

2004 Needs Assessment Brief

Cuyahoga Regional HIV Health Services Planning Council

December 2004

Executive Summary of 2004 Needs Assessment

Background

Annual Needs Assessments are studies conducted to canvass the HIV/AIDS client base and determine service gaps in the continuum of care for People Living With HIV/AIDS (PLWHA). 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 groups¹. Severe need groups are demographic/exposure subsets of the community disproportionately impacted by the epidemic. A recent focus of the Annual Needs Assessment process is to survey PLWHA who are "Aware and Not in Care"² and determine their unmet needs. PLWHA failing to access primary medical care over longer than a year time period are deemed 'Out of Care'. Primary Medical Care is technically defined as three forms of service—use of (1) antiretroviral drugs (2) CD4 lab tests and (3) Viral Load lab test.³

The 6-county Cleveland Eligible Metropolitan Area (EMA), represented by the Cuyahoga Regional HIV Services Planning Council, commissioned the 2004 Annual Needs Assessment in August of 2004. Two (2) separate but interrelated processes occurred in the Fall of 2004—Surveys for the 'In Care' and Out of Care populations. The 'In Care' population was further subdivided into In Care, In System (Ryan White HIV Care Delivery System) and In Care, Out of System (private HIV delivery system). 281 total In Care PLWH/A responded to the survey, of whom 204 or 73% were In Care, In System and 27% or 77 In Care, Out of System. The survey instrument for the In Care population asked questions about service needs, barriers to care and gaps in services. Detailed information was collected about housing, medication adherence and referrals to medical care/delay entering care.

Out of Care survey respondents were stratified by those 'Erratically Out of Care' – individuals who had entered primary medical care but were not receiving medical services for over a 12-month period and Never in Care. 264 respondents participated in this survey process, with 196 or 74% Out of Care and 68 or 26% Never in Care. The 'erratically Out of Care' population consisted of three subsets—(1) those newly diagnosed (within 3 months of positive HIV diagnosis) (2) those not in medical care for over 6 months but less than 1 year and (3) the group meeting the HRSA definition of Out of Care (*footnote #2*) – those not accessing primary medical care or lab testing for over a year. These six (6) groups are summarized with respondent totals and percentages.

¹ Six (6) severe need groups: 1) Anglo MSM (Males having Sex with Males) 2) African American MSM 3) IDU (Injection Drug Users) 4) Substance Abusers 5) Women of Childbearing Age (15-44) 6) Youth (13-24)

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.

2 SURVEY POOLS	IN CARE – 281 RESPONDENTS	OUT OF CARE RESPONDENTS – 264
IN CARE (281 OR 52%)	In Care, In System – 204 (73% IC)	Out of Care > 12 mos – 87 (33%)
OUT OF CARE (264 OR 48%)	In Care- Out of System – 77 (27%)	Out of Care > 6 mos – 94 (36%)
TOTAL – 545		Newly diagnosed –15 (6%)
		NEVER in Care 68 (26%)

Out of Care survey respondents were also asked demographic questions with information collected about their reason for being tested, referral to care and rationale for delay into care (if any). Comparable data was collected about risk factors including substance abuse, mental health, unprotected sex, co-morbidities including sexually transmitted infections and housing situation.

Overview

Based on conduct of the 2003 Out of Care survey, the ability to trend line results to 2004 and to further explore key questions resulted in being able to pose certain hypotheses. Among these were:

- 1)** Does the 'In Care' population present with an advanced stage of HIV disease? (Are they 'In Care' because they are sicker?)
- 2)** Does being 'In Care' improve your health status?
- 3)** How crucial is an aggressive referral/linkage to care at the moment you are diagnosed HIV positive?
- 4)** Does self-management of lab values for the 'Out of Care' population result in adequate treatment of the disease or is their marked progression from an initial HIV diagnosis to AIDS?
- 5)** What impact does self-management or erratic compliance with HIV medication regimens have on the disease process? What does it do to create resistance to HIV medications?
- 6)** What factors are most correlated to getting into primary medical care and which are most helpful in keeping PLWH in care?
- 7)** What is the relative scale of risk for PLWH in Cleveland specific to their tendency to not access care or go out of care? What contributing factors including housing, income, geography, age, remote location, diseases other than HIV, substance use have on their risk of being Out of Care? Are there certain severe need groups that are more at risk for being out of care, and therefore pose secondary HIV transmission risk? Who are these groups?
- 8)** Do severe need groups have a common (generic) and an unique Continuum of Care at different points in the HIV service delivery system?
- 9)** What is the profile of an 'In Care' person? Does it differ for In Care, In System (accessing care in the Ryan White HIV or public delivery system) from the In Care, Out of System PLWH (access care in the private HIV delivery system)? How do these HIV delivery systems differ? How are they alike?
- 10)** What is the profile of an 'Out of Care' person? Does this profile differ for newly diagnosed, erratically Out of Care for less than a year (over 6 months), for over a year and for Never in Care? How do we use this information to convince 'Out of Care' PLWH to get into primary medical care? To stay in care once they enter? Do they need extra support to maintain their care regimen?

These questions arose from discussion with the Cuyahoga Regional HIV Services Planning Council at the onset of the 2003 Needs Assessment and are further detailed and trended in the 2004 findings.

HIV Seroprevalence in Cleveland EMA

The 2002 Epidemiologic Profile shows that the 'In Care' respondents mirror the overall epidemiologic profile by racial, ethnic and risk group, with variance for race (slightly higher Anglo representation in the 2004 Needs Assessment.) The 'Out of Care' population is higher in female representation, African American and Hispanic response. MSMs responded but not in proportion to the Epidemiologic Profile. More IDUs responded to the Out of Care survey process. Heterosexuals were consistent with the Epidemiologic Profile for both In and Out of Care.

This VARIANCE may reflect the actual composition of the 'Out of Care' community, or may be an artifact of a confidential yet rigorous recruitment and screening protocol. Further studies will need to determine if this profile of higher African Americans, Hispanics, Injection Drug Users and slightly more females represents the 'Aware and Not in Care' PLWHA community in the 6-County Cleveland EMA. This trend, however, is identical to that of the 2003 Needs Assessment, supported by 2.4 times the total respondent pool (264 vs. 110). Further stratification of the Out of Care population is given by Out of Care and Never in Care. Detail was provided of respondent residence by all groups by zip code level, allowing targeted outreach and capacity building efforts.

Cleveland EMA (6 County)	Group	Sample	Sample	Total In	Total In	TOT	Total
		Frame	Frame	Care	Care	OOO	OOO
		#	%	#	%	#	%
GENDER	Male	2928	79%	220	78%	201	76%
	Female	768	21%	61	22%	63	24%
		3,696	100%	281	100%	264	135%
RACE/ETHNICITY	African American	1938	52%	131	47%	169	64%
	Anglo	1293	35%	116	41%	66	25%
	Hispanic	362	10%	31	11%	29	11%
	Native American	12	0.3%				
	Asian Pacific	11	0.3%				
	Other/ MultiRace	81	3%	3	1%		
		3,697	100%	281	100%	264	100%
RISK GROUP/EXPOSURE MODE	MSM	1975	53%	162	58%	121	46%
	IDU	671	18%	50	18%	66	25%
	MSM/IDU	216	6%	16	6%	21	8%
	Heterosexual	748	20%	52	19%	56	21%
	Blood D/O	38	1%	1	0.4%		
	RIRR	49	1%				
		3,697	100%	281	100%	264	100%

(Source: Ohio Department of Health, HIV/AIDS Reporting System)

A key finding is the high percentage of Elderly (defined by HRSA as over 50 years of age) in both the In Care and Out of Care populations. In 2004, 20 or 7% of the IN CARE group was over 50 years of age compared to 6% in 2003. The OUT OF CARE segment had almost 20% or 52 'elderly' respondents compared to 31% (34) in 2003. This compares to a national percentage of 12.5%.

HIV Status

In Care survey respondents presented with advanced HIV disease as indicated by the percentage of HIV versus AIDS cases. This finding was compatible with the 2003 Epidemiologic Profile, but differed from the 2003 In Care Needs Assessment. The In Care population was significantly different from the Out of Care survey respondents, who were primarily HIV+ in both the 2003 and 2004 surveys.

This variance in disease status from 2003 to 2004 is considered to be an artifact of the methodology. In 2003, focus groups were used to conduct the research, with a self-selected (more well) population believed to have registered. In 2004, a wider net was cast of providers, segments of the PLWH population and a lower socioeconomic group. It is doubtful that the population advanced to a 'sicker' presentation in one year or that any epidemiology has worsened in the prevalent or 'living with HIV' community.

STATUS	# IC, IS	% IC, IS	# IC, OOS	% IC, OOS	TOTAL IC 2004	% TOT IC 2004	TOTAL IC 2003	% IC 2003
HIV	94	46%	41	53%	135	48%	229	74%
AIDS	110	54%	36	47%	146	52%	81	26%
TOTAL	204	100%	77	100%	281	100%	310	100%

IC, IS – In Care, In System (Ryan White or public delivery system) IC, OOS – In Care, Out of System (private delivery system)

STATUS	# E OOC	% E OOC	# NIC	% NIC	TOTAL OOC 2004	% OOC 2004	TOT OOC 2003	OOC % 2003
HIV	149	76%	41	60%	190	72%	69	63%
AIDS	47	24%	27	40%	74	28%	41	37%
TOTAL	196	100%	68	100%	264	100%	110	100%

E OOC : erratically Out of Care NIC – Never in Care

Non-referral was a troubling issue in the 'Out of Care' population. Frequent experience or perception of non-referral for primary medical care upon confirmatory diagnosis occurred due to a variety of factors related to testing circumstance. The rates of perceived non-referral were

Non-referral to Primary Medical Care

	2004		2003	
IN CARE REFERRAL	#	%	#	%
Referred for medical care for HIV	263	94%	288	93%
Not referred for any services	18	6%	22	7%
TOTAL	281	100%	310	100%

OUT OF CARE REFERRAL	#	%	#	%
Referred for medical care for HIV	195	74%	76	69%
Not referred for any services	69	26%	34	31%
TOTAL	264	100%	110	100%

Finding: Reported non-referral rates in 2004 were 6% for In Care and 26% for Out of Care compared to 7% for 'In Care' and 31% for 'Out of Care' in 2003. Higher referral rates to other services were reported by In Care (1.5 times) vs. the Out of Care population (1.2 times). This finding is almost identical to the rates determined in 2003. (1.46 and 1.13)

Reasons offered by the Out of Care respondents as to why they weren't referred for primary medical care included three (3) main factors:

- (1) The source of testing confirming their HIV diagnosis
- (2) Diagnosis by a non-HIV provider (outside the HIV delivery system)
- (3) Diagnosis out of state many years prior to treatment (or failure to seek care)

Reasons were explored with survey respondents stating that they were not referred to medical care upon a positive HIV diagnosis. Testing circumstances were examined to determine how aggressive different channels were directed infected individuals into the HIV delivery system.

<i>REASON NOT REFERRED</i>	IN CARE		OUT OF CARE		Not referred/ Testing Circumstance
	#	%	#	%	Ratio total
Diagnosed outside OH	7	39%	25	36%	17/47 = 36%
Diagnosed at Blood/Plasma Center	16	28%	25	36%	25/59 = 42%
Physical for Substance Abuse	12	21%	6	9%	6/22=27%
Diagnosed outside HIV Delivery System	2	11%	7	10%	7/21=25%
Physical from Military	2	3%	6	9%	6/6=100%
TOTAL	58	100%	69	100%	

The highest volume responses are 'diagnosed outside Ohio' and 'diagnosed at a Plasma Center or Blood Bank.' The ratio of total individuals 'diagnosed' at a Blood Bank or Plasma Center' that was not referred for HIV medical care is 42%. Further inquiry in 2004 about the location of blood or plasma donation resulted in detail of the center—of the 16 In Care and 25 Out of Care donors who claimed non-referral, 13/16 (81%) In Care and 23/25 OOC (92%) donated at the Aventis Plasma Center on West 25th Street. The other 3 IC and 2 OOC were blood donors at the Euclid Red Cross site.

Mention of Health Physicals as the testing circumstance in which HIV was discovered was better explained in 2004. Two primary sources of physical exams occur in this population—mandatory exams while entering substance abuse treatment or while in the military. Armed forces that are residents of, or stationed in, Ohio are referred to Dayton if determined to be positive. This explains the 100% positivity rate for this testing circumstance, all of which were perceived to result in non-referrals to treatment.

Diagnosis outside the HIV delivery system was an issue of concern in 2003, with 7 In Care and 15 Out of Care respondents stating that they were not referred after testing positive in either an indigent clinic (not as AIDS clinic) or a private physician's office. This non-referral figure drastically reduced in 2004 to 2 In Care and 7 Out of Care respondents. All respondents were diagnosed in clinics and perceived the centers as not caring or not interested in aggressively referring them for care. 2 of these 8 individuals reported being given a list of HIV care centers that they were to access on their own. 3 of the 9 stated that their medical condition other than HIV was treated, with no explanation of how to enter care for their HIV disease.

Diagnosis outside the HIV Delivery System:

	2004 # In Care not referred to care	% not referred to care	2003 # In Care not referred to care	% not referred to care
Clinic (not ASO)	2	25%	11	73%
Private Physician	6	75%	4	27%
TOTAL	8	100%	15	100%

Frequent anecdotal stories among both 'In Care' and 'Out of Care' respondents lend credence to the perception that private physicians and clinics feel uncomfortable dealing with HIV disease. The private physicians referenced in 'Diagnosis outside HIV Delivery System' are primarily primary care practitioners and community internal medicine physicians. Their focus is on treating the urgent medical conditions with which these respondents presented for care. This trepidation in dealing with HIV is not a recurrent trend in the private sector, however, in that a significant volume of HIV patients access a care delivery system proficient in dealing with HIV for either quality, confidentiality or other reasons. This care delivery system in the private sector is primarily composed of infectious disease physicians with a specific subset of rheumatology doctors.

In 2004, the In Care, Out of System component was explored to fully account for the volume of patients accessing HIV care. It was determined that among the In Care population in the Cleveland

EMA approximately 760-810 patients access the private delivery system. This figure represents more than a third of the capacity of the RWCA system (In Care, In System). It is composed of 2 significant volume providers.

A consistent 8-10% of patients that qualify for the public HIV delivery system (Ryan White supported) choose to access the private HIV delivery system. Two providers dominate this private delivery system, with Cleveland Clinic and St. Vincent's the majority choice, and a unique stream of patients that qualify for the Veteran's Administration accessing care in that venue. A glimpse of the racial/ethnic mix and payer mix shows the subset that moves between the private and public HIV delivery systems.

PROVIDER	# PATIENTS	% IN CARE, Out Of SYSTEM	# 2004 NEEDS ASSESSMENT	% 2004 NEEDS ASSESSMENT
Cleveland Clinic	480-500 (350 ID, 130-150 Rheum)	64%	40	52%
VAMC	200	25%	28	36%
St. Vincent's	60	8%	5	7%
Private Physicians	20-50	3%	2	3%
Other Hospitals			2	
TOTAL	760-810		77	100%

- **Cleveland Clinic ID:**
 - **350 total clients**
 - **52% Anglo**
 - **39% African American**
 - **5% Hispanic**
 - **4% Other**
 - **24% Public pay source**
 - **24% HMO**
 - **19% Medicare**
 - **13% Managed Care**
 - **8% Self pay**
 - **7% CC employee**
 - **5% Commercial**

Further exploration of the ways in which HIV medical care is offered to the entire patient spectrum (particularly the 8-10% that moves between the private and public HIV delivery system) would benefit the overall Cleveland affected community and might help resolve thorny issues such as unmet need and financing of care.

Delayed entry into primary medical care is an evident issue in dealing with HIV at a population level. Of the In Care, In System respondents, 19% or 39 people delayed entry into primary medical care. Due to this delay, 12 or 31% of the 39 In Care group progressed from an initial HIV diagnosis to AIDS. 32% of Out of Care or 87 people delayed entry, of whom 39 (44%) progressed to AIDS

RATIONALE	#	% OF DELAY INTO CARE	MODE OF TRANSMISSION	AVERAGE DELAY	PROGRESS TO AIDS?	#
DENIAL	12	31%	5 AA MSM 3 Anglo MSM 2 AA Het (1 M, 1 F) 1 IDU 1 TG	1.7 years (without 9 year delay by Anglo MSM, would be 6 month average)	9 year delay (Anglo MSM)	3
INCARCERATED	7	18%	3 AA MSM 2 AA HET Male 1 AA IDU 1 AA Het Female	1.8 years (consistent mode of almost 2 years)	6 year delay (AA MSM)	2
NOT REFERRED (3 Plasma Center, 1 private Doctor)	5	13%	3 AA TG 1 AA Het Male 1 AA MSM	1 year	3 year delay (AA TG, Bi)	2
DXED OUTSIDE OHIO	4	10%	MI, AZ, TN, CA (2 Anglo + 2 AA MSM)	2 years, 9 month avg. (ALL HOMELESS)	5 year delay (Anglo MSM)	1
UNDOCUMENTED	3	7.7%	3 Hispanic MSM	7 month average	2 year delay (HIS MSM)	1
SCARED OF MEDS	3	7.7%	1 Anglo MSM, 1 AA Het IDU, 1 AA MSM	2.6 years	1 Anglo MSM (5 years)	1
USING DRUGS	3	7.7%	1 AA Female IDU, 2 HIS Het Male IDU	3.2 years	1 HIS Het Male IDU (4 years)	2
LEARN MORE	2	5%	1 AA IDU, 1 AA MSM	8 months	NONE	0
TOTAL	39			AVG: 1.8 years		12

The Out of Care survey respondents offered one of their dominant underlying reasons for exiting care as fear of HIV meds. This response 'hardens' with more time spent out of care, as fear of disclosure is the #1 reason offered among those out of care over 6 months and the only response among the newly diagnosed. Substance use and cost issues are stated among the 6 month Out of Care and over 1 year Out of Care groups. The Never in Care, also known as the 'Unconnected' offer a different rationale, with fear of HIV meds listed after Fear of Authority, Organized Systems (including health care) and 'Feel Healthy'. This group also reports extensive substance use, criminal histories and cost issues.

Out of Care survey respondents were asked why they do not access primary medical care. Responses were compared to the newly diagnosed, those not accessing care after 6 and 12 months, and those Never in Care. This detail was not fully explored in 2003.

Why not in care?	#	%
Denial, Shock	81	31%
Fear of HIV meds	65	25%
Feel healthy	55	21%
Worried people will find out	39	15%
Fear/Distrust of authority	32	12%
Using substances	29	11%
Can't afford it	26	10%
Was in prison	10	4%
Transportation	8	3%
TOTAL	264	100%

Why not in care newly diagnosed?	#	%
Worried people will find out	10	67%
Fear of disclosure	5	33%
TOTAL	15	100%

Why not in care over 6 mos?	#	%
Worried people will find out	57	61%
Don't want to take HIV drugs	23	26%
Can't afford	11	13%
TOTAL	94	100%

Why not in care over 1 year?	#	%
Don't want to take HIV drugs	39	45%
Didn't feel sick	30	34%
Using substances	14	16%
Can't afford it	4	5%
TOTAL	87	100%

Why not in care-NEVER?	#	%
Fear of Authority	23	34%
Fear of Doctors	11	16%
Feel healthy	10	15%
Don't want to take HIV drugs	9	13%
Fear of disclosure	5	7%
Using substances	4	6%
Transportation	3	4%
Was in jail	2	3%
Can't afford it	1	1%
TOTAL	68	100%

Medication Adherence is the key to successful treatment of HIV disease (defined as HIV RNA levels below detectable limits). The near perfect adherence needed to achieve optimal results requires exceptionally high adherence to often complicated medication regimens. Without this adherence, issues of resistance to drugs escalate in probability.

Clinical literature indicates that the level of antiretroviral therapy required to achieve undetectable HIV RNA levels (achieved by only 50% of patients) is as high as 95% for an indefinite or permanent time period prior to optimal viral suppression. Detailed questions were asked of the In Care and Erratically Out of Care groups about medication adherence. These queries are contrasted for the 2 In Care populations and compared to those Out of Care who 'ever' took HIV medication. It is apparent that the In Care, Out of System are most compliant, aided by the lowest rate of side effects. A higher correlation of Out of Care occurs for those affected who had multiple medication regimen changes (although their resistance might be due to poor adherence). These individuals missed more medication doses while on meds, with reasons listed for missing doses and frequency of missing doses given.

Take HIV Meds

- 65% of In Care, In System take HIV medications**
- 72% of In Care, Out of System**
- 37% of erratically Out of Care 'ever' took Meds**
- Side Effects
 - 52% of In Care, In System experienced side effects
 - 45% of In Care, Out of System
 - 63% of Erratically Out of Care
- HIV Medication Regimen Change
 - 24% of In Care, In System had their medication regimens changed, average of 6 times
 - 15% of In Care, Out of System, average of 4 times
 - 37% of Erratically Out of Care, average of 8-10 times
- Miss HIV medication dose
 - 29% of In Care, In System missed a HIV medication dose
 - 22% of In Care, Out of System
 - 54% of Erratically Out of Care
- How often miss dose
 - 10% of In Care, In System 'often-over once a month or more often miss than take'
 - 3% of In Care, Out of System
 - 30% of Erratically Out of Care
- Why missed?
 - In Care, In System: too complicated
 - In Care, Out of System: trouble taking at work
 - Erratically Out of Care: too many pills and too many side effects, couldn't remember

Services referenced by '**In Care**' to maintain adherence were:

The top 5 '**In Care**' service needs in 2004 slightly changed from 2003. **Housing moved from a tie for 6th place to 4th.**

1) Medications 2) Lab 3) Primary Medical Care 4) Case Management 5) Transportation with a tie for 5th place with Housing

Similar **barriers were cited for 'In Care'** except the #1-3 slots are now occupied by:

(2004) 1) Housing 2) Transportation 3) Food Bank Reasons cited were funding decreases resulting in deficits in availability of services coupled with worsening economic conditions in the Cleveland region.

(2003) 1) Discrimination or stigma 2) Cost or worry about insurance 3) Desire for convenience or one-stop shopping 4) Perception that case managers play 'favorites' 5) Transportation.

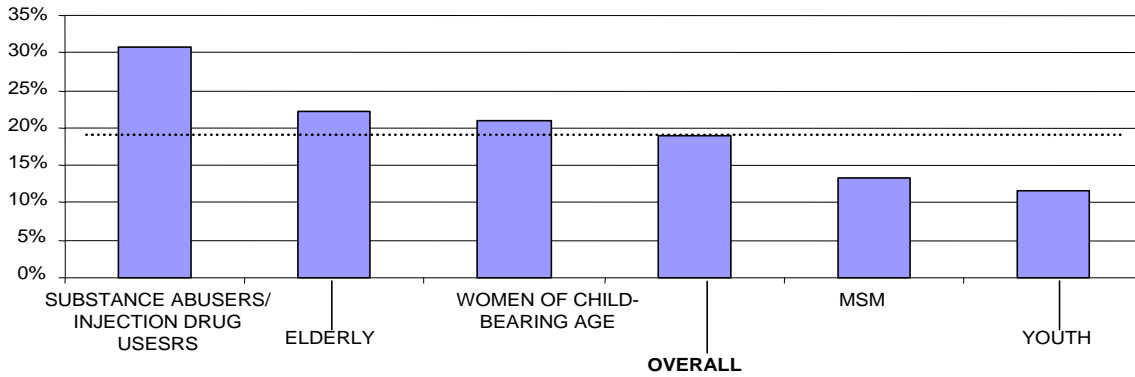
The top 5 '**Out of Care**' **unmet needs** (or services required to enable them to access Primary Medical Care) remained consistent from 2003 to 2004:

1) Housing 2) Case Management tied with Substance Abuse Treatment 3) Mental Health with a tie for 3rd place with Nutritional Counseling 4) Transportation and 5) Transitional Housing.

Hypotheses as to why the Housing situation has deteriorated since 2003 include the worsening economy, perception or reality of funding decreases and a more in-depth, quantitative assessment of the In Care and Out of Care populations. Both populations were assessed with segregation of both In Care and Out of Care into specific components.

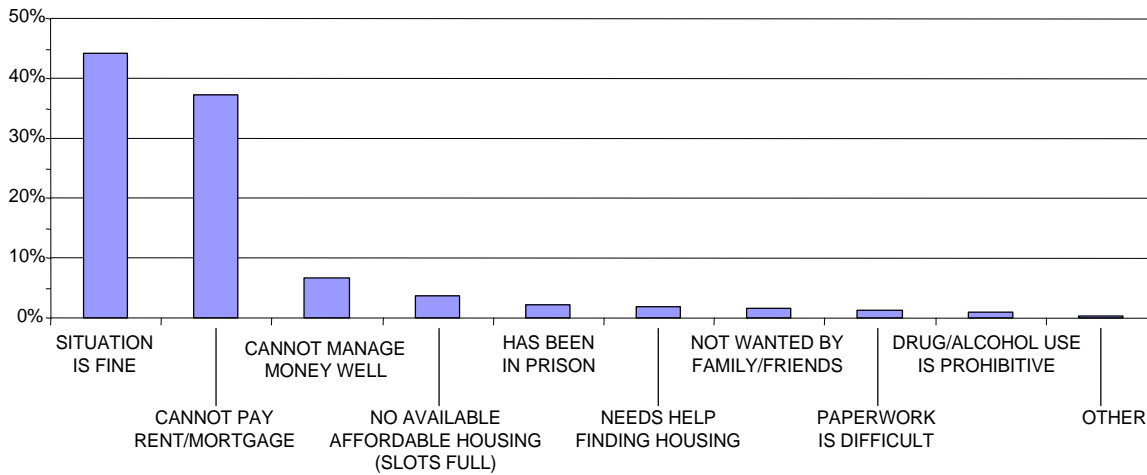
Two new questions were posed in 2004. One contracted the timeframe of homelessness from the past 2 years to the last year. The other asked what specific housing issue was of most concern.

PERCENTAGE OF INDIVIDUALS, HOMELESS SOMETIME IN THE LAST TWELVE MONTHS



Substance Abusers and Injection Drug Users are the most likely to have experienced homeless in the last year (30%). This fact could be related to the high degree of incarceration in both populations (65% reported within last 2 years). Less than 20% (19.7%) indicated an episode of homelessness within the last year.

WHAT IS THE HARDEST THING ABOUT YOUR HOUSING SITUATION?



44% of respondents indicated that they were satisfied with their housing situation. *Of the remaining respondents, the leading complaint (37%) was difficulty paying rent or mortgage.*

Contributing Factors

Contributing factors are those characteristics that were reported as barriers to accessing primary medical care. These ranged from physical or mental health conditions, including other co-morbidities or medical diseases than HIV/AIDS to sexually transmitted diseases and mental health or substance abuse issues. Also, social factors represented potential issues including housing, transportation, or remote living situations such as rural residence or undocumented citizenship status.

The Severe Need Groups studied in detail in 2003 were:

1. Males having Sex with Males (MSM—African American, Anglo & Hispanic)
2. African American (MSM, Heterosexual Males & Females)
3. Hispanic (MSM, Heterosexual Males & Females)
4. Women of Childbearing Age (15-44 years)
5. Injection Drug Users
6. Elderly

Two severe need groups were included in 2004:

7. Youth (13-24 years old) and
8. Transgendered

Sexually Transmitted Diseases were reported as the most prevalent co-morbidity, by 67% of the 2004 Out of Care respondents and 65% of the 2003 Out of Care respondents. Co-morbidities were reported by 73% of In Care in 2003, and all Out of Care respondents (with a 23% rate of multiple co-morbidities among the Out of Care population). This trend repeated in 2004, with 74% of In Care respondents reporting co-morbidities, and all Out of Care survey respondents reporting at least 1 other illness. The multiple rate was slightly lower, at 12% multiple co-morbid ratio.

Further detail was gathered about knowledge of whether the co-morbidity existed prior to the HIV disease, was co-incident or was directly attributable to the HIV disease or drug regimen. This question was posed with full knowledge that self-reported data would be second-hand clinical knowledge or not fully credible. Cardiac conditions, diabetes, liver & kidney problems and neuropathy were most frequently cited as HIV-related diseases or those attributable to side effects of HIV medications.

(2) 7% of In Care and 20% of Out of Care were 'elderly' (over 50) in 2004 compared to 6% of In Care in 2003 and 31% of Out of Care. Among the elderly Out of Care, the rate of homelessness within the past year stayed constant at approximately 50%. In 2003, 26% of the elderly Out of Care or 9 individuals had never been in care. This group was over-sampled in 2004 to determine if this ratio was valid. 27/68 of Never in Care or almost 40% are elderly in the 2004 Never in Care respondent pool. This is the only subset with a higher Never in Care fraction than Out of Care response. Repeated reasons offered are the entrenched belief that HIV medications are more lethal than the disease itself, shock over contracting a disease that the affected did not believe they were at risk for and confusion over the multiple co-morbidities and life situations that this group is dealing with. A similar percentage of 25% in both study years are long-term survivors in the over 50 group (diagnosed before 1986). Approximately 45% in both years are recently diagnosed, however, testing positive within the last 3 years. The remaining 30% offer a host of responses, primarily related to their priority need for stable housing prior to accessing medical care.

(3) Substance Abuse remained at an over 40% level (44% in 2004 and 42% in 2003). Mental Health was close in incidence at 37% in 2004 and 38%. These findings were reported by all severe need groups. Injection drug use was most frequently cited (now and 'ever') by Hispanics at a consistent 33% in both 2004 and 2003.

(4) Dual Diagnosed (Mental Health & Substance Abuse) comprise 16% of total Out of Care respondents. Almost two-thirds of dual diagnosed have severe and multiple mental and emotional health issues confirmed by a specific question about prescribed medication for drugs other than for HIV or a medical co-morbidity.

(5) Self-reported bisexuality continued as another repeat trend from 2003. The rate of bisexuality was 11% for the In Care population with a higher (21%) rate for In Care, In System than the 13% reported by In Care, Out of System respondents. Out of Care continued to out-pace In Care with overall rates of 31% (28% for Out of Care, 34% for Never in Care).

It should be noted that this report of bisexuality was explicit in only a few cases as a confirmed lifestyle choice. The majority of reported bisexuality was in response to detailed questions about whether the respondent had slept with an individual of the same sex compared to their declared sexual orientation as 'heterosexual'.

(6) Another high risk population that received focused attention in 2004 was the transgendered population, considered by many to be a 'bridge group' to HIV transmission due to numerous risk factors including commercial sex work, stigma and black market injection drug use for silicone.

Twelve (12) transgender persons, all male to female, were surveyed, 8 of whom were In Care, and four (4) out of care. All reported multiple reasons that accessing care was compromised, and significant risk factors. Most barriers to care access included stigma at every level (sexual orientation, employment, community, care continuum with specific mention of access to hormone therapy).

All twelve were African American, 100% were male to female transgender in various stages of their sex evolution. Differences were profound in what sexual orientation they choose—approximately 55% declared as lesbian, 30% as gay and the remaining 15% as straight. The distinction between sexual orientation and gender is a critical knowledge element in dealing in a culturally sensitive manner with the transgender population.

Conclusions

The objective of this study was to review service need patterns of the 'In Care' population, and to further refine the baseline of the 'OUT OF CARE' population developed in 2003 for the 6-county Cleveland EMA. Analysis of the demographic, racial/ethnic, gender, age and exposure group occurred for both IN CARE and OUT OF CARE with further stratification of both groups. IN CARE was further subdivided into In Care, In System (RWCA) and In Care, Out of System (private HIV delivery system). OUT OF CARE was detailed by a) newly diagnosed (within 3 months of diagnosis), b) Out of Care over 6 months c) Out of Care over 12 months and d) Never in Care.

Severe Need Group definition (those groups experiencing disproportionate HIV/AIDS to their ratio to the population) occurred for both IN CARE and OUT OF CARE populations. Efforts to determine contributing factors or barriers to accessing primary medical care were derived by severe need group.

Findings of the 2004 Needs Assessment echo results of the 2003 study. The 2004 respondent pool more than doubled the OUT OF CARE contribution with a 1/3 larger overall respondent pool than that in 2003. In addition to further exploring issues discovered in the 2003 Needs Assessment, new populations of interest and more precise topical areas were addressed. Detailed studies of specific findings will help refine strategies, including:

- 1)** Housing as the key support service for accessing medical care
- 2)** Referral/linkage to care, especially for key severe need groups
- 3)** Delay of access to primary medical care, stated rationale for delay and progression to AIDS
- 4)** Crucial role of medication adherence
- 5)** Generic points in the Continuum of Care for Cleveland EMA PLWH with key distinction points by severe need group (e.g. importance of hormone therapy for transgender, substance abuse treatment for IDU and housing for incarcerated/recently released)

Recommendations

- (1)** That an ad hoc group be formed to discuss the entire HIV delivery system in the Cleveland area composed of both the Ryan White medical providers and the private delivery system providers (Cleveland Clinic, St. Vincent's Charity Hospital and the Veteran's Administration).
- (2)** Exploration of referral/linkage especially with Plasma Center
- (3)** Education/social marketing on referral and linkage to care emphasizing crucial role of medical care in lessening or preventing progression of HIV to AIDS
- (4)** Consideration of intense medication and/or treatment adherence programs for erratically Out of Care with possible determination of risk factors by individual entering care or for severe need groups
- (5)** Further exploration of housing options
- (6)** Review of distinctive points in the Continuum of Care by severe need group

Response to Findings

Response to the findings of the 2004 Cleveland EMA Needs Assessment will be development of Action Plans by the Cuyahoga Regional HIV Services Planning Council plans. These plans will aim to bring more PLWHA 'Aware and Not in Care' into primary medical care and maintain their involvement in that treatment.

This study was created for the Cuyahoga Regional HIV Services Planning Council by:

