Cleveland TGA Ryan White Part A

Cuyahoga Regional HIV Health Services Planning Council

'In Care' Needs Assessment of Persons Living with HIV/AIDS in the Cleveland TGA

2008 REPORT OF FINDINGS

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COLLABORATIVE RESEARCH

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2008 "In Care" PLWHA Needs Assessment

Cleveland TGA—Cuyahoga Regional HIV Health Services Planning Council

Executive Summary

The 2008 HIV/AIDS Needs Assessment provides a "snapshot" of the Ryan White 'In Care' community service needs, usage, barriers, and gaps as expressed by consumers of HIV related services. The 2008 'In Care' survey instrument provides information to assist the Cuyahoga Regional Planning Council to establish priorities for future service funding.

Relevance of the Part A Comprehensive "In Care" Needs Assessment

Ohio's newly defined cases of HIV exceed those of AIDS cases by a ratio of almost 4 to1. Prevalent HIV cases are near equal to prevalent AIDS cases for the Cleveland TGA. The targeted minority groups, their sub-populations and the TGA's severe needs groups remain a major focus of study for the planning area. The Planning Council is continuously challenged in identifying the changing needs of the PLWHA community in order to best facilitate access, engagement and retention in care for all those living with HIV/AIDS in the service area.

An additional focus for the Planning Council is the further refinement of prevention strategies aimed at successfully reducing the further spread of HIV within the TGA. To that end, the 2008 Needs Assessment contains a detailed sexual and drug use risk assessment of PLWHA, from which expanded 'prevention with positives' interventions may be implemented, particularly for those populations most disproportionately impacted by the epidemic in the planning area.

Health System Disparities

Race/Ethnic Group

The three racial/ethnic groups experiencing disparities in incidence and prevalence of HIV and AIDS are African Americans, Hispanic/Latinos and Multiracial individuals. The most disproportionate incidence and prevalence are among African Americans who comprise an average of 7.2% of the population in the TGA (highest in Cuyahoga County with 27.4%) yet comprise 55% of newly diagnosed AIDS cases. This equates to a 764% rate over their representation in the population, and a 201% rate for Cuyahoga County. African Americans are half of all people living with AIDS and over half of people living with HIV in the Cleveland TGA.

For Hispanics, their population incidence is 2.6% of the general population in the 6-county TGA (highest in Lorain County with 6.9%, followed by Cuyahoga with 3.4%, then Ashtabula with

2.2%). Hispanics constitute 9% of newly diagnosed AIDS cases (3.5 times their representation in the general population), 11% of people living with AIDS and 9% of people living with HIV.

Age

The only age group with disparities for HIV and AIDS prevalence and AIDS incidence is the 20-44 year old age group. The 45+ age group has disparities only for AIDS prevalence.

Gender

Gender disparity occurs in every county in the TGA for HIV and AIDS prevalence and AIDS incidence for Males. Based upon their disproportionate impact within the TGA, the 'In Care' needs assessment survey process and resulting report highlights the differing needs, uses, gaps and barriers to HIV primary medical care experienced by all PLWHA residing within the Cleveland TGA, and to the extent possible, by the seven severe need groups: Latinos/as; African Americans; Women; MSM; IDU; Youth; and Rural PLWHA.

Overview of 'In Care' Study Findings

The 'In Care' client surveys were scheduled over a two-month period in the winter of 2008, with a total of 210 surveys completed utilizing the on-line "Survey Monkey". Posters announcing the survey opportunity and the survey instruments were widely distributed among all Ryan White funded primary care and case management sites in order to obtain the desired level of participation. Respondents were provided with a $20 Walmart gift card for their participation in the needs assessment survey process.

Demographic Profile of 2008 'In Care' Survey Respondents

Race/Ethnicity

Over 40% of the 'In Care' survey respondents (43%) identify as African American or Black, and almost 15% identify as Hispanic/Latino, reflecting high participation among these severe needs groups. Almost 39% of all 'In Care' respondents reported their race as White, followed by 7 American Indian respondents (3.4%) and 9 Multiracial survey respondents (4.3%).

Survey Representation by Severe Need Group

The 2008 'In Care' Needs Assessment process garnered the participation of strong representation among each of the TGA's Severe Need Groups, as evidenced in the table below.

Table 1. 2008 Survey Respondents by SNG

Severe Need Group	2008 #	2008 %
Hispanics	31	15%
African Americans	89	42%
Youth<25	7	3.3%
MSM	85	40%
Women	67	32%
IDU	12	6%

Rural	34	16%

Risk Groupings

Further detail by race and gender for each risk group evidences excellent representation by the members of the affected communities most heavily impacted in the Planning Area.

Table 2 . Risk Groupings of 'In Care' Survey Participants:		
Answer Options	**Percent**	**Count**
African American MSM	18.5%	36
Anglo American MSM	23.1%	45
Hispanic MSM	2.1%	4
Hispanic Female	7.7%	15
African American Female	12.3%	24
Incarcerated/Recently Released	6.2%	12
Substance Abuser	14.9%	29
Injection Drug User	6.2%	12
Woman of Childbearing Age	14.9%	29
Bisexual	5.6%	11
Transgender	3.1%	6
45+ PLWHA	39.5%	77
	answered	195

Transmission Risk

Forty-five percent (45%) of the "In Care" respondents report acquiring HIV as a result of MSM risk behavior; 33.7% as a result of heterosexual risk behavior; 6.9% as a result of injection drug use; 10.9% as a result of sex with a drug user; 2.5% as a result of behavior in prison; and 4% of all respondents cite sexual assault as the mode of HIV infection. One respondent reports 'transfusion' as their mode of transmission and one respondent cites 'Mother with HIV/AIDS' as their transmission mode. Twenty respondents (10%) report their mode of HIV transmission as "unknown". (Several respondents indicated more than one transmission risk.)

Degrees of Homelessness and Previous Incarceration

A total of 42% of the "In Care" survey respondent group reports a previous period of homelessness, (and 7% report current homelessness) which indicates a very high degree of housing instability within this community. This finding would indicate substantial challenge in successfully facilitating entry and retention in HIV primary care and services for a large segment of the PLWHA population residing in the TGA. Over 14% of the 'In Care' respondents report having been incarcerated over the past 6 months, (*and almost half or 44% of the 'In Care' respondents report previous incarceration*) evidencing another significant risk factor contributing to primary care instability.

History of Diagnosis and/or Treatment for Mental Illness/Substance Abuse Disorders

Fully 36% of the 2008 'In Care' survey respondent group reports previous diagnosis and/or treatment for mental health and/or substance abuse disorders. This level of co-morbidity represents a challenge in successfully assisting PLWHA to enter, engage with and remain in care unless these issues are satisfactorily addressed.

History of High Risk Sexual Practices

Overall, the survey respondents indicate a high level of high risk sexual practices, including 1) 20% reporting the exchange of sex for money, rent, drugs, and/or personal protection; 25% reporting having been a victim of domestic violence; and 28% reporting a history of sexual assault. Twenty nine percent of all 'In Care' respondents reports having unprotected sex since being diagnosed, and 18% report using medication to enhance sexual performance.

Extent of Referral into Care upon Diagnosis and Degree of Entry into Care

The 2008 'In Care' survey respondents report that 83% received direct referrals into HIV primary medical care upon learning their HIV status and 64% report entering care within three months of diagnosis. A substantial minority (17%) delayed entry into care by more than one year. Of those PLWHA who delayed entering care for more than one year following their HIV/AIDS diagnosis, the reasons cited include: "shock about/denial of diagnosis" (48%); "felt well"; "fears of others finding out"; and "scared of starting meds". 'Other' reasons for care delay included: *Ashamed--happened in jail (2); didn't know where to go (3); couldn't afford to (2); on wait list/waiting for papers (3); moved out of state (1); and didn't want to die/people I knew on AZT died/was unsure of treatment back then (3).*

Earlier Care Entry Motivators

Interventions which might have helped this survey respondent group to enter care earlier include more counseling/education about HIV disease upon diagnosis (42%); more information about the health risks related to not getting care (27%); and an HIV peer to help them navigate the system (23%). Respondents offered other motivating factors which may have speeded their entry into care, including: "someone to tell me where to go"; "free medical care"; "not being homeless"; and acute illness.

Overview of Current High Risk Drug Use and Sexual Practices among PLWHA

Substance Use Risk Behaviors

Twenty percent (20%) of the 'In Care' survey respondents affirmed current substance use.
Of the types of substances used, marijuana leads with 63% of the respondents, followed by 52% use of alcohol. Over 17% of survey respondents report using cocaine, and over 4% report crystal methamphetamine abuse.

Twelve percent of all 'In Care' survey respondents admit to ever injecting drugs. The drugs most frequently injected by the 2008 'In Care' survey respondents include Cocaine (48%); Heroin

(36%); Crystal meth (28%); and Speedball (16%). None of the 'In Care' survey respondents admits to current injection drug use.

IDU Risk Practices

The 2008 'In Care' survey respondents report a high level of previous risk when injecting drugs. Thirteen of the 53 survey respondents who answered this question (25%) report previously sharing needles; 70% of those IDU did NOT clean their needles/works before sharing. Of the 30% who did report cleaning their works prior to sharing, 35% correctly used bleach; 13% used alcohol; 26% used water; and 30.4% used nothing.

Level of Current Sexual Activity and Sexual Risk

Seventy percent (70%) of the 'In Care' respondents reports current/recent sexual activity. The majority of male and female respondents report sex with men (71%); 21% report sex with women; and 7% report bisexual sex. Over half of the sexually active survey respondents reports sex with only one partner during the past six months. Another 18% reports having had two to five sexual partners during the same time period; and 5% of all survey respondents reports as many as 6-10 sexual partners over the past six months. Only one PLWHA respondent reports their number of sexual partners in the range of 21 to 50 in the past six months.

A substantial minority of the 'In Care' survey respondents (41%) reports "always" using condoms for *vaginal* sexual intercourse. Another 11% reports condom use "sometimes"; and 8% reports "never" using condoms for vaginal intercourse.

Only 35% of those reporting anal intercourse "always" use a condom; 10% report "sometimes" using a condom for *anal* sex and 6% report "never" using a condom for anal intercourse. Almost half of the 2008 survey respondent group (48.5%) denies engaging in anal intercourse.

Only a small portion of the 'In Care' survey respondent group (17%) reports routine use of condoms for sexual intercourse since learning their HIV ser-status. Almost half of the respondents report "sometimes" using condoms since their HIV diagnosis and over 1/3 of persons answering this question (36%) reports "never" using condoms, even since learning they were HIV positive.

By far, the most frequent reason offered for their lack of protected sex is "It Feels good", reported by 53% of all respondents. ***A substantial minority (34%) report that their "partner won't let them use protection", a finding of serious concern, representing a significant barrier for successful prevention efforts among high risk communities.*** *Another 15% report a lack of personal risk ("don't feel I'm at risk)* and 12% report lack of time to use protection.

Almost 19% of all the 'In Care' survey respondents report currently engaging in sexual intercourse with 'casual' partners. And, almost 11% (or 22) of the 2008 'In Care' survey respondents affirmatively reports going on-line to locate anonymous sex partners.

Over one-third of all "In Care' survey respondents (35%) thought they were **NOT** at risk for HIV disease prior to their diagnosis. The reasons offered to explain the lack of personal risk

awareness include belief that they were engaged in a monogamous relationship with the "Same partner" (72%); followed by "Age" (22%); and 'Other' responses which included "Married" and/or "Straight.

Twenty one percent (21%) of all 'In Care' respondents report affirmatively their "have to have" need for sexual activity. The reasons offered to explain the high need for sex include: "Age" (34%); "Being single" (32%); "Only way to connect (18%); and 11% report the need to have sex as a means of "exchanging money, drugs or personal protection". 'Other' reasons offered by 18% of the respondents to explain the need for sex include: "urge", "being married", "love it!", "addicted to sex", or "duty as a wife".

Overview of 2008 'In Care' Need, Use, Barrier Rankings

The top ranking Needs reported by the 2008 'In Care' survey respondents include a strong emphasis on core medical services (#1 Primary Medical Care, #2 Medications, #3 Medical Case management and #5 Oral Health services) along with a high ranking need for Housing services (ranked as the #4 greatest Need).

Two of the top ranking Needs are also identified as the # 1 and #2 top ranking Barriers (Housing services and Oral Health services, respectively.

Table 3. 2008 'In Care' NEED, USE, & BARRIER MATRIX

Service Category	Need Rank	Use Rank	Barrier Rank	Barrier Reasons
Primary Medical Care	**1**	**1**	**7**	No reason offered
Medications	**2**	**2**	**5**	Had trouble qualifying for awhile
Medical Case Management	**3**	**3**	**13**	Case management and non medical case management - don't know stuff
Housing services	**4**	**7**	**1**	Housing - not worth time to not get help, long waits, no info, then turned down; hard to understand how to get long term housing one to tell me what my status is - went to ATF no help; can't find house we can afford -only help is $ for heat or temporary housing; lack of info; long waits; don't know where to go; too much red tape; not much available, takes too long, confusing; finally got it after 3 years; not worth time to not get help, long waits, no info, then turned down; hard to understand how to get long term housing; tried - no luck - too young - not poor enough.
Oral health care	**5**	**4**	**2**	Dental care-need transportation; no insurance and dentist retired; no one available to take me
Health Insurance	**6**	**6**	**7**	Lack of knowledge to qualify people; red tape

Specialty Medical Care	**7**	**5**	**7**	Specialty med care-need insurance
Medical Transportation	**8**	**9**	**6**	Transportation - didn't know where to go and embarrassed
Medicaid Assistance	**9**	**12**	**3**	Lost Medicaid once, had a lot of trouble getting it back, still don't know why I lost it; haven't met anyone who knows what to do; and when they sent me, they didn't know don't get why my MA was, then not, then back, tried to fix, no one to help me; help - denied 2 times, then got, then lost, don't know why! lost MA once, had a lot of trouble getting it back, still don't know why I lost it; need someone to help - MA lapse; Medicaid pending
Mental Health Counseling	**10**	**13**	**11**	Mental health counseling - not much for people my age (young); slipped disk, in pain;
Non-Medical Case Management	**11**	**8**	**12**	Case management and non medical case management - don't know stuff
Nutrition (health)	**12**	**10**	**4**	Food not as good or reliable as was; food stamps are not enough to last a whole month to have healthy foods. I don't eat junk food and fresh fruit and veggies cost too much.
Substance Abuse Treatment	**13**	**15**	**14**	No reason offered
Nutrition (afford)	**14**	**11**	**7**	Food not as good or reliable as was; food stamps are not enough to last a whole month to have healthy foods. I don't eat junk food and fresh fruit and veggies cost too much.
Nutrition counseling-Dietician	**15**	**14**	**14**	No reason offered

Chapter 1: Introduction

Annual Needs Assessments are "snapshot" studies in time conducted to determine the priority service needs, barriers, and 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 accessibility, acceptability quality of services delivered, especially to the designated 'Severe Need Groups/Special Populations'. The Cuyahoga Regional HIV Services Planning Council commissioned Collaborative Research, Inc to perform a comprehensive assessment of the service needs, gaps and barriers of "In Care" [1] PLWHA within the Cleveland TGA, which was conducted in the winter of 2008. This assessment of need included an "In Care" on-line survey questionnaire of PLWHA receiving Ryan White funded services utilizing 'Survey Monkey.

The Cleveland TGA, while composed of six (6) counties (including Ashtabula, Cuyahoga, Geauga, Lake, Lorain and Medina), has three (3) distinct geographic regions with differing epidemiologic features. The Central region, composed of Cuyahoga and Median counties, represents the highest concentration of PLWHA within the six county planning area, and is composed of African Americans with smaller Hispanic and White subpopulations, with recent increases in heterosexual transmission of HIV disease.

The Eastern region is comprised of Ashtabula, Lake and Lorain counties, with a profile similar to the initial onset of the epidemic of Anglo Men who have sex with Men (MSM). Increasingly, communities of color (Hispanics-- primarily of Mexican descent and African Americans) are present in the Eastern region.

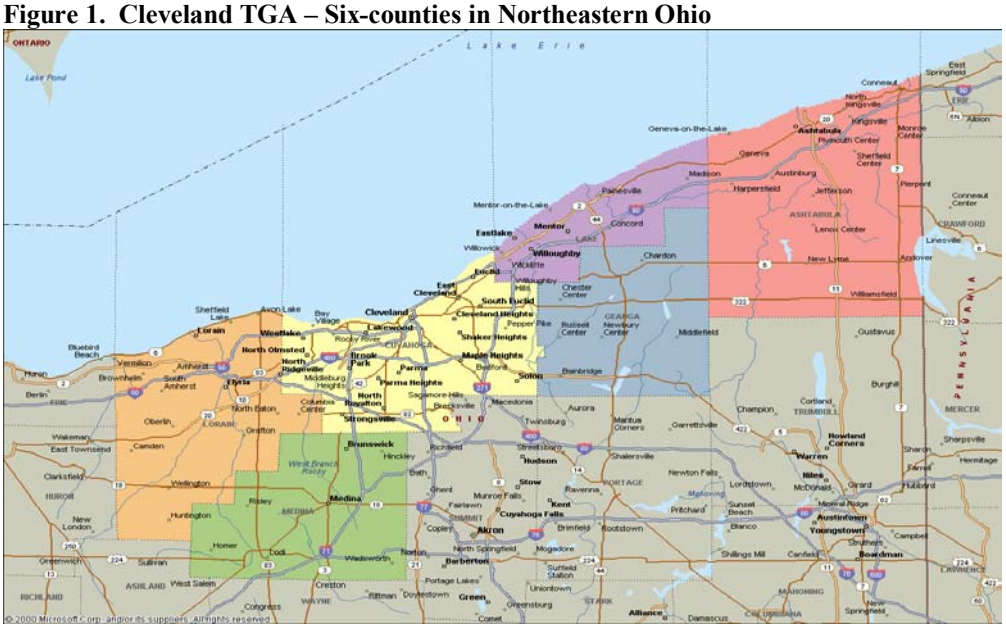
The Western region (composed of a single county-- Lorain County) comprises a large concentration of Injection Drug Users, primarily Latino/Latina of Puerto Rican descent. Heterosexual transmission is emerging in this region, as is migration of IDU exposure to the Anglo population.

Regarding racial/ethnic group for People Living with HIV, the highest region for Anglos is the Eastern region; for Hispanics, the Western region; and for African Americans, the Central Region. By gender, the only region displaying differences is the Western region with a high of 34% female PLWHA, compared to an average of 25% for the Central and Eastern regions. By age group, only the Western region has adolescent PLWH although for PLWH it is the 'oldest' region (this is not true for PLWA). By exposure, the mode of transmission is IDU for the Western region, then heterosexual versus MSM for the Central and Eastern regions.

(See Figure 1 on the following page)

[1] 1) **CD4 – CD4 (T4) or CD4 + CELL COUNT and PERCENT**.
2) **VIRAL LOAD TEST** - Test that measures the quantity of HIV RNA in the blood.
3) **ANTIRETROVIRAL DRUGS** - Substances used to interfere with replication or inhibit the multiplication of retroviruses such as HIV.

Figure 1. Cleveland TGA – Six-counties in Northeastern Ohio



Cleveland TGA HIGHLIGHTS FROM 2005 EPIDEMIOLOGIC DATA

❶ The total of new AIDS diagnoses increased 8% from 155 to 169 from 2004 to 2005. This figure has risen, however, by 7.6% in the five year period**.**

❷ While Cuyahoga county continues to experience the highest overall numbers and the highest AIDS case rate (rate per population); significant spikes have been experienced in the rest of the TGA (Lake, Lorain-2004, Ashtabula (2003).

❸ The Cleveland TGA represents 27.2% of new AIDS cases over the five years from 2001-2005 and 21.3% of HIV cases in 2004.

❹ Cuyahoga County has 22% of all PLWHA in Ohio, the highest PLWHA case rate (220.9 individuals per 100,000 population, with ¼ (25%) of all PLWHA in Title II Consortia.)

Table 4. HIV/AIDS Newly Diagnosed Cases, People Living With HIV/AIDS Cleveland TGA

Cleveland TGA	NEW AIDS CASES		PEOPLE LIVING WITH AIDS		PEOPLE LIVING WITH HIV	
as of Dec 31, 2005	#	%	#	%	#	%
Total	**155**	**100%**	**2,205**	**100%**	**1,870**	**100%**
Sex						
Male	118	76%	1,779	81%	1,446	77%
Female	37	24%	426	19%	424	23%
Race/Ethnicity						
Black	91	59%	1,143	52%	1,051	56%
White	45	29%	827	38%	630	34%
Hispanic	18	12%	220	10%	175	9%
Asian/Pac. Island			6		9	<1%
Native American			4		4	<1%
Other/Unknown	1	1%	5		1	<1%

Age group (years)										
< 13					12	1%			19	1%
13-14					1	<1%			1	<1%
15-24	7	5%			38	2%			94	5%
25-34	47	30%			226	10%			358	19%
35-44	61	39%			877	40%			730	39%
45-54	32	21%			771	35%			489	26%
55-64	5	3%			226	10%			150	8%
65+	3	2%			54	2%			29	2%
County of Residence										
Ashtabula	2	1%			34	2%			18	1%
Cuyahoga	133	86%			1,860	84%			1,489	80%
Geauga					17	1%			6	<1%
Lake	4	3%			58	3%			36	2%
Lorain	16	10%			221	10%			309	17%
Medina					15	1%			12	1%
Transmission Risk										
MSM (gay males)	64	41%			1,090	49%			643	34%
IDU history	11	7%			279	13%			187	10%
MSM/IDU	5	3%			130	6%			59	3%
Heterosexual	17	11%			271	12%			194	10%
Perinatal					19	1%			23	1%
Other/Unknown	58	37%			416	19%			764	41%

Table 5. NEWLY DIAGNOSED AIDS BY COUNTY (AIDS CASES) FROM 2001 – 2005 IN CLEVELAND TGA

COUNTY	2001	2002	2003	2OO4	2005	TOTAL
Ashtabula	3	2	7	2	2	16
Cuyahoga	129	139	159	134	133	694
Geauga	1	1	4	0	0	6
Lake	5	5	4	10	4	28
Lorain	5	9	8	20	16	58
Medina	1			3		4
Cleveland TGA	**144**	**156**	**182**	**169**	**155**	**806**
Ohio	**531**	**553**	**717**	**600**	**562**	**2,963**
% OH	**27.1%**	**28.2%**	**25.4%**	**28.2%**	**27.6%**	**27.2%**

(Source: Ohio Department of Health, Reported Cases of AIDS by year of diagnosis)

Epidemiologic Trends in the Cleveland TGA

1. Race/Ethnic Group

The most disproportionately impacted race compared to their proportion in the general population is the African Americans. They consistently comprise 55% or higher of newly diagnosed cases and 50% of People Living with AIDS and People Living with HIV. The 50% or higher figure compares to a 7.2% representation in the overall population of the TGA, with 27% in Cuyahoga County. Sixty percent (60%) of all newly diagnosed AIDS cases occur in the Central region, dominated by Cuyahoga County. Hispanics are the next most disproportionate share group, representing 9% of all newly diagnosed AIDS cases. The Western region accounts for 10% of these cases, closely followed by the Central region with 9%.

2. Gender

A total of 74% of newly diagnosed AIDS cases are Male and 26% Female. This figure is rising for newly diagnosed HIV cases, but not for AIDS cases. This may represent an earlier stage diagnosis for females, or a worsening trend for MSM in the Cleveland TGA. The region with the most newly diagnosed AIDS cases for females is the Central region. The region with the most newly diagnosed HIV cases for females is the Western region.

3. Age group - 'Aged' PLWH/A

The proportion of 'aging PLWHA' evidences the 7th highest increases among all Part A TGAs and is most dominant in African Americans, then Anglos, with the highest transmission risks among Heterosexuals then MSM. Unlike the HIV and AIDS prevalence figures, the Western region does not display any adolescent cases for newly diagnosed AIDS. The Western region is also the 'oldest' region to present with 43% of newly diagnosed cases that are 'aged' (45 years+). This is a newer development, as it contrasts with the HIV and AIDS prevalence figures that show the Eastern region to be the most 'aged'.

Infection among Adolescents is on the rise, especially among Males (with only 20% Females) in the Western region, with risk exposure predominately IDU, then MSM.

4. Exposure – MSM resurgence

The future projection of HIV/AIDS cases based on newly diagnosed AIDS cases shows that some trends continue—the highest proportion of MSM is in the Eastern region as displayed in the PLWH and PLWA tables and the highest proportion of IDU remains in the Western region. All racial/ethnic groups are impacted, with highest rates among African Americans, ages 20-45 years, especially among new cases. Cases of IDU are most dominant in the Western region, followed by the Central region, and occur in the 13-19, 20-45 and 45+ age groups. Transmission of HIV through Bisexual risk behavior is most prominent in the Central region, among persons ages 13-19, 20-45, and 45+. While evident throughout all races, Bisexual risk behavior is most dominant in the African American and Hispanic communities.

EPIDEMIOLOGIC TRENDS FOR CLEVELAND TGA, 2003-2005

Table 6a. Gender Trends:

		2005			2004			2003	
GENDER	Newly Diagnosed AIDS	PLWA	PLWH	Newly Diagnosed AIDS	PLWA	PLWH	Newly Diagnosed AIDS	PLWA	PLWH
Male	74%	81%	77%	74%	80%	72%	72%	80%	77%
Female	26%	19%	23%	26%	20%	28%	28%	20%	23%
TOTAL	**100**	**100**	**100**	**100**	**100**	**100**	**100**	**100**	**100**

Table 6b. Race/Ethnic Group Trends:

		2005			2004			2003	
RACE/ ETHNIC GROUP	Newly Diagnosed AIDS	PLWA	PLWH	Newly Diagnosd AIDS	PLWA	PLWH	Newly Diagnosed AIDS	PLWA	PLWH
White	32%	38%	34%	34%	37%	32%	34%	38%	32%
Black	57%	52%	56%	57%	52%	55%	59%	58%	54%
Hispanic	11%	10%	9%	9%	10%	9%	7%	10%	9%
Asian	.31%	.27%	.48%	0.2%	0.3%	0.5%		0.3%	0.3%
Amer. Indian	-	.18%	.21%		0.3%	0.2%		0.3%	0.3%
Multiracial	.62%	.23%	.05%	0.2%	0.4%	0.03 %			0.1%
TOTAL	**100**	**100**	**100**	**100**	**100**	**100**	**100**	**100**	**100**

Table 6c. Trends in Exposure/Transmission Category:

		2005			2004			2003	
EXPOSURE MODE	Newly Diagnosed AIDS	PLWA	PLWH	Newly Diagnosed AIDS	PLWA	PLWH	Newly Diagnosed AIDS	PLWA	PLWH
MSM	43%	49%	35%	54%	56%	52%	50%	55%	50%
IDU	6%	13%	10%	16%	17%	15%	18%	18%	17%
MSM/IDU	4%	6%	3%	6%	7%	4%	5%	7%	5%
Heterosexual	10%	12%	10%	23%	19%	28%	25%	18%	26%
RNR/Other	36%	19%	41%	1%			2%	2%	
TOTAL	**100**	**100**	**100**	**100**	**100**	**100**	**100**	**100**	**100**

(Source: CDC Epidemiologic Tables for Part A Ryan White EMAs/TGAs)

Relevance of the Part A Comprehensive "In Care" Needs Assessment

Ohio's newly defined cases of HIV exceed those of AIDS cases by a ratio of almost 4 to1. Prevalent HIV cases are near equal to prevalent AIDS cases for the Cleveland TGA. The targeted minority groups, their sub-populations and the TGA's severe needs groups remain a major focus of study for the planning area. The Planning Council is continuously challenged in identifying the changing needs of the PLWHA community in order to best facilitate access, engagement and retention in care for all those living with HIV/AIDS in the service area. An additional focus for

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Health System Disparities

Race/Ethnic Group

The three racial/ethnic groups experiencing disparities in incidence and prevalence of HIV and AIDS are African Americans, Hispanic/Latinos and Multiracial.

The most disproportionate incidence and prevalence is among African Americans who comprise an average of 7.2% of the population in the TGA (highest in Cuyahoga County with 27.4%) yet have 55% of newly diagnosed AIDS cases. This equates to a 764% rate over their representation in the population, and a 201% rate for Cuyahoga County. African Americans are half of all people living with AIDS and over half of people living with HIV in the Cleveland TGA.

For Hispanics, their population incidence is 2.6% of the general population in the 6-county TGA (highest in Lorain County with 6.9%, followed by Cuyahoga with 3.4%, then Ashtabula with 2.2%). Hispanics constitute 9% of newly diagnosed AIDS cases (3.5 times their representation in the general population), 11% of people living with AIDS and 9% of people living with HIV.

Age

The only age group with disparities for HIV and AIDS prevalence and AIDS incidence is the 20-44 year old age group. The 45+ age group has disparities only for AIDS prevalence. (PLWA)

Gender

Gender disparity occurs in every county in the TGA for HIV and AIDS prevalence and AIDS incidence for males. Based upon their disproportionate impact within the TGA, the 'In Care' needs assessment survey process and resulting report highlights the differing needs, uses, gaps and barriers to HIV primary medical care experienced by all PLWHA residing within the Cleveland TGA, and to the extent possible, by the seven severe need groups: Latinos/as; African Americans; Women; MSM; IDU; Youth; and Rural PLWHA.

The 2008 'In Care' survey respondent profile is depicted in the diagram below, evidencing strong representation from each of the TGA's targeted Severe Need Groups.

Severe Need Group	2008 #	2008 %
Hispanics	31	15%
African Americans	89	42%
Youth<25	7	3.3%
MSM	85	40%
Women	67	32%
IDU	12	6%
Rural	34	16%

Chapter 2: "In Care" Survey Findings[2]

The 2008 HIV/AIDS Needs Assessment provides a "snapshot" of the 'In Care' community service needs, usage, barriers, and gaps as expressed by consumers of HIV related services. The 2008 'In Care' survey instrument provides information to assist the Cuyahoga Regional Planning Council to establish priorities for future service funding, including:

1) A sample that facilitates valid and reliable statistical conclusions on service needs of people with HIV/AIDS related to the epidemiological profile for the TGA

2) Information that will assist the Planning Council to address the question of which Ryan White eligible services are needed most by persons living with HIV/AIDS, in order to keep them healthy and maintain independence

3) Identifies TGA's gaps in services for 'In Care' persons living with HIV/AIDS

4) Identifies TGA's barriers to accessing specific services by 'In Care' PLWHA so that the Planning Council could determine how to enhance the current service delivery system.

5) Identifies extensive sexual and risk behavioral information which provides a solid foundation for primary and secondary prevention efforts among 'In Care' PLWHA

Target Sample Set

The goal of the 'In Care' survey process was to achieve a 95% confidence interval for the level of participation by the 'In Care/In System' clients, hereafter referred to as 'In Care' population (N=150-200). The actual 'In Care' participation rate was 210 survey respondents. Survey Monkey was utilized as the primary vehicle for the on-line needs assessment survey process. This level of participation provides a sound representative sample for comparison to previous needs assessment findings and for future assessments of need among PLWHA in the Cleveland TGA. Participation in the 2008 needs assessment survey process among the targeted TGA special populations and severe needs groups is evidenced in the tables below and on the following page. (Several survey respondents report identification with more than one risk group.)

Table 7. 2008 'In Care' Survey Respondent Representation by SNG

Severe Need Group	2008 #	2008 %
Hispanics	31	15%
African Americans	89	42%
Youth<25	7	3.3%
MSM	85	40%
Women	67	32%
IDU	12	6%
Rural	34	16%

[2] In Care – defined by HRSA as receiving one or more of the following services 1) Viral Load test 2) CD4 Cell Count and/or 3) Antiretroviral drugs within the past 12 months

Table 8. Risk Groupings of 'In Care' Survey Participants:		
Answer Options	Response Percent	Response Count
African American MSM	18.5%	36
Anglo American MSM	23.1%	45
Hispanic MSM	2.1%	4
Hispanic Female	7.7%	15
African American Female	12.3%	24
Incarcerated/Recently Released	6.2%	12
Substance Abuser	14.9%	29
Injection Drug User	6.2%	12
Woman of Childbearing Age	14.9%	29
Bisexual	5.6%	11
Transgender	3.1%	6
45+ PLWHA	39.5%	77
	answered	195

Overview of the "In Care" Survey Results

The 'In Care' client surveys were scheduled over a two-month period in the winter of 2008, with a total of 210 surveys completed utilizing the on-line "Survey Monkey". Posters announcing the survey opportunity and the survey instruments were widely distributed among all Ryan White funded primary care and case management sites, including Metro Health Medical Center, the Free Clinic, Cleveland Clinic, University Hospitals, Lake County General Hospital, Care Alliance and Projecto luz, in order to obtain the desired level of participation. Respondents were provided with a $20 Walmart gift card for their participation in the needs assessment survey process.

When the 'In Care' respondents were asked how or where they had learned about the survey opportunity, the following answers were supplied:

Table 9. How did you hear about this project?		
Answer Options	Response Percent	Response Count
Friend	31.0%	61
Provider - whom?	67.5%	133
Poster - where?	2.5%	5
Ad - where?	1.5%	3
	Whom? Where?	138
	answered	202

When asked whether any of the current 'In Care' survey participants had previously participated in a survey process, 35% reported that they had done so: 22% within the past year and 52% over one year ago. Thirty one percent (31%) of the previously surveyed reported completing one previous survey process; 28% reported previously completing two to three surveys; and 19% reported completing more than three surveys previously.

The 'In Care' survey respondents were queried regarding their familiarity with and use of Ryan White Part A Program services in the following survey items (See tables 10 and 11 below). Only 6% reported unfamiliarity with the "Ryan White Part A Program" (and 5% reported not knowing whether they were familiar with the Part A program). Sixty five percent of the 'In Care' respondents answered in the affirmative to access and use of Part A services, while 15% reported they had not; and 20% of all survey respondents reported not knowing whether the services they had accessed were Ryan White Part A services.

Table 10. Are you familiar with the Ryan White Title I/Part A Program?

Answer Options	Percent	Count
Yes	88.5%	184
No	6.3%	13
Don't know	5.3%	11
	answered	208

Table 11. Have you ever used Title I/Part A Services?

Answer Options	Percent	Count
Yes	64.6%	133
No	15.0%	31
Don't know	20.4%	42
	If yes, which services?	94
	answered	210

The 'In Care' survey respondents listed the different Part A services they currently use or previously accessed, including: Primary Medical Care, Medications, Case Management, Dental Care, Mental Health services, Substance abuse counseling services, Transportation assistance, and Housing and utility assistance.

The 'In Care' respondents were also queried regarding their familiarity with the "Ryan White Part B Program". Almost 19% of all 'In Care' respondents reported unfamiliarity with the Part B Program (compared with the 6% who were not familiar with the Part A Program) and only 45% acknowledged use of Part B services, accessing ADAP, Food, Transportation, Housing and utility assistance, Medications, Emergency financial assistance and Case management services.

Table 12. Are you familiar with the Ryan White Title II/Part B Program?

Answer Options	Percent	Count
Yes	68.3%	140
No	18.5%	38
Don't know	13.2%	27
	answered	205

Table 13. Have you ever used Title II/Part B Assistance?

Answer Options	Percent	Count
Yes	44.9%	89
No	22.7%	45
Don't know	32.3%	64
	If yes, which services?	60
	answered	198

Regarding the extent of recognition of the TGA's care "logo", only 39% of the 'In Care' respondents reported they had seen it before, in doctors' offices, RTA bus, hospitals and STD clinics, case management offices, Gay People's Chronicle, Call and Post and Lorain Journal.

Finally, when queried as to whether they had a copy of the current HIV services guide, only 28% reported that they did, in fact, possess a copy.

Demographic Profile of 'In Care' Respondents

Below is an overview discussion of the age, gender, race/ethnicity, and sexual orientation of the 'In Care' survey population.

Age

The greatest proportion of the 'In Care' survey participants (45%) report their dates of birth in the 40-49 age range. A substantial minority--(20%)--report their ages in the 30-39 age range, with an additional 19% reporting their age in the 50-59 age range, with an additional 8% reporting an age between 60-69 years, representing an aging group of PLWHA, overall. More than 8% percent of respondents report their ages between 20 and 29 years of age, and 3.3% report their age as 24 years or less.

Gender

Over two-thirds of the 2008 'In Care' survey respondents were Male (66 %%), almost 33% were Female, and three respondents (or 1.5%) identified as Transgender.

Race/Ethnicity

Over 40% of the 'In Care' survey respondents (43%) identify as African American or Black, and almost 15% identify as Hispanic/Latino, reflecting high participation among these severe need groups. Almost 39% of all 'In Care' respondents reported their race as White, followed by 7 American Indian respondents (3.4%) and 9 Multiracial survey respondents (4.3%). No explanations were given to describe the 'Other' responses. (Several respondents indicated more than one race.)

Table 14. Race/Ethnicity:

Answer Options	Percent	Count
African American	42.8%	89
Caucasian	38.9%	81
Hispanic/Latino	14.9%	31
American Indian	3.4%	7
Asian/Pacific Islander	0.0%	0
Multi-racial	4.3%	9
Other:	1.4%	3
RTA	0.5%	1
	answered	209

Sexual Orientation

As evidenced by the table below, the greatest proportion of survey respondents identify as heterosexual (51%), reflective of the minority populations impacted by HIV in the TGA. Almost 38% identify as 'gay' and a substantial minority identify as bisexual (10.1%). Eight respondents (or 3.9%) reported 'other'.

Table 15. What is your sexual orientation?		
Options	**Response Percent**	**Response Count**
Gay	37.9%	75
Lesbian	1.0%	2
Bisexual	10.1%	20
Heterosexual	51.0%	101
	Other:	8
	answered	206

**Other: "originally gay, got religion, now straight"; remaining 7 responses N/A—(item checked, but no response)*

Table 16. Have you had sex with men, women, or both?		
Answer Options	**Response Percent**	**Response Count**
Men	70.7%	140
Women	21.2%	42
Both	7.1%	14
RTA	1.5%	3
	answered	199

Zip Code and County of Residence

Almost two-thirds (130 or 62%) of the 'In Care' survey respondents reported their current residence in one of the following 13 zip codes, in rank order from greatest to least: 44102 (25); 44107 (15); 44004 (14); 44052 (12); 44055 (9); 44104 (8); 44108 (8); 44106 (7); 44030 (6); 44077 (6); 44111 (6); 44118 (6); and 44120 (6). The remainder reported a wide variation in zip code of residence. The survey respondents' county of residence is identified in the table below, evidencing 61% reporting Cuyahoga as their county of residence.

Table 17. What county do you live in?		
Answer Options	**Response Percent**	**Response Count**
Ashtabula	14.1%	28
Cuyahoga	60.6%	120
Geauga	3.0%	6
Lake	7.1%	14
Lorain	15.2%	30
Medina	0.0%	0
	***Other: 9 Summit; 1 Huron**	10
	answered	208

Annual Income and Benefits

The 2008 'In Care' survey respondents represent a highly impoverished group overall, with over 80% of all survey respondents reporting annual incomes equal to or less than 200% of the federal poverty level. Almost half (49%) report incomes between $0 and $9,999; followed by an additional 33 % of respondents who report incomes between $10-$19,999 per year, and 12% who report incomes between $20-29,999. Only 13 respondents reported an annual income over $30,000. Seventy-three percent (73%) of respondents report the receipt of either SSI or SSDI disability benefits, and over 40% receive food stamp assistance.

Table 18. What is your approximate yearly income?

Answer Options	Response Percent	Response Count
$0 - 9,999	48.5%	99
$10,000 - 19,999	32.8%	67
$20,000 - 29,999	12.3%	25
$30,000 - 39,999	3.4%	7
$40,000 - 49,999	2.0%	4
Over $50,000	1.0%	2
answered		204

Table 19. Do you currently receive:

Options	Response Percent	Response Count
SSI	44.7%	71
SSDI	28.3%	45
TANF	1.9%	3
Food Stamps	40.3%	64
Don't know	3.1%	5
Other:	8.8%	14
answered		202

* Other benefits assistance reported includes: Unemployment insurance (1); Medicaid (2); Social security or pension (5); ADC (1); Welfare (1); Section 8 (1); Workers comp (1); Disability (2).

Insurance

The vast majority of 'In Care' respondents (82%) have acquired Medicaid or Medicare health benefits. Twenty percent (20%) report private health insurance and 11% report VA benefits. Only 18% report no form of health benefit.

Table 20. Do you currently have health insurance?

Answer Options	Response Percent	Response Count
Medicare	28.0%	58
Medicaid (Title XIX)	53.6%	111
VA	10.6%	22
None	18.4%	38
Private/Other:	20.3%	42
answered question		207

Employment

Fewer than 40% of the 'In Care' respondents report current employment, which correlates with their reported level of income and degree of benefits assistance.

Table 21. Are you currently employed?		
Answer Options	Response Percent	Response Count
Yes	39.2%	82
No	60.8%	127
	answered	209

Education

The 'In Care' respondents report a fairly wide range of educational backgrounds, with almost 42% reporting completion of high school and almost 25% reporting some college. In contrast, almost one quarter of all 'In Care' respondents (24%) report only some high school education or grade school or less. Less than 4% of the 'In Care' survey sample holds a college degree, and an additional 3% report some graduate level coursework.

Table 22. What is your highest level of education?		
Answer Options	Response Percent	Response Count
Grade school or less	6.7%	14
Some high school	17.2%	36
High school grad/GED	41.6%	87
Some College	24.4%	51
College degree	3.8%	8
Some graduate school	3.3%	7
Graduate level	2.9%	6
	answered	209

HIV/AIDS Status

The majority of the "In Care" survey respondents (76%) report a diagnosis of HIV and only 22% report a current AIDS diagnosis, representing a more recently diagnosed/healthier group of PLWHA, overall. (Approximately 2% reported not knowing their current HIV/AIDS status.)

Table 23. Are you HIV positive or has your HIV progressed to AIDS?		
Options	Response Percent	Response Count
HIV	76.1%	159
AIDS	22.0%	46
Don't know	1.9%	4
	answered question	209

Year of HIV Diagnosis

As evidenced by the table below, there is a wide range of years reported as the year of 'first HIV diagnosis' by this sample of 'In Care' survey respondents. "Peak" years reported by 9 or more of the survey participants include 1986, 1989, 1992, 1993,1996, 1998, 1999, 2003, 2004, 2005, 2006 and 2007. Over half of the survey respondents (N=116) report learning their sero-status in the years following the advent of triple combination therapy in 1996. Nine survey respondents reported their year of HIV diagnosis as "unknown".

Table 24. What year were you diagnosed with HIV?

Answer Options	Percent	Count
1975	0.5%	1
1982	1.0%	2
1983	0.5%	1
1984	1.5%	3
1985	1.0%	2
1986	4.5%	9
1987	2.0%	4
1988	2.5%	5
1989	4.5%	9
1990	3.0%	6
1991	1.5%	3
1992	5.0%	10
1993	5.5%	11
1994	2.0%	4
1995	2.0%	4
1996	4.5%	9
1997	2.0%	4
1998	6.0%	12
1999	5.0%	10
2000	4.0%	8
2001	3.5%	7
2002	2.5%	5
2003	7.0%	14
2004	5.5%	11
2005	5.0%	10
2006	6.5%	13
2007	5.5%	11
2008	1.0%	2
Unknown	4.5%	9

Year of AIDS Diagnosis

Twenty five of the 48 'In Care' survey participants (52%) who answered in the affirmative as currently living with an AIDS diagnosis reported their year of AIDS diagnosis since the year

2000, evidencing a relatively recent transition to an AIDS diagnosis for the majority of the 'In Care' respondents.

Table 25. What year were you diagnosed with AIDS?		
Options	Response Percent	Response Count
1977	2.1%	1
1985	2.1%	1
1986	2.1%	1
1991	2.1%	1
1992	6.3%	3
1993	2.1%	1
1994	4.2%	2
1995	4.2%	2
1996	4.2%	2
1997	4.2%	2
1998	6.3%	3
2000	6.3%	3
2001	2.1%	1
2002	8.3%	4
2003	4.2%	2
2004	8.3%	4
2005	6.3%	3
2006	8.3%	4
2007	6.3%	3
2008	2.1%	1
Unknown	8.3%	4
	answered question	48

Location of HIV Diagnosis

One hundred twenty eight (128) or sixty-three percent (63%) of all of the 'In Care' survey respondents report learning their HIV or AIDS status in Cleveland, Ohio. An additional 41 respondents (or 20%) report learning their HIV/AIDS diagnosis elsewhere in Ohio.

Therefore, only slightly less than 20% of all the 'In Care' respondents report receiving their first HIV/AIDS diagnosis in a state other than Ohio. The states most frequently identified included: Florida, (10); California (4); New York (4); Texas (3); Pennsylvania (2); New Jersey (2); North Carolina (2); and Arizona (2).

The desire to be close to family was the reason cited most frequently by those PLWHA diagnosed out of state and returning to the Cleveland area for care. The next most frequently offered reason for their return to the Cleveland area was the "quality of healthcare" available for HIV positive individuals (13%); followed by "desire to be with my partner" (9%). The 'other' answers essentially reflected the same sentiments in similar proportions.

(See Table 26 on the following page)

Table 26. If you were diagnosed somewhere other than Cleveland, why did you move to Cleveland?		
Options	**Response Percent**	**Response Count**
Quality of the healthcare	12.5%	10
To be with my partner	8.8%	7
To be close to my family	53.8%	43
Other	42.5%	34
	answered	**94**

HIV Transmission Risk

Forty-five percent (45%) of the "In Care" respondents report acquiring HIV as a result of MSM risk behavior; 33.7% as a result of heterosexual risk behavior; 6.9% as a result of injection drug use; 10.9% as a result of sex with a drug user; 2.5% as a result of behavior in prison; and 4% of all respondents cite sexual assault as the mode of HIV infection. One respondent reports 'transfusion' as their mode of transmission and one respondent cites 'Mother with HIV/AIDS' as their transmission mode. Twenty respondents (10%) report their mode of HIV transmission as "unknown". (Several respondents indicated more than one transmission risk.)

Table 27. Do you know how you may have acquired HIV/AIDS? (please check all that apply)		
Answer Options	**Response Percent**	**Response Count**
Men who have Sex with Men (MSM)	45.0%	91
Female Sex with Females	1.5%	3
Heterosexual sex	33.7%	68
Prison	2.5%	5
Injection Drug Use	6.9%	14
Sex w/ Drug User	10.9%	22
Sexual Assault	4.0%	8
Transfusion	0.5%	1
Mother with HIV/AIDS	0.5%	1
Unknown	9.9%	20
	Other:	7
	answered	**240**

Other: Tatoos (2); helping bleeding man (1); sex (1); boyfriend open cut and so I did; 2 N/A.

Living Arrangements

Only 15% of the 'In Care' respondents report owning their home; nearly two-thirds (62.8%) report currently renting a home or apartment; and almost 16% of all survey participants report being 'temporarily housed', currently staying with friends or relatives. When the 'other' answers are examined, the majority refer to transitional housing arrangements (i.e., live with friend/relative sometimes), increasing the proportion of 'temporarily housed' to 20%. Only 2% of this survey respondent group reports currently residing in a shelter. (See Table 28 on the following page)

Table 28. If not currently homeless, do you:		
Answer Options	Response Percent	Response Count
Own your home	15.3%	30
Rent	62.8%	123
Live with a Friend/Relative	15.8%	31
Live on the street	0.0%	0
Stay in a Shelter	2.0%	4
Other:	4.1%	8
	answered	196

Help with Rent

A sizeable minority (41%) of the 'In Care' respondents affirmatively report their receipt of rental assistance. The forms of assistance received are displayed in the table below.

Table 29. If you get help with rent, which assistance do you receive?		
Answer Options	Response Percent	Response Count
MRAP	15.3%	13
ARAP	7.1%	6
Title II EMAs	3.5%	3
Shelter Plus Care	17.6%	15
Section 8/Choice Voucher	43.5%	37
Don't know	10.6%	9
Other:	2.4%	2
	answered	85

Currently and Ever Homeless

Only 7% of this 'In Care' survey sample reports current homelessness. However, a substantial minority of the "In Care' survey respondents (N=88 or 42%) reports a period of previous homelessness.

Table 30. Are you currently homeless?		
Answer Options	Percent	Count
Yes	7.1%	15
No	92.4%	194
Don't know	0.5%	1
	answered	210

Table 31. Have you ever been homeless in the past?		
Answer Options	Percent	Count
Yes	41.9%	88
No	57.6%	121
Don't know	0.5%	1
	answered	210

The fact that a total of 42% of the "In Care" survey respondent group reports a previous period of homelessness, (and 7% report current homelessness) indicates a very high degree of housing instability within this community. This finding would indicate substantial challenge in successfully facilitating entry and retention in HIV primary care and services for a large segment of the PLWHA population residing in the TGA.

Incarceration in Past Six Months or Previously

Over 14% of the 'In Care' respondents report having been incarcerated over the past 6 months, ***(and almost half or 44% of the 'In Care' respondents report previous incarceration)*** evidencing another significant risk factor contributing to primary care instability.

Table 32. Have you been in jail or prison in the past 6 months?		
Answer Options	**Percent**	**Count**
Yes	3.8%	8
No	96.2%	201
	answered	**209**

Table 33. Have you ever been in jail or prison in the past?		
Answer Options	**Percent**	**Count**
Yes	43.8%	91
No	56.3%	117
	answered	**208**

Motivation for HIV Testing

Almost half of the 'In Care' survey respondents (or 47%) report learning their HIV status upon becoming ill or entering a hospital for treatment of a serious illness. Over 26% of respondents report accepting HIV testing as a result of a request by their partners/ result of partner notification. Another 22% voluntarily sought HIV testing due to risky sexual and/or drug use practices. Seventeen percent (17%) of all respondents report the receipt of HIV testing and diagnosis during a routine physical examination.

Table 34. What caused you to get tested?		
Answer Options	**Percent**	**Count**
I was sick	32.4%	58
My partner told me to	18.4%	33
Risky sexual practice	16.8%	30
Used injection drugs	5.0%	9
Officials told me I was exposed	7.8%	14
Tested when I had a physical exam	16.8%	30
Admitted to hospital, tested there	14.5%	26
	*Other:	10
	answered	**210**

('Other' responses included: Routine HIV testing every 6 months (2); tested in prison (4); tested upon blood/plasma donation (4); or result of husband's or wife's death (2).*

Location of Testing

A substantial minority of the 'In Care' respondents (40%) report the location of their HIV testing and diagnosis in their doctors' offices; 28% at an HIV testing/counseling site; and over 42% report learning their ser-status in a hospital or ER setting.

Table 35. Where did you go to get tested?		
Answer Options	**Response Percent**	**Response Count**
HIV testing & counseling site	28.4%	48
Doctor's office	39.6%	67
Hospital	33.1%	56
Emergency Department	8.3%	14
*Other:		25
answered		210

**'Other' responses included: Free clinic (6) and Health department (4).*

Extent of Serial Testing Among 'In Care' PLWHA

Over half of all the 'In Care' respondents (54%) reports having been tested only one time before testing HIV positive. Eighty eight respondents (42%) report testing two or more times before testing positive, of which 8% report 'serially testing'; or testing for HIV/AIDS more than three times before they were diagnosed as HIV positive.

Table 36. How many times were you tested for HIV/AIDS before you tested positive?		
Answer Options	**Response Percent**	**Response Count**
Once	56.4%	114
2 - 3 times	35.1%	71
More than 3 times	8.4%	17
answered		202

Time Period since First Positive Test

Of this sample of 'In Care' respondents, over 10% are 'newly diagnosed' within the past year or less, and 89% report learning their HIV/AIDS diagnosis over one year or more ago.

Table 37. When did you first have a positive test?		
Answer Options	**Response Percent**	**Response Count**
Less than one month ago	1.9%	4
1 - 6 months ago	3.4%	7
6 months - 1 year ago	5.8%	12
Over 1 year ago	88.9%	184
answered		207

Extent of Referral into Care upon HIV Diagnosis

The majority of the 'In Care' respondents (83%) report direct referral into HIV primary medical care upon HIV diagnosis, evidencing strong HIV testing-to-care linkages within the TGA. Only 17% report no referral into HIV care upon diagnosis.

Table 38. When you first had a positive test, were you referred to an HIV clinic/doctor?

Answer Options	Response Percent	Response Count
Yes	83.1%	172
No	16.9%	35
	answered	207

Delay in Entering HIV Primary Medical Care

Two thirds (or 64%) of all 'In Care' respondents report entering HIV primary medical care within three months of diagnosis per CDC/HRSA standard; almost 12% report entering care within 4-6 months of diagnosis; 7% entered care within the latter half of the first year following HIV diagnosis; and ***over 17% delayed their entry into HIV primary medical care for more than one year.***

Table 39. How long after you found out you were HIV+ did it take until you entered medical care?

Answer Options	Percent	Count
1-3 months of diagnosis	64.3%	133
4-6 months	11.6%	24
7-12 months	6.8%	14
Over a year after HIV+	17.4%	36
	answered	207

Reasons for Delay

Of those PLWHA who delayed entering care for more than one year following their HIV/AIDS diagnosis (17%), the reasons cited include: "shock about/denial of diagnosis" (48%); "felt well"; "fears of others finding out"; and "scared of starting meds".

Table 40. If you delayed getting medical care for your HIV, why?

Answer Options	Percent	Count
In denial/shock about HIV	47.6%	40
Scared to start meds	26.2%	22
Didn't want anyone to know	27.4%	23
Didn't feel sick	31.0%	26
	*Other:	21
	answered	132

'Other' reasons for care delay included: *Ashamed--happened in jail (2); didn't know where to go (3); couldn't afford to (2); on wait list/waiting for papers (3); moved out of state (1); and didn't want to die/people I knew on AZT died/was unsure of treatment back then (3).*

Reasons for Entering Primary Care

For the majority of PLWHA who entered care in a timely manner, the top ranking reason was admittance to a hospital because 'was sick'; followed by "got real about disease", and Case Manager encouraged me to".

Table 41. What caused you to get medical care?

Answer Options	Response Percent	Response Count
Admitted to hospital	23.6%	43
Got real about my disease	31.3%	57
Case manager encouraged me to	21.4%	39
*Other	29.7%	54
	answered	193

**'Other reasons: "Almost died/cancer" (2); "got sick" (3); "pregnant" (2); and "friends/family urging me to go" (3).*

Earlier Care Entry Motivators

Interventions which might have helped this survey respondent group to enter care earlier include: 1) more counseling/education about HIV disease upon diagnosis (42%); 2) more information about the health risks related to not getting care (27%); and 3) an HIV peer to help them navigate the system (23%). Respondents offered other motivating factors which may have speeded their entry into care, including: "someone to tell me where to go"; "free medical care"; "not being homeless"; and acute illness.

Table 42. What might have helped you get medical care earlier?

Answer Options	Percent	Count
Talk/counseling about HIV when I was first diagnosed	42.3%	58
Someone with HIV to help me	23.4%	32
Someone to tell me about the problems I could have NOT getting care	27.0%	37
Other	17.5%	24
	answered	151

Admission of Delay when Advised to Start ART

One-third of the 'In Care' respondents report that when they were advised to start ART, they did NOT do so. The top ranking reasons offered to explain their delay in starting ART was "Didn't feel sick" (33%), "worried about side effects" (31%); "didn't want to take meds forever"(12%); "couldn't afford meds" (12%); or "tried to hide from my partner/friends" (12%) 'Other' reasons

included: “denial”; “didn’t care”; “didn’t need meds”; “didn’t want to get sick”; “T cells too high”; “waiting for T cell count to get to 200 to start”; “no meds available”; “too long ago to remember”. (See Table 43 below)

Reasons for Delay of ART

Table 43. Why did you either not take or delay taking ART?		
Answer Options	**Response Percent**	**Response Count**
Didn’t feel sick	32.5%	27
Worried about side effects of meds	31.3%	26
Didn’t want to be take meds forever	12.0%	10
Couldn’t afford meds	12.0%	10
Tried to hide from my partner, friends	12.0%	10
Other	18.1%	15
	answered	83

Level of Reported ART Non-adherence

Once this sample of PLWHA started antiretroviral medications, over half (or56%) reported ever missing a dose.

Table 44. Once you started taking meds, did you ever miss a dose?		
Answer Options	**Response Percent**	**Response Count**
Yes	55.6%	109
No	44.4%	87
	answered	196

Reasons for Non-Adherence

Top reasons offered by the 2008 ‘In Care’ respondents to explain antiretroviral non-adherence included: “Forgot” (64%) and “Didn’t have meds with me” (27%); followed by “Tried to hide from my partner/friends” (12%); “Couldn’t afford meds for a while” (10%); and “Advised to take a break” (4%). ‘Other’ reasons offered include: “Denial”, “drinking”, “pot use”, “got sick”, “made me sick”, “made me sicker than I was”; “interactions with hormones”; “jail”, and “diarrhea side effects while working”.

Table 45. If you missed a dose, why?		
Answer Options	**Response Percent**	**Response Count**
Forgot	64.2%	70
Didn't have meds with me	26.6%	29
Doctor/nurse told me to 'take a break'	3.7%	4
Couldn't afford meds for a while	10.1%	11
Tried to hide from my partner/friends	11.9%	13
Other	14.7%	16
	answered	143

Extent of Chronic Illness other than HIV Disease

This 'In Care' sample of survey respondents report a fairly high degree of chronic disease with diseases other than HIV disease, as evidenced by the table below. High blood pressure is reported by 44%, Diabetes Mellitus by 22% and heart disease by 15% of all respondents. Fourteen percent of all survey respondents report Hepatitis C infection, most frequently associated with IDU.

Table 46. Have you ever been diagnosed with any of the following?

Answer Options	Response Percent	Response Count
Cardiac Problems/Heart Disease	15.0%	22
High blood pressure	44.2%	65
Cancer	8.8%	13
Diabetes or metabolic problem	21.8%	32
Nerve Issues (epilepsy, neuropathy)	17.0%	25
Hep	9.5%	14
Hep A	3.4%	5
Hep B	8.8%	13
Hep C	14.3%	21
Tuberculosis/TB	6.1%	9
Other	15.0%	22
	answered	147

'Other' chronic illnesses: Anal cancer (2); Asthma (5); AVN (2); Breast disease (1); Crohn's disease (1); COPD (1); Hodgkin's disease (1); Ulcers (1); KS (1); Anemia (1); Uterine disease (1); Pancreatitis (1); and depression/mental health issues (4).

Extent of HIV Symptoms and AIDS Indicators

The 'In Care' respondents also report high levels of AIDS indicators and/or HIV symptomatology, as evidenced in the table below.

Table 47. Have you had any of the following?

Answer Options	Response Percent	Response Count
Pneumonia	45.2%	56
Oral or Esophageal thrush	43.5%	54
Vaginal thrush	3.2%	4
Neuropathy (nerve tingling)	32.3%	40
Muscle wasting	21.0%	26
Lipodystrophy (body fat re-deposited)	19.4%	24
Rashes	44.4%	55
*Other	6.5%	8
	answered	124

**'Other' symptoms include: shingles (3); weight loss (1); and lipoatrophy (1).*

Drug Use Risk Assessment

Extent of Substance Use

Twenty percent (20%) of the 'In Care' survey respondents affirmed current substance use.

Table 48. Do you currently use substances?		
Answer Options	Response Percent	Response Count
Yes	19.9%	41
No	80.1%	165
	answered	206

Types of Substances Used

Of the types of substances used, marijuana leads with 63% of the respondents, followed by 52% use of alcohol. Over 17% of survey respondents report using cocaine, and over 4% report crystal methamphetamine abuse. None of the respondents admitted to heroin use. 'Other" responses included "use of alcohol" and "used to sell crystal meth".

Table 49. Types of substances:		
Answer Options	Response Percent	Response Count
Alcohol	52.2%	24
Cocaine	17.4%	8
Crystal	4.3%	2
Heroin	0.0%	0
Speedball	0.0%	0
Marijuana	63.0%	29
Other	4.3%	2
	answered	46

Ever Injected Drugs

Twelve percent (12%) of all 2008 'In Care' survey respondents admit to ever injecting drugs.

Table 50. Have you ever injected?		
Answer Options	Percent	Response Count
Yes	11.7%	24
No	88.3%	182
	answered	206

Types of Substances Injected

The drugs most frequently injected by the 2008 'In Care' survey respondents include Cocaine (48%); Heroin (36%); Crystal meth (28%); and Speedball (16%). 'Other' responses included "Morphine" and "hormones". (See Table 51 on the following page)

Table 51. Types of injected substances:		
Answer Options	Response Percent	Response Count
Cocaine	48.0%	12
Crystal	28.0%	7
Heroin	36.0%	9
Speedball	16.0%	4
Other:	8.0%	2
	answered	25

Current IDU

Of the 180 PLWHA who answered the question "Do you currently inject drugs?" none admitted to current injection drug use.

History of IDU Risk Practices

The 2008 'In Care' survey respondents report a high level of previous risk when injecting drugs. Thirteen of the 53 survey respondents who answered this question (25%) report previously sharing needles; 70% of those IDU did not clean their needles/works before sharing. Of the 30% who did report cleaning their works prior to sharing needles, 35% correctly used bleach; 13% used alcohol; 26% used water; and 30.4% used nothing.

Table 53a. Have you ever used a needle from or given a needle to someone?		
Answer Options	Percent	Count
Yes	24.5%	13
No	75.5%	40
	answered	53

Table 53b. Did you clean the needle first?		
Answer Options	Percent	Count
Yes	30.0%	9
No	70.0%	21
	answered	30

Table 53c. What did you use to clean the syringes?		
Answer Options	Percent	Count
Bleach	34.8%	8
Alcohol	13.0%	3
Water	26.1%	6
Nothing	30.4%	7
	answered	23

Sexual Risk Assessment

Level of Current Sexual Activity and Sexual Preference

Seventy percent (70%) of the 'In Care' respondents reports current/recent sexual activity. The majority of male and female respondents report sex with men (71%); 21% report sex with women; and 7% report bisexual sex.

Table 54a. Have you had sex in the past 6 months?		
Answer Options	**Percent**	**Count**
Yes	70.3%	147
No	29.7%	62
	answered	209

Table 54b. Have you had sex with men, women, or both?		
Answer Options	**Response Percent**	**Response Count**
Men	70.7%	140
Women	21.2%	42
Both	7.1%	14
RTA	1.5%	3
	answered	199

Number of Sexual Partners

Over half of the sexually active survey respondents reports sex with only one partner during the past six months. Another 18% reports having had two to five sexual partners during the same time period; and 5% of all survey respondents reports as many as 6-10 sexual partners over the past six months. Only one PLWHA respondent reports their number of sexual partners in the range of 21 to 50 in the past six months.

Table 55. How many sex partners have you had in the past 6 months?		
Answer Options	**Response Percent**	**Response Count**
0	16.0%	30
1	57.4%	108
2 to 5	18.1%	34
6 to 10	4.8%	9
11 to 20	0.0%	0
21 to 50	0.5%	1
RTA	3.2%	6
	answered	188

Frequency of Condom Use during Vaginal Intercourse

A substantial minority of the 'In Care' survey respondents (41%) reports "always" using condoms for vaginal sexual intercourse. Another 11% reports condom use "sometimes"; and 8%

reports "never" using condoms for vaginal intercourse. Forty percent (40%) of this respondent group reports no vaginal intercourse.

Table 56. In the past 6 months, during vaginal sex how often did you use a condom?		
Answer Options	Response Percent	Response Count
Always	41.4%	67
Sometimes	10.5%	17
Never	8.0%	13
No vaginal sex	40.1%	65
	answered	162

Frequency of Condom Use during Anal Intercourse

Only 35% of those reporting anal intercourse "always" use a condom; 10% report "sometimes" using a condom for anal sex and 6% report "never" using a condom for anal intercourse.
Almost half of the 2008 survey respondent group (48.5%) denies engaging in anal intercourse.

Table 57. In the past 6 months, during anal sex how often did you use a condom?		
Answer Options	Percent	Count
Always	35.1%	60
Sometimes	9.9%	17
Never	6.4%	11
No anal sex	48.5%	83
	answered	171

Regularity of Condom Usage since HIV Diagnosis

Only a minority of the entire 'In Care' survey respondent group reports routine use of condoms for sexual intercourse since learning their HIV ser-status. Almost half of the respondents report "sometimes" using condoms since their HIV diagnosis and over 1/3 of persons answering this question (36%) reports "never" using condoms, even since learning they were HIV positive.

Table 58. Since being diagnosed HIV positive how often do you have sex without condoms?		
Answer Options	Percent	Count
Always	16.5%	18
Sometimes	47.7%	52
Never	35.8%	39
	answered	109

Reasons for Unprotected Sex

By far, the most frequent reason offered for their lack of protected sex is "It Feels good", reported by 53% of all respondents. A substantial minority (34%) report that their "partner won't

let them use protection", a finding of serious concern, representing a significant barrier for successful prevention efforts among high risk communities. Another 15% report a lack of personal risk ("don't feel I'm at risk) and 12% report lack of time to use protection. 'Other' reasons offered for lack of condom usage by 5% of respondents include "Intoxicated" and "Partner and I are both positive".

Table 59. Why do you have unprotected sex?		
Options	**Percent**	**Count**
It Feels good - better than using a condom	52.5%	32
Don't feel that I'm at risk	14.8%	9
Don't have time to use protection	11.5%	7
Partner won't let me use protection	34.4%	21
Other:	4.9%	3
	answered	61

Sex with Casual Partners& Gender of Casual Partners

Almost 19% of all the 'In Care' survey respondents' reports currently engaging in sexual intercourse with 'casual' partners. The majority of casual sex partners are reported as same-sex (56%); 30% are reported as opposite sex; and 14% report casual sex with persons of the same and the opposite sex.

Table 60a. Do you have sex with casual partners?		
Answer Options	**Percent**	**Count**
Yes	18.8%	38
No	81.2%	164
	answered	202

Table 60b. Are these casual partners:		
Answer Options	**Percent**	**Count**
Same sex	56.3%	36
Opposite sex	29.7%	19
Both	14.1%	9
	answered	64

Personalization of Risk

While 2/3 of this survey respondent group acknowledged their personal risk for STD/HIV; over one-third of all "In Care' survey respondents (35%) thought they were **NOT** at risk for HIV disease prior to their diagnosis.

Table 61a. Did you think that you were not at risk for disease (HIV, STD) with sex?		
Options	**Percent**	**Count**
Yes	35.2%	64
No	64.8%	118
	answered	182

Reasons for Lack of Personal Risk Awareness

The reasons offered by ¾ of those answering this question, to explain the lack of personal risk awareness include belief that they were engaged in a monogamous relationship with the "Same partner"(72%); followed by "Age"(22%); and 'Other' responses which included "Married" and/or "Straight. Only one respondent cited 'post menopausal status' as a reason to explain their lack of personalized risk for HIV.

Table 61b. Why did/didn't you think that you were not at risk for disease (HIV, STD) with sex?		
Answer Options	**Percent**	**Count**
Age	22.4%	17
Same partner	72.4%	55
Beyond menopause	1.3%	1
Other (please specify)	11.8%	9
	answered	76

Perception of Need for Sex & Reasons underlying Need for Sex

Twenty one percent (21%) of all 'In Care' respondents report affirmatively their "have to have" need for sexual activity. The reasons offered to explain the high n3ed for sex include: "Age" (34%); "Being single" (32%); "Only way to connect (18%); and 11% report the need to have sex as a means of "exchanging money, drugs or personal protection". 'Other' reasons offered by 18% of the respondents to explain the need for sex include: "urge", "being married", "love it!", "addicted to sex", or "duty as a wife".

Table 62a. Do you feel that you 'have to have sex'?		
Answer Options	**Response Percent**	**Response Count**
Yes	20.7%	41
No	79.3%	157
	answered	198

Table 62b. Why do you feel that you 'have to have sex'?		
Answer Options	**Response Percent**	**Response Count**
Age	34.1%	15
Being single	31.8%	14
Many women, not many men	0.0%	0
Made or forced to'	2.3%	1
Only way to connect	18.2%	8
Exchange sex-money, drugs, protection	11.4%	5
Other	18.2%	8
	answered	44

Anonymous Partners

Almost 11% (or 22) of the 2008 'In Care' survey respondents affirmatively reports going on-line to locate anonymous sex partners.

63. Do you ever go online to find sex partners?		
Answer Options	**Percent**	**Count**
Yes	10.7%	22
No	89.3%	184
	answered	206

History of High Risk Sexual Practices

Overall, the survey respondents indicate a high level of high risk sexual practices, including 1) 20% reporting the exchange of sex for money, rent, drugs, and/or personal protection; 25% reporting having been a victim of domestic violence; and 28% reporting a history of sexual assault. Twenty nine percent of all 'In Care' respondents reports having unprotected sex since being diagnosed, and 18% report using medication to enhance sexual performance.

Table 64. Have you ever:			
Yes/No			
Answer Options	**Yes**	**No**	**Count**
Had sex with someone for money, drugs, rent or protection?	41	165	206
Been the victim of domestic violence?	51	155	206
Been the victim of sexual assault?	58	147	205
Taken medicine to help your sexual performance?	37	170	207
Had sex without condoms since being diagnosed HIV positive?	59	148	207
		answered	209

Health Insurance

The vast majority of 'In Care' respondents cite Medicaid or Medicare (82%) as their primary health benefit resource. Only 18% report no health insurance benefits and 20% of respondents reported private health insurance benefits. Approximately 11% reports having VA health benefit.

Table 65. Do you currently have health insurance?		
Answer Options	**Response Percent**	**Response Count**
Medicare	28.0%	58
Medicaid (Title XIX)	53.6%	111
VA	10.6%	22
None	18.4%	38
Private/Other:	20.3%	42
	answered	207

Current Primary Care Physician and Clinic

Table 66. Where do you receive your medical care?		
Answer Options	**Percent**	**Count**
Cleveland Clinic	12.7%	26
Community Health Partners	12.7%	26
Free Clinic	7.3%	15
Metro Health	22.0%	45
University	24.4%	50
Private Practice Physician	0.5%	1
Other:	20.5%	42
	answered	**205**

Approximately one-fourth of all of the 'In Care' survey respondents' (50 or 24.4%) report the University Health System as their primary medical home. Another 22% report Metro Health as their location for primary medical care and almost 13% each report accessing the Cleveland Clinic and Community Health Partners, respectively, for their HIV primary medical care. Seven percent (7%) of respondents report the Free Clinic as their location for primary medical care. The remaining respondents reported individual physicians as their HIV primary care specialist. Almost 20% of all respondents report seeing more than one provider for their HIV disease care. Those responding as 'other' report accessing their primary medical care through Care Alliance, the VA, Metro Health, the Free Clinic and other combinations of above referenced locations.

Primary Care Visit and Lab Monitoring Indicators of "In Care" Status

The majority of the 2008 'In Care' respondents report a strong and active "In Care" status, with most persons (of the 197 respondents who answered the question) reporting seeing their physician and receiving laboratory services in the past four to six months or less (in 11/07, 12/07, or the first three months of 2008). Only 17 respondents reported an 'erratically in care' status in the past 12 months to 24 months, with 4 of these respondents just returning to care. Similar visit patterns are reported for laboratory monitoring of CD4 cell counts and viral load levels.

Current Antiretroviral Therapy

The vast majority of 'In Care' survey respondents (86.4%) report the current receipt of antiretroviral therapy, as evidenced in the table below. And, as stated above, there are reports of strong adherence with routine laboratory monitoring visits to effectively track immunologic response to antiretroviral therapy.

Table 67. Are you currently taking HIV medications (ART)?		
Answer Options	**Response Percent**	**Response Count**
Yes	86.4%	178
No	13.6%	28
Don't know	0.0%	0
	answered	**206**

Use of Case Management Services for Services Needs, Information and Referrals

The vast majority of survey respondents indicates their regular access of social service case management, while only two-thirds (64%) report utilizing a case manager to manage their medical needs (i.e. schedule doctor and/or lab appointments. Over one-third of the survey respondents reports seeing more than one case manager to meet their care coordination needs. (See Tables 68 a, b, and c below)

Table 68a. Do you see a case manager or social worker to help you determine your service needs or understand programs and services?

Options	Percent	Count
Yes	85.6%	178
No	14.4%	30
	answered	208

Table 68b. Do you see a case manager or social worker to help you manage your medical care, make your doctor's appointments and schedule lab tests?

Answer Options	Percent	Count
Yes	63.6%	131
No	36.4%	75
	answered	206

Table 68c. Do you see more than one case manager or social worker?

Answer Options	Percent	Count
Yes	36.4%	76
No	63.6%	133
	answered	209

History of Mental Illness and/or Substance Abuse Diagnosis and/or Treatment

Thirty six percent (36%) of all 'In Care' respondents reported a history of mental health issues, and a similar proportion (36%) report diagnosis and/or treatment for a substance abuse disorder.

Table 69a. Have you ever been diagnosed with or treated for a mental illness?

Answer Options	Percent	Count
Yes	35.7%	70
No	64.3%	126
	answered	196

Table 69b. Have you ever been diagnosed or treated for substance abuse?

Options	Response Percent	Response Count
Yes	35.9%	74
No	64.1%	132
	answered	206

Diagnosis and/or Treatment of STDs and/or Treatment of Diseases other than HIV Disease

Over one third (or 37%) of this 'In Care' survey sample reports a history of other STDs, including most frequently a history of Chlamydia and/or gonorrhea, followed by herpes, trichamonas, syphilis, HPV, Hepatitis and HIV.

Table 70. Have you ever been diagnosed with or treated for any other sexually transmitted diseases (STD)?

Answer Options	Response Percent	Response Count
Yes	36.7%	76
No	59.4%	123
Don't know	3.4%	7
RTA	0.5%	1
	When/what	60
	answered	207

USE, NEEDS, and BARRIERS RANKINGS

A Use, Needs, Gaps and Barriers ranking was developed for all 'In Care' respondents. The 2008 HIV/AIDS Needs Assessment provides a "snapshot" of the community service needs, barriers, and gaps as expressed by consumers of HIV related services. The rankings of the Needs Assessment were displayed for all 'In Care' respondents, with separation into Need, Use, Gap and Barrier. This can be further defined as:

Need	**Number of 'In Care' client survey respondents who stated "I currently need this service."**
Use	**Number of 'In Care' client survey respondents who indicated service use in the past year**
Gap	**Sum of 'In Care' client survey respondents who answered 'Yes' to Need and 'No' to availability of that service**
Barrier	**Number of 'In Care' client survey respondents who indicated that a service is 'Hard to Get'**

NEED

Four of the top 5 service Needs expressed by the 2008 'In Care' survey respondents are core medical services---with the highest priority Needs representative of the core trio of services essential to quality care and care coordination—those being Primary Medical Care, Medications, and Medical Case Management. Housing services are ranked as a #4 highest service Need.

All but three of the top 10 ranking service Needs are core medical services with the exception of Medical Transportation and Medicaid assistance, ranked #8 and #9, respectively. The next rankings from #11-to #15 are more heavily supportive services, with the exception of Substance abuse services, ranked at #13 and Nutrition counseling (ranked #15).

The 15 Top Ranking Service <u>NEEDS</u> for ALL "In Care" respondents

The highest priority HIV service needs reported by the Cleveland TGA "In Care" survey participants, in rank order, include: 1) Primary Medical Care; 2) Medications; 3) Medical Case Management; 4) Housing services; 5) Oral health care; 6) Health insurance; 7) Specialty Medical care; 8) Medical Transportation, 9) Medicaid assistance; 10) Mental Health services; 11) Non-medical Case Management; 12) Nutrition (health); 13) Substance abuse services; 14) Nutrition (afford); and 15) Nutrition counseling/Dietician services.

Table 71. Top Ranking 'In Care' Service Needs

Answer Options	Response Count
#1 Primary Medical Care	**201**
#2 Medications	**194**
#3 Medical Case Management	**146**
#4 Housing services	**134**
#5 Oral health care	**133**
#6 Health Insurance	**126**
#7 Specialty Medical Care	**124**
#8 Medical Transportation	**118**
#9 Medicaid Assistance	**107**
#10 Mental Health Counseling	**102**
#11 Non-Medical Case Management	**96**
#12 Nutrition (health)	**94**
#13 Substance Abuse Treatment	**92**
#14 Nutrition (afford)	**78**
#15 Dietician	**74**
Home Health Aide	70
Home Health Nurse	68
Home Delivered Meals	67
Child Care	64

Service USES

The top 15 services reported as most often currently 'used' by ALL 'In Care' respondents include:
1) Primary Medical Care;
2) Medications;
3) Medical Case Management;
4) Oral health services;
5) Specialty Medical Care;
6) Health insurance;
7) Housing services;
8) Non-medical case Management;
9) Medical Transportation;
10) Nutrition –health;

11) Nutrition—affordability;
12) Medicaid assistance;
13) Mental health counseling;
14) Nutrition counseling; and
15) Substance abuse services.

While home health, home delivered meals and child care were once previously used by more PLWHA, the majority of respondents ranked these services as very infrequently used services currently.

The Top Ranking Service USES for ALL "In Care" respondents

Table 72. 2008 'In Care' Use/need Rankings:					
Answer Options	**Use now**	**Used ever**	**Need now**	**Needed in past**	**Response Count**
#1 Primary Medical Care	200	6	84	14	203
#5 Specialty Medical Care	102	59	52	27	164
#2 Medications	186	15	80	13	198
#4 Oral health services	105	73	59	42	182
#3 Medical Case Management	139	44	43	37	183
#8 Non-Medical Case Management	90	60	26	23	148
Home Health Nurse	11	64	7	8	74
Home Health Aide	11	62	11	8	75
#6 Health Insurance	94	47	55	13	145
#12 Medicaid Assistance	68	54	43	13	137
#14 Nutrition Counseling-Dietician	35	59	16	10	97
#9 Medical Transportation	86	47	39	16	135
#13 Mental Health Counseling	48	78	22	34	127
#15 Substance Abuse services	16	86	16	32	105
#7 Housing services	92	65	64	34	166
Child Care	5	60	8	8	66
#10 Nutrition (health)	83	44	45	13	129
#11 Nutrition (afford)	78	38	45	9	115
Home Delivered Meals	7	60	10	10	69
				Other:	13
				answered	205

Service BARRIERS

The top 10 highest ranking service Barriers include:
1) Housing services;
2) Oral health care;
3) Medicaid assistance;
4) Nutrition—health;
5) Medications;
6) Medical transportation;
7) Primary Medical Care tied with Specialty Medical Care, Health insurance and Nutrition--affordability;

The Top 15 Ranking Service BARRIERS for ALL "In Care" respondents

Table 73. Top Ranking Service Barriers

Answer Options	Response Count
#1 Housing services	47
#2 Oral Health care	40
#3 Medicaid Assistance	30
#4 Nutrition (health)	26
#5 Medications	24
#6 Medical Transportation	23
#7 Primary Medical Care	21
#7 Specialty Medical Care	21
#7 Health Insurance	21
#7 Nutrition (afford)	21
#11 Mental Health Counseling	20
#12 Non-Medical Case Management	18
#13 Medical Case Management	17
#14 Nutrition counseling--Dietician	14
#14 Substance Abuse Treatment	14
#14 Home Delivered Meals	14
#17 Home Health Aide	12
#18 Home Health Nurse	10
#19 Child Care	9

Service Category-Specific Barrier Reasons-ALL 'In Care' Survey Respondents

Table 74: Barrier Reasons by Service Category

Service Category Description	Need Rank	Barrier Rank	Barrier Reasons
#1 Housing	**3**	**1**	Housing - not worth time to not get help, long waits, no info, then turned down; hard to understand how to get long term housing one to tell me what my status is - went to ATF no help; can't find house we can afford -only help is $ for heat or temporary housing; lack of info; long waits; don't know where to go; too much red tape; not much available, takes too long, confusing; finally got it after 3 years; not worth time to not get help, long waits, no info, then turned

			down; hard to understand how to get long term housing; tried - no luck - too young - not poor enough.
#2 Oral Health Care	**4**	**2**	Dental care-need transportation; no insurance and dentist retired; no one available to take me
#3 Medicaid Assistance	**9**	**3**	Lost Medicaid once, had a lot of trouble getting it back, still don't know why I lost it; haven't met anyone who knows what to do; and when they sent me, they didn't know don't get why my MA was, then not, then back, tried to fix, no one to help me; help - denied 2 times, then got, then lost, don't know why! lost MA once, had a lot of trouble getting it back, still don't know why I lost it; need someone to help - MA lapse; Medicaid pending
#4 Nutrition (health)	**12**	**4**	Food not as good or reliable as was; food stamps are not enough to last a whole month to have healthy foods. I don't eat junk food and fresh fruit and veggies cost too much.
#5 Medications	**2**	**5**	Had trouble qualifying for awhile
#6 Medical Transportation	**8**	**6**	Transportation - didn't know where to go and embarrassed
#7 Primary Medical Care	**1**	**7**	No reason offered
#7 Specialty Medical Care	**7**	**7**	Specialty med care-need insurance
#7 Health Insurance	**6**	**7**	Lack of knowledge to qualify people; red tape
#7 Nutrition (afford)	**14**	**7**	Food stamps are not enough to last a whole month to have healthy foods. I don't eat junk food and fresh fruit and veggies cost too much.
#11 Mental Health Counseling	**10**	**11**	Mental health counseling - not much for people my age (young); slipped disk, in pain;
#12 Non-Medical Case Management	**11**	**12**	Case management and non medical case management - don't know stuff
#13 Medical Case Management	**3**	**13**	Case management and non medical case management - don't know stuff
#14 Nutrition counseling/Dietician	**15**	**14**	No reason offered
#14 Substance Abuse Treatment	**13**	**14**	No reason offered
#14 Home Delivered Meals		14	No reason offered
#17 Home Health Aide		17	No reason offered
#18 Home Health Nurse		18	No reason offered
#19 Child Care		19	No reason offered

The top service Barriers—Housing assistance and Oral Health services are a recurring theme among Cleveland TGA survey respondents. And, the perceived difficulty in accessing Medicaid assistance acts as a barrier to other service needs.

Barrier reasons reveal a significant circularity and inter-relationship. For example: the lack of transportation is cited as a barrier to obtaining dental care services; the lack of Medicaid and/or health insurance blocks access to specialty care and other services, and failure to meet eligibility criteria blocks access to numerous services.

Additional Comments from the 2008 'In Care' Survey Respondents

The additional comments and recommendations directed to the members of the Planning Council generally reiterate previous findings in the 2008 Needs Assessment. There is a predominance of gratitude for the service delivery system and people who deliver the services, and additional requests for added assistance with transportation, housing, financial assistance and food as well as more opportunities for social support among PLWHA.

Table 75. Additional Comments for Planning Council
More social activities for HIV+ people.
I think housing, dental, and eye care are the most important things you need.
I do appreciate all the services that are offered and the good people that you have providing the services.
I have no answers for the barriers section because between the community health partners and case managers & the Moll Cancer Center case mgr I have had kind and sincere assistance w/ getting everything I needed through the toughest, sickest, most desolate times of my life. They are to be commended. They have been a blessing.
Much more resources and money from the federal government as this disease will be going into its 3rd decade. It's a shame and a scam that there is not more done for this disease.
Larger gas cards due to the gas price. Money for parking at hospital parking garage. Extra cash card for Claritin D 24 hr approx $32 month not covered by medical. Extra food market cards for things you can't buy with food stamps, such as toilet paper, under arm deodorant, soaps of all kinds, shaving cream, razors, cleaning supplies, etc
I feel that each race and language needs knowledge.
No! Thank you very much for all support!!!
I would like it if people living w/ HIV/AIDS would be able to get together more for fellowship. I think right now the services are great.
No, I believe I am getting excellent care in this area.
More advertisement.
An HIV friendly directory of businesses that will help in all aspects of life. Everything from a plumber to where to find housing.
I just want to thank you for everything that you do and I don't know what I would have done without Gail Anderson. She has done so much for me and to help me through it all! Thank you so much!
Eye care
Provide more Cleveland RTA bus tickets.
Paying bills is hard.
Hard to pay bills
I would like more visits from my case manager – at least once a day
Just that you need to ensure these programs continue so we can keep getting the help we need to stay healthy!
One thing that I have noticed from talking to individuals living with HIV/AIDS is the fact that so many, including myself, have to live with parents or family members. I hope someday we will be able to get more housing assistance for people with HIV/AIDS so we all can be on our own and have more of a life and feel more independent.
Better understanding of legal terms of disability and how each can affect benefits available
Have some gatherings more often
I try to eat a lot of fresh fruit and veggies - some chicken and fish. Very little beef and no pork. It's hard to buy healthy foods for the whole month on the food card.

Yes, social security getting off their butts and helping us
It would be nice to receive voucher cards again, like we used to. With my HIV, the neuropathy in my feet is getting worse which is making it hard for me to work. I live with my mate who is on SSI /SSA making things hard for food. thanks
More funding for groups
Treatment centers in rural areas and rent payments
I am living a healthy life because of all the help I have received from Ryan White 1,2,3
I would like to start to volunteer for home services if possible
Better nutrition bags
I need help getting SSI. I have applied and have been denied. There are people receiving SSI that are not even in worse conditions than me. I have just been in hospital this month-Feb 2008 and I have started dialysis and have to take insulin. I have to make another appeal. Thank you.

Chapter 3: Comparison to Previous Needs Assessments

This chapter will analyze and present the varying similarities and differences in the findings between the needs assessment surveys conducted previously, in 2003, 2004 and 2005 with those findings revealed in the 2008 'In Care' needs assessment process.

The top service needs, barriers and gaps in 2003 and 2004 were:

2003

- **In Care 'Top 5' Service Needs**

1) Medications
2) Lab
3) Primary Medical Care
4) Case Management
5) Transportation
6) Affordable housing

> For rural, transportation #1

- **Top 5 Service Barriers**

1) Discrimination (worried re: job, family and neighborhood support)
2) Cost (perception of high cost, unaware of affordability of services, meds)
3) One-stop shopping/convenience preference
4) Perception of case management as 'playing favorites' – withholding information or unaware/uneducated about services
5) Specific concern about felonious assault bill
6) Repeated suggestion of peer advocate system for newly diagnosed

Service Gaps	**Rural**
1) Transportation	1) Transportation
2) Dental care	2) Dental care
3) Home delivered meals	3) Child care
4) Affordable housing	4) Substance abuse treatment

2004

- **In Care 'Top 5' Service Needs**

1) Medications
2) Lab
3) Primary Medical Care
4) Housing
5) Case Management
6) Transportation
7) Food Bank

- **Top 5 Service Barriers**

1) Housing
2) Transportation
3) Food Bank
4) Cost (perception of high cost, unaware of affordability of services, meds)
5) Perception of case management as 'playing favorites' – withholding information or unaware/uneducated about services

Service Gaps

1) **Housing**
2) Transportation
3) Nutrition (Counseling, Dietary Supplements, Food Bank)
4) Substance Abuse Treatment

(same Rural gaps in 2003 as 2004)

The top 5 Service Needs rankings reported by the 2008 'In Care' survey respondents are highly similar to previous TGA Need rankings and include all core medical services (1) Primary Medical Care; 2) Medications; 3) Medical Case Management; 4) Housing services; 5) Oral health care) with the exception of Housing services, a 'supportive service' which is ranked as a #4 priority service Need. Medical Transportation is ranked as a #8 Need, ranked slightly lower than in 2003 (#5) and 2004 (#6). Food-related Needs also show considerably lower rankings in 2008 than in 2003 or 2004, with Nutrition—health ranked #12; Nutrition—affordability ranked #14; and Nutrition counseling/Dietician services ranked #15.

The top 2008 service Barriers—Housing assistance and Oral Health services--- are recurring themes among Cleveland TGA survey respondents. Housing was listed as a #4 Need and #1 service Gap and Barrier by the 2004 'In Care' respondents. And Oral Health care was ranked as a #2 service Gap by the 2003 'In Care' survey respondents. The 2008 respondents' perceived difficulty in accessing Medicaid assistance acts as a barrier to other service needs, and reflects

top ranking service Barriers related to costs of care, cited as #2 and #4 ranking service Barriers in the 2003 and 2004 needs assessments, respectively.

For the 2005 'special focus' Needs Assessment on the 'aged or 45 years+ PLWH/A), service needs, barriers and gaps were:

In Care Top 5 Service Needs:

1) Medications
2) Lab Tests
3) Primary Medical Care
4) Housing
5) Case Management

In Care Top 5 Service Barriers:

1) Transportation (all, most severe with rural)
2) Health Insurance
3) Life Insurance
4) Financial Assistance (can't work, too old to get jobs)
5) Support (emotional & geographic isolation)

In Care Top 5 Gaps:

1) Transportation
2) Insurance (life and health insurance)
3) Housing

Services to Engage or Re-engage Out of Care:

1) Transportation
2) Help with costs
3) Peer advocates of own age/situation

Again, upon comparison of the 2005 Needs Assessment survey findings of 'In Care' PLWHA 45+ to the 2008 'In Care' survey findings, there are great similarities between the respective Need rankings. The top five service Needs are identical (when laboratory services are combined with Primary Medical Care).

Though the rankings differ slightly, the top Needs remain Primary Medical Care, Medications, Medical Case Management, and Housing. The only exception is that Oral Health services is ranked as the #5 priority service Need in 2008, and is not ranked as a top Need, Gap, or Barrier by the 45+ PLWHA in 2005.

The top ranking Barriers in 2008 include: Housing services, Oral health care, Medicaid Assistance, Nutrition—health, and Medications. A review of the 2008 top 10 service Barrier rankings reveals consistency with the top ranked Barriers from the 2005 survey process, though the actual rankings have changed somewhat.

2005 Gaps/Barriers versus	**2008 Barriers**
#1 Transportation	**#6 Transportation**
# 2 Insurance	**# 7 Health Insurance**
# 3 Housing	**#1 Housing services**
#4 Financial assistance	**#3 Medicaid Assistance**

2004 versus 2008 'In Care' Needs Assessment Survey Findings

Needs were assessed by Service Category for all respondents, and ranked from 1 through 15 priority in the Consumer Survey. The ranking for all respondents is displayed below for 2004, with a side-by-side comparison to the Needs rankings performed by the 2008 consumer group. Once again, the rise in the priority Need ranking for Housing services is apparent. Additionally, the Substance abuse services ranking in 2004 (#8) dropped to #13 in 2008, and Nutrition counseling dropped from a #9 service Need in 2004 to a #15 service Need ranking in 2008, while the ranking for Mental health services remained the same at #10 for 2004 and 2008.

The remainder of the Needs rankings remained relatively stable, except for those priority service Need rankings in 2008 which did not receive any rankings in 2004. For example, the #6 Health insurance, #7 Specialty Medical Care and #9 Medicaid Assistance Needs rankings in 2008 received only Barrier rankings in 2004 (#2 Health Insurance and #4 Financial Assistance Barrier rankings, respectively), or no ranking as a separate service category in the case of Specialty Medical services.

Table 76. SERVICE CATEGORY NEED RANKING

Service Category Description	2004 Need Rank	2008 Need Rank
Prescription Med Assistance	1	2
Medical Laboratory Testing	2	NR
Primary Medical Care-outpatient	3	1
(Medical) Case Management	4	3
Medical Transportation	5	8
Dental Care/Oral Health Services	6	5
Housing services	7	4
Substance Abuse Counseling/Treatment	8	13
Nutritional Counseling	9	15
Mental Health Counseling	10	10
Housing-related services	11	NR
Home Delivered Meals	11	NR
Transitional Housing	12	NR
Child Care Assistance	13	NR
Home Health Care	14	NR
Hospice Care	15	NR

Comparisons of 2003 & 2004 to 2008 Barriers to Care

Overall, tremendous progress is evidenced in the TGA's success in reducing many of the barriers to care in the TGA. The changes noted in the level and types of service Barriers, noted from the previous findings (in 2003 and 2004) to the 2008 needs assessment survey findings are discussed below.

The 2004 Barriers to care included the following factors:
1) Health Insurance

2) Passive or no linkage to care upon positive HIV test
3) Stigma towards HIV in certain cultures, geographies and age groups
4) Fear of HIV medications
5) Cost of treatment

1) Barriers to Health Insurance—2003/2004 to 2008

As evidenced in the table below, the proportion of persons receiving Medicaid benefits dropped in 2004 from 2003, but has risen to 54% of the survey respondent group in 2008. During this same time period, the number and proportion of Medicare recipients has increased from 16% of survey respondents in 2003 to 28% of respondents in 2008. The number of persons receiving private or other health insurance benefits has actually increased from 7% to over 20%. *The proportion of persons claiming no health benefits has decreased slightly over the same time frame.* Despite the evident progress, PLWHA continue to express frustration regarding difficulties in accessing Medicaid assistance and achieving Medicaid eligibility.

Table 77. Changes in Insurance Acquisition

Insurance	2003 #	2003%	2004#	2004%	2008#	2008%
Medicare	50	16%	48	17%	58	28%
Medicaid	161	52%	96	34%	111	53.6%
VA	12	4%	28	10%	22	10.6%
None	59	19%	59	21%	38	18.4%
Private/Other:	21/6	7%/2%	48/2	17%/1%	42	20.3%
TOTAL	**310**		**281**		**207**	

2) 2004 versus 2008 Passive or no linkage to care upon positive HIV test Barriers

Much progress has been evidenced with regard to the barriers to testing and linkages to care within the TGA. The 2008 'In Care' survey respondents indicated that 83% received direct referrals into HIV primary medical care upon HIV diagnosis. Sixty four percent of the entire survey respondent group entered care within three month's time. However, 17% delayed their entry into care for more than one year.

Related findings include the fact that less than 25% of the survey group were familiar with or had in hand the new HIV services guide, and several PLWHA comments revealed that they did not know where to go for services or how to access some of the 'hardest to get' services.. Further distribution of this service guide should help improve the progress made and strengthen the testing-to-care referrals and linkages within the TGA.

Finally, there were few comments regarding the perception that case manager's lacked the knowledge about available resources necessary to implement effective referrals, as in past surveys. In fact, there were several positive comments regarding the PLWHA's gratitude for the excellent care coordination services they had received.

3) 2003/2004 versus 2008 Changes in Impact of Stigma as a Barrier

In response to the 2004 'In Care' survey question "Which of these barriers would prevent you from continuing to receive medical care?" 22% of all survey respondents indicated that fear or experience of discrimination or stigma would prevent them from remaining in care. The perception of 'stigma' as an overt barrier to care has apparently been reduced over the past 3-4 years. The 2008 PLWHA respondents rarely mention stigma nor do they specifically attribute any access barriers to the presence of stigma.

However, within the 2008 survey findings there is definitely information to support the fact that cultural and sexual stigmas, particularly in the minority communities, are acting as significant barriers to reducing the further transmission of HIV owing to the continuation of high risk sexual practices. In particular, the relatively high rate of unprotected sexual practices among the HIV positive community because "my partner won't let me use condoms" or due to fears of personal violence of loss of protection reveal that stigma is still impacting the community and contributes to great challenges in realizing successful 'prevention with positives' initiatives. This topic will be addressed in greater length in Chapter 4: Recommendations for the Comprehensive Strategic Plan.

4) 2004 versus 2008 Changes in Barrier: Fear of HIV Medications

Twenty-six percent (26%) of the 132 survey respondents who in 2008 answered the question regarding the reasons for their delay into care indicated "fear of starting meds' as a primary reason. *One-third of the 2008 'In Care' respondents report that they did NOT start ART when advised to do so.* The top ranking reasons offered to explain their delay in starting ART was "Didn't feel sick" (33%), "worried about side effects" (31%); "didn't want to take meds forever"(12%); "couldn't afford meds" (12%); or "tried to hide from my partner/friends" (12%) 'Other' reasons included: "denial"; "didn't care"; "didn't need meds"; "didn't want to get sick"; "T cells too high"; "waiting for T cell count to get to 200 to start"; "no meds available"; "too long ago to remember".

However, overall, the survey results support the notion that medication fears are less of a barrier to care than in the past. The strategic interventions implemented throughout the TGA to inform PLWHA about the benefits of care and treatment are apparently making a positive impact. The 2008 PLWHA respondents have embraced the value of current and improved ART regimens, evidenced in part by the 86% of all PLWHA respondents who report current ART, and an active 'In Care' status overall**.**

5) 2003/2004 versus 2008 Cost of treatment

The cost of treatment has been a notable barrier to care in the 2003 and 2004 survey findings. And, the 2008 results evidence this as a continuing concern for low income, impoverished PLWHA. Concerns about the cost of care were stated reasons for delaying entry into care, and financial constraints act as real and perceived barriers to many services, including food, housing, transportation, oral health care, medical specialty care and more.

Recommendations for expanded efforts to reduce disparities in care and overcome the continuing barriers are discussed in the following chapter.

Chapter 4: Recommendations for Comprehensive Strategic Plan

I. Address 'In Care' Service Barriers to Care

Table 78. Top Ranking Service Barriers

BARRIERS	Rank
Housing services	1
Oral Health care	2
Medicaid Assistance	3
Nutrition (health)	4
Medications	5
Medical Transportation	6
Primary Medical Care	7
Specialty Medical Care	7
Health Insurance	7
Nutrition (afford)	7
Mental Health Counseling	11
Non-Medical Case Management	12
Medical Case Management	13
Nutrition counseling--Dietician	14
Substance Abuse Treatment	14

The issue of Housing as a continuing service Barrier in the TGA deserves additional attention. The 2008 'In Care' survey respondents indicate extremely high levels of previous homelessness (42% previously and 7% currently). Many homeless adults bring forward poor childhood experiences including low school performance, malnourishment and physical or emotional trauma. These conditions negatively impact self esteem and the confidence required to independently sustain self sufficiency, and persons often succumb to chronic alcoholism, drug dependency and poor health or other outcomes.

The implications for the community to reduce the barriers to housing and overcome chronic homelessness include:

- Assuring access to all public benefits, such as social security income, food stamps, Medicaid and others.
- Sustaining a continuum of care strategy that maximizes the community's ability to assist homeless persons in transitioning to permanent housing.
- Increasing, through collaborative efforts with other local providers, the number of permanent housing units, ideally those supporting on-site meals, healthcare, mental health care and substance abuse treatment.

II. Summary of Recommended Priority Strategies to Increase Linkage, Engagement and Retention in care

- **Engaging clients in care when first diagnosed as HIV positive.** Survey respondents offer the following additions to strengthen this initial linkage and

facilitate successful entry into care for a greater proportion of those testing positive each year: 1) Provide more counseling/education about HIV disease upon diagnosis (42%); 2) Provide more information about the health risks related to not getting care (27%); and 3) Offer an HIV positive peer to help them navigate the system (23%). Respondents offered other motivating factors which may have speeded their entry into care, including: "someone to tell me where to go"; "free medical care"; "not being homeless"; and acute illness.

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- **Fully assessing clients' needs when entering care; targeting those deemed at high risk for erratic care use and/or disengagement from care and strongly engaging them in care during the first year of primary medical care participation**

- **Ensuring optimal cultural and linguistic competence of Case Management, Mental Health and Primary Medical Care providers to meet the needs of the targeted sub-populations and severe need groups**

- **Aligning planning processes to respond to service delivery issues**
    1. Service Delivery: Expand Housing and Housing-Related Services
    2. Service Delivery: Ensure ready availability of culturally competent providers
    3. Service Delivery: Expand/seek additional funding to support the unmet food, transportation and financial assistance needs reported by the 'In Care' populations
    4. Service Delivery: Ensure optimal collaboration among core medical and supportive services providers, co-locating to the extent possible all priority services

- **Assuring services availability information- Information about service availability is still limited, despite the new HIV service guide**

- **Assuring high-quality services - Information about service quality is limited**

- **Retaining clients in care - employing systematic approaches to missed appointments/lost to follow-up and maximizing Ryan White and other funding resources**

- **Assisting re-entry into care – expanding peer counselors and other outreach strategies identified as highly effective in facilitating their return to care/keeping them in care**

III. Summary of Recommended Priority Strategies to Strengthen 'Prevention with Positives' Interventions and Programming within Ryan White funded Primary Care Clinics

The 2008 'In Care' survey results yield a rich wealth of data highly useful to inform the TGA's expansion of 'prevention with positives' strategies in the Planning Area. The 2008 needs

assessment findings reveal a high level of continuing risk behavior among the 'In Care' clientele, which left unaddressed will only further fuel the epidemic within the Cleveland TGA.

A brief overview of the sexual risk practices reported by the current 'In Care' PLWHA include the following:

- Seventy percent (70%) of the 'In Care' respondents reports current/recent sexual activity.

- The majority of male and female respondents report sex with men (71%); 21% report sex with women; and 7% report bisexual sex. 18% reports having had two to five sexual partners during the same time period; and 5% of all survey respondents reports as many as 6-10 sexual partners over the past six months. Only one PLWHA respondent reports their number of sexual partners in the range of 21 to 50 in the past six months.

- ***Only a small portion of the 'In Care' survey respondent group (17%) reports routine use of condoms for sexual intercourse since learning their HIV ser-status. Almost half of the respondents report "sometimes" using condoms since their HIV diagnosis and over 1/3 of persons answering this question (36%) reports "never" using condoms, even since learning they were HIV positive.***

- Reason offered for their lack of protected reported by a substantial minority (34%) report that their ***"partner won't let them use protection", a finding of serious concern, representing a significant barrier for successful prevention efforts among high risk communities.*** *Another 15% report a lack of personal risk ("don't feel I'm at risk)* and 12% report lack of time to use protection.

- Almost 19% of all the 'In Care' survey respondents report currently engaging in sexual intercourse with 'casual' partners. And, almost 11% (or 22) of the 2008 'In Care' survey respondents affirmatively reports going on-line to locate anonymous sex partners.

One prevention intervention strategy that has been highly successful with HIV positive persons in other TGAs/EMAs is the training of all primary care staff in the use of the Transtheoretical Model and in Motivational Interviewing Techniques, so that primary care providers may, on each client's visit to the clinic, perform brief risk assessments and deliver brief motivational prevention messages. The use of licensed mental health staff as prevention care management education counselors strengthens this model.

TRANSTHEORETICAL MODEL OF CHANGE

The **Transtheoretical Model of Change** or "Stages of Change Model" (Prochaska & DiClemente, 1983; Prochaska, DiClemente & Norcross, 1992; Prochaska & Velicer, 1997) is an integrative model of intentional behavior change, integrating key constructs from other theories, that focuses on the decision-making processes of individuals. The Transtheoretical Model considers the contextual variables influencing one's intention and self-efficacy to change, and acknowledges the important roles for emotion, cognition, and behavior. The Transtheoretical

Stages of Change Model is often chosen for use to guide all 'prevention with positives' programmatic interventions for its positive impact on five critical program areas: *recruitment, retention, progress, process, and outcome.*
The Transtheoretical Model is an appropriate model for the **recruitment** of an entire population, because it recognizes that individuals are all in different stages of change and require interventions appropriate to that stage. As a result, high participation rates are facilitated, with interventions available to all, no matter what stage the person is in, so that movement along the behavioral change process may be promoted. The Model can result in high **retention** rates, because it is designed to develop specific interventions that are matched to the individuals' needs, and therefore more readily create a match between the person's needs and readiness, reducing dropout due to inappropriate demand characteristics. The Model can provide more sensitive measures of **progress**, because it includes a set of outcome measures that are sensitive to a full range of cognitive, emotional, and behavioral changes and recognizes and reinforces smaller, incremental changes. Process monitoring capacity is rich under this model. Given the multiple constructs and clearly defined relationships, the model can facilitate a process analysis and guide the modification and improvement of the intervention. The Transtheoretical Model can support a more appropriate **assessment of outcome**. Interventions based upon the Model have the potential both for a high efficacy rate and high recruitment rate, dramatically increasing the potential for positively impacting the level of behavioral risk among an entire population.

MOTIVATIONAL INTERVIEWING

Motivational Interviewing (MI) is a cognitive-behavioral approach to working with an individual that is designed to enhance motivation to change, resolve ambivalence, and reduce "resistance". Motivational Interviewing is defined as a client-centered, directive provider-based interviewing style for enhancing intrinsic motivation to change and eliciting behavior change by helping patients explore and resolve ambivalence and therefore reduce resistance to behavior change, using techniques and strategies based on the Stages of Change Model developed by Proschaska and DiClemente. Motivational Interviewing is an excellent intervention to use with persons in the early stages of change as well as in the later stages as they prepare for change, take action and maintain the change over time. The "spirit" of motivational interviewing involves collaboration—a partnership with the patient; evocation—drawing on the person's own perceptions, goals and values; autonomy—in affirming the individual's right and capacity for self-direction, facilitating informed choice. (Miller & Rollnick).

Motivational Interviewing can be delivered in short clinic-based interventions and is characterized in the following key points: 1) Motivation to change is elicited from the patient and not imposed from without; 2) It is the patient's task, not the provider's, to articulate and resolve his/her own ambivalence; 3) Direct persuasion is not an effective method for resolving ambivalence; 4) The interviewing style is generally a quiet and eliciting one; 5) The provider/counselor is directive in helping the patient to examine and resolve ambivalence; 6) Readiness to change is not a patient trait, but a fluctuating product of interpersonal interaction; and 7) The therapeutic provider/patient relationship is more like a partnership than expert/recipient roles. The therapist respects the patient's autonomy and freedom of choice (and consequences) regarding his/her own behavior. (Rollnick & Miller, 1995)

The goal of MI is to elicit self-motivational statements from the person about change, and direct these statements toward change, in five key motivational areas:

- **Self Esteem:** Statements from the person that they are OK. People have to believe they are OK to be able to change. Raising self-esteem is a cornerstone of MI.
- **Concern:** Statements from the person evidencing concern about their behaviors.
- **Competence/Confidence:** Statements from the person reflecting an ability to do things.
- **Knowledge of the problem:** Statements from the person recognizing problem behavior**.**
- **Knowledge of Strategies:** Statements reflecting strategies for change.
- **Desire to Change:** Statements reflecting a desire for things to be different. (Miller & Rollnick, *Motivational Interviewing*, 1991)

Stages of Change **Proschaska & DiClemente**	**Motivational Interviewing Task** *Miller & Rollnick*
Precontemplation Stage	Raise doubt; increase person's perceptions of risk and problems with current behavior. Express empathy and assess readiness.
Contemplation Stage	Explore pros/cons of change; evoke reasons to change and risks of not changing; resolve ambivalence; strengthen self-efficacy.
Preparation/Determination Stage	Help person determine best course of action; develop treatment/prevention plan; strengthen self-efficacy by finding something in the person's attitude, intention, behavior, efforts, or motivation to affirm.
Action Stage	Help person implement strategies to take steps toward change; strengthen self-efficacy; support incremental change steps; alter plan as indicated.
Maintenance Stage	Help person to identify and use strategies to prevent relapse; which is viewed as a normal part of the change process; support and reinforce changes achieved; help person to develop and use network of supports and rewards.
Relapse Stage	Help person renew process of contemplation, determination and action, without becoming stuck or demoralized due to relapse.

Example Goals and Objectives for an expanded 'Prevention with Positives' intervention package:

1) **<u>Short Term Goal:</u>**

Increase the number of HIV positive persons in care who receive comprehensive HIV prevention case management/PCRS services, mental health and/or substance abuse counseling and medical and social service supports necessary to effectively adopt and sustain HIV/STD risk reduction behaviors.

2) **<u>Intermediate Goal:</u>**

Increase to at least 80% the proportion of active PLWHA clients who adopt and sustain risk reduction behaviors six months following delivery of the intervention.

3) **Long Term Goal:**

Reduce by 2 % the number of newly reported HIV infections within the TGA by 2011.

Example Outcome Objectives:

By the end of the project year, increase to "X" the number of HIV-infected patients who have completed the minimum number of Counselor sessions (N=3).

By the end of the project year, increase to "X" the number of HIV-infected patients who demonstrate, from baseline to repeat behavioral risk assessment, reductions in specific risk behaviors including:

1. 40% reduction in number of sexual partners of unknown and/or negative serostatus;
2. 40% reduction in total number of sexual partners;
3. 40% reduction in the use/frequency of alcohol and other substances prior to or during sexual activity;
4. 40% reduction in unprotected anal and vaginal receptive and insertive intercourse; and
5. 40% reduction in needle sharing and sharing of injection equipment among active IDUs.

By the end of the project year, increase to "X" the number of HIV infected patients who demonstrate incremental increases in their "Stage of Change" scores from baseline to repeat assessments upon each visit, including:

1. 50% increase in motivation to and confidence in ability to change high-risk behaviors:
2. 50% increase in intention to change; and
3. 60% increase in movement along documented stages of change with regard to sexual and drug using risk behaviors.

By the end of the project period, increase to "X" the number of HIV-infected patients who demonstrate, from baseline to repeat behavioral risk assessment measures, improvements in their actual safer sexual and needle-cleaning behaviors, including:

1. 60% increase in self-efficacy to change high risk sexual and drug use behaviors.
2. 50% increase in self-reported safer sexual activity, including correct and consistent condom usage for anal and vaginal intercourse with sero-negative main and non-main sexual partners and partners of unknown sero-status;
3. 50% increase in self-reported correct and consistent use of bleach for needle cleaning among injecting drug users who share injection equipment.