

# **REPORT OF THE GREATER HARTFORD TGA 2008 HIV/AIDS NEEDS ASSESSMENT**

**SUBMITTED TO:  
THE GREATER HARTFORD RYAN WHITE PLANNING  
COUNCIL**

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# Table of Contents

Introduction

Sampling Plan

Instrument Development

Institutional Review Board Review

Survey Protocol and Recruitment

Survey Tracking

Outreach

Focus Groups

Data Management and Analysis

Findings

Limitations to the Data

Summary

References

Appendix

- a. Surveys
- b. Survey Protocol
- c. Focus Group Demographic Sheet and Guide
- d. Informed Consent Information Sheets
- e. Recruitment Card
- f. Field Observation Log
- g. Case Manager Survey Log
- h. Survey Packet Receipt
- i. Participating Agencies
- j. Outreach Sites

## INTRODUCTION

Current data from the State of Connecticut Department of Public Health reports 9,871 persons living with HIV/AIDS in Connecticut (as of December 2006)<sup>1</sup>. There are approximately 3700 persons living with HIV or AIDS in the Greater Hartford Transitional Grant Area (TGA), which is comprised of Hartford, Tolland, and Middlesex Counties<sup>2</sup>. The Ryan White HIV/AIDS Treatment Modernization Act provides HIV Emergency Relief Part A funds to the TGA for the provision of medical care and support services for persons with HIV/AIDS. Under Section 2602(b)(4) of the Act the TGA is required to conduct a needs assessment that determines the needs of the population of individuals with HIV disease, both those receiving medical care and those not in care, and to use the results of the needs assessment to set priorities and allocations for the use of federal HIV Emergency Relief funds to provide needed services. The needs assessment, conducted every three years, is the primary source of data for determining and monitoring service gaps, with the previous Hartford TGA needs assessment conducted in 2005.

In December of 2007 the Institute for Community Research was subcontracted by the Hartford Ryan White Planning Council (HRWPC) to conduct the 2008 Greater Hartford TGA HIV/AIDS Needs Assessment. The Institute for Community Research (ICR), founded in 1987, is a community-based research organization with offices located in Hartford, CT. With 2 decades of experience in the conduct of successful federally and nationally funded research, ICR conducts research in collaboration with community partners to promote justice and equity in a diverse, multiethnic, multicultural world; engages in and supports community-based research partnerships to reverse inequities, promote positive changes in public health and education; and fosters cultural conservation and development.

Through meetings with HRWPC staff, the following activities were identified and carried out:

- finalize both the in-care and out-of-care surveys;
- develop the sampling plan;
- train Ryan White case managers in survey administration, including human subjects protections protocols;
- conduct limited ethnographic data collection to understand where out-of-care PWHIV/AIDS can be reached and/or barriers to and use of services;
- facilitate administration of surveys by case managers and other Ryan White personnel with a target sample of 350-400 in-care PWHIV/AIDS in the Greater Hartford TGA, including distribution and collection of surveys at sites (such as HIV clinics and community-based organizations);
- conduct surveys with a target sample of 75-100 out-of-care PWHIV in the Greater Hartford TGA;
- enter, clean, and prepare data for analysis;
- conduct general descriptive analyses of the survey data according to the plan developed with the HRWPC;

- conduct focus groups with HIV positive Latino male IDUs, African American females, Latinas and homeless individuals; and
- summarize quantitative and qualitative data into a Needs Assessment report.

The results of the Needs Assessment will be used to develop a) a Comprehensive HIV Service Plan, b) specific strategies for addressing the HIV epidemic in the TGA, and c) an annual implementation plan for the delivery of services funded under the Ryan White Treatment Modernization Act.

What follows is a description of the process for finalization of instruments; receipt of approval of the protocol from ICR's Institutional Review Board (IRB); development and implementation the targeted sampling plan, including administration of in-care and out-of-care surveys and focus group interviews; data management and analysis; discussion of findings; limitations of the data collection; and summary. The Appendix includes copies of all instruments, consent forms, and project-related documents that are described in the report narrative.

### **SURVEY SAMPLING PLAN**

In care participants were primarily recruited through Ryan White case managers and other health and social service providers and some from street outreach in targeted communities. The HRWPC provided a list of 28 Ryan White case managers from 17 health care institutions and social service agencies (see Appendix) that would take part in the survey administration process, along with the ICR Needs Assessment Team. All but one facility agreed to participate. Surveys were distributed to all Part A and Part B case managers in the TGA. The number of surveys distributed to each case manager was based on the number of clients being served by the individual case manager and/or the agency where the case manager was situated. Case managers were asked to refer their eligible clients to the Need Assessment Project until the end of the data collection (April 4, 2008). Out-of-care participants were recruited primarily through street outreach by the ICR Assessment Team in targeted communities in the Greater Hartford TGA.

### **INSTRUMENT DEVELOPMENT**

In-Care and Out-of-Care survey instruments and a focus group guide were developed by ICR staff in collaboration with the HRWPC, after review of earlier instruments. All instruments were translated into Spanish and back translated by experienced bilingual researchers at ICR who were familiar with the communities and populations targeted for recruitment. All instruments were submitted to the HRWPC for final approval prior to implementation. Data collection was anonymous; no identifier information (name, address, date of birth) was gathered as part of the interview process.

### **INSTITUTIONAL REVIEW BOARD REVIEW**

The Institute for Community Research has had its own Institutional Review Board (IRB) since its establishment in 1987. The IRB is a peer review committee providing strict and

formal oversight for the protection of human subjects in accordance with federal guidelines of the Office for Human Research Protections of the U.S. Department of Health and Human Services. IRB members include representatives from study communities, local community advocates, university faculty and ICR staff who are knowledgeable of study populations, the focus of the research, the context in which the research takes place, and the mission of the organization; consider community as well as individual subject protection; understand the politics of research and the inequities in research design; and are sensitive to vulnerabilities of research staff from these communities.

Application for initial review of a project is submitted to ICR's Research Administrator. The application is then forwarded to the IRB committee for review. At its bi-monthly meeting, the committee discusses the proposed project with the Principal Investigator and/or Project Director and then either approves the application at that time or issues a conditional approval. In the latter instance, the IRB forwards its written comments to the Principal Investigator who, in turn, responds in writing. Once the IRB has determined that the PI has satisfactorily met its conditions, approval is granted. In either instance, an approval letter signed by the Chair of the IRB is sent to the Principal Investigator of the study, indicating that the IRB is satisfied that the rights and welfare of the project participants are adequately protected. Investigators may begin gathering data from participants only after receiving the signed approval letter.

On December 17, 2007, Application for Initial Approval of the *Greater Hartford Ryan White Part A Transitional Grant Area (TGA) Needs Assessment 2008* was submitted for review to ICR's IRB, following the above-mentioned protocol. Conditional approval was issued, with requests for minor revisions to the language of survey and focus group consent forms and assurance that survey administration training would emphasize the importance of sample diversity of both in-care and out-of-care participants, and of the maintenance of anonymity in both the documentation and reporting of focus group activities. Upon receipt of written assurance of compliance with the IRB's requests by PI Margaret Weeks, Ph.D., initial approval was granted and participant recruitment and data collection began in January 2008.

## **SURVEY TRAINING, RECRUITMENT AND ADMINISTRATION PROTOCOL**

### **Survey Administration Training**

ICR staff developed a Protocol for Survey Administration, a training tool for case managers and Needs Assessment staff involved in recruitment and survey data collection (see Appendix). The Protocol included recruitment criteria, interview procedures, survey collection and human subjects protections. ICR staff conducted a training session with case managers on January 18, 2008, with a follow-up review session on February 14, 2008. In addition to case managers, all ICR project staff were trained and monitored to insure adherence to survey administration protocol and maintenance of confidentiality under the supervision of the Institute for Community Research.

## Recruitment

Ryan White case managers were primarily responsible for the recruitment and survey administration of PWHIV residing in the Greater Hartford TGA and designated as “in-care” (target N = 350-400). ICR project staff facilitated the administration of surveys, conducted approximately 25% of in-care surveys, and were responsible for the distribution and collection of surveys and related materials at sites throughout the TGA. The number of surveys distributed to individual case managers ranged from 5 to 30, depending on client caseload. A client was designated as “in-care” if he/she met the following criteria:

- HIV positive
- Answered “yes” to at least one of the following –
  - received a CD4 count check in the past 12 months
  - had viral load checked in the past 12 months
  - taken anti-retroviral medication in the past 12 months

ICR staff with many years of experience in community-based research and street outreach were responsible for the recruitment and survey administration of PWHIV living in the Greater Hartford TGA, designated as “out-of-care” (target N = 75 –100). This experience, as well as additional ethnographic observations or informal interviews with local service providers helped identify likely locations and optimal times for recruitment. If case managers identified an individual as “out-of-care”, they were requested to administer an “out-of-care” survey. A participant was designated as “out-of-care” if he/she met the following criteria:

- HIV positive
- Answered “no” to all of the following –
  - received a CD4 count check in the past 12 months
  - had viral load checked in the past 12 months
  - taken anti-retroviral medication in the past 12 months

HIV positive individuals 18 years of age and older living in Hartford, Tolland or Middlesex counties were eligible to participate in the Needs Assessment. Participants were recruited through Ryan White case managers, other health and social service providers and street outreach in targeted communities in the Hartford TGA. Surveys were anonymous. No personal identifier data was attached to the survey. Each county, town and agency was given a unique code number. A numbering system for participant interviews incorporated the combination of these code numbers with a series of consecutive numbers (beginning with 001). Case managers and project staff reviewed the Informed Consent Information Sheet with participants and verbal, rather than written, consent was obtained prior to survey administration. The Informed Consent Information Sheet described the study and the survey; explained the terms of participation; identified risks, benefits and compensation; and provided contact information if participants had questions regarding the study or their participation. Participants received a \$10.00 gift certificate for completion of the survey instrument.

Due to the difficulty in finding and recruiting out-of-care participants (see Limitations of the Study), the HRWPC identified a non-study affiliated community member who was reimbursed \$10.00 for each individual recruited for participation in the Out-of-Care survey administration. This individual, known to the HRWPC but not employed by them or ICR, or in any way included as staff of the *Greater Hartford Ryan White Part A Transitional Grant Area (TGA) Needs Assessment 2008*, briefly collaborated with ICR staff as they neared the end of the out-of-care recruitment phase of the project. Funds were provided by the HRWPC directly to the community recruiter and was in no way used as additional monetary incentive for study participants or staff.

### **Informed Consent**

To maintain participant anonymity, verbal rather than written consent was obtained. An informed consent information sheet, approved by the ICR IRB (see Appendix), described the study and the survey/focus group, explained the terms of participation, and identified risks, benefits and compensation and was reviewed with each prospective participant prior to administering the survey or initiating the focus group. Individuals had the opportunity to read the form or have it read to them, and to ask questions regarding participation in the Needs Assessment. No identifying information, including signature, was obtained and a copy of the document was given to each participant. A consent clause was printed clearly on Page 1 of all surveys and all case managers and ICR staff were instructed to read the agreement statement and obtain verbal consent prior to initiating the survey interview. Likewise, verbal consent was obtained from each focus group participant prior to beginning the focus group.

### **Survey Administration**

In order to insure privacy, case managers and Assessment Team staff were instructed to secure a space to obtain informed consent, respond to questions, and where the participant could complete the survey undisturbed by other staff or clients.

The Needs Assessment Survey was available in English and Spanish and was designed to be self-administered. If the participant was unable to do so, the case manager/Assessment Team staff conducted the survey. Regardless of whether or not the survey was self-administered, the initial eligibility questions (to determine HIV status and In-Care vs. Out-of-Care) were asked and filled in by the Case Manger/Assessment Team Staff.

Participants were informed that the survey would take approximately ½ hour to complete. Blue or black ink pens were provided. No pencil or other color ink was allowed to record participant responses. Additionally, participants were instructed 1) to turn off cell phones/pagers if possible; 2) to print clearly; 3) to draw a line through any erroneous responses; 4) to write additional comments/explanations in margins or the reverse sides of pages; and 5) to place a small check mark beside any question that was unclear/problematic, complete the remainder of the survey and then come back to the question/s and request clarification.

Upon completion, the survey was returned to the case manager/Needs Assessment Team member, who was instructed to review the survey for errors and missing data, and answer any questions the participant may have had as he/she responded to each item. This was an important step, since the survey was anonymous and, therefore, participants could not be contacted after leaving the survey location in the event that questions arose or errors were identified regarding any items on the instrument.

The final step in the survey administration process was receipt of a \$10.00 Dunkin Donuts gift card as a thank you for participation in the Needs Assessment.

### **PROCESS OF TRACKING SURVEYS AND INCENTIVES**

A numbering system for both in-care and out-of-care survey instruments incorporated a unique 6-digit code identifying the county, town and agency where the survey was administered (for example County = 01, city = 01, Agency = 06) with a series of consecutive numbers (beginning with 001) that provided an ongoing tally, as names and other personal identifier data was excluded from the surveys. Since surveys were anonymous, this system facilitated tracking and helped to eliminate duplication as much as possible. In addition, each case manager was assigned his/her unique identifier number that also was documented on the cover page of the survey instrument.

The Assessment Team created a tracking instrument, the Survey Log, that included the following information: case manager, agency and total number of surveys and gift cards distributed to each case manager. A file was created for each case manager to facilitate tracking of surveys and related information. When case managers received their packages, they were required to count the survey instruments and gift cards and sign for the package, thus confirming the contents they had received. Upon completion of a survey, the case managers would review the instrument, checking for legibility, errors, and missed questions, give out the \$10.00 gift card, fill out the receipt and staple it to the completed survey. A Batch Sheet was created for their personal use as a convenient and organized method to keep track of surveys, gift cards and receipts and was included in the folder provided by the project to hold all survey materials.

Survey pick-ups occurred weekly. When members of the Assessment Team collected completed surveys and attached receipts, reviewed the Batch Sheet, and subtracted that week's completed surveys from the number of unused survey packets remaining in each case manager's possession. Both Assessment Team member and case manager would sign the Survey Log to confirm the transaction. At the final pick-up from each case manager (April 4, 2008) the Assessment Team collected all surveys, completed and uncompleted, and all undistributed gift cards. The final entry in the Survey Log was signed by both the Case Manager and the ICR Assessment Team member.

All Survey Logs and packets, upon return to ICR, were reviewed by the Assessment Coordinator. This included removal of receipts from the surveys, review of each completed survey for errors and missing data, and storage of both surveys and receipts in locked file cabinets prior to data entry.



Survey data were entered into password protected computer files by the Data Manager and the Assessment Team at ICR. No member of the Assessment Team was allowed to input data from surveys that he/she had administered. The dataset was cleaned and prepared for analysis and a codebook created by the Data Manager (see Data Management and Analysis).

## **OUTREACH**

The main goals of outreach were 1) to inform the communities of the Hartford, Middlesex and Tolland Counties that the Institute for Community Research, in collaboration with the Hartford Ryan White Planning Council, was conducting a Needs Assessment Survey and recruiting qualified clients to take part in a brief anonymous survey, and 2) to find and recruit individuals from the Greater Hartford TGA who met the “out-of-care” criteria. While community outreach was conducted primarily for the recruitment of HIV positive “out-of-care” individuals, participants identified as “in care” but who had not been interviewed through contact with their case managers were also identified and recruited through the outreach process.

Outreach was conducted by three members of the Assessment Team, including two bilingual (English/Spanish) staff, with over 40 years of combined experience in HIV prevention, community outreach and case management. A flyer and information card, in English and Spanish, was created to inform community members about the Needs Assessment survey (see Appendix). After contacting service providers, staff visited all recruitment sites known to them to post flyers and distribute information cards. They frequented all shelters, soup kitchens, social service agencies and public places that they knew people to congregate (see Appendix, Table A). The outreach workers interviewed clients on the spot when a private area was available. An ICR van also was useful as a confidential interviewing space. If the client could not take part in the survey at the time of recruitment the outreach worker would schedule an appointment to take place at the offices of ICR or return at a later date or time at the client’s convenience in order to recruit and interview as many participants as possible.

As it became more challenging to find and recruit individuals who meet the out-of-care criteria, ICR outreach staff coordinated with community agencies in the TGA to recruit participants and conduct surveys on site on a regularly scheduled basis. These sites included HIV group homes, shelters, soup kitchens, and other agencies from Hartford, Middlesex, and Tolland Counties (see Appendix). Posted flyers provided information about the needs assessment, and the increased visibility of the outreach workers facilitated survey recruitment as clients became aware of the opportunity to participate in the surveys and the days and times when staff would be on hand to administer the survey interviews.

## **FOCUS GROUPS**

Four focus groups were conducted at ICR by the Assessment Coordinator and Director, two bilingual researchers with extensive experience in HIV prevention and ethnographic research methods. Targeted focus groups were: 1) Latino male injection drug users (IDUs), 2) African American women, 3) Latina women, and 4) homeless individuals. All participants were HIV positive and recruited through outreach in the Hartford area. A focus group guide, approved by the HRWPC, facilitated the discussion that elicited information about 1) knowledge of local services, 2) access to services, including general and HIV-related medical care, and 3) access to out-of-care HIV positive individuals (see Appendix). Verbal consent was obtained. Participation was anonymous, and each participant was identified by a number rather than by name throughout the focus group. Each focus group lasted approximately 2 to 2 ½ hours with audiotape and written documentation. Participants were reminded that they would be sharing their answers and opinions with others in the focus group, of the confidential nature of the discussion, and were cautioned not to discuss any information outside of the group. Refreshments were provided and each participant received a \$10.00 Dunkin Donut gift certificate.

## **SURVEY DATA COLLECTION, MANAGEMENT AND ANALYSIS**

Questionnaire Development System (QDS) version 2.5 was used for systematic computerized data collection and management. First, QDS Design Studio was used to develop a control file to be installed on handheld computer devices and laptop computers. The final databases, blank surveys and codebooks were also generated in QDS Design Studio. For logistical reasons, all surveys were administered in paper-pencil format first. The completed surveys were reviewed by the Assessment Coordinator and Data Manager for quality control. After approximately 10% of the in-care surveys were administered and reviewed, common survey errors were identified, the ICR Assessment Team reported this feedback to HRWPC staff, and a follow-up survey administration protocol review session was held with approximately half of the case managers responsible for in-care data collection. All completed in-care and out-of-care surveys were reviewed and entered into QDS-generated computer assisted data collection form. The raw data were then uploaded and imported into QDS Data Warehouse for data cleaning and maintenance. At the completion of data entry, final data were exported into SPSS for analysis.

In order to maintain confidentiality of survey participants, no personal identifier data were collected. All paper format data were maintained in locked file cabinets, and electronic data were password-protected, to which only project staff had access.

Findings from surveys and focus groups are reported below.

## FINDINGS

### SURVEY: IN-CARE (N = 380)

**Table 1: In-Care Sample by County**

County	Frequency	Percent	Valid Percent	Cumulative Percent
Hartford <sup>1</sup>	346	91.1	91.1	91.1
Middlesex	20	5.3	5.3	96.3
Tolland	14	3.7	3.7	100.0
Total	380	100.0	100.0	

<sup>1</sup>The majority of surveys were conducted in Hartford County. The data reflect the populations and needs that predominate in Hartford County.

**Table 2: In-Care Sample by Town**

Town	Frequency	Percent	Valid Percent	Cumulative Percent
Hartford	279	73.4	73.4	73.4
New Britain	39	10.3	10.3	83.7
Manchester	16	4.2	4.2	87.9
Bristol	5	1.3	1.3	89.2
Windsor	1	0.3	0.3	89.5
Farmington	1	0.3	0.3	89.7
Middletown	21	5.5	5.5	95.3
Vernon	14	3.7	3.7	98.9
Other	4	1.1	1.1	100.0
Total	380	100.0	100.0	

**Table 3: In-Care – Age**

	Age	Frequency	Percent	Valid Percent	Cumulative Percent
Valid	18-19	4	1.1	1.1	1.1
	20-29	21	5.5	5.6	6.6
	30-39	56	14.7	14.8	21.4
	40 - 49	172	45.3	45.5	66.9
	50+	125	32.9	33.1	100.0
	Total		378	99.5	100.0
Missing	Missing Data	2	0.5		
Total		380	100.0		

Data from our In-Care sample shows the age to be somewhat higher in the 40-49 and 50+ groups, with fewer in the 20-29 and 30-39 age ranges when compared to the CT HIV/AIDS cases by age reported for 2006. Of a total of 1,346 reported cases of

HIV/AIDS in CT for 2006, 9.1% were in the 20-29 age range, 23.8% in the 30-39 age range, 39.9% in the 40-49 age range and 26.3% were ages 50 and above<sup>1</sup>.

**Table 4: In-Care - Gender**

	<b>Gender</b>	<b>Frequency</b>	<b>Percent</b>	<b>Valid Percent</b>	<b>Cumulative Percent</b>
Valid	Female	126	33.2	33.3	33.3
	Male	248	65.3	65.6	98.9
	Transgender	4	1.1	1.1	100.0
	Total	378	99.5	100.0	
Missing	Missing data	2	0.5		
Total		380	100.0		

Percents of female and male participants in the In-Care sample are similar to the 2006 CT HIV/AIDS data that show 38.4% female and 61.6% male of the total 1,346 reported cases for that year<sup>1</sup>.

**Table 5: In-Care – Sexual Orientation**

	<b>Sexual Orientation</b>	<b>Frequency</b>	<b>Percent</b>	<b>Valid Percent</b>	<b>Cumulative Percent</b>
Valid	Gay	68	17.9	18.6	18.6
	Lesbian	7	1.8	1.9	20.5
	Bisexual	24	6.3	6.6	27.1
	Heterosexual/straight	258	67.9	70.7	97.8
	Not sure/don't know	8	2.1	2.2	100.0
	Total	365	96.1	100.0	
Missing	Missing data	15	3.9		
Total		380	100.0		

**Table 6: In-Care – Race/Ethnicity**

	<b>Ethnicity</b>	<b>Frequency</b>	<b>Percent</b>	<b>Valid Percent</b>	<b>Cumulative Percent</b>
	African American	141	37.1	37.1	37.1
	West Indian/Caribbean	6	1.6	1.6	38.7
	Latino or Hispanic	149	39.2	39.2	77.9
	American Indian/Alaska Native	2	0.5	0.5	78.4
	White	72	18.9	18.9	97.4
	Multi-Racial/Multi-Ethnic	10	2.6	2.6	100.0
	Total	380	100.0	100.0	

There are differences across race/ethnicity between the Needs Assessment In-Care sample and CT 2006 data for reported HIV/AIDS cases that identified 25.5% Black,

35.2% Hispanic, 34.4% White and 4.9% Other (N=1,346)<sup>1</sup>. This difference, particularly for African Americans and Whites may be attributed to the fact that 73.4% of the In-Care sample was recruited from the city of Hartford and reflects the city's racial/ethnic demographics.

**Table 7: In-Care – Preferred Language to Receive Services**

Language	Frequency	Percent
English	316	83.2
Spanish	91	23.9
Other	2	0.5
Total	409	107.6

<sup>1</sup>Some participants chose more than one response.

**Table 8: In-Care – Education**

	Education Level	Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Grade school or less	46	12.1	12.2	12.2
	Some high school, did not graduate	105	27.6	27.8	39.9
	High school grad or GED	135	35.5	35.7	75.7
	Some college, did not graduate	43	11.3	11.4	87.0
	College	24	6.3	6.3	93.4
	Vocational/Technical Cert.	19	5.0	5.0	98.4
	Graduate Education	3	0.8	0.8	99.2
	Other	3	0.8	0.8	100.0
	Total	378	99.5	100.0	
Missing	Missing data	2	0.5		
Total		380	100.0		

**Table 9: In-Care – Employment Status**

	Employment Status	Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No, I am not working	309	81.3	81.5	81.5
	Yes, I am working full time	24	6.3	6.3	87.9
	Yes, I am working part time	31	8.2	8.2	96.0
	I am retired	15	3.9	4.0	100.0
	Total	379	99.7	100.0	
Missing	Missing data	1	0.3		
Total		380	100.0		

**Table 10: In-Care – Income Last Month**

	<b>Income</b>	<b>Frequency</b>	<b>Percent</b>	<b>Valid Percent</b>	<b>Cumulative Percent</b>
Valid	\$0 to \$499 per month	142	37.4	37.5	37.5
	\$500 to \$999 per month	170	44.7	44.9	82.3
	\$1000 to \$1999 per month	46	12.1	12.1	94.5
	\$2000 or more per month	13	3.4	3.4	97.9
	Missing data	8	2.1	2.1	100.0
	<b>Total</b>	<b>379</b>	<b>99.7</b>	<b>100.0</b>	
Missing	Refused to answer	1	0.3		
<b>Total</b>		<b>380</b>	<b>100.0</b>		

**Table 11: In Care - Income by Race/Ethnicity**

	<b>Income last month</b>					<b>Total</b>
	<b>\$0 to \$499 per month</b>	<b>\$500 to \$999 per month</b>	<b>\$1000 to \$1999 per month</b>	<b>\$2000 or more per month</b>	<b>Missing data</b>	
Black	51 36.4%	67 47.9%	12 8.6%	7 5.0%	3 2.1%	140 100.0%
White	23 31.9%	26 36.1%	21 29.2%	1 1.4%	1 1.4%	72 100.0%
Hispanic	65 43.6%	67 45.0%	10 6.7%	5 3.4%	2 1.3%	149 100.0%
Other	2 25.0%	2 25.0%	2 25.0%	0 .0%	2 25.0%	8 100.0%
<b>Total</b>	141 38.2%	162 43.9%	45 12.2%	13 3.5%	8 2.2%	369 100.0%

**Table 12: In-Care – Current Housing Status**

	<b>Current Housing</b>	<b>Frequency</b>	<b>Percent</b>	<b>Valid Percent</b>	<b>Cumulative Percent</b>
Valid	I am homeless (living on the street, in a car, park, crack house)	15	3.9	4.0	4.0
	I stay at a homeless shelter	23	6.1	6.1	10.2
	I crash at different people's places	3	.8	.8	11.0
	I have temporary, transitional housing	22	5.8	5.9	16.8
	I am living in an HIV/AIDS group home	26	6.8	7.0	23.8
	I am in a nursing home	2	0.5	.5	24.3
	I am in a residential care facility	9	2.4	2.4	26.7
	I am staying free with friends or relatives	24	6.3	6.4	33.2
	I rent a room in a house or hotel	13	3.4	3.5	36.6
	I share an apartment	30	7.9	8.0	44.7
	I have my own apartment	172	45.3	46.0	90.6
	I have my own house or condo	18	4.7	4.8	95.5
	Other	17	4.5	4.5	100.0
	Total	374	98.4	100.0	
	Missing	Missing data	6	1.6	
Total		380	100.0		

**Table 13: In-Care – Incarceration in Past 12 Months**

	<b>Jail/Prison</b>	<b>Frequency</b>	<b>Percent</b>	<b>Valid Percent</b>	<b>Cumulative Percent</b>
Valid	No	314	82.6	83.5	83.5
	Yes	62	16.3	16.5	100.0
	Total	376	98.9	100.0	
Missing	Missing data	4	1.1		
Total		380	100.0		

**Table 14: In-Care – Illegal Drug Use on Regular Basis<sup>1</sup>**

Regular Illegal Drug Use		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	309	81.3	82.0	82.0
	Yes	68	17.9	18.0	100.0
	Total	377	99.2	100.0	
Missing	Missing data	2	0.5		
	Not Applicable	1	0.3		
	Total	3	0.8		
Total		380	100.0		

<sup>1</sup>"Use on Regular Basis" was defined by participant

**Table 14a: In-Care – Injection Drug Use in Past 6 Months**

IDU in Past 6 Months		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	117	30.8	66.9	66.9
	Yes	58	15.3	33.1	100.0
	Total	175	46.1	100.00	
Missing	Missing data	1	0.3		
	Not Applicable	204	53.7		
	Total	205	53.9		
Total		380	100.0		

**Table 14b: In-Care – Ever Injected Illegal Drugs**

IDU Ever	Frequency	Percent	Valid Percent	Cumulative Percent
No	204	53.7	53.7	53.7
Yes	176	46.3	46.3	100.0
Total	380	100.0	100.0	

**Table 15: In-Care – HIV Exposure**

Exposure Category	N	%
Having sex with HIV+ male	157	43.3
Having sex with HIV+ female	61	16.8
Sharing needles or works	116	32.0
Blood Transfusion	10	2.8
Mother to Child	5	1.4
Don't know	39	10.7
Total	388	107.0



**Table 15a: In-Care – HIV Exposure by Race/Ethnicity and Gender**

Exposure	Ethnicity								Gender					
	Black		White		Hispanic		Other		Female		Male		Transgender	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Having sex with a man with HIV	49	32.7	48	32.0	48	32.0	5	3.3	86	55.1	68	43.6	2	1.3%
Having sex with a woman with HIV	14	23.3	14	23.3	30	50.0	2	3.3	2	3.3	59	96.7	0	0
Sharing needles or works	59	51.3	12	10.4	42	36.5	2	1.7	28	24.1	86	74.1	2	1.7
Blood Transfusion	5	50.0	3	30.0	2	20.0	0	0	1	10.0	9	90.0	0	0
Mother to Child	1	20.0	0	0	4	80.0	0	0	2	40.0	3	60.0	0	0
Don't know	16	42.1	8	21.1	14	36.8	0	0	13	34.2	25	65.8	0	0

We note a difference between the Needs Assessment In-Care sample and the 2006 CT data for heterosexual transmission (38.1% and 15.7%, respectively) and pediatric, identified as “Mother to Child” transmission in the Needs Assessment (1.4% and 0.5%, respectively)<sup>1</sup>.

**Table 15b: In-Care – HIV Exposure by Age**

Exposure	Age									
	18-19		20-29		30-39		40 - 49		50+	
	N	%	N	%	N	%	N	%	N	%
Having sex with a man with HIV	2	1.3	10	6.5	29	18.7	69	44.5	45	29.0
Having sex with a woman with HIV	0	0	1	1.6	11	18.0	28	45.9	21	34.4
Sharing needles or works	0	0	1	.9	12	10.3	54	46.6	49	42.2
Blood Transfusion	0	0	0	0	1	10.0	3	30.0	6	60.0
Mother to Child	2	40.0	3	60.0	0	0	0	0	0	0
Don't know	0	0	4	10.3	3	7.7	16	41.0	16	41.0

**Table 16: In-Care – AIDS Diagnosis**

<b>Diagnosed with AIDS</b>	<b>Frequency</b>	<b>Percent</b>	<b>Valid Percent</b>	<b>Cumulative Percent</b>
No	242	63.7	64.4	64.4
Yes	134	35.3	35.6	100.0
Total	376	98.9	100.0	
Missing Data	4	1.1		
Total	380	100.0		

**Table 17: In-Care – Co-Morbidities<sup>1</sup>**

<b>Health Problem</b>	<b>N</b>	<b>%</b>
Hepatitis A	15	3.9
Hepatitis B	37	9.7
Hepatitis C	177	46.6
Tuberculosis	18	4.7
Psychiatric	117	30.8
Syphilis	23	6.1
Gonorrhea	26	6.8
Chlamydia	18	4.7
Human Papillomavirus (HPV)	16	4.2
Diabetes	45	11.8
PCP Pneumonia	43	11.3
High Blood Pressure	85	22.4

<sup>1</sup>Participants checked all that applied



**Table 17a: In-Care - Co-Morbidities by Race/Ethnicity, IDU, Homelessness**

Health Problem	Ethnicity											
	Black		White		Hispanic		Other		IDU		Homelessness	
	N	%	N	%	N	%	N	%	N	%	N	%
Hepatitis A	7	5.0	1	1.4	7	4.7	0	0	4	6.9	5	5.0
Hepatitis B	12	8.5	10	13.9	14	9.4	0	0	8	13.8	11	10.9
Hepatitis C	76	53.9	25	34.7	69	46.3	3	37.5	49	84.5	64	63.4
Tuberculosis	9	6.4	1	1.4	7	4.7	0	0	3	5.2	4	4.0
Psychiatric	41	29.1	26	36.1	48	32.2	0	0	27	46.6	41	40.6
Syphilis	9	6.4	5	6.9	7	4.7	1	12.5	5	8.6	7	6.9
Gonorrhea	7	5.0	10	13.9	8	5.4	1	12.5	8	13.8	6	5.9
Chlamydia	5	3.5	5	6.9	4	2.7	1	12.5	6	10.3	7	6.9
Human Papillomavirus (HPV)	4	2.8	7	9.7	4	2.7	0	0	3	5.2	6	5.9
Diabetes	25	17.7	9	12.5	10	6.7	0	0	4	6.9	7	6.9
PCP Pneumonia	15	10.6	8	11.1	19	12.8	1	12.5	10	17.2	15	14.9
High Blood Pressure	45	31.9	16	22.2	20	13.4	1	12.5	16	27.6	24	23.8

**Table 18: In-Care - Access to Medical Care for HIV**

<b>Provider</b>	<b>N</b>	<b>%</b>
Community Health Center	174	47.9
Hospital HIV Clinic	122	33.6
Private Doctor	62	17.1
Emergency Room	13	3.6
Homeless Shelter	1	.3
Other	12	3.3

**Table 18a: In-Care - Access to Medical Care for HIV by Race/Ethnicity/IDU/Homelessness/Incarceration**

<b>Provider</b>	<b>Ethnicity</b>													
	<b>Black</b>		<b>White</b>		<b>Hispanic</b>		<b>Other</b>		<b>IDU</b>		<b>Homeless</b>		<b>Incarc'd</b>	
	<b>N</b>	<b>%</b>	<b>N</b>	<b>%</b>	<b>N</b>	<b>%</b>	<b>N</b>	<b>%</b>	<b>N</b>	<b>%</b>	<b>N</b>	<b>%</b>	<b>N</b>	<b>%</b>
Community Health Center	83	61.0	14	20.0	69	49.6	4	50.0	34	61.8	65	65.7	38	65.5
Hospital HIV Clinic	36	26.5	27	38.6	51	36.7	3	37.5	16	29.1	28	28.3	13	22.4
Private Doctor	13	9.6	29	41.4	14	10.1	3	37.5	5	9.1	7	7.1	6	10.3
Emergency Room	4	2.9	2	2.9	5	3.6	0	0	1	1.8	5	5.1	3	5.2
Homeless Shelter	1	.7	0	0	0	0	0	0	0	0	1	1.0	1	1.7
Other	5	3.7	2	2.9	5	3.6	0	0	1	1.8	0	0	1	1.7

**Table 19: In-Care – Medical Insurance/Medication Payment**

<b>Payment Type</b>	<b>N</b>	<b>%</b>
Private Insurance	25	6.6
SAGA	117	30.9
CADAP	75	19.8
Title 19/Medicaid	179	47.2
Medicare	104	27.4
Husky Program	6	1.6
Veteran's Administration for care	2	.5
I pay myself	10	2.6
Ryan White	55	14.5
No one pays for my medical care	5	1.3
Other	10	2.6

**Table 20: In-Care – HIV Medication**

<b>On ART</b>	<b>Frequency</b>	<b>Percent</b>	<b>Valid Percent</b>	<b>Cumulative Percent</b>
No	54	14.2	14.2	14.2
Yes	325	85.5	85.8	100.0
Total	379	99.7	100.0	
Missing Data	1	.3		
Total	380	100.0		

**Table 21: In-Care – Why Not Taking HIV Medications<sup>1</sup>**

	<b>N</b>	<b>%</b>
I can't keep to the treatment schedule	4	4.5
I don't like the side effects	7	7.9
I can't afford the medications	1	1.1
My religious beliefs oppose medications	0	0
My drug or alcohol use gets in the way	5	5.6
My doctor did not prescribe medications	55	61.8
The medications don't work	1	1.1
I don't want to take medications	4	4.5
I am homeless	2	2.2

<sup>1</sup>Participants checked all that applied

**Table 22: In-Care – Missed Taking HIV Medication**

		<b>Frequency</b>	<b>Percent</b>	<b>Valid Percent</b>	<b>Cumulative Percent</b>
Valid	I never miss taking my medications	140	36.8	48.6	48.6
	I rarely miss (once or twice a month)	97	25.5	33.7	82.3
	I miss occasionally (once or twice a week)	39	10.3	13.5	95.8
	I frequently miss taking the medications (3 times a week or	11	2.9	3.8	99.7
	I am not taking medications	1	.3	.3	100.0
	Total	288	75.8	100.0	
Missing	Missing data	10	2.6		
	Not Applicable	82	21.6		
	Total	92	24.2		
Total		380	100.0		

**Table 23: In-Care - Services Used and Services Needed**

	I HAVE USED this service at least once in the last 12 months		I NEED this service, but HAVE NOT USED it in the past 12 months		I NEED this service, but I CAN'T GET it		I DO NOT NEED this service	
	N	%	N	%	N	%	N	%
Medical Care for HIV	337	91.1	18	4.9	3	.8	12	3.2
Medical Case Management	308	85.8	23	6.4	6	1.7	22	6.1
CADAP	117	38.0	25	8.1	16	5.2	150	48.7
Help Paying for Co-pays and Medications	162	46.7	28	8.1	12	3.5	145	41.8
Substance Abuse Treatment	123	34.9	25	7.1	2	.6	202	57.4
Mental Health Treatment	161	46.0	28	8.0	5	1.4	156	44.6
Dental Care	215	58.9	92	25.2	24	6.6	34	9.3
Medication Adherence Support	111	32.1	29	8.4	5	1.4	201	58.1
Home Health Care	34	10.0	13	3.8	12	3.5	282	82.7
Emergency Financial Assistance	88	25.6	55	16.0	57	16.6	144	41.9
Help Finding an Apartment	71	20.3	72	20.6	37	10.6	170	48.6
Help Paying Rent	108	30.8	63	17.9	45	12.8	135	38.5
Transportation to Appointments	137	38.7	64	18.1	25	7.1	128	36.2
Food Programs	175	49.2	52	14.6	28	7.9	101	28.4
Nutritional Counseling	93	27.2	50	14.6	22	6.4	177	51.8
Legal Assistance	54	15.7	39	11.3	17	4.9	235	68.1
Child Care	12	3.5	6	1.8	4	1.2	319	93.5
Translation Services	38	11.0	12	3.5	7	2.0	289	83.5
Drop-in Centers	136	39.1	34	9.8	5	1.4	173	49.7

If participants checked any services that they needed but were unable to get, they were asked to indicate which ones, up to 3, were the most important to them. The 3 services most frequently identified as most important but were unable to get were: 1) emergency financial assistance (16.6%), 2) help paying rent (12.8%), and 3) help finding an apartment (10.6%).

Table 20 presents the barriers listed by participants to accessing these 3 services. The N for each service indicates the number of participants who indicated the service as one of the up to 3 most important but unable to obtain. The column below each of the 3 services shows the percent of each sub-sample who identified each specific barrier.



**Table 24: In-Care - Barriers to Accessing Services**

	<b>EMERGENCY FIN ASST</b>	<b>HELP PAYING RENT</b>	<b>HELP FINDING AN APT</b>
	<b>N=42</b>	<b>N=40</b>	<b>N=32</b>
	<b>%</b>	<b>%</b>	<b>%</b>
I didn't know this service was available	59.5	62.5	71.9
I don't know where to go to get this service	64.3	65.0	81.3
The service is located too far away	23.8	20.0	28.1
I have no transportation to get to the service	28.6	30.0	34.4
There are no openings for this service/I am on a waiting list	21.4	35.0	37.5
I was getting this service and was asked to leave	11.9	15.0	12.5
I used up all the services that I am eligible for this year	16.7	12.5	12.5
I am disabled and the service cannot meet my special needs	14.3	15.0	9.4
I earn too much money	21.4	15.0	6.3
I can't afford to pay for this service	35.7	45.0	46.9
I don't have any insurance	11.9	12.5	9.4
My insurance doesn't cover this service	21.4	22.5	15.6
I am afraid people will find out that I have HIV	28.6	22.5	34.4
I am afraid people will think that I am gay	14.3	10.0	12.5
I am afraid people will think that I am a drug user	23.8	20.0	18.8
I feel I get treated unfairly by service providers	28.6	20.0	28.1
I am not legal/I am undocumented	7.1	10.0	3.1
I don't speak English well enough	14.3	22.5	15.6
I don't have anyone to take care of my kids	4.8	7.5	3.1
I have a drug problem	11.9	17.5	18.8
I have a mental health problems	19.0	17.5	25.0
I am homeless	21.4	15.0	28.1
I have a prison record	26.2	32.5	40.6

**Table 25: In-Care – Three (3) Core Medical Services That Are MOST IMPORTANT**

<b>Core Medical Service</b>	<b>N</b>	<b>%</b>
Medical Care for HIV	323	85.2
Medical Case Management	178	47.0
Paying for Medications	127	33.5
Substance Abuse Treatment	89	23.5
Mental Health Treatment	117	30.9
Dental Care	173	45.6
Medication Adherence Support	15	4.0
Home Health Care	22	5.8
Insurance Continuation	85	22.4

**Table 26: In-Care - Three (3) Support Services That Are MOST IMPORTANT**

<b>Support Service</b>	<b>N</b>	<b>%</b>
Transportation to Appointment	186	48.9
Food Programs	178	46.8
HIV Education	93	24.5
Emergency Financial Assistance	148	38.9
Help Finding an Apartment	120	31.6
Help Paying Rent	174	45.8
Outreach to Connect to Services	61	16.1
Nutritional Counseling	39	10.3
Legal Assistance	40	10.5
Translation Services	23	6.1
Drop-in Centers	72	18.9
Child Care	12	3.2

**Table 27: In-Care – Services USED IN THE PAST, but CAN'T GET ANYMORE**

<b>Service</b>	<b>N</b>	<b>%</b>
Medical Care for HIV	29	9.3
Medical Case Management	25	8.0
Paying for Medications	19	6.1
Substance Abuse Treatment	20	6.4
Mental Health Treatment	15	4.8
Dental Care	55	17.6
Medication Adherence Support	7	2.2
Home Health Care	14	4.5
HIV Education	22	7.1
Translation Services	12	3.8
Emergency Financial Assistance	52	16.7
Transportation to Appointment	45	14.4
Food Programs	62	19.9
Help Finding Housing	42	13.5
Help Paying for Housing	54	17.3
Outreach to Connect to Services	14	4.5
Nutritional Counseling	12	3.8
Legal Assistance	15	4.8
Complementary/Alternative Therapies	48	15.4
Drop-in Centers	14	4.5

**SURVEY: OUT-OF-CARE (N=28)**

**Table 28: Out-of-Care Sample by County**

<b>County</b>	<b>Frequency</b>	<b>Percent</b>	<b>Valid Percent</b>	<b>Cumulative Percent</b>
Hartford	22	78.6	78.6	78.6
Middlesex	1	3.6	3.6	82.1
Tolland	5	17.9	17.9	100.0
Total	28	100.0	100.0	

**Table 29: Out-of-Care Sample by Town**

	<b>Town</b>	<b>Frequency</b>	<b>Percent</b>	<b>Valid Percent</b>	<b>Cumulative Percent</b>
Valid	Hartford	18	64.3	66.7	66.7
	Manchester	2	7.1	7.4	74.1
	Bristol	1	3.6	3.7	77.8
	Middletown	1	3.6	3.7	81.5
	Rockville	2	7.1	7.4	88.9
	Willington	3	10.7	11.1	100.0
	Total	27	96.4	100.0	
Missing	Missing data	1	3.6		
Total		28	100.0		

**Table 30: Out-of-Care – Age**

<b>Age Category</b>	<b>Frequency</b>	<b>Percent</b>	<b>Valid Percent</b>	<b>Cumulative Percent</b>
18-19	1	3.6	3.6	3.6
20-29	1	3.6	3.6	7.1
30-39	7	25.0	25.0	32.1
40 - 49	12	42.9	42.9	75.0
50+	7	25.0	25.0	100.0
Total	28	100.0	100.0	

**Table 31: Out-of-Care- Gender**

<b>Gender</b>	<b>Frequency</b>	<b>Percent</b>	<b>Valid Percent</b>	<b>Cumulative Percent</b>
Female	9	32.1	32.1	32.1
Male	19	67.9	67.9	100.0
Total	28	100.0	100.0	

**Table 32: Out-of-Care - Sexual Orientation**

<b>Sexual Orientation</b>	<b>Frequency</b>	<b>Percent</b>	<b>Valid Percent</b>	<b>Cumulative Percent</b>
Gay	4	14.3	14.3	14.3
Bisexual	5	17.9	17.9	32.1
Heterosexual/straight	19	67.9	67.9	100.0
Total	28	100.0	100.0	

**Table 33: Out-of-Care – Race/Ethnicity**

<b>Ethnicity</b>	<b>Frequency</b>	<b>Percent</b>	<b>Valid Percent</b>	<b>Cumulative Percent</b>
African American	12	42.9	42.9	42.9
West Indian/Caribbean	1	3.6	3.6	46.4
Latino or Hispanic	4	14.3	14.3	60.7
American Indian/Alaska Native	2	7.1	7.1	67.9
White	8	28.6	28.6	96.4
Multi-Racial/Multi-Ethnic	1	3.6	3.6	100.0
Total	28	100.0	100.0	

**Table 34: Out-of-Care – Preferred Language to Receive Services**

<b>Language</b>	<b>Frequency</b>	<b>Percent</b>
English	26	92.9
Spanish	3	10.7
Total <sup>1</sup>	29	103.6

<sup>1</sup>One participant chose more than one response.

**Table 35: Out-of-Care - Education Level**

<b>Education Level</b>	<b>Frequency</b>	<b>Percent</b>	<b>Valid Percent</b>	<b>Cumulative Percent</b>
Grade school or less	5	17.9	17.9	17.9
Some high school, did not graduate	7	25.0	25.0	42.9
High school grad or GED	8	28.6	28.6	71.4
Some college, did not graduate	5	17.9	17.9	89.3
College grad	2	7.1	7.1	96.4
Vocational/Technical Certificate	1	3.6	3.6	100.0
Total	28	100.0	100.0	

**Table 36: Out-of-Care – Employment Status**

<b>Employment Status</b>	<b>Frequency</b>	<b>Percent</b>	<b>Valid Percent</b>	<b>Cumulative Percent</b>
No, I am not working	21	75.0	75.0	75.0
Yes, I am working full time	1	3.6	3.6	78.6
Yes, I am working part time	6	21.4	21.4	100.0
Total	28	100.0	100.0	

**Table 37: Out-of-Care –Income Last Month**

<b>Income</b>	<b>Frequency</b>	<b>Percent</b>	<b>Valid Percent</b>	<b>Cumulative Percent</b>
\$0 to \$499 per month	13	46.4	46.4	46.4
\$500 to \$999 per month	11	39.3	39.3	85.7
\$1000 to \$1999 per month	4	14.3	14.3	100.0
Total	28	100.0	100.0	

**Table 37a: Out-of-Care - Income by Race/Ethnicity**

	Income last month			Total
	\$0 to \$499 per month	\$500 to \$999 per month	\$1000 to \$1999 per month	
Black	6	6	0	12
	50.0%	50.0%	.0%	100.0%
White	5	2	1	8
	62.5%	25.0%	12.5%	100.0%
Hispanic	2	1	1	4
	50.0%	25.0%	25.0%	100.0%
Other	0	1	2	3
	.0%	33.3%	66.7%	100.0%
9.00	0	1	0	1
	.0%	100.0%	.0%	100.0%
Total	13	11	4	28
	46.4%	39.3%	14.3%	100.0%

**Table 38: Out-of-Care – Current Housing Status**

	<b>Current Housing</b>	<b>Frequency</b>	<b>Percent</b>	<b>Valid Percent</b>	<b>Cumulative Percent</b>
Valid	I am homeless (living on the street, in a car, park, crack house)	5	17.9	18.5	18.5
	I stay at a homeless shelter	2	7.1	7.4	25.9
	I crash at different people's places	3	10.7	11.1	37.0
	I have temporary, transitional housing	2	7.1	7.4	44.4
	I am staying free with friends or relatives	4	14.3	14.8	59.3
	I share an apartment	5	17.9	18.5	77.8
	I have my own apartment	6	21.4	22.2	100.0
	Total	27	96.4	100.0	
	Missing data	1	3.6		
Missing Total	28	100.0			

**Table 39: Out-of-Care – Incarceration in Past 12 Months**

<b>Jail/Prison</b>	<b>Frequency</b>	<b>Percent</b>	<b>Valid Percent</b>	<b>Cumulative Percent</b>
No	22	78.6	78.6	78.6
Yes	6	21.4	21.4	100.0
Total	28	100.0	100.0	

**Table 40: Out-of-Care – Illegal Drug Use on a Regular Basis**

<b>Drug</b>	<b>N</b>	<b>%</b>
Marijuana or Hash	11	42.3
Ecstasy	0	0
Cocaine	9	34.6
Crack	6	23.1
Heroin	7	26.9
Crystal	0	0
Meth/Methamphetamines		
Alcohol	10	38.5
Other drug	4	15.4

<sup>1</sup>"Use on Regular Basis" was defined by participant

**Table 40a: Out-of-Care – Injection Drug Use in Past 6 Months**

<b>IDU in Past 6 Months</b>	<b>Frequency</b>	<b>Percent</b>	<b>Valid Percent</b>	<b>Cumulative Percent</b>
No	8	28.6	28.6	28.6
Yes	20	71.4	71.4	100.0
Total	28	100.0	100.0	

**Table 41: Out-of-Care – HIV Exposure**

<b>Exposure Category</b>	<b>N</b>	<b>%</b>
Having sex with HIV+ male	12	44.4
Having sex with HIV+ female	5	18.5
Sharing needles or works	15	55.6
Blood Transfusion	1	3.7
Mother to Child	0	0
Don't know	2	7.4
Total	35	129.6





**Table 41a: Out-of-Care – HIV Exposure by Race/Ethnicity and Gender**

Exposure	Ethnicity								Gender					
	Black		White		Hispanic		Other		Female		Male		Transgender	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Having sex with a man with HIV	49	32.7	48	32.0	48	32.0	5	3.3	86	55.1	68	43.6	2	1.3
Having sex with a woman with HIV	14	23.3	14	23.3	30	50.0	2	3.3	2	3.3	59	96.7	0	0
Sharing needles or works	59	51.3	12	10.4	42	36.5	2	1.7	28	24.1	86	74.1	2	1.7
Blood Transfusion	5	50.0	3	30.0	2	20.0	0	0	1	10.0	9	90.0	0	0
Mother to Child	1	20.0	0	0	4	80.0	0	0	2	40.0	3	60.0	0	0
Don't know									13	34.2	25	65.8	0	0

**Table 41b: Out-of-Care – HIV Exposure by Age**

Exposure	Age									
	18-19		20-29		30-39		40 - 49		50+	
	N	%	N	%	N	%	N	%	N	%
Having sex with a man with HIV	2	1.3	10	6.5	29	18.7	69	44.5	45	29.0
Having sex with a woman with HIV	0	0	1	1.6	11	18.0	28	45.9	21	34.4
Sharing needles or works	0	0	1	.9	12	10.3	54	46.6	49	42.2
Blood Transfusion	0	0	0	0	1	10.0	3	30.0	6	60.0
Mother to Child	2	40.0	3	60.0	0	0	0	0	0	0
Don't know	0	0	4	10.3	3	7.7	16	41.0	16	41.0



**Table 42: Out-of-Care – AIDS Diagnosis**

<b>Diagnosed w/AIDS</b>	<b>Frequency</b>	<b>Percent</b>	<b>Valid Percent</b>	<b>Cumulative Percent</b>
No	27	96.4	96.4	96.4
Yes	1	3.6	3.6	100.0
Total	28	100.0	100.0	

**Table 43: Out-of-Care - Access to Medical Care for HIV**

<b>Provider</b>	<b>N</b>	<b>%</b>
Community Health Center	8	29.6
Hospital HIV Clinic	3	11.1
Private Doctor	2	7.4
Emergency Room	6	22.2
Other	4	14.8

**Table 43a: Out-of-Care - Access to Medical Care for HIV by Race/Ethnicity/IDU/Homelessness/Incarceration**

Provider	Ethnicity								IDU		Homeless		In Jail	
	Black		White		Hispanic		Other		N	%	N	%	N	%
	N	%	N	%	N	%	N	%						
Community Health Center	4	50.0	2	25.0	0	0	2	25.0	0	0	3	37.5	1	12.5
Hospital HIV Clinic	2	66.7	0	0	0	0	1	33.3	1	50.0	2	66.7	0	0
Private Doctor	0	0	2	100	0	0	0	0	1	100	1	50.0	1	50.0
Emergency Room	3	50.0	3	50.0	0	0	0	0	3	60.0	3	50.0	1	16.7
Other	2	50.0	1	25.0	1	25.0	0	0	3	100	2	50.0	2	50.0

**Table 44: Out-of-Care - Medical Insurance/Medication Payment**

Payment Type	N	%
Private Insurance	0	0
SAGA	5	17.9
CADAP	0	0
Title 19/Medicaid	4	14.3
Medicare	3	10.7
Husky Program	0	0
Veteran's Administration for care	0	0
I pay myself	3	10.7
Ryan White	1	3.6
No one pays for my medical care	10	35.7
Other	2	7.1

**Table 45: Out-of-Care - Services Used and Services Needed**

Services	I HAVE USED this service at least once in the last 12 months		I NEED this service, but have NOT USED it in the past 12 months		I NEED this service, but I CAN'T GET it		I DO NOT NEED this service	
	N	%	N	%	N	%	N	%
Medical Care for HIV	3	11.1	16	59.3	1	3.7	7	25.9
Medical Case Management	8	28.6	11	39.3	2	7.1	7	25.0
CADAP	3	11.5	6	23.1	4	15.4	13	50.0
Help Paying for Co-pays and Medications	3	11.1	8	29.6	1	3.7	15	55.6
Substance Abuse Treatment	6	21.4	7	25.0	1	3.6	14	50.0
Mental Health Treatment	6	21.4	4	14.3	0	0	18	64.3
Dental Care	7	25.0	14	50.0	1	3.6	6	21.4
Medication Adherence Support	2	7.4	5	18.5	1	3.7	19	70.4
Home Health Care	1	3.7	2	7.4	0	0	24	88.9
Emergency Financial Assistance	3	11.1	12	44.4	2	7.4	10	37.0
Help Finding an Apartment	4	14.3	9	32.1	1	3.6	14	50.0
Help Paying Rent	3	10.7	13	46.4	4	14.3	8	28.6
Transportation to Appointments	2	7.1	14	50.0	3	10.7	9	32.1
Food Programs	5	17.9	10	35.7	4	14.3	9	32.1
Nutritional Counseling	1	3.6	10	35.7	1	3.6	16	57.1
Legal Assistance	1	3.6	3	10.7	1	3.6	23	82.1
Child Care	1	3.6	1	3.6	1	3.6	25	89.3
Translation Services	1	3.6	2	7.1	1	3.6	24	85.7
Drop-in Centers	3	10.7	6	21.4	2	7.1	17	60.7

If participants checked any services that they needed but were unable to get, they were asked to indicate which ones, up to 3, were the most important to them. Considering the small sample size (N=28), two services were each identified by 3 individuals: emergency financial assistance and help paying rent. Dental care, food programs and medical case management were identified by 2 participants each; drop-in centers, and medical care were identified each by 1 participant.

Participants were asked to check all of the reasons why they could not obtain the services they listed as most important but unable to get. For Emergency Financial Assistance, the most common barrier to accessing this service was lack of knowledge of where to go to get the service. The most frequently noted barriers to accessing help

to pay rent were not knowing the service was available, fear that others would find out that the participant was HIV positive, and homelessness.

**Table 46: Out-of-Care - Three (3) core medical services that are MOST IMPORTANT**

<b>Service</b>	<b>N</b>	<b>%</b>
Medical Care for HIV	19	67.9
Medical Case Management	16	57.1
Paying for Medications	8	28.6
Substance Abuse Treatment	10	35.7
Mental Health Treatment	7	25.0
Dental Care	17	60.7
Medication Adherence Support	0	0
Home Health Care	0	0

**Table 47: Out-of-Care - Three (3) support services that are MOST IMPORTANT**

<b>Service</b>	<b>N</b>	<b>%</b>
Transportation to Appointment	12	42.9
Food Programs	13	46.4
HIV Education	4	14.3
Emergency Financial Assistance	11	39.3
Help Finding an Apartment	10	35.7
Help Paying Rent	16	57.1
Outreach to Connect to Services	3	10.7
Nutritional Counseling	2	7.1
Legal Assistance	6	21.4
Translation Services	2	7.1
Drop-in Centers	1	3.6
Child Care	1	3.6

**Table 48: Out-of-Care - Services USED IN THE PAST, but CAN'T GET ANYMORE**

<b>Service</b>	<b>N</b>	<b>%</b>
Medical Care for HIV	4	14.8
Medical Case Management	3	11.1
Paying for Medications	3	11.1
Substance Abuse Treatment	1	3.7
Mental Health Treatment	3	11.1
Dental Care	3	11.1
Medication Adherence Support	0	0
Home Health Care	1	3.7
HIV Education	0	0
Translation Services	0	0
Emergency Financial Assistance	6	22.2
Transportation to Appointment	4	14.8
Food Programs	5	18.5
Help Finding Housing	1	3.7
Help Paying for Housing	6	22.2
Outreach to Connect to Services	1	3.7
Nutritional Counseling	2	7.4
Legal Assistance	2	7.4
Complementary/Alternative Therapies	3	11.1
Drop-in Centers	1	3.7

**Table 49: Out-of-Care – Co-Morbidities<sup>1</sup>**

	<b>N</b>	<b>%</b>
Hepatitis A	0	0
Hepatitis B	2	7.1
Hepatitis C	12	42.9
Tuberculosis	1	3.6
Psychiatric	5	17.9
Syphilis	1	3.6
Gonorrhea	2	7.1
Chlamydia	2	7.1
Human Papillomavirus (HPV)	1	3.6
Diabetes	3	10.7
PCP Pneumonia	2	7.1
High Blood Pressure	6	21.4

<sup>1</sup>Participants could choose more than one response



**Table 49a: Out-of-Care - Co-Morbidities by Race/Ethnicity, IDU, Homelessness**

Health Problem	Ethnicity								IDU		Homelessness	
	Black		White		Hispanic		Other		N	%	N	%
	N	%	N	%	N	%	N	%				
Hepatitis A	0	0	0	0	0	0	0	0	0	0	0	0
Hepatitis B	0	0	1	50.0	1	50.0	0	0	1	50.0	2	100.0
Hepatitis C	5	41.7	2	16.7	4	33.3	0	0	7	58.3	6	50.0
Tuberculosis	1	100.0	0	0	0	0	0	0	0	0	0	0
Psychiatric	2	40.0	1	20.0	1	20.0	1	20.0	3	75.0	1	20.0
Syphilis	0	0	1	100.0	0	0	0	0	0	0	0	0
Gonorrhea	0	0	2	100.0	0	0	0	0	1	50.0	1	50.0
Chlamydia	1	50.0	0	0	0	0	1	50.0	0	0	1	50.0
Human Papillomavirus (HPV)	0	0	0	0	0	0	1	100.0	0	0	0	0
Diabetes	2	66.7	1	33.3	0	0	0	0	1	33.3	2	66.7
PCP Pneumonia	2	100.0	0	0	0	0	0	0	2	100.0	0	0
High Blood Pressure	3	50.0	0	0	2	33.3	0	0	1	16.7	1	16.7

## **FOCUS GROUPS**

### **Focus Group: Latino Male IDUs**

Seven HIV positive Latino males, all current injection drug users, were recruited via street outreach in Hartford. Five turned up on the scheduled date and time to participate in the focus group. All but one were completely bilingual, so the facilitators conducted the focus group in English and Spanish. Ages ranged from 37 to 57 years of age, all 5 identified as heterosexual. Three were unemployed and claimed a monthly income between \$500.00 and \$999.00. Two (ages 53 and 57) were retired, with a monthly income between \$00.00 and \$499.00. Three participants had their own apartment, including the 2 retired individuals, 1 shared an apartment and 1 was homeless. Length of residency at the current location ranged between 6 months to more than 5 years. Four of the 5 had completed some high school but did not graduate and 1 had attended graduate school. All participants were identified as in-care, with 4 having had their CD4 count and viral load checked and taken anti-retroviral medication in the past 12 months. One had only his CD4 count checked in the prior 12 months.

### **Local Services**

The group constructed an extensive list of services that they knew about and/or had accessed at some point in time:

- Mental health services
- Shelters (Mercy, Immaculate Conception)
- Utility payments
- Substance abuse/addiction services (Hartford Dispensary, NEP van, “rehab” services)
- Latino Community Services
- Hospital
- CONNECT
- Services specifically for PWHIV
- Laboratory
- CT Transit (transportation)
- Fire department
- Hartford Hospital/Brownstone Building
- Shelter plus care
- Community Renewal Team
- Tabor House
- Food pantry
- House of Bread
- Gift of Love
- Clothing
- Salvation Army
- Basic needs
- Case management
- AIDS Project Hartford
- Connections
- Manchester Area Network on AIDS

- Wellness Center
- Temporary labor services
- Ryan White services

Participants then were asked to fill out the Services Used and Services Needed matrix (see Appendix) and then discuss what services they needed but have been unable to get and the barriers to accessing needed services. Medical care for HIV, medical case management, substance abuse treatment, mental health treatment, transportation, food programs and drop-in centers were identified by all focus group participants as services used at least once in the previous 12 months. Dental care, help finding an apartment and paying the rent, nutritional counseling and legal assistance were pinpointed as used by 3 of the 4 participants. Only one participant identified services that he needed but could not get, those being transportation and translation services. Help in paying co-pays and medications and childcare, followed by CADAP, medication adherence support, and home health care were the most commonly identified services not needed by this group.

### **Services Needed But Unable to Get**

In further discussion, participants listed bus passes/transportation, assistance in finding employment and housing as services they needed but were unable to get. Background checks that required and documented prior arrest and incarceration information were, they felt, the primary barriers to receiving certain services. Although they were aware of a process to apply for a pardon or to expunge their record, most were not knowledgeable of the process or saw the process itself, including associated fees, as daunting.

### **Missed Medical Appointments**

The reasons mentioned for missing medical appointments were:

- forgetting the appointment,
- difficulty contacting the office when necessary to reschedule an appointment, and
- drug addiction.

### **General Medical Care and HIV-Related Health Care**

Most participants stated that they received both general and HIV-related health care from practitioners at the same facility. The Brownstone Building, an outpatient facility of Hartford Hospital where both primary care practitioners and specialists are located was mentioned, as well as the Charter Oak Health Center. Capitol Region Mental Health Center was identified for mental health services.

### **Knowledge of Case Management and other Services**

Participants learned about case management and other services available in the community through their association with:

- The Wellness Center,
- Department of Correction and
- Latino Community Services.

### **Why People Are Unable to Get Services Needed**

Participants were asked why, in their opinion, PWHIV were unable to get the services they needed and gave the following reasons:

- lack of communication,
- not letting people know what services are available,
- language barrier (Spanish),
- stigma - receiving services but denying it so that HIV status is not known,
- lack of transportation,
- not making the attempt to get services,
- giving up/giving up hope, and
- other things in life take priority (i.e.: getting high).

### **How to Contact Out-of-Care PWHIV**

We explained our interest in contacting people who were considered “out-of-care” and asked participants to come up with places or strategies to find these individuals.

Responses included the following:

- street outreach, specifically to shelters, parks, basketball courts, areas in Hartford along the Connecticut River, drug use sites, corner stores, and identified streets in the city (Park Street, Albany Avenue, Homestead Avenue);
- outreach by HIV positive persons;
- office buildings; and
- word of mouth.

The group agreed that there are PWHIV who are not connected to services and, in their opinion, reasons were denial, not wanting their HIV status made public, and fear of rejection or of being treated differently if others knew that they were HIV positive.

### **Focus Group: African American Women**

Three HIV positive African American women, of the 7 initially recruited via street outreach in Hartford, attended the focus group. Ages were 35, 42 and 51 years of age; all 3 identified as heterosexual. All were unemployed. The two younger women claimed a monthly income between \$500.00 and \$999.00, and the 51 year old claimed a monthly income, including food stamps, of \$1100.00. The 2 younger women lived in a group home for PWHIV/PWAIDS and had resided there between 1 and 2 years. The older of the 3 women, who was caring for her toddler son, had lived in her own apartment between 1 and 6 months. The 51 year old had received her GED, while the 35 and 42 years old had completed some high school but did not graduate. All 3 met the criteria for in-care.

### **Local Services**

The following is a list of services that they knew about and/or had accessed at some point in time:

- Peter’s Retreat
- Department of Social Services
- Capitol Region Mental Health Center

- MANA
- Chrysalis Center
- Connections
- Case management
- Transportation
- Mercy Housing
- Catholic Family Services
- Furniture
- Food pantry

Participants filled out the Services Used and Services Needed matrix and then discussed the services they needed but had been unable to get and the barriers they encountered. All 3 women had used medical care for HIV, medical case management, and mental health treatment at least once in the previous 12 months. Two of the women also identified substance abuse treatment, dental care, medication adherence support and the use of drop-in centers. Only one participant identified services that she needed but could not get; those being emergency financial assistance, help finding an apartment and paying the rent, food programs and nutritional counseling. CADAP, help in paying co-pays and medications, home health care, childcare, and translation services were identified by all three participants as services not needed.

### **Services Needed But Unable to Get**

When asked to talk in greater detail about services they needed but were unable to access, the women came up with an additional list of services that included:

- Housing;
- dental care;
- furniture;
- help with finances, including credit counseling;
- an educational retreat to become more knowledgeable about available services and how to access them;
- a liaison to help them and support them to “get on track”;
- food; and
- general case management.

Barriers to accessing services or receiving basic needs included lack of money, a poor credit record, a criminal record, and case managers.

### **Missed Medical Appointments**

The reasons mentioned for missing medical appointments were:

- not feeling well,
- too busy “running the streets”,
- not writing down the appointment information, and
- lack of transportation.

### **General Medical Care and HIV-Related Health Care**

Participants received both general medical care and HIV-related care at Hartford Hospital, including the Brownstone Building, and Charter Oak Health Center. One woman received mental health services at the Institute of Living (also part of Hartford Hospital).

### **Knowledge of Case Management and other Services**

Participants learned about case management and other available services through their association with:

- Peter's Retreat,
- Connections,
- The Chrysalis Center,
- Capitol Region Mental Health Center, and
- Charter Oak Health Center.

### **Why People Are Unable to Get Services Needed**

The following are reasons participants gave when asked why, in their opinion, PWHIV were unable to get the services they needed:

- afraid,
- afraid of rejection,
- not wanting to get involved,
- don't want to know if they are HIV positive,
- feeling like an outcast,
- lack of knowledge, and
- laziness on the part of the individual.

### **How to Contact Out-of-Care PWHIV**

Participants came up with the following places to find "out-of-care" individuals:

- Park Street
- shelters, including Immaculate Conception and South Park Inn, and
- various drug use sites.

The women felt that people might not be "in care" because of a lack of HIV education for those affected as well as infected, and the pain of rejection or alienation if their HIV status was made known.

### **Focus Group: Latina Women**

The focus group consisted of 3 Latina females who are living with HIV, ages 37, 40 and 62, half the number of the 6 women originally recruited. One of the women spoke only Spanish so the session was conducted in both English and Spanish by two bilingual facilitators. All 3 identified as heterosexual. Two were unemployed and one had full time employment. Monthly income from all sources ranged from 0 - \$499.00 to \$1000.00 - \$1999.00. One individual lived with her parents and paid rent, one shared an apartment and one had her own apartment. Length of residence ranged from 1 to 2 years to more than 5 years. The 62 year old had completed primary school or less, the 37 year old had

completed high school/GED, and the 40 year old had graduated from university with a bachelor's degree. All 3 met the criteria for in-care.

### **Local Services**

Many of the services that the participants knew about or had used were those named by participants in the previous focus groups, with a few additions.

- health services at the Brownstone Building,
- Burgdorf Clinic,
- Latino Community Services,
- Institute for Community Research,
- Ryan White services,
- rent payment,
- transportation,
- methadone treatment,
- psychiatric services,
- energy assistance, and
- case management.

They spoke about the difficulty accessing the services mentioned, what had to be done to qualify, when someone could receive those services, who needed to be contacted, the case manager's role, and what services could be obtained from specific agencies (for example: HIV case management and bus passes from Latino Community Services). Data from the Services Used and Services Needed matrix show that all 3 women listed medical care for HIV, medical case management, mental health treatment, and dental care as services used at least once in the past 12 months. Two of the 3 also listed transportation to appointments and food programs. Only one participant listed a service that she needed but was unable to get; and that being help in finding an apartment. Of those services not needed, all 3 listed CADAP, help paying for co-pays and medications, medication adherence support, home health care, and emergency financial assistance.

### **Services Needed But Unable to Get**

When asked to talk further about services they needed but were unable to access, the services that the women felt they needed more were housing, specifically Section 8 and transportation. They expressed their ongoing frustration with not being able to find low income housing and at times having to live in group homes in order to have somewhere to live. They felt that certain factors that contributed to their inability to obtain certain services or meet basic needs were just too difficult to overcome, for example background and credit checks and lack of finances. Age was another factor. In relation to obtaining housing, they spoke of the difficult position of being offered housing for themselves only, but not wanting to leave other family members behind.

### **Missed Medical Appointments**

Lack of transportation was the unanimous response for missing medical appointments.

### **General Medical Care and HIV-Related Health Care**

Participants stated that they received both general medical care and HIV-related care at the Brownstone Building at Hartford Hospital and the Burgdorf Clinic. They felt lucky that both their HIV and medical care were together at the same location because of transportation and their wish to see only one doctor.

### **Knowledge of Case Management and other Services**

The women learned of case management and other services at the group home where they were currently living, and at the agencies where they were seeking services.

### **Why People Are Unable to Get Services Needed**

When asked their opinion as to why people are unable to get needed services the participants agreed that it was a combination of factors. There are many reasons including not knowing about programs or services, and denial of their HIV status.

### **Focus Group: Homeless Individuals**

Three people of the 7 people contacted through street outreach attended the focus group – 1 bisexual African American male age 51, 1 heterosexual African American male age 59, and one 42 year old lesbian African American who was new to the Hartford region. All 3 were unemployed. Two a monthly income of 0 to \$499.00 and 1 had a monthly income of \$500.00 to \$999.00. The 2 males were staying in a shelter and the female was staying free with family or friends, and all 3 had been at their current location between 1 to 6 months. All 3 had completed high school or obtained their GED. All 3 met the criteria for “in care”.

In addition, data from the Services Used/Services Needed matrix show that Medical Care for HIV was the one service used by all 3 participants at least once in the past 12 months. Medical case management, substance abuse and mental health treatment, food programs and drop-in centers were accessed by 2 of the 3 participants. Two participants listed emergency financial assistance and 1 checked help paying rent as services needed but unable to access. Help paying for co-pays and medications, home health care, childcare and translation services were listed by all 3 as services they did not need.

### **Local Services**

Once again, many of the services that the participants knew about or had used in the previous 12 months also had been mentioned by other focus group participants and included:

- Charter Oak Health Center;
- Ryan White case management;
- shelter case management and specific administrative staff;
- Community Health Services, including AMIR and women’s programs;
- financial assistance;
- methadone treatment and other addiction services;



- South Congregational Church;
- clothing, food pantry and other basic needs;
- Connections;
- Community Renewal Team;
- transportation;
- the Brownstone clinics at Hartford Hospital;
- disability;
- legal aid; and
- SAGA.

### **Services Needed But Unable to Get**

While none of the focus group members listed transportation on the matrix as a needed but inaccessible service, further discussion about access to services highlighted the need for transportation, as well as the wish for case managers to accompany clients to appointments and greater one-on-one assistance in linking with available services.

Barriers to obtaining needed services included:

- decreased funding for services;
- insufficient outreach;
- insufficient client participation in programs which, they felt was an important factor in the elimination of certain programs;
- lack of client initiative;
- lack of knowledge of services;
- lack of information sharing - case manager to client and across agencies; and
- not knowing where to go for information about services, especially if one was new to the area.

### **Missed Medical Appointments**

Lack of transportation, a negative relationship with one's doctor and lack of energy were reasons given for missed medical appointments.

### **General Medical Care and HIV-Related Health Care**

Participants obtained both general health and HIV-specific medical care at Community Health Services, Charter Oak Health Center and the Brownstone clinics at Hartford Hospital. One participant also mentioned that he occasionally used the Hartford Hospital Emergency Department for health care.

### **Knowledge of Case Management and other Services**

Shelter staff and a previous case manager and counselor, in the case of the newly arrived female participant, were means of finding out about local case management and other programs and services.

### **How to Contact Out-of-Care PWHIV**

Participants came up with the following strategies for finding "out-of-care" PWHIV:

- go to where people may be, such as shelters, clinics, drug use sites and parks;
- street outreach;
- flyers;

- any means possible to get the information about the needs assessment out to the community.

### **Summary of Focus Group Discussions**

All focus group participants met the “in care” criteria, indicating that each individual had, to a greater or lesser degree, been connected to case management and other services, including medical care, within the previous 12 months. This is an important consideration when reflecting on their responses. While some responses were consistent across focus groups, clearly there are services utilized and unmet needs discussed by the members of each focus group that were group-specific.

The following items listed in the Services Used and Services Needed matrix as having been used at least once in the previous 12 months were identified across all 4 focus groups:

- medical care for HIV,
- medical case management, and
- mental health treatment.

Identified by having been used in the past 12 months by members of 3 of the 4 groups were:

- substance abuse treatment,
- dental care,
- food programs, and
- drop-in centers.

Information about available services, including case management, was frequently acquired through other area programs and agencies.

All 4 groups listed help paying for co-pays and medications and home health care as unneeded services, with participants in the Latino IDU, African American female and Latina female groups listing CADAP as not needed. No complaints were noted regarding inability to obtain or pay for medications and all participants were connected with general and HIV-specific medical care, most often located in the same health care facility, except for mental health treatment for some individuals. Although access to health care was not a logistical issue, a few participants expressed dissatisfaction with the quality of care and the relationship with one’s primary health care provider.

Each focus group came up with a variety of barriers distinct to their individual circumstances. However, both the Latino male IDUs and the African American females mentioned background checks related to a criminal record as a barrier to service provision. Several focus group participants discussed transportation as both a need to be accessed as well as a primary reason for missed medical appointments. As one Latina stated, “Not everyone has a car or a bus pass and it can get expensive if you must go from here to there all day long”.

Two reasons in particular as to why PWHIV were unable, or reluctant to get services were echoed across groups – lack of knowledge about existing services and programs and the stigma that continues to be connected with a diagnosis of HIV.

## **LIMITATIONS**

### **Sampling Issues**

Due to time limits and collaboration complexity, we were not able to implement random strategies in recruiting participants from targeted agencies. Instead, we asked case managers and other service providers to refer as many of their eligible clients as possible to the Needs Assessment Project within the data collection time frame. Each case manager was given a specific number of surveys to administer, based on caseload and agency. Following this protocol was important to obtain a representative sample of the true in-care populations. Furthermore, the smaller size of sub-samples within the larger In-Care dataset make certain analyses more complex and of limited value.

It was not possible to make comparisons across counties as participant recruitment was heavily focused in Hartford County and the city of Hartford. This must also be considered when attempting to make comparisons between the Needs Assessment data and CT DPH HIV/AIDS epidemiologic data.

It was exceedingly difficult to recruit individuals who met the “out-of-care” criteria. Experienced community researchers with many years conducting street outreach implemented a variety of strategies in collaboration with service providers in more than 50 agencies in communities throughout the Greater Hartford TGA to find and recruit participants who were eligible for the out-of-care survey. The Assessment Team spoke with HIV/AIDS researchers and service providers who explained the difficulty of finding PWHIV who were considered out-of-care by the HRWPC definition as related to the speed at which people who test positive for HIV are connected to case management and services they need. This is very different from the case management situation and ability to access services of several years ago. Focus group data also points to the stigma that continues to be connected with a diagnosis of HIV as a reason that people who have been diagnosed do not openly seek services, or are reluctant to divulge that information for fear of alienation and rejection. The goal of 75 to 100 out-of-care surveys was not met, thus limiting the scope of analyses and raising important questions for future research.

### **Data Quality Issues**

Due to the participants’ educational level and their complicated life situations, it is unrealistic to expect participants to complete the Needs Assessment Surveys accurately without assistance, although the survey questionnaires were designed for a 6<sup>th</sup> grade reading level and relatively brief (see Appendix). Case managers and service providers were requested to provide a minimum of explanation prior to the survey, and check for completion and accuracy afterwards, and received initial and follow-up training in survey administration protocol. Given the already extensive requirements of their jobs and caseload, and relative unfamiliarity with survey research and data collection, there was

variation in the quality of data obtained and the capacity to administer the number of surveys requested, resulting in missing values and survey errors. Consideration might be made to the subcontracting of all data collection to trained survey interviewers who would administer the individual surveys, rather than depend upon self-administration by participants with varying degrees of case manager oversight, and thereby decreasing the incidence of errors in data collection. This could be done in collaboration with case managers and staff of local health and social service agencies who might provide interview space compatible with their schedules and assist with recruitment primarily of In-Care individuals.

### **Participant Incentive**

It is important to state that some people who were eligible for the Needs Assessment refused to participate because of the compensation they would receive. They did not like the idea of a Dunkin Donuts gift card. Some who participated later commented that they felt cheated and others expressed their displeasure at this stipend, even though it had been made clear during the consent process that they would receive a \$10.00 Dunkin Donut gift card as incentive for their participation. For some, it was the fact that they preferred a cash reimbursement and for others it was the choice of gift card that was unsatisfactory.

### **Recruitment of Focus Group Participants**

Assessment Team members recruited 6 to 7 prospective participants for each of the four focus groups (Latino male IDUs, African American women, Latina women and homeless persons). However, far fewer kept their appointments than were originally scheduled to attend on a given date and time. This may be related to other more urgent needs taking precedence, including appointments with health care or social service providers or, for some, the issues related to drug use and addiction. For some, it may have simply been a matter of forgetting the appointment or, as noted above, a reimbursement that provided little incentive to dedicate a minimum of 2 hours for which they saw little personal benefit. All participants were identified as in-care, and exhibited a sound knowledge of available services and were relatively well-connected to services, although level of satisfaction varied and they verbalized frustration in navigating the system. Lacking are the responses from out-of-care individuals, which questions the bias of the data and is a limitation that needs to be understood and calls for further research. Although every attempt was made to include out-of-care PLWHIV, as noted above, this was one of the challenges of conducting this Needs Assessment.

## **SUMMARY**

The 2008 Greater Hartford TGA HIV/AIDS Needs Assessment provides a point-in-time overview of the services used, needed but unable to obtain, and the barriers to accessing those needed services among In-Care and Out-of-Care PLWHIV/AIDS, as defined by the Greater Hartford Ryan White Planning Council.

Focus group data reinforce survey data in respect to services used and needed and barriers to accessing those services, contextualizing and personalizing the quantitative data analyses and underscoring the importance of integrating qualitative and quantitative methods. Not surprisingly, medical care for HIV and medical case management were the services most frequently identified by in-care participants as being used in the previous 12 months, followed by dental care, food programs, payment for co-pays and medications, and mental health treatment. Participants in all 4 focus groups also listed medical care for HIV and medical case management, as well as mental health treatment as services used at least once in the previous 12 months. Members in 3 of the 4 focus groups also named substance abuse treatment, dental care and drop-in centers as services used in that time period. Help finding an apartment was one of the 3 services most frequently identified by the In-Care sample as needed but unable to get. Help finding an apartment/housing also was identified in 3 of the focus group discussions as a needed but unable to obtain. Emergency financial assistance, another of the 3 services most frequently identified as needed but unable to get was also mentioned in 2 of the 4 focus group sessions.

Transportation is an important issue identified throughout the Needs Assessment data. Lack of transportation was documented in 3 of the 4 focus group as a service needed but unable to obtain. Lack of transportation was one of the most frequently listed barriers to obtaining emergency financial assistance, help in paying rent and help in finding an apartment. Other frequently noted barriers to obtaining these services include lack of knowledge of service location or availability, being treated unfairly by service providers, inability to pay for the service, fear that others would find out the participant was HIV positive, no openings or being placed on a waiting list, and having a prison record. Several focus group participants also mentioned knowledge of their prison or criminal records as a result of background checks as a barrier to service provision. The stigma of HIV is still prevalent in our communities, as revealed in the frequency that the fear of one's HIV status becoming public knowledge was identified as a barrier to seeking or obtaining services.

Data are over-representative of Hartford County, and the city of Hartford in particular, and it was extremely difficult to find and recruit Out-of-Care PLWHIV/AIDS. Significant outreach was conducted in locations where out-of-care individuals might be expected to be encountered, with virtually no recruitment in these sites. The question of how and where to contact PLWHIV/AIDS who we define as out-of-care was posed to focus group participants. Their responses were strategies already in place by the Needs Assessment staff. In addition, anecdotal evidence points to a more rapid movement from diagnosis to case management and care than in the past, which may account for a decrease in persons defined as out-of-care. Further research that includes in-depth interviews with community advocates and activists, health and social service providers, clergy and outreach workers, for example, is needed to discern as yet untapped sites and community resources where people unconnected to services may be contacted.

Despite the above-mentioned problems with the survey data, and the complexity of some analyses, much can be gleaned from these data. While some analyses are limited

by sample size, additional analyses are possible. It is hoped that the data included in this report will serve to identify the services used, those needed and the barriers to accessing needed services in order to establish priorities and allocation of funds for the delivery of services under the Ryan White Treatment Modernization Act.

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