highest of any group with the notable exception of food [explained by provision of 3 months of food stamps upon release.] **Only substance abuse treatment appears in both the ranked order of services to motivate entry or re-entry into care (#1 for Out of Care, #3 for newly diagnosed), explained by the high incidence and prevalence of poly-substance abuse in the TGA.**



Substance Use

The majority of OOC survey respondents admit to a history of regular use and/or current regular use of alcohol and/or drugs (158/204 or 78%) on a frequent basis. Only 40 OOC respondents report no substance use and six respondents did not answer the question. Seven OOC respondents report current IDU and 21 admit to sharing needles (historically or currently).

Table 25: Frequency of Reported Substance Use Among OOC Respondents

	Use	Daily	Weekly	% of 'using'	% of OOC respondents
Heroin	87	87		56%	43%
Alcohol	27	9	18	17%	13%
Tobacco	18	18		11%	9%
Cocaine	6	6		4%	3%
Crack	6	6		4%	3%
Marijuana or hash	6	6		4%	3%
Crystal Meth	3	3		2%	2%
Speedball	3		3	2%	2%
Ecstasy	2		2	1%	1%
No answer	6			4%	3%
Total	158	135	23	100%	78%

** Results are slightly higher than 100% despite the fact that the respondents were asked to select their 'primary drug'—a few selected two primary drugs that are currently used.*

Communicable and Other Disease Co-Morbidity

The OOC respondents report a high co-morbidity rate of sexually transmitted communicable diseases. Approximately forty percent report one or more forms of Hepatitis co-infection---primarily Hepatitis C. A history of Sexually Transmitted Infections was reported by 40% of the OOC respondents.

Table 26: Communicable Disease Reports of OOC Respondents

Communicable Disease	Total	
	#	%
Hepatitis (ABC)	77	38%
<i>Sexually Transmitted Infections:</i>		
Gonorrhea	24	12%
Chlamydia	21	10%
Yeast infections	21	10%
Herpes (genital)	6	3%
Syphilis	6	3%
Genital warts	3	1%
HPV (Human Papilloma Virus)	3	1%
<i>Other communicable disease:</i>		
Tuberculosis	7	3%
Other:	6	3%
TOTAL Diseases Reported	163	100%

Some respondents reported histories of more than one type of hepatitis.

Hepatitis Infection by type:

A	B	C	Total
2	9	66	77
2%	12%	86%	100%

The most frequently cited chronic illnesses include liver problems and emotional problems (each cited by 36 or 18%, respectively of all 204 OOC respondents). Other reported illnesses include diabetes (9%), high blood pressure (12%), lung problems (9%), heart problems (6%), and problems with thought or memory (6%). and hypercholesterolemia (6%).

Table 27: Chronic Disease Reports of OOC Respondents

Chronic Disease	#	%
Liver Problems	36	18%
Emotional Problems	36	18%
High Blood Pressure	24	12%
Diabetes	18	9%
Lung/Breathing Problems	18	9%
Neuropathy	15	7%
Heart Problems	12	6%
High Cholesterol	13	6%
Problems with Thought or Memory	12	6%
Myobacterium Avian Complex (MAC)	7	3%
Kidney Problems	4	2%
Back problems	5	2%
Cancer	3	1%
PCP Pneumonia	3	1%
Wasting	3	1%
Other: Malaria: 1/Lupus:1	2	1%
Cervical Cancer	1	<1%
Total Diseases Reported	209	100%

Sixty-six OOC respondents (or 32%) report taking one or more medications for their physical illness (other than HIV meds). Fifteen respondents (7%) report mental health drugs; 30 respondents (15%) report methadone maintenance; and several other OOC respondents report taking some type of medicine for their blood pressure, asthma, or other chronic illness.

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, barrier (perceived accessibility) and gap ranking (perceived unavailability ranking) was developed for ALL Out of Care respondents and as well as by Severe Need Group, by Region.

Service Needs

Needs	Sum of Out of Care survey respondents who answered ‘Yes’ to Need (1 is highest ranking)
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The top ranking service NEEDS reported by the entire TGA Out of Care respondent group include a mixture of ‘essential core medical’ and ‘supportive services’: Housing, HIV Primary Medical Care, Other Primary Medical Care, Medical Transportation, Substance Abuse Treatment/Help staying sober, HIV Medications, Dental Care, Methadone Maintenance, Mental Health Counseling, Employment, Confidentiality/Privacy, Health Insurance, Case Management, and Other Medications (including Hepatitis C medications).

Table 28: Top Ranking NEEDS of ALL New Haven-Fairfield OOC Respondents

Service Category Description	Need Rank
HOUSING	1
HIV PRIMARY MEDICAL CARE	2
OTHER PRIMARY MEDICAL CARE	3
TRANSPORTATION	3
SA TREATMENT/HELP STAYING SOBER	4
HIV MEDICATIONS	4
DENTAL CARE	4
METHADONE MAINTENANCE	5
MENTAL HEALTH COUNSELING	5
EMPLOYMENT	6
CONFIDENTIALITY/PRIVACY	7
HEALTH INSURANCE	7
CASE MANAGEMENT	7
OTHER MEDS (including Hepatitis C Meds)	7
CULTURALLY RELEVANT PROVIDERS/SENSITIVITY	8
FINANCIAL ASSISTANCE	8
SUPPORT	8
TREATMENT ADHERENCE SUPPORT (HIV & Hep C)	9
OTHER MEDICAL SPECIALTY (including GYN)	9
CHILD CARE	9
OUTREACH WORKER	9
FOOD	9

A listing of needs, barriers and gaps for OOC respondents by four of the five regions is provided in an Appendix.

Comparison of Service NEEDS BY REGION indicates that

Service Category Description	Need Rank: NH FF TGA	Region 1: New Haven	Region 2: Waterbury	Region 3: Bridgeport	Region 4: Stamford/ Norwalk
HOUSING	1	1	2	1	3
HIV PRIMARY MEDICAL CARE	2	2		4	4
OTHER PRIMARY MEDICAL CARE	3			5	
TRANSPORTATION	3				
REHAB/SA TREATMENT/HELP STAYING SOBER	4	3		7	2
HIV MEDICATIONS	4	4		8	
DENTAL CARE	4	5		2	6
METHADONE MAINTENANCE	5	5			1
MENTAL HEALTH COUNSELING	5	9	1	6	4
EMPLOYMENT/EMPLOYMENT ASSISTANCE	6				5
CONFIDENTIALITY/PRIVACY	7			9	
HEALTH INSURANCE	7	6	3		
CASE MANAGEMENT	7		4		
OTHER MEDS (including Hepatitis C Meds)	7	4			4
CULTURALLY RELEVANT PROVIDERS/SENSITIVITY	8	10		3	
FINANCIAL ASSISTANCE	8				
SUPPORT	8				
TREATMENT ADHERENCE SUPPORT (HIV & Hep C)	9				6
OTHER MEDICAL SPECIALTY (including GYN)	9	7		9	
CHILD CARE	9	8		10	
OUTREACH WORKER	9				
FOOD	9				

Service Barriers/Accessibility of Services

Barrier	Difficult to Access/Service Barriers. Out of Care survey respondents who indicated Reasons why a NEEDED service is “hard to get.”
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Table 48: BARRIERS to Service NEEDS Reported by ALL OOC Respondents

Service Category Description	Barrier Rank	REASONS FOR BARRIERS
HOUSING	1	LACK OF FUNDS
TRANSPORTATION	2	NOT ENOUGH ACCESS
TIMELY MENTAL HEALTH/PSYCH SERVICES	3	NO SPANISH SPEAKING COUNSELORS
EMPLOYMENT ASSISTANCE	3	DO NOT KNOW
HELP STAYING SOBER	4	DO NOT KNOW
CULTURALLY RELEVANT PROVIDERS/SENSITIVITY	4	AUTHORITY
DENTAL CARE	4	FUNDING
INSURANCE	4	TOO EXPENSIVE
LAB WORK (PAYING FOR IT)	4	NO FUNDING
DRUG PROGRAM/MEDICATIONS	5	FUNDING
LEGAL ASSISTANCE	6	BUREACRACY
CO-LOCATED PMC (HIV AND OTHER)	6	DO NOT KNOW
CO-LOCATED SA TX AND PMC	6	DO NOT KNOW
State Assistance	6	FUNDING

Common barriers to care for PLWH/A 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). The specific barriers offered by the New Haven-Fairfield OOC population yield potentially useful information for planners and providers, alike. Several of the service categories received barrier reasons that are readily amenable to intervention.

Lack of available housing (and evidence of current/recent homelessness) act as powerful deterrents to retention in care. Lack of 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 within the TGA. The disconnection between rehabilitation facilities/services and primary medical care services acts as another huge barrier in the TGA, compounded by the fact that half of the PLWH/A population is IDU, and the majority of the remaining PLWH/A use/abuse non-injection substances and alcohol. Non-timely receipt of Mental Health Counseling is attributed to a perceived lack of Spanish-speaking Mental Health Counselors. The disconnect between HIV Primary Medical Care (PMC) and PMC for other diseases/health concerns is considered a significant barrier. Finally, privacy issues and cultural issues are reported by OOC Respondents as barriers to care. Drug abuse treatment services, mental health services and dental care services are also cited as “hard to get” in the TGA.

Reasons given by OOC Respondents to explain service barriers included the following:

“Not enough services because planners/funders don’t understand the needs”; “Services too expensive”; “It’s hard to access services when you’re not sober/not drug free”; “Wait lists are too long”; “Can’t get transportation when homeless”; “I don’t know how to get them”; and “Funding”.

Comparison of Service BARRIERS BY REGION indicates that:

Service Category Description	Barrier Rank: NH FF TGA	Barrier Reason	REGION 1: NEW HAVEN	REGION 3: BRIDGEPORT	REGION 4: STAMFORD/NORWALK
HOUSING	1	WAIT LISTS/NOT ENOUGH RESOURCES/ JAIL HISTORY	1	1	
TRANSPORTATION	1	HOMELESS/NOT ACCESSIBLE	1		
LAB WORK/INSURANCE	2	TOO EXPENSIVE			
WAITS FOR MENTAL HEALTH SERVICE	2			2	1
MENTAL HEALTH & PSYCH SERVICES	2	NOT ENOUGH/THERAPISTS DON'T SPEAK SPANISH		2	
NON CO-LOCATION OF HIV and OTHER PMC	2	DO NOT KNOW	2		
EMPLOYMENT ASSISTANCE	2	DON'T KNOW HOW TO GET			
DISCONNECT BETWEEN SA TX AND PMC	2	DO NOT KNOW HOW OR WHERE TO ACCESS BOTH SERVICES THAT IS 'SAFE'	2	3	3
MEDICATION PROGRAM	3	HARD TO GET WHEN YOU'RE NOT DRUG FREE			
PRIMARY MEDICAL CARE APPTS	3	DON'T KNOW			
HELP STAYING SOBER	3	NO RESOURCES	3		
STATE ASSISTANCE	3	FUNDING			
LACK OF CULTURALLY RELEVANT PROVIDERS	4			1	2
LEGAL HELP	5				3
DENTAL CARE	5				4

Service Gaps and Reasons for Gaps

Gap	Sum of Out of Care survey respondents who listed a NEEDED service as UNAVAILABLE
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Table 58: Service GAPS Cited by ALL OOC Respondents

Service Category Description	Gap Rank	Gap Reason
INSURANCE	1	TOO EXPENSIVE
HOUSING	1	WAIT LISTS
SOCIAL SECURITY BENEFITS	2	LONG WAITING PERIOD
SPANISH SPEAKING MH COUNSELOR	2	DO NOT KNOW
CULTURALLY RELEVANT PROVIDERS	3	THE SYSTEM
SPANISH SPEAKING PRIMARY CARE PROVIDER	3	DO NOT KNOW/NOT AVAILABLE
REHAB TIED TO MEDICAL CARE	4	THE SYSTEM
PRIVACY-NO GENERAL CLINICS-ONLY HIV CLINICS	4	DON'T KNOW
LEGAL ASSISTANCE	5	DO NOT KNOW
TRANSPORTATION	6	NO EASY ACCESSIBILITY
SERVICES FOR VETERANS	7	FUNDING
ALTERNATIVE MEDS/SELF CARE	8	AUTHORITY

The Service Gaps listed by the New Haven-Fairfield TGA's Out of Care population (services needed but perceived as unavailable) include a mixture of essential core services and support services. Funding and service cutbacks/long waits are perceived to be at least part of the reason(s) for the perceived unavailability of needed services. OOC PLWH/A clearly do not understand why there is a perceived lack of Spanish speaking primary medical and mental health counselors available in the TGA, and apparently believe their care could be improved by more strongly linking substance abuse treatment and ongoing support with primary medical care.

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

Ideally, PLWH/A transition from being “unaware of HIV status” to being “fully engaged in care”; however, patients also transition from full engagement to “dropping out of care”. Thus, the continuum is bidirectional, indicating that both initial engagement and ongoing retention require thoughtful consideration and strategic planning. (*AIDS Patient Care and STDs*, Vol. 21, Supp. 1, 2007) Addressing the disengaged, non-retained, and never-in-care PLWH/A (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 Title I and Title II 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.

The New Haven-Fairfield TGA evidences exceptionally strong linkages between testing/counseling & referral into primary medical care, with 70% of the OOC respondents reporting initial entry into primary HIV medical care within three months of initial diagnosis. Less strong are the engagement and retention strategies for PLWH/A, and particularly for Men and Women of Color, IDU, Homeless and Mentally ill and substance using PLWH/A.

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, Barriers, and GAPS as perceived by the entire OOC population and for each individual Severe Need Group. 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 New Haven-Fairfield TGA.

Retention of newly diagnosed persons in HIV primary medical care is essential for providing access to ART that can delay disease progression, and is especially critical for those PLWH/A whose immune systems are already seriously compromised. Retention in care also has the added benefit of preventing the further transmission of HIV by promoting safer sex practices.

Suggested Strategies for Newly Diagnosed PLWHA:

Improved links and system navigation 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/system navigators to ease transition into care and assist with navigation of care systems, accompany patients to appointments as needed, and help reduce barriers to care*
- 6. Implementing service need level assessments which target those persons newly entering care who are most likely to drop out or be most challenging to retain in care, and creating intensive care coordination plans to enhance engagement/retention.*
- 7. Assess funded providers for training needs relative to relationship building and skills development relative to engaging, validating and partnering as key patient engagement and retention strategies*

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 implement more routine follow-up strategies to inquire about and encourage entry/re-entry into primary medical care for those ‘erratically’ in 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. Expansion of Spanish speaking Therapists and Primary Care Providers and/or interpreters in settings where substantial numbers of non-English speaking PLWH/A receive services*
- 4. Require cultural awareness/sensitivity trainings to ensure cultural competency among funded providers*
- 5. Strengthen substance abuse treatment and primary medical care linkages; consider co-location of these services wherever possible and ensure ongoing on-site support for recovering PLWH/A*
- 6. Co-locate, to the extent possible, HIV PMC and other primary medical and specialty care services*
- 7. Strengthen peer/van outreach to ensure engagement/retention linkages with the most underserved and most likely to disengage*

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; regularly reassess changing needs; 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/van outreach to locate, help reduce barriers and facilitate re-entry 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/van Outreach to specific populations and locations, including homeless shelters, drug treatment centers, 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*
- 5. Co-location of primary medical care services with substance abuse treatment/rehab services*
- 6. Co-location of HIV PMC and other PMC wherever possible.*

Summary

In summary, the persons living with HIV/AIDS in the New Haven-Fairfield Counties' TGA most likely to be out of care include Men and Women of Color and IDU. Blacks and Latinos/as are disproportionately impacted among the OOC populations, compared to their representation in the local epidemic and proportion in the general population.

Over one third (34%) of OOC respondents report their residence in one of six major zip codes, including 06401, 06511, 06606, 06704, 06708 and 06904. The remainder report their current residence within multiple other zip codes within the TGA. The OOC population includes significant history of homelessness (46% report recent homelessness and 42% report currently being temporarily housed). The majority of the OOC respondents report their risk exposure category as Heterosexual, followed by IDU (though this is contradicted both by non-disclosure in the full population study but also by conflicting comorbid conditions such as Hepatitis C). Most OOC respondents have little formal education, with the majority reporting some high school education or graduation from high school.

The New Haven-Fairfield OOC population includes the erratically in care, those who have dropped out of care and are 'technically' out of care, and those who have never entered primary HIV medical care. *The HRSA SPNS Outreach Initiative (published in AIDS Patient Care and STDs, Vol. 21, Supp.1, 2007) investigated the process of engagement in HIV medical care and their findings reveal that PLWH/A who cycled in and out of care did so for reasons related to: their level of acceptance of being diagnosed with HIV; their ability to cope with substance use, mental illness, and stigma; their health care provider relationships; the presence of external support systems; and their ability to overcome practical barriers to care.* The 'motivators' most frequently cited by the OOC population which would prompt re-entry into care included "substance abuse treatment", "acute illness", "free medical care", "transportation", "more outreach services", "insurance", "better quality of services", and "more information about services". The top ranking service NEEDS reported by the entire Out of Care respondent group include: Housing, HIV Primary Medical Care, Other Primary Medical Care, Transportation, Substance Abuse Treatment/Help staying sober, HIV Medications, Dental Care, Methadone Maintenance, Mental Health Counseling, Employment, Confidentiality/Privacy, Health Insurance, Case Management, non-HIV meds (including Hepatitis C meds), Culturally relevant providers/cultural sensitivity, and Financial assistance.

A useful framework for examining barriers to care which hinder effective engagement and retention in HIV primary medical care is provided by the Institute of Medicine, which characterizes barriers to health care into three primary categories: structural, financial, and personal/cultural (Tobias, et al., *AIDS Patient Care and STDs*, 2007, p. S-4) The HRSA SPNS "Outreach Initiative" defined four main barriers to care: **1) Practical/Structural barriers** which include six items: finding a place for HIV medical care; paying for care; not having a telephone to make appointments; getting someone to answer calls for appointments; finding convenient times for appointments; and having providers who speak your language. **2) Stigma barriers** include fears that people would find out about HIV status; worries about people finding out about sexual orientation; worries that family members or partners would be upset; fears that children would be taken away; worries that providers would ask about drug use; worries that

providers would ask about sexual practices; and worries that providers would ask if you were taking HIV medications. **3) Belief barriers** included feeling too healthy to seek care; spiritual beliefs; believing there is no cure for HIV; believing the medications are worse than the disease; preferring alternative treatments; mistrust of the medical system; believing HIV does not exist; making basic needs a higher priority than addressing HIV. **4) Unmet need for support services barriers** including unmet needs for mental health counseling and treatment; substance abuse counseling/treatment; housing; financial; transportation; food; and benefits/entitlements. *The New Haven/Fairfield OOC respondents cited many of these barriers as reasons why PLWH/A are not in care/delayed entry or return into primary medical care, including: Can't afford; Privacy & confidentiality issues; Feel healthy/Don't need it; Don't trust Doctors; Drug use/relapse; Depression; Don't want to take HIV meds; Communication difficulties; and Cultural issues.*

The majority of the service needs received high Barrier rankings by the OOC respondents, evidencing perceived difficulty in accessing the most needed services.. Lack of available housing is the number one barrier and transportation, particularly medical transportation assistance to physician appointments, is also frequently cited. A perceived lack of access to insurance assistance is another barrier to access services in the TGA. The disconnect between substance abuse treatment and ongoing help staying sober within the primary medical care setting and non co-location of HIV and other primary medical care services are both frequently cited as significant barriers and gaps in services. The perceived lack of Spanish speaking mental health counselors, and to a lesser extent, the lack of Spanish speaking medical providers, are viewed as serious barriers to essential services within the existing system of care.

The Service Gaps listed by the Out of Care population (services needed but perceived as unavailable) include a mixture of essential core services and support services. A lack of housing and health insurance are ranked as #1 barriers. Lack of Spanish speaking Therapists and Primary Care Providers, and the dislocation between substance abuse treatment/rehab services and primary care services are frequently cited gaps. Funding and service cutbacks are perceived to be at least part of the reason(s) for the perceived unavailability of needed services.

Different strategies will be necessary for different sub-groups of PLWHA. For example, different strategies should be used to engage the Newly diagnosed, for PLWHA receiving medical and supportive services other than primary HIV medical care, for those PLWHA who have 'erratically' been in care or 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. 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 New Haven-Fairfield TGA.

Recommended Priority Strategies to Reduce Unmet Need:

1. Engaging clients in care immediately upon diagnosis as HIV positive.
2. Fully assessing clients needs when entering care; targeting those deemed at high risk for erratic care use and/or disengagement from care and strongly engaging them in care during the first year of primary medical care participation. Key subgroups responding as high risk of not entering care were Anglo MSM, IDU and MSM of color. Key subgroups reporting as high risk to be erratically in care include women of color, particularly if a history of domestic violence or unresolved custody issues or incarceration are present.
3. Ensuring cultural and linguistic competence of Mental Health and Primary Medical Care providers to meet the needs of sub-populations. The group typically considered are Spanish only speaking, although Creole, numerous Spanish dialects ranging from Puerto Rican to Mexican, Concoabal and Portugese were reported by Out of Care respondents. In Regions 3 and 4 (Bridgeport and Stamford/Norwalk) sizable representation of continental African refugees or émigrés also report language and cultural difficulties in accessing care.
4. Aligning planning processes to respond to service delivery issues
 - a. Service Delivery: Housing and Housing-Related Services
 - b. Service Delivery: Spanish speaking Mental Health/Primary Care providers
 - c. Service Delivery: Consider co-location of services with possible
 - i. Co-location of Substance Abuse Treatment and Primary Medical Care services
 - ii. Co-location of Mental Health and Primary Medical Care
 - d. Service Delivery: Co-location of HIV and Other Primary Medical and Specialty Care Services (most frequently reported are HIV care and Liver care (HIV: Hepatitis C co-infected followed by more need for specialty GYN care)
 - e. Determine where co-location of Primary Medical Care could be a deterrent to accessing services for certain severe need groups
 - i. Develop/promote 'self-managed' protocols for long-term survivors or those resistant to engaging in structured care systems (i.e. Anglo MSM or MSM of color resistant to entering organized or case managed care and/or educated in services/treatment but requiring expert resources in crisis).
5. Assuring high-quality services - Information about service quality is limited
6. Retaining clients in care - employing systematic approaches to missed appointments/lost to follow-up and maximizing Ryan White and other funding resources. Integrating the triad of Primary Medical Care, Case Management and Targeted Outreach to problem-prone subgroups might be a strategy effective at retaining those who tend to be erratically in care.
7. Assisting re-entry into care – expanding van outreach, peer counselors and other outreach strategies identified by OOC as highly effective in facilitating their return to care/keeping them in care. Using peer counselors and targeted educational/information campaigns to update PLWHA in the TGA about newer services (i.e. once a day medication regimens, self-managed protocols in Primary Medical Care, etc.)

APPENDIX OF OOC Needs and Barrier by REGION and Severe Need Group and Out of Care Survey Instrument

1. NEED RANKINGS

A. New Haven-Fairfield Region #1 Need Rankings

Service Category Description	Need Rank: NH FF TGA	Region 1: New Haven
HOUSING	1	1
HIV PRIMARY MEDICAL CARE	2	2
OTHER PRIMARY MEDICAL CARE	3	
TRANSPORTATION	3	
REHAB/SA TREATMENT/HELP STAYING SOBER	4	3
HIV MEDICATIONS	4	4
DENTAL CARE	4	5
METHADONE MAINTENANCE	5	5
MENTAL HEALTH COUNSELING	5	9
EMPLOYMENT/EMPLOYMENT ASSISTANCE	6	
CONFIDENTIALITY/PRIVACY	7	
HEALTH INSURANCE	7	6
CASE MANAGEMENT	7	
OTHER MEDS (including Hepatitis C Meds)	7	4
CULTURALLY RELEVANT PROVIDERS/SENSITIVITY	8	10
FINANCIAL ASSISTANCE	8	
SUPPORT	8	
TREATMENT ADHERENCE SUPPORT (HIV & Hep C)	9	
OTHER MEDICAL SPECIALTY (including GYN)	9	7
CHILD CARE	9	8
OUTREACH WORKER	9	
FOOD	9	

Table 29: Top Ranking NEEDS of OOC Hispanic MSM in Region #1

Service Category Description	Need Rank
TRANSPORTATION TO THE DOCTOR	1
HIV MEDICATIONS	2
EMPLOYMENT	3
FAMILY SUPPORT	4
NON-HIV MEDICATIONS	5

Table 30: Top Ranking NEEDS of OOC AA MSM/IDU in Region #1

Service Category Description	Need Rank
SUBSTANCE ABUSE TREATMENT	1
MEDICATIONS	2
EMPLOYMENT	3
NA/AA MEETINGS	4
FAMILY SUPPORT	5

Table 31: Top Ranking NEEDS of OOC High Risk HET Males in Region #1

Service Category Description	Need Rank
SUBSTANCE ABUSE TREATMENT	1
OTHER PRIMARY MEDICAL CARE	2
TRANSPORTATION	3
CASE MANAGEMENT	4
HOUSING	5
MEDICAL CARE	6
SUPPORT FOR STAYING SOBER	7

Table 32: Top Ranking NEEDS of OOC WCB/Women of Color in Region #1

Service Category Description	Need Rank
PRIVACY ISSUES	1
MEDICAL CARE	2
MEDICATIONS	3
SUBSTANCE ABUSE TREATMENT	3
OTHER PRIMARY MEDICAL CARE	4
MENTAL HEALTH COUNSELING	4
SOCIAL SUPPORT	4
CASE MANAGEMENT	5
OUTREACH-CHC VAN	6
FINANCIAL ASST/INSURANCE	6
HOUSING	7
EMPLOYMENT	7
TRANSPORTATION	8

Table 33: Top Ranking NEEDS of OOC IDU in Region #1

Service Category Description	Need Rank
SUBSTANCE ABUSE TREATMENT	1
MEDICAL CARE	2
HOUSING	3
TRANSPORTATION	4
OUTREACH WORKER	5
CASE MANAGEMENT	6

Table 34: Top Ranking NEEDS of OOC I/RR in Region #1

Service Category Description	Need Rank
MENTAL HEALTH COUNSELING	1
SUBSTANCE ABUSE TREATMENT	2
INSURANCE/FINANCIAL ASST	3
HOUSING	4
EMPLOYMENT	5

B. Waterbury Region #2 Need Rankings

Table 35: Top Ranking NEEDS of ALL OOC PLWH/A in Region #2

Service Category Description	NH-FF Counties TGA Need Rank	Region #2 Waterbury
MENTAL HEALTH COUNSELING	5	1
HOUSING	1	2
HEALTH INSURANCE	7	3
CASE MANAGEMENT	7	4

Table 36: Top Ranking NEEDS of OOC High Risk HET Males in Region #2

Service Category Description	Need Rank
MENTAL HEALTH COUNSELING	1
HOUSING	2
HEALTH INSURANCE	3
CASE MANAGEMENT	4

Table 37: Top Ranking NEEDS of OOC WCB/Women of Color in Region #2

Service Category Description	Need Rank
MEDICAL CARE/SPECIALTY MEDICAL	1
DRUG TREATMENT/REHAB	2
MENTAL HEALTH COUNSELING	3
ADHERENCE COUNSELING	3
INSURANCE/HEALTH BENEFITS	4
EMPLOYMENT	4
HOUSING	5
TRANSPORTATION	6

Table 38: Top Ranking NEEDS of OOC IDU In Region #2

Service Category Description	Need Rank
SUBSTANCE ABUSE TREATMENT/REHAB	1
HOUSING	2
EMPLOYMENT	3

C. Bridgeport Region #3 Need Rankings by SNG

Table 39: Top Ranking NEEDS of ALL OOC PLWH/A in Region #3

Service Category Description	NH-FF Counties TGA Need Rank	Region #3 Bridgeport
HOUSING	1	1
DENTAL CARE	4	2
CULTURALLY RELEVANT PROVIDERS	7	3
PRIMARY HIV MEDICAL CARE	2	4
OTHER PRIMARY MEDICAL CARE	3	5
MENTAL HEALTH COUNSELING	5	6
REHAB/SUBSTANCE ABUSE TREATMENT	4	7
HIV MEDICATIONS	4	8
CONFIDENTIALITY/PRIVACY ISSUES	7	9
MEDICAL SPECIALTY CARE (INC GYN)	9	9
CHILD CARE	9	10

Table 40: Top Ranking NEEDS of OOC AA MSM in Region #3

Service Category Description	Need Rank
DENTAL CARE	1
CULTURALLY RELEVANT PROVIDERS	2
MENTAL HEALTH COUNSELING	3

Table 41: Top Ranking NEEDS of OOC High Risk HET Males in Region #3

Service Category Description	Need Rank
CONFIDENTIALITY/PRIVACY	1
MEDICATIONS	2
DENTAL CARE	3
HOUSING	4
OTHER PRIMARY MEDICAL CARE	5

Table 42: Top Ranking NEEDS of OOC WCB/Women of Color in Region #3

Service Category Description	Need Rank
CHILD CARE	1
DENTAL CARE	2
HOUSING	3
PRIMARY MEDICAL CARE	4
MEDICAL SPECIALTY CARE (INCL GYN)	5

Table 43: Top Ranking NEEDS of OOC IDU In Region #3

Service Category Description	Need Rank
PROVIDERS WHO UNDERSTAND MY CULTURE	1
CONFIDENTIALITY	2
SUBSTANCE ABUSE TREATMENT/REHAB	3
DENTAL CARE	4
OTHER PRIMARY MEDICAL CARE	5
MENTAL HEALTH COUNSELING	6
MEDICATIONS	7
HOUSING	8

D. Stamford/Norwalk Region #4 Need Rankings

Table 44: Top Ranking NEEDS of ALL OOC PLWH/A in Region #4

Service Category Description	NH-FF Counties TGA Need Rank	Region #5 Stamford/Norwalk
METHADONE MAINTENANCE	5	1
MEDICAL CARE TIED TO REHAB	4	2
HOUSING	1	3
MEDICATIONS FOR HEPATITIS C/ HIV AND METHADONE MAINTENANCE	7/5	4
MENTAL HEALTH COUNSELING	5	4
EMPLOYMENT ASSISTANCE	6	5
ADHERENCE COUNSELING	8	6
DENTAL CARE	4	6

Table 45: Top Ranking NEEDS of OOC MSM/IDU in Region #4

Service Category Description	Need Rank
METHADONE MAINTENANCE	1
HOUSING	2
MEDICATIONS FOR HEPATITIS C/ HIV AND METHADONE MAINTENANCE	3
ADHERENCE COUNSELING	4
HOUSING	5

Table 46: Top Ranking NEEDS of OOC IDU in Region #4

Service Category Description	Need Rank
REHAB/METHADONE MAINTENANCE	1
MEDICAL CARE TIED TO REHAB	2
HOUSING	3
HEPATITIS C MEDICATIONS	4
EMPLOYMENT ASSISTANCE	5
MENTAL HEALTH COUNSELING	5
DENTAL CARE	5

Table 47: Top Ranking NEEDS of OOC I/RR in Region #4

Service Category Description	Need Rank
HOUSING	1

Housing barriers for IDU/I/RR typically relate to felony charges on record, precluding participation in many housing assistance programs.

2. BARRIER RANKINGS

Table 49: BARRIERS to Service NEEDS Reported by New Haven-Fairfield OOC Respondents

Service Category Description	Barrier Rank	Barrier Reason
HOUSING	1	WAIT LISTS/NOT ENOUGH RESOURCES/ JAIL HISTORY
TRANSPORTATION	1	HOMELESS/NOT ACCESSIBLE
LAB WORK/INSURANCE	2	TOO EXPENSIVE
MENTAL HEALTH & PSYCH SERVICES	2	NOT ENOUGH/THERAPISTS DON'T SPEAK SPANISH
NON CO-LOCATION OF HIV and OTHER PMC	2	DO NOT KNOW
EMPLOYMENT ASSISTANCE	2	DON'T KNOW HOW TO GET
DISCONNECT BETWEEN SA TX AND PMC	2	DO NOT KNOW WHERE TO ACCESS BOTH SERVICES THAT IS 'SAFE'
MEDICATION PROGRAM	3	HARD TO GET WHEN YOU'RE NOT DRUG FREE
PRIMARY MEDICAL CARE APPTS	3	DON'T KNOW
HELP STAYING SOBER	3	NO RESOURCES
STATE ASSISTANCE	3	FUNDING

(No Barriers rankings offered by Waterbury OOC Respondents)

Table 50: BARRIERS to Service NEEDS Reported by Bridgeport OOC Respondents

Service Category Description	Barrier Rank	Barrier Reason
HOUSING	1	DON'T KNOW
LACK OF CULTURALLY RELEVANT PROVIDERS	1	THE SYSTEM
WAITS FOR MENTAL HEALTH/PSYCH SERVICES	2	PROVIDERS DON'T SPEAK SPANISH

Table 51: BARRIERS to Service NEEDS Reported by Norwalk OOC Respondents

Service Category Description	Barrier Rank	Barrier Reason
TIMELY MENTAL HEALTH SERVICES	1	NO SPANISH SPEAKING COUNSELORS
ATTITUDES	2	AUTHORITY
LEGAL HELP	3	DON'T KNOW
DENTAL CARE	4	DON'T KNOW

BARRIERS by Severe Need Group

Table 52: BARRIERS Reported by African American MSM OOC Respondents

Service Category Description	Barrier Rank	Barrier Reason
LACK OF CULTURALLY RELEVANT PROVIDERS	1	THE SYSTEM

Table 53: BARRIERS Reported by African American MSM/IDU OOC Respondents

Service Category Description	Barrier Rank	Barrier Reason
HOUSING	1	DON'T KNOW HOW TO GET
TEMPORARY EMPLOYMENT	2	NOT AVAILABLE
DEATH BENEFITS/LIFE INSURANCE FOR FAMILY	3	DON'T KNOW

Table 54: BARRIERS to Service NEEDS Reported by High Risk Heterosexual OOC Respondents

Service Category Description	Barrier Rank	Barrier Reason
HOUSING	1	JAIL HISTORY
TRANSPORTATION	1	HOMELESS/NOT ACCESSIBLE
NON CO-LOCATION OF SA AND PMC SERVICES	2	DON'T KNOW

Table 55: BARRIERS to Service NEEDS Reported by WCB OOC Respondents

Service Category Description	Barrier Rank	Barrier Reason
PSYCH/MENTAL HEALTH	1	NOT ENOUGH/NO SPANISH SPEAKING
DENTAL CARE	2	TOO EXPENSIVE
INSURANCE/STATE ASSISTANCE	3	NOT ENOUGH
TRANSPORTATION	4	NOT ACCESSIBLE
HOUSING	5	WAIT LISTS
EMPLOYMENT ASSISTANCE	6	NO SERVICES

Table 56: BARRIERS to Service NEEDS Reported by IDU OOC Respondents

Service Category Description	Barrier Rank	Barrier Reason
MEDICATION PROGRAM	1	HARD TO GET WHEN YOU'RE NOT SOBER/DRUG FREE
MEDICAL APPTS	2	DON'T KNOW
STAYING SOBER/DRUG ABUSE TREATMENT SUPPPORT	3	NOT AVAILABLE
MENTAL HEALTH COUNSELING WAITS	4	NO SPANISH SPEAKING COUNSELORS
SA TREATMENT NOT CONNECTED TO PMC	5	SYSTEM
HOUSING	5	WAIT LISTS
TRANSPORTATION	6	DON'T KNOW

Table 57: BARRIERS to Service NEEDS Reported by I/RR OOC Respondents

Service Category Description	Barrier Rank	Barrier Reason
HOUSING	1	WAIT LISTS
EMPLOYMENT ASSISTANCE	2	NOT ENOUGH
MENTAL HEALTH COUNSELING	3	NOT AVAILABLE