



## **2008 HIV Needs Assessment Report**

Ryan White Title I

Denver Transitional Grant Area

Submitted to: The Denver HIV Resources Planning Council  
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**ACRONYMS AND DEFINITIONS**

ADAP	AIDS Drug Assistance Program
AIDS	Acquired Immune Deficiency Syndrome
Council	Denver HIV Resources Planning Council
CRS	Center for Research Strategies
DTGA	Denver Transitional Grant Area
HIV	Human Immunodeficiency Virus
HRSA	Health Resources and Services Administration
IDU	Injection Drug Users
MCSM	Men of Color Who Have Sex with Men
MSM/IDU	Men Who Have Sex with Men who are also Injection Drug Users
OOC	Out of Care
PLWH/As	People Living with HIV or AIDS
WMSM	White Men Who Have Sex with Men
WoC	Women of Color

## **Preface to the 2008 DTGA HIV Needs Assessment**

## Executive Summary

Every two years, the Denver HIV Resources Planning Council conducts a needs assessment of people living with HIV or AIDS (PLWH/As) in the Denver Transitional Grant Area (DTGA). This needs assessment is mandated by the legislation that established the Ryan White CARE ACT and is used by the Council to determine how to prioritize the funds available for services within the DTGA. The Center for Research Strategies conducted the 2008 HIV Needs Assessment for the Denver HIV Resources Planning Council.

### **Goals**

1. To obtain client feedback on the prioritization of funding for services.
2. To collect information in a variety of ways to understand why some PLWH/As do not receive medical care.

### **Methodology**

Within the 2008 Needs Assessment, information was collected from PLWH/As within five high risk groups:

1. White MSM (Men Who Have Sex with Men)
2. MCSM (Men of Color Who Have Sex with Men)
3. WoC (Women of Color)
4. IDU (Injection Drug Users)
5. MSM/IDU (Men Who Have Sex with Men who are also Injection Drug Users)

The Center for Research Strategies (CRS) utilized two different methods to collect information for the 2008 Needs Assessment: surveys and focus groups. Survey data were collected from PLWH/As who were currently receiving medical care (In Care) and from PLWH/As who were considered out of medical care (OOC). The current report summarizes data obtained from 207 In Care participants and 121 Out of Care participants.

In addition, CRS conducted a series of five focus groups with PLWH/As. The focus groups addressed the barriers individuals face in obtaining care and identified potential solutions that could help people to get into and to remain in care. Feedback from focus group participants has been included throughout the report to add insight into the survey responses.

Finally, information was obtained from service providers who represent those agencies that receive Ryan White funding from the Denver HIV Resources Planning Council. Survey data were collected from 39 providers; additionally, 13 providers participated in a focus group. Summaries of these results can be found in the Supplement to the 2008 HIV Needs Assessment.

### **Key Findings**

#### *Prioritization of Service Funding*

Client and provider participants rank ordered the importance of Ryan White funded services categories. There was consensus that Medical Care and Access to Medicines were the most important service categories, but opinions differed about the importance of the remaining categories. Client participants ranked Dental Care third, Health Insurance fourth, and Housing fifth in order of importance. In contrast, the service providers' top five list of important services included Case Management, Mental Health Counseling, and Substance Abuse Treatment. See Table 2 for the overall ranking of services as well as service rankings by group.

### *Difficulty Accessing Services*

Very few people reported difficulty accessing Medical Care or Hospice services. In contrast, more than 40% of participants reported that Emergency Financial Assistance, Emergency Housing Assistance, and Transportation were either hard to access or took some effort. Barriers to these three service categories were repeatedly noted throughout the survey and focus group responses.

- Financial Assistance – Focus group participants reported that some case managers and counselors did not provide them with accurate information about the amount of financial assistance they qualify for under Ryan White. This lack of information made it harder to access available financial resources.
- Housing – Participants reported that long waitlists as well as limited housing for people with a criminal record or with substance abuse issues were major access issues.
- Transportation – People think the token system is not working. Participants often had too few tokens to allow them to get to all of their service and medical appointments. Moving from the token system to a monthly or annual pass was repeatedly suggested by participants as a solution to the problem.

### *Addressing the Out of Care Problem*

With the current needs assessment, the Council wanted to identify reasons why people are out of care as well as potential solutions to this problem. Both PLWH/As and service providers agreed that there are six main reasons why people are out of care, as listed below.

- Meeting **basic living needs** is critical for PLWH/As. When they struggle to house or feed themselves, HIV-related medical care is not a priority.
- **Health beliefs and literacy** should be addressed. Health literacy refers to the ability to process and understand health information for the purpose of making health decisions<sup>1</sup>. Many PLWH/As believe that receiving care means taking HIV medications and that they do not need to see a doctor for their HIV if they feel well. This suggests that they may be misunderstanding information communicated by doctors and other service providers.
- **Taking a break** from HIV, medications, and the system was a major theme reported by PLWH/As. Being out of care allows them to feel a “sense of normalcy” and to get on with their lives. Doing what they need to do to be in care feels like a 24/7 job to many PLWH/As. Some felt that seeking medical care was so time consuming that it was difficult to have a job and receive medical services.
- There is still a **knowledge gap**. Many PLWH/As do not know where to go to find services or what services are available. Currently, many PLWH/As depend on peers for information because they feel the information they receive from agencies is not complete or up to date.
- Limited **financial resources** affect PLWH/As’ ability to stay in care. Some cannot afford the co-pays for medical care, medications, and transportation to and from care. While assistance is available, they have difficulty accessing that assistance in part because of transportation and paperwork barriers.
- Other **untreated conditions** such as mental illness and drug use interfere with the ability to seek HIV care. When treatment for these other conditions is completely separate from treatment for their HIV, the burden of navigating the system to seek care increases substantially. A coordinated system that treats the whole person rather than just HIV could help to increase participation in care.

## Denver Transitional Grant Area – 2008 HIV Needs Assessment

### Description of the DTGA

According to the United States Census bureau, an estimated 2.4 million persons resided in the Denver–Aurora Metropolitan Statistical Area (MSA) in 2006, making it the 21st most populated MSA in the United States.<sup>2</sup> The Denver-Aurora MSA includes the City and County of Denver and the following nine suburban counties: Adams, Arapahoe, Broomfield, Clear Creek, Douglas, Elbert, Gilpin, Jefferson, and Park. For planning purposes, however, most persons residing in Denver consider the metropolitan area to be comprised of the 2.3 million persons living in the Adams, Arapahoe, Broomfield, Denver, Douglas, and Jefferson six county region (i.e. Denver PMSA).

Through June 2007, a cumulative total of 8,845 cases of AIDS and 6,182 cases of HIV infection had been reported in the state of Colorado.<sup>3</sup> Of that cumulative total, 7,291 (83%) AIDS cases and 5,151 (83%) HIV cases were reported in the ten counties that comprise the Denver-Aurora MSA. Between July 2006 and July 2007, 273 new AIDS diagnoses and 306 new HIV diagnoses were reported in Colorado.

Approximately 60% of the newly diagnosed HIV/AIDS cases are among men who have sex with men and roughly 6% are among injection drug users. While an estimated 10% of newly diagnosed cases report high risk heterosexual contact as the exposure source, a sizeable proportion (around 20%) report that their mode of exposure is unknown. The Denver-Aurora MSA is ranked 21<sup>st</sup> among the participating National HIV Behavioral Surveillance NHBS sites in AIDS prevalence.

- Cases of HIV in Colorado increased 26 percent from 2002 to 2006.
- There has been an 18 percent decrease in the number of reported AIDS related deaths from 2002 to 2006.
- In Colorado, 50.5 percent of AIDS cases are White, 19.6 percent are Black and 26.5 percent are Hispanic.
- Blacks continue to be disproportionately affected by the HIV/AIDS epidemic in Colorado, representing 13.9 percent of prevalent cases and only 3.7 percent of the state’s population.
- The average number of HIV cases reported among females in Colorado has increased by 17.2 percent since the beginning of the epidemic in 1987.
- The rate of HIV/AIDS among males has increased by 7.8 percent from 2002 to 2006.
- The majority of HIV cases reported among males and females are in the 30-49 age group.
- Ninety three percent of all HIV/AIDS cases are reported in urban areas.

Table 1. Demographic Characteristics of People Living with HIV/AIDS in the DTGA and Survey Sample

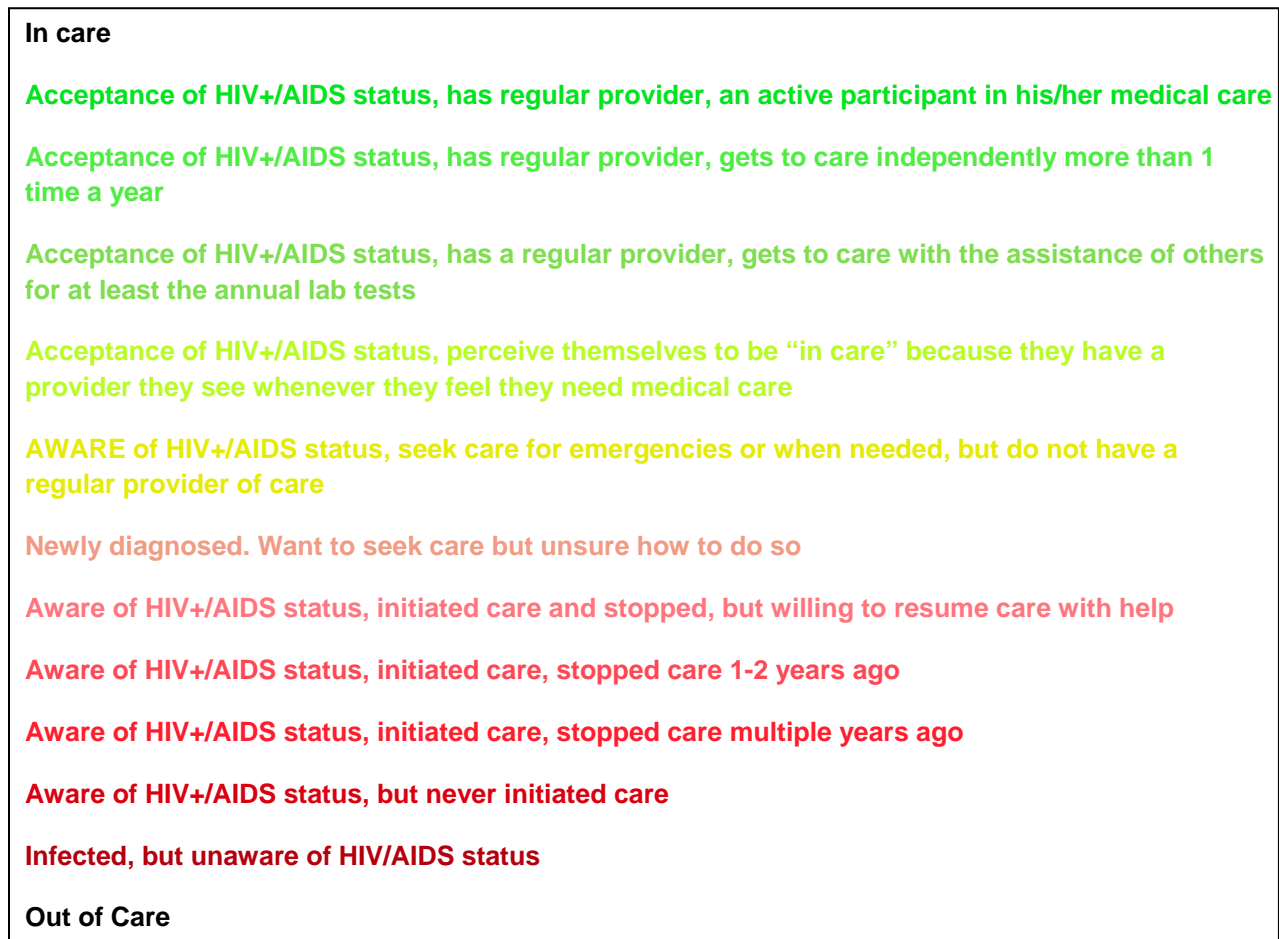
Demographics		DTGA		In Care Sample		Out of Care Sample	
		N	%	N	%	N	%
GENDER	Male	6937	90.8	174	84.1	104	86.0
	Female	699	9.2	28	13.5	16	13.2
	Transgender			4	1.9	1	0.8
	Missing	0	0.0	1	0.5	0	0.0
	<b>TOTAL</b>	<b>7636</b>	<b>100.0</b>	<b>207</b>	<b>100.0</b>	<b>121</b>	<b>100.0</b>
RACE /ETHNICITY	White	5138	67.3	113	69.3	62	51.2
	Black/African American	1102	14.4	32	19.6	31	25.6
	Hispanic/Latino	1264	16.6	44	21.3	19	15.7
	Asian/Pacific Islander/Hawaiian	59	0.8	0	0.0	0	0.0
	Native American	57	.7	3	1.8	2	1.7
	Multiple Race	16	.2	8	4.9	3	2.5
	Other	0	0.0	5	3.0	2	1.7
	Missing	0	0.0	2	1.2	2	1.7
<b>TOTAL</b>	<b>7636</b>	<b>100.0</b>	<b>207</b>	<b>100.0</b>	<b>121</b>	<b>100.0</b>	

### Care Status Continuum

Individuals working with PLWH/As often make a distinction between people who are “in care” and people who are “out of care”. In the current needs assessment, CRS was asked to collect data that would enable the Council to understand why some people do not receive medical care for their HIV and more importantly, to identify what the Council can do to get people in care and keep them there.

Early in the process we developed a Care Status Continuum that reflects the wide variety of factors that influence whether PLWH/As are or are not receiving medical care (see Figure 1). We believe this continuum can serve as a framework to understand results from this needs assessment. However, we would caution that the experiences of individual PLWH/As may vary substantially and not follow a predictable path. More work needs to be done to understand this complex issue.

Figure 1. Care Status Continuum



### **Priority Ranking of Services**

Participants ranked the services in order of importance. There was almost unanimous agreement that Medical Care and Access to Medicines were the most important services. Substantial differences emerged in the ranking of services after these two. Rankings for the entire sample as well as by subgroups are presented in Table 2.

All participants were asked to rank the five most important services in the order of importance. Early in the data collection process, we found that many participants had trouble answering this question so survey coordinators assisted survey participants when necessary. In future versions of the survey, the Council should revise the manner in which this question is worded. One concern is that the question doesn't clarify whether a service is being ranked important because it is not being received or conversely that it is important independent of whether the service is being used or not. Hence, survey respondents may not have been answering the question in the same way, resulting in service rankings that are not completely accurate.

The following pieces of information were used to develop the rank order below:

- Number of participants who ranked the service
- The median ranking for the service
- The percentage of participants who gave the service a rank of 1, and
- The percentage of participants who gave the service a rank of 1 or 2.

This method differs from the approach used in the last needs assessment. The last needs assessment did not ask participants to rank order the services. Rather, they used the question "Do you currently need this service" to develop the rank order, hence, the rank order presented in the prior needs assessment was based simply on the number of people who stated they needed each service.

Table 2. 2008 DTGA Service Ranking by Survey Respondent Groups

Service Category	2008 DTGA Rank	In Care	Out of Care	WMSM	MCSM	WoC	IDU	MSM/ IDU	In Care Focus Group	Provider
	N=321	N=201	N=120	N=110	N=88	N=34	N=36	N=59	N=22	N = 39
Medical Care	1	1	1	1	1	1	1	1	1	1
Medicines	2	2	3	2	2	2	2	2	2	2
Dental Care	3	3	5	3	3	5	3	3	3	8
Housing	4	6	2	5	6	4	4	4	6	6
Health Insurance	5	4	4	4	4	3	9	8	10	7
Case Management	6	5	6	7	5	8	5	7	7	3
Mental Health	7	9	7	6	8	9	8	6	5	4
Transportation	8	7	9	10	7	6	7	9	8	10
Substance Abuse Treatment	9	10	8	8	10	14	6	5	11	5
Nutrition	10	8	10	9	9	7	10	10	4	11
Home Health Care Aide	11	13	13	11	12	12	12	14	13	11
Home Delivered Meals	12	14	12	13	11	11	11	14	---	9
Home Health Nurse	13	11	14	12	13	13	14	14	---	11
Child Care	14	12	11	14	14	10	14	11	---	14
1 <sup>st</sup>	highest ranked service	2 <sup>nd</sup>	highest ranked service	3 <sup>rd</sup>	highest ranked service	4 <sup>th</sup>	highest ranked service	5 <sup>th</sup>	highest ranked service	

### Service Accessibility

For each service used in the past year, participants indicated how difficult the service was to use (either “easy,” “took some effort” or “hard”). Access difficulty was determined by calculating the percentage of users who stated a service was “hard to access” or “took some effort.” Using this method, the most difficult services to access were Financial Assistance, Housing Assistance, Transportation, and Health Insurance (See Table 3).

Table 3. Ranking of Services by Access Difficulty for In Care Participants

Rank	Service Category	% of Users	Rank	Service Category	% of Users
1	Emergency Financial Assistance	48.2	8	Mental Health Services	27.3
2	Emergency Housing Assistance	43.0	9	Substance Abuse Services	26.1
3	Transportation	41.0	10	Prescription Drugs	25.8
4	Health Insurance Continuation	35.9	11	Client Advocacy	24.7
5	Dental	29.8	12	Home Health Care	23.3
6	Case Management	27.8	13	Hospice	20.8
7	Food Bank/Home Delivered Meals	27.4	14	Medical Care	18.4

These topics repeatedly emerged throughout the survey and focus group responses. Comments provided by the survey participants provide additional information about barriers they have encountered in accessing the four most difficult to access services (See Table 4).

- Financial Assistance** – The comments provided suggested that people had difficulty getting to appointments due to transportation, the paperwork required and lack of identification required. An additional problem encountered was that the agencies they were referred to were out of funds. One focus group participant noted that,

” The places that are supposed to help with electricity and stuff like [Agency], you go down there and we don’t have no money... The places that you are referred to are supposed to have funding to help you pay for this or this but don’t have any, every time you go down there. I have been going four years now I have been going to the [Agency], I have been trying to get at least a little bit of help here or there.
- Housing Assistance** – Long waitlists as well as limited housing for people with a criminal record or with substance abuse issues were major access issues. Problems with staff may also be important as participants reported feeling like no one would help them, the availability of housing assistance wasn’t mentioned, or they had difficulty talking to their case manager about the issue. Focus group participants also reported feeling discriminated against in accessing housing because of race or transgender status.

- Transportation - PLWH/As believe the token system is not working. Participants often had too few tokens to allow them to get to all of their service and medical appointments. Moving from the token system to a monthly or annual pass was repeatedly suggested by participants as a solution to the problem.

"It used to be a roll of bus tokens would last us for two weeks, it does not last us for two weeks anymore. If we have got doctor appointments, the psychiatrist and the doctor and we have to go to CAP last to go get our food and then we have to go to maybe another food bank to get some more food because of the stuff we do not get there, then you know we are using a whole role of bus tokens in a week now. I mean if you don't have some kind of handicap card which is hard to get like you said unless you have some kind of bipolar or some disorder, then you are just kind of screwed out."

- Health Insurance – Out of care focus group participants repeatedly mentioned that medical services and medications cannot be afforded without some type of financial assistance (i.e., CICIP) or insurance to cover the expenses. They also mentioned a lack of information about what Ryan White moneys they qualify for, what that money can pay for, and how to access that funding.

Table 4. Service Barriers Listed by Survey (in care and out of care responses combined) and Focus Group Participants

Service Category*	Barriers to Accessing Service Survey Comments	Focus Group Quotes
Dental Care	Long waiting list; availability; insurance; don't qualify; money; difficult and frustrating intake process; red tape; Transportation; no information on where to go; embarrassing	<ul style="list-style-type: none"> <li>• "If you miss two appointments you are out for a year. Sometimes things happen and you can't always give a 24 hour notice."</li> <li>• "I was put on the waiting list but there isn't a way for them to get a hold of me. I don't know if they have called or not."</li> <li>• "I have been diagnosed for a year and have been on Howard Dental's list for 11 months."</li> </ul>
Medical Care	Transportation – cost, need tokens, bad location for buses; Red tape; Doctor only in on certain days, embarrassing; not sick yet	<ul style="list-style-type: none"> <li>• "I haven't done any currently because I can't afford the co-pays right now, but I've been out of care for about a year."</li> <li>• "I only make \$230.00 a month on A &amp; D and I can't afford the co-pays and my medications."</li> <li>• "I don't have medical insurance. I have CICIP, but they told me that is not insurance and that was only for that clinic"</li> </ul>
Housing	No places or too many people; transportation costs; long wait; no one was of help at first; service not mentioned; difficulty talking to case manager; housing limited for felons	<ul style="list-style-type: none"> <li>• "They will let you become homeless before they will provide you with services. They could help just a little in the beginning instead of a huge amount of help later."</li> <li>• "In order to get housing outside of CAPS buildings you need to get Section 8. CAP only has a limited amount of vouchers. If they could increase them to meet the need that would be good."</li> </ul>

Service Category*	Barriers to Accessing Service Survey Comments	Focus Group Quotes
Medications	Cost; transportation - cost, need tokens; paperwork; confused about varieties; confused about insurance needed; clinic moved farther away; motivation	<ul style="list-style-type: none"> <li>• "I depend upon tokens and see the trickle down effect if okay I go to the pharmacy where I get my drugs at University. You try to schedule your appointments around your medications and then appointments may be extended out longer than they need to be...I'm out here, can't we do this, oh you have two more days until we can fill this prescription. And I'm like, you know, then university needs to pick up the tab on bus tokens and the IV Clinic but then it will trickle down so that they have to pick it up for everybody else then."</li> <li>• "I can take it [medication] and then when [the doctor] told me how much it was going to cost me, that just made it..... that medicine is high"</li> </ul>
Insurance	Paperwork; financial constraints; not affordable; no job; too expensive; don't understand how; unable to get Medicaid assistant	<ul style="list-style-type: none"> <li>• "I went there to make an appointment and I went up there and the lady said that's all right, we wouldn't be able to see you anyway because you don't have an ID."</li> </ul>
Case Management	Transportation; child care; dropped as a client; wasn't helpful; extremely hard to communicate with; me – I just haven't done it; just need help; found the services on my own – case manager did not work	<ul style="list-style-type: none"> <li>• "Some case managers treat you like a dog if you make them upset. They take you off of lists."</li> <li>• "I was looking for housing three months and [Agency] wouldn't help me at all. [Agency] didn't help until later on when a worker changed and then it got better."</li> <li>• "It would be helpful if...organizations would dovetail information so if they can't help us then they could tell us where to go. Why aren't we organized enough that a case manager can direct or assist you to where you need to go? More information to share with case managers with people of authority that says let's do this instead of coming to a dead end."</li> </ul>
Food Bank	Transportation costs; location; red tape/paperwork; need a program that works; lack of variety; finances	<ul style="list-style-type: none"> <li>• "There are food banks all over...when you are poor it's hard to run to Aurora then to Federal and with tokens and bus passes not being given out. Places are too far apart."</li> </ul>
Mental Health Counseling	Transportation cost; referral line not helpful; I have found no one who will take Medicare; just need help; it hasn't come up with my doctor yet	
Substance Abuse Treatment	Transportation costs; Hard to find group for women; can't find housing that promotes no substance abuse	<ul style="list-style-type: none"> <li>• "It's about if you want it, if you have Medicare and Medicaid I was in 90 day inpatient alcohol and rehab I didn't have to pay a dime, not food or shelter. But some people don't want it."</li> </ul>
Emergency Financial Assistance	Don't have CO ID and birth certificate; transportation costs; getting to appointments; paperwork	<ul style="list-style-type: none"> <li>• "I've had problems with emergency financial assistance. [Agency] wouldn't pay the entire amount or past due amounts."</li> <li>• "If you get a place and you need to set up electricity or phone they won't pay activation fees. If you are sick like us you need a phone, and they refuse."</li> </ul>

\*Listed in order of number of comments made per topic.

## Utilization of Medical Care

Prior to completing the survey, each participant answered screening questions to determine their eligibility to participate and to determine whether they should complete the “in care” or “out of care” version of the survey. While there was overlap between the two versions, all questions were not asked of all participants. Throughout the report and appendices, we will note which survey data results are being reported and when information is only available from some of the survey respondents.

### *Information Provided about HIV Services at the Time of Diagnosis*

PLWH/As who completed the out of care survey were asked to report which category of services they were told about when they were first diagnosed with HIV (See Table 5). The majority reported receiving information on one or more service, with medical care the most frequently reported service.

While, not addressed in the survey, many participants in the focus groups reported that one of the biggest challenges they encounter is the lack of information about other available services. After their diagnosis, they explained that they need to educate themselves not only about the disease but also about the services available to them. A high number of focus group participants reported that counselors, case managers, and other healthcare providers are unfamiliar with or unaware of all the services available to PLWH/As. Sometimes, they said, the information they receive is outdated. Their best source of information about available services is reportedly through word-of-mouth from other PLWH/As, especially those people who are long-term survivors.

Focus group participants mentioned that when they were first diagnosed with HIV, healthcare providers asked if they have any questions. Participants said often they do not know what to ask or what services they will need. In one participant’s words, “Sometimes I hear *What can we do for you?* Sometimes I’d like to hear someone say *“This is what we can do for you,”* [...] because I don’t know what I can do for myself, how am I going to tell another person what you can do for me?”

Table 5. Service Information Received at the Time of Diagnosis as Reported by Out of Care Participants

Service	N	%	Service	N	%
Medical care for HIV	50	41.3	Substance use counseling/treatment	23	19.0
Case management services	49	40.5	I was not told about any services	16	13.2
Mental health services	29	24.0	Other*	13	10.7
Medical care for condition other than HIV	25	20.7	Missing	6	5.0
Don’t know or don’t remember	24	19.8			

\*Other services included (Hope Project, POCA, Food Bank, Housing, CICP, CDC, Ryan White)

### ***Delay between diagnosis and entry into care***

An early transition to care is critical to getting and keeping PLWH/As in care. Almost 60% of in care participants reported seeking care within 3 months of their diagnosis. In contrast, less than 35% of out of care participants reported receiving care within 3 months (See Table 6). A Chi-square analysis showed that people who accessed care within three months of receiving their diagnosis were significantly more likely to be in care,  $\chi^2(1, 288) = 12.4, p < .001$ . Unfortunately, participants were only asked to report why they delayed entry into care if the delay was longer than one year. In future needs assessments, it may be helpful to examine reasons for delaying entry into care by longer than 3 months. A number of focus group participants shared that the shock of finding their HIV status was enough to keep them away from seeking medical services, while others reported that their drug use or certain mental health conditions interfered with their ability to seek medical care.

Table 6. Delay between Diagnosis and Entry into Care

Delay in Entry to Care	In Care		Out of Care	
	N	%	N	%
Never tried to get care	0	0.0	13	10.7
Tried to get care within 3 months	120	58.0	39	32.2
Tried to get care within 4-6 months	12	5.8	2	1.7
Tried to get care within 7-12 months	13	6.3	6	5.0
Tried to get care more than a year after diagnosis	47	22.7	36	29.8
Don't remember/Other	13	6.3	24	19.8
Missing	2	1.0	1	0.8

### ***Reasons for delaying entry into care***

Participants who delayed entry into medical care were asked to report the reasons why they did not seek care (See Table 7). During the course of the data collection, we noted that multiple participants thought that receiving medical care meant taking HIV medications, with 20.5% of in care participants reporting that their care provider told them that they didn't need care at that time. One possibility is whether these individuals misinterpreted the message that they didn't need medications to mean they didn't need medical care.

The survey results also show that many people do not think they needed medical care because they do not feel sick. This was the most frequently endorsed reason for both the in care and out of care groups. A number of focus group participants explained that the shock of learning their HIV status kept them away from seeking medical services, while others reported that drug use or mental health conditions interfered with their ability to seek medical care. Other causes that focus group participants reported for delaying their entry into care included lack of insurance or financial resources to pay for the services and a lack of knowledge as to what to do or where to find services.

Table 7. Reasons for Delaying Entry into Care

Reasons for delaying entry into care	In Care		Out of Care	
	N	%	N	%
I did not think that I needed medical care then because I wasn't sick	23	42.6	36	29.8
I was scared or nervous about going to a doctor or nurse about HIV	13	24.1	15	12.4
My doctor or nurse told me that I did not need medical care at that time	8	14.8	8	6.6
I did not want to receive medical care	8	14.8	17	14.0
I couldn't pay for medical care at that time	5	9.3	6	5.0
I did not think that medical care would do me any good	5	9.3	2	1.7
No one told me that I needed to get medical care for HIV	3	5.6	5	4.1
I did not find a doctor or nurse who I wanted to treat me	3	5.6	0	0.0
I did not know where to go for medical care	3	5.6	9	7.4
I used alternative treatments	2	3.7	2	1.7
Other*	5	12.8	11	9.1

Other reasons listed by out of care participants included denial, being in prison, waiting to die, or good viral load or CD4. Other reasons listed by in care participants included "I don't like pills", denial, alcoholism, no medical care available, and concern that medical care would jeopardize health insurance coverage.

*Reasons for currently being out of care*

When asked why they have been out of care in the past two years, almost one-third of participants said they did not need care because they were not sick (See Table 8). The prevalence of this response highlights an opportunity for intervention. Service providers also identified a similar barrier to care in their focus group and thought that one way to have people who don't feel sick get into and stay in care is to develop trusting relationships with PLWH/As. Another factor to consider is that some focus group participants who consider themselves to be out of care are actually having blood work done and are attentive to their viral load and t-cell counts.

Another frequently reported challenge keeping PLWH/As out of care is the burdens imposed by the lack of coordinated services. PLWH/As feel it is a 24/7 job to keep up with all the appointments and regimens associated with being in-care. Side effects of medications, complications associated with other untreated conditions, and a lack of financial resources to pay for medical services and transportation were also reported as reasons for staying out of care.

Table 8. Reasons why People were Out of Care within the Past 24 Months

Reasons for being out of care	Out of Care	
	N	%
I did not think that I needed medical care then because I wasn't sick	38	31.4
I didn't want to take the medications	26	21.5
I get scared or nervous about going to a doctor or nurse about HIV	16	13.2
I couldn't pay for medical care and/or medications	14	11.6
I did not want to receive medical care	16	13.2
I was in jail	14	11.6
My doctor or nurse told me that I did not need medical care at that time	13	10.7
I did not know where to go for medical care	4	3.3
I had not found a doctor I was comfortable with seeing for treatment	2	1.7
I did not have transportation to get to medical care appointments	1	0.8
I used alternative treatments	1	0.8
I couldn't get an appointment	0	0.0
I did not have child care for medical care appointments	0	0.0
Other	27	22.3
Missing	9	7.4

Other reasons for not being in care included homelessness, the hospital moved, relapsed, and kidneys.

*How do you keep people in medical care?*

In the out of care survey, participants were asked to report which services would help them stay in medical care for their HIV (See Table 9). Only 8% of participants said there was nothing that could be done to help them stay in care, suggesting that options do exist to encourage more PLWH/As to seek medical care. Insurance and help with basic needs were the most frequently endorsed solutions. Given that 63% of this sample has been homeless at some time and that 68% are low or very low on food security (see Table A2), it is not surprising that help with basic needs was identified as an important type of assistance for helping them to get into and to stay in care.

Focus group participants indicated that many services being offered could be improved, efforts which in turn would help them to seek medical care. Financial assistance to pay for medical costs is critical, as would be help with housing. Participants explained,

- “[HIV] is a big issue, this is like a lifetime issue that is going to be here forever but while I’m living I’m not going to be sleeping on the streets”

- “You need that housing to keep you, like you could be stable in the housing then your meds are set, then you can go for your mental status or substance abuse, co-dependencies.

Having services that are conveniently located and easy to access both geographically and in terms of office hours were also mentioned as improvements that would help PLWH/As receive medical care.

Table 9. Factors that Could Help PLWH/As Get into or Stay in Care

	N	%		N	%
Insurance	48	39.7	Referrals or advice	19	15.7
Help with basic needs (like housing or food)	38	31.4	Help identifying a doctor sensitive to my culture or needs	15	12.4
Case manager	29	24.0	Acute illness	12	9.9
Substance use treatment	28	23.1	Nothing	10	8.3
Better quality of services	23	19.0	Buddy/Peer to help me get care	7	5.8
Transportation	22	18.2	Child care	4	3.3
More outreach services	19	15.7	Other	20	16.5

A persistent theme in focus group sessions was the lack of coordinated services not only in terms of location but also how services are compartmentalized. Participants mentioned that many PLWH/As have co-dependencies that need to be treated as one big problem, not many small issues to be treated by a number of different doctors. Participants also reported the need to travel to multiple locations to receive the services needed. They suggested that having all services available under one roof would make seeking medical care much easier. Similarly, information about services available should be accessible on a 24 hour/7 days a week basis. Participants suggested that a website or a hotline could be created with updated information on services available as a tool for improving the lives of PLWH/As.

The need for respectful and culturally competent providers was an issue, although participants varied in how they described their needs. MSM and transgender participants indicated that hospital settings feel unwelcoming and make them feel hesitant about seeking services. They noted that having welcoming settings that feel like a house, inside and outside, would make them feel at ease. Female and transgendered participants believe that currently available services are highly oriented towards the male gay community. They feel stigmatized and left out of the system because of who they are in terms of being racial and gender minorities.

A recurring suggestion from focus group participants for addressing the cultural competence and comfort issue was to use peer counselors or people “like them.” One participant explained, “Someone with HIV can counsel someone else better than someone who has book smarts [...] They are going through the same thing, have been through the same thing.” This recommendation was supported by participants’ perception that PLWH/As know a lot about available services and feel comfortable talking with other PLWH/As. Participants thought that using peer counselors would help more people stay in care and the peer counselors could also benefit from the arrangement in terms of increased self esteem, having a sense of purpose and potentially improving their financial situation if it were a paid position.

## Conclusions

### *Prioritization of Service Funding*

- Medical care and medicines remain the top ranked services for funding.
- However basic needs (e.g., food, housing) take priority and when these needs are not met, PLWH/As have great difficulty remaining in HIV medical care.
- While transportation only ranked 8<sup>th</sup> in priority for service funding, it consistently was mentioned by survey and focus group participants as a barrier to accessing all other services and as a barrier to remaining in HIV care.

### *Utilization of Medical Care*

- What is HIV medical care and why participate?
  - Many people seem to equate medical care with taking medications. This is undesirable for several reasons.
    - People who are not prescribed HIV medications for valid medical reasons may believe that they are not receiving medical care or that they are receiving substandard medical care.
    - People who do not want to take medications may avoid seeking HIV medical care since they know of no other reason to engage in care.
    - People may not seek medical care until they feel sick because they do not think they need medications unless they are sick.
  - There appears to be an opportunity address the health literacy of the population and through health literacy potentially impact care utilization.
- Care status is a dynamic continuum, not a static dichotomous state.
  - Focus group participants report leaving and entering care throughout their history with HIV.
  - While some PLWH/As may always be in or out of care, it may be the case that the norm is for people to cycle in and out of HIV care.
  - The Council may want to explore this issue further in future needs assessments as it could have implications for outreach and retention in care efforts.
- Any delay in seeking medical care following diagnosis is undesirable.
  - Survey questions seem to define a delay in care entry as waiting at least a year before entering HIV care.
  - However, the data suggest that delaying first entry into care more than 3 months after diagnosis is related to current care status.
    - People who sought care within 3 months of their diagnosis were more likely to be in care currently.
    - The percentage of people delaying entry into care by more than 3 months varied significantly by high risk group,  $\chi^2(4, 288) = 11.2, p < .02$ .
      - WMSM = 50.5%
      - MCSM = 38.5%
      - Women = 25%
      - IDU = 41.95%
      - MSM/IDU = 58%

### *Service Accessibility*

- PLWH/As do find some needed services difficult to access.
  - In some cases, it appears that services may be available, but not accessed. For example, while 54% of in care participants earn less than \$10,000 per year and 65% of were low or very low on food security, only 34% reported receiving food stamps.
    - Do people know that they are eligible for services such as food stamps and if so, do they know how to sign up for those services?
  - In many cases, people knew about services but did not know what to do to get those services or were unable to access the service despite their attempts to do so.

- PLWH/As do not necessarily know what they need to stay in HIV care, particularly when first diagnosed. In addition, what services they need to stay in HIV care may change over time as life circumstances change.
  - One barrier to accessing services seems to be a lack of knowledge about what services are available and how to access those services.
  - Initial and continuing patient education about the range of services available, not just those they ask about, may help to reduce barriers to services and increase participation in medical care.

#### *Evaluation*

- Timing
  - The needs assessment is a large evaluation project. Previously, work on the project was limited to a few months a year.
  - Planning for the needs assessment should be on-going and not just in the few weeks prior to the start of data collection.
  - The current timeframe substantially limits the Council's ability to use information from prior needs assessments to improve the process and ensure that they are collecting valid data that will help them meet their objectives.
- Validity of Needs Assessment Data
  - The validity of the data in the Needs Assessment report is only as good as the survey used to collect the data.
    - While the survey was revised substantially from earlier editions prior to collecting data this year, there are multiple questions that still need to be revised and improved.
    - Some questions used in the past and still used are confusing to participants or have multiple different interpretations making it difficult to know what it meant by participants responses.
      - Examples of problem questions include the question asking participants to rank services and the question asking participants whether they need specific services.

## Appendix A

### Information Related to Currently Funded Service Categories

The current needs assessment incorporated two questions from the Urban Institute’s 2002 National Survey of American Families questionnaire to address difficulty paying for housing and utilities in the past year and a single question from the Illinois Family Study to assess homelessness in the past year. We additionally asked participants whether they had ever been homeless.

The results show that those who answered the survey are fairly transient. In care participants lived in an average of 1.7 places during the past 12 months. Out of care participants tended to move more often. On average, they lived in 2.0 places in the past 12 months. While we did not ask the reasons why people moved, the data in Table A1 suggest that the cost of housing may be one factor that influenced the decision to move. Analyses indicated that people who said they were unable to pay their mortgage, rent, or utility bills in the last 12 months lived in significantly more places in the last year than people who answered “No” to this question [In Care:  $F(1, 188) = 13.8, p < .001$ ; Out of Care:  $F(1, 113) = 19.4, p < .001$ ]

Table A1. The Number and Percent of Participants who Reported Housing Insecurity by Care Status

	In Care		Out of Care	
	N	%	N	%
Unable to pay mortgage, rent, or utility bills in last 12 months.				
Yes	112	54.1	73	60.3
Missing	3	1.4	0	0.0
Moved in with another person or had someone move in with them because they couldn’t afford mortgage, rent, or utility bills in last 12 months.				
Yes	66	31.9	59	48.8
Missing	9	5.3	0	0.0
Homeless in the past year				
Yes	61	29.5	54	44.6
Missing	10	4.8	0	0.0
Ever homeless				
Yes	118	57.0	68	56.2
Missing	15	7.3	2	1.7

Significantly more people who were out of care reported being homeless in the past year,  $\chi^2(1, 316) = 6.2, p < .01$ . Homelessness takes many forms including living on the streets, staying at a shelter, or staying with friends or relatives for short periods of time because there is nowhere else to stay. Depending on the form and duration, people may not self-identify as homeless and therefore these figures may underestimate the problem. In the current Needs Assessment, three in care participants and eight out of care participants reported they experienced living conditions that qualified them as homeless in the past year, but self-reported that they had never been homeless. Thus, rates of (ever) homelessness should be at least 58.5% for the in care sample and 62.8% for the out of care sample.

Table A2. Food Security by Care Status

	In Care		Out of Care	
Mean Food Security	2.0		2.0	
Food Security Category	N	%	N	%
High	51	24.6	33	27.3
Marginal	11	5.3	4	3.3
Low or Very Low	135	65.2	82	67.8
Missing	10	4.8	2	1.7

Basic subsistence needs are likely to impact the ability of individuals to seek HIV medical care. Three questions from the USDA’s U.S. Household Food Security Survey Module were included in both versions of the Needs Assessment. These are typically used as screening questions to determine whether the entire survey should be completed. We estimated food security on the basis of the screening questions because the entire survey could not be included in the Needs Assessment due to time constraints.

For the purpose of this survey, a score of 0 means an individual is high on food security and has no concerns about their ability to obtain quantity and quality of food to meet their nutritional needs. A score of 1 indicates marginal food security and a score of 2 or 3 indicates low to very low food security. Individuals who are low or very low on food security have on-going concerns about their ability to afford enough food, do not have money to purchase new food when they have no more food, and cannot afford to eat balanced meals.

Table A3. Substance abuse use and treatment by Care Status

	In Care		Out of Care	
	N	%	N	%
Since you got HIV, have you had any treatment for alcohol or drug use?				
Yes	75	36.2	41	33.9
Missing	2	1.0	0	0.0
Do you think you need treatment for alcohol or drug use now?				
Yes	45	21.7	54	44.6
Missing	2	1.0	2	1.7
Have you ever injected substances that were not given to you by a medical provider?				
Yes	71	34.3	58	47.9
Missing	5	2.4	2	1.7
Do you currently inject substances that are not given to you by a medical provider?				
Yes	16	7.7	24	19.8
Missing	3	1.5	2	1.7

On-going substance use and abuse can make it difficult for people to get into and stay in care. Providers typically rate substance abuse treatment as one of the most important services for funding, although clients tend to rate it lower. A similar percentage of in care and out of care participants reported receiving substance abuse treatment since their diagnosis, any use of injection drugs, and current usage of injection drugs. In contrast, a significantly higher percentage of out of care participants (45% vs. 22%)

reported a current need for substance abuse treatment,  $\chi^2(1, 324) = 19.5, p < .001$ . Several OOC focus group participants mentioned that HIV and substance abuse go hand-in-hand. They reported that sometimes HIV is a by-product of their drug addictions while other times they use drugs to cope with the fact that they are HIV positive. These data suggest that interventions targeted towards these individuals should address both problems at once.

As with many other services, focus group participants expressed that drug counseling is difficult to access because it is expensive.

- One participant shared, "Most people that want to quit can't afford to quit because they can't afford to go to the hospital or check into a rehab. If you don't have money oh well you are going to be in detox for two days and then you are back out on the streets."
- Another participant stated that cost was not a factor, "As far as substance abuse I don't care if you are in jail 10 years. It's about if you want it, if you have Medicare and Medicaid I was in 90 day inpatient alcohol and rehab I didn't have to pay a dime, not food or shelter. But some people don't want it."

Given the very different perspectives, it may be important to determine whether adequate funding is available and if available whether PLWH/As need more information about how to get funding for substance abuse treatment.

Table A4. Mental Health by Care Status

	In Care		Out of Care	
	N	%	N	%
Has anyone ever told you that you need mental health services	---	---	36	29.8
Since you got HIV, which mental health services have you used?*				
Individual therapy with a psychiatrist	75	36.2	---	---
Medicine prescribed by a psychiatrist	56	27.1	---	---
Individual therapy with a psychologist, social worker, etc	86	41.5	---	---
Group therapy with a psychologist, social worker, etc.	46	22.2	---	---
Was the treatment...?				
Outpatient	104	50.2	--	--
Inpatient	4	1.9	--	--
Both	11	5.3	--	--
Not Applicable	63	30.4	--	--
Missing	25	12.1	--	--

\*Values will not add up to 100% because participants could choose more than one response.

The in care and out of care surveys asked different questions about mental health issues. In the future, it would be helpful to have the same questions asked of all participants. Over 50% of in care participants have received mental health counseling. While not comparable, only 30% of out of care participants reported that others had told them they needed mental health services.

Table A5. Transportation Used to Access Services by In Care Participants

<b>Transportation Type*</b>	<b>N</b>	<b>%</b>
City bus or light rail	130	62.8
Own car	68	32.9
Walked or rode a bike	30	14.5
Rode with friend/family or borrowed their car	24	11.6
Taxi	7	3.4
Transportation service	9	4.3
Other	2	1.0
Missing	6	2.9

\*Values will not add up to 100% because participants could choose more than one response.

Table A6. Transportation Barrier Frequency by Service Type for In Care Participants

<b>Service</b>	<b>N Valid</b>	<b>Constantly / Often</b>	<b>Sometimes</b>	<b>Rarely / Never</b>
Basic services like food pantry, etc	174	29.3	16.1	54.6
Transportation	169	25.5	24.3	50.3
Social services like case managers, etc	168	20.2	19.6	60.1
Doctor appointments	198	17.2	21.7	61.2
Mental health or substance abuse appointments	155	16.8	16.1	67.1
Dental appointments	171	15.8	17.5	66.6
Child Care	102	12.7	3.9	83.3

Client participants were asked to report how often they had difficulty accessing different services on a five point scale ranging from Never to Constantly. For ease of interpretation, the scale was condensed to a three point scale in the table below. Participants reported the greatest difficulty getting from their home to basic services such as a food pantry and to transportation. Half or more of the respondents reported they rarely or never had difficulty accessing the service categories. While this could be interpreted to indicate that transportation is not a major barrier to accessing services, these data should be interpreted with caution. Participants were given the option to rate all of the services, not just those they utilized.

Participants may have stated they never had difficulty getting to a service because they didn't use the service. Responses related to child care services suggest that this confusion may have occurred.

## Appendix B Service Usage

Table B1. Percentage of In Care Participants Reporting Whether a Service was Available to Them

Service Category	Yes	No	Missing
Doctor's Office	94.7	1.0	4.3
Prescription Drugs	94.2	1.9	3.9
Case Management	83.1	5.8	11.1
Dental Care	83.1	10.1	6.8
Food Bank/Home Delivered Meals	79.2	10.1	10.6
Mental Health Services	76.8	11.6	11.6
Substance Abuse Services	69.1	14.0	16.9
Health Insurance Continuation	65.2	23.2	11.6
Client Advocacy	64.3	18.4	17.4
Transportation	67.6	19.3	13.0
Emergency Housing Assistance	63.8	20.8	15.5
Emergency Financial Aid	58.5	24.6	16.9
Home Health Care	40.6	36.2	23.2
Hospice	35.3	39.1	25.6

Participants were asked to report whether they thought the various service categories were available to them. Almost all participants reported that a Doctor's Office and Prescription Drugs were available to them. Multiple respondents did not provide a response for individual categories. One interpretation of the missing responses is they represent uncertainty about what the service is and/or whether they qualify for the service.

Table B2. Percentage of In Care Participants Reporting they Need a Service

<b>Service Category</b>	<b>Yes</b>	<b>No</b>	<b>Don't Know</b>	<b>Missing</b>
Dental Care	57.0	32.4	0.0	10.6
Prescription Drugs	50.7	38.6	0.5	10.1
Doctor's Office	50.2	39.6	0.0	10.1
Emergency Financial Aid	47.9	34.5	2.4	15.2
Food Bank/Home Delivered Meals	39.6	40.6	1.9	17.9
Case Management	39.6	40.1	1.9	18.4
Health Insurance Continuation	39.1	36.9	5.8	15.5
Transportation	38.6	38.6	1.4	21.3
Emergency Housing Assistance	31.4	46.4	1.4	20.8
Mental Health Services	29.5	48.3	3.9	18.4
Client Advocacy	24.6	46.4	4.8	24.2
Substance Abuse Services	21.3	54.6	1.4	22.7
Home Health Care	11.6	58.9	2.9	26.6
Hospice	7.2	63.3	1.9	27.5

Participants were asked to report whether they currently need different services. Throughout the data collection, it became clear that participants had different interpretations of this question. Some participants only reported they “needed” a service if they didn’t currently have it. For example, if someone had a doctor, then they reported they didn’t need one. Other participants interpreted the question in the manner intended. Specifically, if they need a doctor to live healthy with HIV, they responded yes to that service even if they already had a doctor. Due to participants interpreting the question in different ways, the data should be interpreted with caution. *This question was used in the prior needs assessment to determine the priority ranking of services.*

# Appendix C

## PLWH/A Focus Group Data

### Methodology

CRS conducted four focus groups with people who were not in medical care or who had recently been out of medical care. A fifth focus group was conducted with people who currently were in care. Since many of the people who attended the “in care” focus group reported being out of care at some point, the demographic information is collapsed across the in care and out of care groups. A summary of the qualitative data is provided below. Participant demographic characteristics can be found in Appendix D while information on care history is located at the end of this appendix.

Sessions were conducted in the offices of service provider organizations familiar to PLWH/A. Conversations were scheduled at times when service providers suggested would be easier to be attended by the target groups. Conversations were staffed by one facilitator and one note-taker from the Center for Research Strategies. Focus group sessions were audiotaped. Before the beginning of the sessions participants were asked to sign a consent form to participate and to be audiotaped.

A focus group protocol was developed to help guide the conversations. The main areas addressed during these sessions were:

- ✓ How many participants have actually been without medical care for a period of 12 or more months since they were diagnosed
- ✓ Reasons why they were out of medical care
- ✓ When they went out of care, what would had helped them stay in care or go back to care
- ✓ From a list of services we asked the following: 1) had they ever used that service; 2) how useful was the service; 3) how would they change the service to make it more useful and user-friendly.  
The services listed included:
  - Peer counseling
  - Intensive case management
  - Substance abuse counseling
  - Mental health services
  - Assistance with housing
  - Assistance with transportation

### Data analysis

Data collected via audiotapes were transcribed and complemented with the notes taken during the focus group sessions. A content analysis was performed to identify emerging themes. Data from each focus group session was individually analyzed. The following results are presented as overall findings of all the focus groups. Themes that were not mentioned by all of the groups are indicated throughout the Results section.

### Results

#### *Out of care status*

Although it was a minority of participants who were out of care at the time of the focus group sessions, all of them reported having been without medical care for a period of time since they were first diagnosed. Results indicate that it is common for participants to consider that not taking medications is the same as being out of care. Throughout the focus group conversations it was necessary to continually remind participants of this distinction.

### *Reasons for being out of care / barriers to medical care*

Results indicate that there are a variety of reasons why PLWH/A do not seek medical care. The following list of motives for being out-of-care are not presented in any particular order.

**Denial:** Some participants explained that when they first found out their HIV/AIDS diagnosis, they decided to ignore it and go on with their lives as if that was not happening to them. This denial stage may have lasted certain period of time immediately after diagnosis, but once medical care was sought, denial was not a reason mentioned by participants for deciding not to seek further medical care. In short, denial was a reason for being out of care only immediately after diagnosis.

**Not knowing what to do:** After finding out of their HIV positive status, many participants explained they didn't know what to do, where to look for help, figure out what services they would need. Only one participant mentioned that the diagnosis was provided to her with no additional counseling nor information on available services. Other participants shared that the mere shock of the diagnosis was enough to keep them away from seeking medical services.

**Other untreated conditions:** Participants explained that other conditions such as mental illness and drug and alcohol use interfere with their ability to seek medical care. They shared that HIV diagnosis frequently goes hand-in-hand with addictions and with mental illnesses, and that unless those conditions are addressed simultaneously, it is possible that PLWH/A will continue to stay out of medical care.

**Financial reasons:** A reason often mentioned for being out of care was the lack of financial resources to pay for medical appointments and medications. Participants explained that without medical insurance it is practically impossible to get medical services.

**Not a priority:** Participants shared that within the scope of their daily needs, obtaining medical care is not at the top of their list. Having a place to live and food on the table were ranked higher in their every day priorities.

**Complexity of the system:** All focus group participants mentioned that finding their way through what they felt was a very complex system of services was a 24/7 job. From finding what services are available, which of those services they qualify for, being able to complete all the needed paperwork, and actually getting the services is an overwhelming task for most of them. Some participants mentioned that seeking medical care was so time consuming and demanding that it was difficult to hold a job and receive medical services.

**Treatment side effects:** Several participants explained that the side effects of medications were so unbearable that they decided to stop taking medications. This is one of the cases where participants confused taking medications with receiving medical care. Nonetheless, the result was overall the same, because these participants did not report asking their healthcare providers for alternative medications with more tolerable side effects, they stayed away from medical treatment.

**Taking a break:** A common reaction to dealing with the complexities of the system and with treatment side effects was to take a break from receiving medical care. PLWH/A expressed a need to feel a "sense of normalcy" in their lives which was offered by these breaks from the HIV/AIDS medical system.

**Accessibility of services:** Participants explained that sometimes it was very difficult to receive services because the provider agencies are not accessible to them. Geographic location, lack of

transportation, and inconvenient providers' office hours contribute to the out of care status of PLWH/A. Although these services may not be medical services, all of them contribute to the burden of accessing medical care.

#### *Improving services*

Focus group participants addressed ways in which current services can be improved so they could seek and receive medical care. Participants' suggestions addressed the barriers listed above.

**Streamlining and better funding the medical system:** Participants suggested that simplifying and reducing the requirements to access medical care (getting rid of 'renewal' processes, accelerating time for paperwork) are necessary to increase the number of patients who receive medical care. Increasing funding to medical services (i.e., rehabilitation, /detox services, CACP, Medicaid, Ryan White) was also mentioned as a suggestion to improve this area of concern.

**Coordination of and information about services:** Focus group participants suggested that improving the information about what services are available, their eligibility criteria, and the streamlining the paperwork needed to access those services are necessary steps to help PLWH/A receive needed medical care. This information must be accurate, updated and complete. Specific suggestions included the creation of a database of services that can be accessed online and/or via a hotline (i.e., something similar to a 311 or 211 specific to HIV/AIDS). A recommendation was made to have college interns in charge of periodically updating this database.

**Comprehensive services:** Participants suggested that service providers should be trained in the identification and treatment of various concomitant conditions often present in PLWH/A (i.e., mental illness, substance abuse). A coordinated system that treats the whole person rather than just HIV could help to increase receiving medical care.

**Additional medical information:** PLWH/A suggested increasing their access to medical information so they are more knowledgeable about why they do not need treatment if their viral load is low and their t-cell count is high. They need to be better informed that even when they do not feel sick, they need to maintain medical care. They should also be informed of potential side effects of their medications and of medical studies that could be of their benefit to participate.

**Housing and food bank:** Participants expressed high dissatisfaction with the low availability of affordable housing and the lack of supplies in the food bank. They also mentioned the need of housing (i.e., transitional housing) where their medical condition is understood when coming out of the justice system. They suggested better funding in these areas.

**Peer counseling:** The majority of focus group participants mentioned that receiving information from people who are also HIV+ will be a welcome service. They explained that PLWH/A understand how they feel and what services they need. Because information is not readily available, other PLWH/A are sometimes better informed than case managers and counselors and would be better at providing this information and counseling each other on the best course of action for their disease. Having paid positions for peer counselors would have the added benefit of improving the financial situation of those who can take on those positions.

**Accessibility of services:** Having service agencies in locations that are more accessible via public transportation was a suggestion by many participants. Increasing their office hours to accommodate those PLWH/A who hold a full time job was another suggestion to support access to care.

**Transportation:** An overwhelming comment by focus group participants was to change the current token system of public transportation to one of monthly or annual passes. Participants mentioned that the lack of transportation is a major reason why they sometimes miss medical appointments. The reduced number of tokens they receive makes them choose which service to seek, with medical care being sometimes relegated after food needs are satisfied.

*Other issues raised by participants*

During the focus group sessions several comments were made by a handful of participants.

**Services for all:** Women, race minorities and transgender focus group participants complained that many services are tailored to the gay population. These participants felt discriminated against when seeking services that were not available to them. They suggested that all services should be made available to everyone regardless of gender, race, and sexual orientation. They also suggested cultural competence training for service providers to avoid negative attitudes towards these groups of patients.

**Housing for older PLWH/A:** One participant mentioned his concerns about what is being done to accommodate HIV+ who are getting old. He mentioned that very soon the population of PLWH/A will need special accommodations and none of those are currently available.

**Public attitudes towards HIV/AIDS:** Women participants expressed their concern about the public's stigma towards PLWH/A. They feel that the lack of knowledge of the general public about why some of them have HIV/AIDS (i.e., spouse/partner was a drug addict, victim of rape) excludes them from enjoying a complete life. They mentioned that they cannot openly talk about their diagnosis without risking losing their jobs or not getting a job. They suggested launching a public campaign such as the one for cancer ("I have cancer, cancer doesn't have me") and educating the public about the realities of HIV and AIDS.

Table C1. Self Report Out of Care History and Time between Diagnosis and First Receiving Care

	N	%		N	%
Ever Out of Care			Time between diagnosis and first receiving care		
Yes	27	67.5	Never received care	1	2.5
No	13	32.5	Within 3 months	9	22.5
			4 – 6 months	3	7.5
			7-12 months	2	5.0
			More than a year	1	2.5
			Don't know	1	2.5
			Missing	1	2.5

## Appendix D Participant Demographic Characteristics

Tables in Appendix D provide information about Participants' demographic characteristics. The same questions were not asked of survey and focus group participants so each table indicates the source of the data. Explanatory text was added only when needed to point out questions that were confusing to participants or to highlight important findings.

Table D1. Age of Participants by Group

	In Care Survey		Out of Care Survey		PLWH/A – Focus Group		Provider – Survey		Provider – Focus Group	
	N	%	N	%	N	%	N	%	N	%
Mean (years)	44.3		40.8		43.5		40.4		42.9	
Age Group	N	%	N	%	N	%	N	%	N	%
< 20	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0
20 - 29	15	7.2	19	15.7	2	5.0	7	17.9	0	0.0
30 – 39	33	15.9	27	22.3	8	20.0	12	30.8	6	46.2
40 – 49	102	49.3	54	44.6	21	52.5	9	23.1	3	23.1
> 49	50	24.2	19	15.7	9	22.5	8	20.5	4	30.8
Missing	7	3.4	2	1.7	0	0.0	3	7.7	0	0.0

Table D2. Gender of Participants by Group

	In Care Survey		Out of Care Survey		PLWH/A – Focus Group		Provider – Survey		Provider – Focus Group	
	N	%	N	%	N	%	N	%	N	%
Male	174	84.1	104	86.0	25	62.5	12	30.8	5	38.5
Female	28	13.5	16	13.2	12	30.0	24	61.5	8	61.5
Transgendered	4	1.9	1	0.8	3	7.5	0	0.0	0	0.0
Missing	1	0.5	0	0.0	0	0.0	3	7.7	0	0.0

### Citizenship

Almost all of the participants reported they were citizens of the United States. Ninety-three percent of in care participants reported United States Citizenship, while 5% were not citizens and almost 2% did not answer the question. Comparable data were observed among the out of care participants; 96% of participants were citizens of the United States.

Table D3. Race and Ethnicity of Participants by Group

	In Care – Survey		Out of Care – Survey		PLWH/A – Focus Group		Provider – Survey		Provider – Focus Group	
	N	%	N	%	N	%	N	%	N	%
<b>Ethnicity</b>										
Hispanic	44	21.3	19	15.7	9	22.5	9	23.1	4	30.8
Non-Hispanic	117	56.5	38	31.4	22	55.0	26	66.7	8	61.5
Missing	46	22.2	64	52.9	9	22.5	4	10.3	1	7.7
<b>Race</b>										
White	123	59.4	65	53.7	21	52.5	26	66.7	11	84.6
Black	34	16.4	31	25.6	11	27.5	3	7.7	0	0.0
Asian/Pacific Islander/ Native Hawaiian	1	0.5	0	0.0	0	0.0	0	0.0	0	0.0
American Indian	4	1.9	3	2.5	1	2.5	1	2.6	1	7.7
Multiple Race	12	5.8	4	3.3	1	2.5	2	5.1	0	0.0
Other	21	10.1	7	5.8	3	7.5	2	5.1	0	0.0
Missing	12	5.8	11	9.1	3	7.5	5	12.8	0	0.0

Table D4. Preferred Language of Participants

Language	In Care		Out of Care	
	N	%	N	%
English	188	90.8	114	94.2
Spanish	4	1.9	2	1.7
Both	10	4.8	2	1.7
Other	2	1.0	2	1.7
Missing	3	1.4	1	0.8

Table D5 Highest Educational Status Attained by Participants

	In Care		Out of Care	
	N	%	N	%
Less than high school degree	22	10.6	21	17.4
High school graduate/GED	63	30.4	36	29.8
Technical or Trade School	18	8.7	10	8.3
Some College or Associates degree	58	28.0	34	28.1
Degree from 4 year college	29	14.0	16	13.2
Graduate level degree	12	5.8	3	2.5
Other	2	1.0	1	0.8
Missing	3	1.4	0	0.0

Table D6. Current County of Residence for Participants

County	In Care		Out of Care	
	N	%	N	%
Adams	11	5.3	5	4.1
Arapahoe	11	5.3	12	9.9
Broomfield	0	0.0	0	0.0
Denver	178	86.0	99	81.8
Douglas	0	0.0	1	0.8
Jefferson	5	2.4	4	3.3
Other (Boulder)	1	0.5	0	0.0
Missing	1	0.5	0	0.0

Table D7. Current Relationship Status of Participants

	In Care		Out of Care	
	N	%	N	%
Single, never married	111	53.6	83	68.6
Legally married	9	4.3	7	5.8
Common Law/Partnered	39	18.8	11	9.1
Divorced	26	12.6	15	12.4
Widowed or partner died	11	5.3	3	2.5
Other	6	2.9	1	0.8
Missing	5	2.4	1	0.8

Table D8. Current Employment Status of Participants

	In Care		Out of Care	
	N	%	N	%
Employed				
Yes	76	36.7	52	43.0
No	129	62.3	69	57.0
Missing	2	1.0	0	0.0
Employment Category*				
Full-Time	31	40.8	27	51.9
Part-Time	41	53.9	21	40.4
Part-Time plus Disability	5	6.6	4	7.7
Unemployment Category**				
Full Disability	50	38.8	17	24.6
Student	5	3.9	5	7.2
Looking for work	29	22.5	15	21.7
Not Working	39	30.2	29	42.0
Retired	7	5.4	2	2.9
Other	0	0.0	5	7.2

\*Percent values reflect the percentage of employed individuals who fall within each category.

\*\* Percent values reflect the percentage of unemployed individuals who fall within each category.

Values may not add up to 100% because people could select more than one option.

Table D9. Current Income of Participants

Income Category	In Care		Out of Care	
	N	%	N	%
\$0 - \$9,999	112	54.1	67	55.4
\$10,000 - \$19,999	48	23.2	22	18.2
\$20,000 - \$29,999	17	8.2	19	15.7
\$30,000 - \$39,000	12	5.8	8	6.6
\$40,000 - \$49,000	3	1.4	2	1.7
Greater than \$50,000	4	1.9	3	2.5
Missing	11	5.3	0	0.0

Table D10. Percentage of In Care Participants Receiving Specific Benefits

Benefits	N	%	Benefits	N	%
HIV/AIDS drugs	101	48.8	Veterans assistance	3	1.4
Food Stamps	70	33.8	Retirement	3	1.4
Social Security Disability Income (SSDI)	61	29.5	WIC	2	1.0
Section 8 Housing	40	19.3	Worker's compensation	0	0.0
Rent supplement	30	14.5	Annuity/Life insurance payments	0	0.0
Supplemental Security Income (SSI)	28	13.5	Not eligible for benefits	14	6.8
Long term disability	27	13.0	Other assistance	19	9.2
Short term disability	3	1.4			

Various benefit programs are available to assist people in meeting their daily needs. Participants who are in medical care were asked to report which benefits they receive. The vast majority of participants (83.1%) report receiving one or more of the following benefits. These may still be a need to educate participants about eligibility for benefits as 7.1% of respondents with an income below \$10,000 did not report receiving benefits and 15.2% only reported receiving HIV/AIDS drugs. If their income is indeed below \$10,000, then they might qualify for other services such as food stamps. In future needs assessments, it would also be helpful to know which benefits out of care participants are receiving.

## Appendix E

### Participants' HIV Diagnosis and Medical Care History

Tables in Appendix E provide information about Participants' diagnosis and history of care for HIV. Explanatory text was added below the tables only when needed to point out questions that were confusing to participants or to highlight important findings.

Table E1. Participant HIV Status

Status	In Care		Out of Care	
	N	%	N	%
HIV positive with no symptoms	98	47.3	71	58.7
HIV positive with symptoms	37	17.9	22	18.2
Living with AIDS	68	32.9	28	23.1
I do not have HIV or AIDS	1	0.5	0	0.0
Missing	3	1.4	0	0.0

\*Please note that one participant said they do not have HIV or AIDS, but then said that they are receiving services for HIV or AIDS.

Some participants were confused about which HIV/AIDS category they should check. They were unsure what qualified as symptoms. There was also confusion over whether they had AIDS or HIV. In future versions of the survey, it would be helpful to clarify this question for participants.

Table E2. Self-Report of In Care Status

	In Care		Out of Care	
	N	%	N	%
Receiving HIV Medical Services	195	94.2	60	49.6
Not Receiving HIV Medical Services	6	2.9	54	44.6
Missing	6	2.9	7	5.8

Some participants were confused about whether they are currently receiving HIV medical services. Six in care participants said they were not receiving services, but then said they last received HIV medical care from a doctor or a nurse within the last year. Survey coordinators did help participants answer this question so I think the confusion is greater than indicated by the data.

Table E3. Most Recent Time Participants Received Medical Care for HIV

Time Since Last Medical Care	In Care		Out of Care	
	N	%	N	%
Never received care	0	0.0	8	6.6
Within the last 3 months	169	81.6	46	38.0
Within the last 4-6 months	29	14.0	13	10.7
Within the last 7-12 months	3	1.4	9	7.4
More than a year ago	1	0.6	32	26.4
Don't remember/Other	3	1.5	13	10.7
Missing	2	1.0	0	0.0

Table E4. Percentage of Participants Reporting a Lapse in Care of at Least 12 Months during the Past 24 Months

Lapse in Care	In Care		Out of Care	
	N	%	N	%
Yes	3	1.4	113	93.4
Missing	1	0.5	0	0.0

Table E5. Self-reported source of HIV Infection

	In Care		Out of Care		PLWH/A Focus Groups	
	N	%	N	%	N	%
Sex with a Man	160	77.3	31	62.0	93	76.9
Sharing Needles	39	18.8	10	20.0	28	23.1
Don't Know	15	7.2	9	18.0	10	8.3
Sex with a Woman	9	4.3	5	10.0	9	7.4
Blood Products/Transfusion	7	3.4	2	4.0	4	3.3
Other	8	3.9	0	0.0	0	0.0
Missing	1	0.5	0	0.0	0	0.0

Table E6. Years Since HIV Diagnosis Received

Years since Diagnosis	In Care		Out of Care		PLWH/A Focus Groups	
	N	%	N	%	N	%
0 – 5	41	19.8	55	45.5	13	32.5
6 – 10	53	25.6	23	19.0	8	20.0
11 – 15	43	20.8	20	16.5	8	20.0
16 – 20	33	15.9	9	7.4	4	10.0
> 20	29	14.0	9	7.4	6	15.0
Missing	8	3.9	5	4.1	1	2.5

Table E7. Source of HIV Diagnosis

	In Care		Out of Care	
	N	%	N	%
From an infectious disease or public health clinic	69	33.3	47	38.8
You went to the hospital or emergency room for another reason	54	26.1	16	13.2
From an outreach clinic or street outreach program that offered HIV testing	29	14.0	23	19.0
As part of a regular physical exam	21	10.1	22	18.2
Jail	12	5.8	5	4.1
You tried to donate blood/plasma	7	3.4	5	4.1
Partner tested positive so I got tested	3	1.4	2	1.7
Intake for substance abuse or mental health treatment	3	1.4	0	0.0
As part of regular care while pregnant	3	1.4	0	0.0
Other	6	2.9	4	3.3
Missing	1	0.5	1	0.8

Table E8. Residence at the Time of HIV Diagnosis

Residence	In Care		Out of Care	
	N	%	N	%
Denver	122	58.9	89	73.6
Colorado, not Denver	36	17.4	16	13.2
US, not Colorado	47	22.7	15	12.4
Outside of US	1	0.5	0	0.0
Missing	1	0.5	1	0.8

Table E9. Person who Suggested the Participant Should be Tested for HIV

	In Care		Out of Care	
	N	%	N	%
I asked the health care provider to test me	91	44.0	42	34.7
A health care provider suggested the test should be done	76	36.7	54	44.6
A friend or boyfriend suggested I get tested	10	4.8	7	5.8
Provider tested without asking (includes jail intake)	5	2.4	2	1.7
Partner tested positive	6	2.9	0	0.0
Other	15	7.2	15	12.4
Missing	4	1.9	1	0.8

Table E10. Location of HIV Care for In Care Participants

	N	%
Hospital/Hospital Clinic such as Denver Health, University Hospital or VA	170	82.1
Private Physician's Office/Clinic	36	17.4
Other	4	1.9
Missing	1	0.5

Table E11. Source of Insurance for In Care Participants

Insurance	N	%	Insurance	N	%
Colorado Indigent Care Program	87	42.0	Insurance through work	19	9.2
Medicare	45	21.7	COBRA	5	2.4
Medicaid	38	18.4	Veterans	3	1.4
No Health Insurance	32	15.5	Other	13	6.3
Ryan White Insurance Continuation	20	9.7	Missing	3	1.4

Table E12. HIV Medication Use and Payment Information for In Care Participants

	N	%
Currently taking HIV/AIDS Medications		
Yes	162	78.3
If taking medications, who pays for the medications		
ADAP	98	47.3
Private Insurance or HMO	18	8.7
Medicaid	26	12.6
CICP	40	19.3
Cover Colorado	0	0.0
Don't Know	2	1.0
Other	20	9.7
If not taking medications, why not?		
They have never been prescribed for me	24	54.5
My medical provider told me to stop taking them	7	15.9
I decided to stop taking them	7	15.9
Can't afford Medication	1	2.3
Missing	5	11.4

Table E13. Time since Last CD4 Count and Since Taking HIV Medication for Out of Care Participants

	CD4 Count		HIV Medication	
	N	%	N	%
Within 3 months	46	38.0	26	21.5
4 – 6 months ago	11	9.1	5	4.1
7 – 12 months ago	10	8.3	6	5.0
More than a year ago	30	24.8	23	19.0
Never	1	0.8	47	38.8
Don't know/remember	17	14.0	9	7.4
Missing	6	5.0	5	4.1

Table E14. Missed HIV Medical and Service Appointments for In Care Participants

	Mean	SD	Range
Medical Appointments	1.5	5.0	0 – 60
HIV Service Appointments	0.9	1.9	0 – 9

Table E15. Frequency of Sex with Regular and Casual Partners for In Care Participants

	Regular Male Partner		Casual Male Partner		Regular Female Partner		Casual Female Partner	
	N	%	N	%	N	%	N	%
Regularly	51	24.6	33	15.9	9	4.3	3	1.4
Infrequently	24	11.6	22	10.6	2	1.0	2	1.0
Almost Never	23	11.1	28	13.5	3	1.4	7	3.4
Never	74	35.7	67	32.4	106	51.2	106	51.2
Missing	35	16.9	57	27.5	87	42.0	89	43.0

Table E16. Frequency of Condom Use with Regular and Casual Partners for In Care Participants who Reported Having Sex with a Regular or Casual Partner

	Regular Partner		Casual Partner	
	N	%	N	%
All the time	49	45.0	32	35.2
Frequently	14	12.8	20	22.0
Sometimes	8	7.3	5	5.5
Rarely	12	11.0	13	14.3
Never	18	16.5	16	17.6
Missing	8	7.3	5	5.5

Failure to use condoms every time they have sex, puts PLWH/As at risk for transmitting HIV to their partner and at risk for contracting Sexually Transmitted Infections (STIs). In the past 12 months, 11.1% of in care and 10.0% of out of care participants reported an STI diagnosis.

## **Appendix F**

### **Recommendations for Future Evaluation**

The community needs assessment conducted for the Denver HIV Resources Planning Council is an important tool for planning HIV related services for the community. The effectiveness of the needs assessment depends upon careful planning and execution. To aid the Council in planning future needs assessment, we are providing feedback on the process and recommendations for future evaluation.

#### **Defining the Population and Subgroups within the Population**

A major emphasis of the needs assessment this year was the out of care population. As illustrated in Figure 1, care status is best conceptualized as a continuum ranging from acceptance of the diagnosis and full participation in continuous medical care to being unaware of or in denial about the diagnosis and not receiving any care. The qualitative data highlighted that care status is fluid and people frequently move in and out of care depending on life circumstances, current health status, and other factors.

Given the fluidity in care status, it seems artificial and inappropriate to categorize people as “in care” or “out of care” for the purpose of the survey. In its current format, in care and out of care participants complete different surveys. While there is overlap, there are also substantial differences which results in a loss of potentially useful information.

*Recommendation: In future years, consider using a single survey for all participants that includes a supplemental section that is only completed by people who have ever been out of care.*

#### **Continuity in Evaluation**

The Denver HIV Resources Planning Council has on-going evaluation needs. Given the level of resources devoted to evaluation, the Council may want to take steps to enhance the continuity of that evaluation process. Recommendations for enhancing the continuity include:

- *Develop a long term relationship with an evaluator.*
  - *If the Council decides that committing to a single evaluator is not in their best interest, the Council should consider ways that they can ensure all relevant evaluation materials are provided to new evaluators.*
- *Working with an evaluator, develop a long term plan for the Council's evaluation activities.*
- *Redefine evaluation as a continuous process rather than a once a year activity.*

#### **Survey Tool**

For the current Needs Assessment, a lot of effort was spent revising the existing survey instrument. These revisions occurred under tight time constraints and were not driven by the long term evaluation needs of the Council. Recommendations for enhancing the survey instrument include:

- *Work with an evaluator to streamline the survey instrument. A major emphasis should be placed on developing an instrument that is concise. Ensure that only questions relevant to the Council's evaluation objectives are included in the final instrument.*

- *Work with an evaluator to develop a core set of questions that can be used in all future Needs Assessments.*
  - *Pilot test the questions with the community to ensure that the meaning of the questions is clear even for those with low literacy.*
  - *Ensure that a Spanish translation of the core questions is available. Determine whether those core questions are culturally appropriate for the Latino population in the Denver metro area.*
- *Work with an evaluator to develop a pool of questions that can be used to assess non-core issues as needed. Non-core issues might be condom use, sexually transmitted diseases, mental health, substance abuse, etc. The non-core issues should be related to the long term plan.*
  - *Pilot test the questions with the community to ensure the meaning of the questions is clear even for those with low literacy.*
  - *Consider translating the non-core questions into Spanish. Consider developing a set of questions specific to the Latino population in the Denver metro area that address the cultural barriers that may impact care usage.*

## Appendix G - Methodology

### Survey Sample

A convenience sample of PLWH/A within the Denver metropolitan region completed the surveys. Prior to collecting data, target recruitment numbers were set for the following five high risk groups:

1. White MSM (Men Who Have Sex with Men)
2. MCSM (Men of Color Who Have Sex with Men)
3. Women of Color
4. IDU (Injection Drug Users)
5. MSM/IDU (Men Who Have Sex with Men who are also Injection Drug Users)

The number of target participants within each high risk group was determined in the following way:

1. Set the final sample size (N = 200 for in care and 200 for out of care)
2. Determine the percentage of PLWH/As in each high risk group within the DEMA.
3. Oversample all groups except for MSM by 50%. The target percentage for MSM was determined after the percentages for the other groups were set.

Table G1. Method for Determining Target In Care and Out of Care Sample Size

High Risk Group	Population Percentage*	Multiplier	Target Percentage	Target In Care Sample	Target Out of Care Sample
MSM	57	---	35.5	71	71
MCSM	19	1.5	28.5	57	57
Women of Color	6	1.5	9.0	18	18
IDU	8	1.5	12.0	24	24
MSM/IDU	10	1.5	15.0	30	30
<b>Total</b>	<b>100</b>	<b>---</b>	<b>100.0</b>	<b>200</b>	<b>200</b>

\*Population percentages derived from the 2006 Needs Assessment Report

This method for determining the sample size differs from the method used in the 2006 Needs Assessment. In 2006, the evaluators chose to sample an equal number of people from each of the high risk groups. Unfortunately, that method gives too much weight to the data from groups that represent a fraction of the population of PLWH/As. The current method oversamples the smaller groups so that data can be broken down by high risk group if desired, but does not result in equal representation across the groups which would not be desirable.

Table G2. Actual In Care and Out of Care Sample by High Risk Group

High Risk Group	Target Sample	Actual In Care Sample (N)	Actual In Care Sample (%)	**Actual Out of Care Sample (N)	Actual Out of Care Sample (%)
MSM	71	71	34.3	39	32.2
MCSM	57	58	28.0	32	26.4
Women of Color	18	21*	10.1	13	10.7
IDU	24	21	10.1	14	11.6
MSM/IDU	30	36	17.4	23	19.0
<b>Total</b>	<b>200</b>	<b>207</b>	<b>100.0</b>	<b>121</b>	<b>100.0</b>

\*Four women were Caucasian.

\*\*Due to the difficulty reaching Out of Care Participants and the great depth of information obtained from the focus groups, it was determined that a smaller Out of Care survey sample was acceptable.

## **Definition of Subgroups**

Participants completed a screening questionnaire to determine their care status and their high risk group. As mentioned above, the distinction between in care and out of care is not always clear because care status appears to be a fluid state in this population. For the purpose of the survey, people were classified as Out of Care if they met the following conditions:

1. Not receiving medical services for HIV OR
2. Last saw a doctor or nurse for HIV care more than a year ago OR
3. In the past 24 months, did not see a doctor or nurse for HIV care for at least 12 months in a row.

Condition three was added to ensure that we captured the people who recently entered care after a lapse in care.

## **Survey Recruitment**

Recruitment is critical to the success of a community needs assessment of high risk, hard to reach populations. We would recommend that the Council retain information about which recruitment efforts were successful and which were not successful so that in future needs assessments, evaluators can utilize approaches that have previously been successful and supplement those as necessary.

### *In Care Participants*

In care participants were primarily recruited within agency settings and had to complete the survey on-site in order to participate. The requirement to participate on-site was present because it was assumed the in care sample would be easy to obtain and because the survey was too long and cumbersome to complete over the phone.

The agencies recommended by the Council were used as initial recruitment sites, but efforts were later expanded beyond those agencies to ensure an adequate number of PLWH/As could be reached for the needs assessment. Recruitment occurred at the following locations:

- Hospitals: Denver Health, University Hospital
- Major Service Agencies: Colorado AIDS Project, Empowerment, It Takes a Village, Mile High Council, Servicios de la Raza
- Other Service Agencies: ARTS, Howard Dental, the Gathering Place, Hope Project, Women's Lighthouse Project

### *Out of Care Participants*

Out of care participants had the option of completing the survey in person or over the phone. The phone option was added because it was reported to be a successful strategy in the past. While we anticipated that in care participants would refer out of care PLWH/As they knew to participate in the study that did not happen. People who were out of care were recruited to participate if they were found at the locations where in care participants were recruited. In addition, we engaged in advertising and outreach efforts.

These included:

- Posting/distributing flyers at bars, parks, bathhouses, agencies that do community outreach, and homeless agencies.
- On-site recruitment at bars that cater to the high risk groups identified for the study.

### *PLWH/A Focus Group Recruitment*

Focus group recruitment occurred during the survey recruitment. People identified as out of care during the month of March were invited by the survey coordinator to participate in a focus group. In addition, in care participants who completed the survey at Denver Health were invited to participate in a focus group.

## **Compensation**

All PLWH/A participants received a King Soopers gift card for participating in the needs assessment.

Compensation varied as follows:

- In Care Survey: \$10
- Out of Care Survey: \$15
- Focus Group: \$25

## References

<sup>1</sup>U.S. Department of Health and Human Services. *Healthy People 2010: Understanding and Improving Health*. 2<sup>nd</sup> ed. With Understanding and Improving Health Objectives for Improving Health. 2 vols. Washington, DC: U.S. Government Printing Office, November 2000. Accessed June 4, 2008 from <http://www.healthypeople.gov/Document/pdf/uih/2010uih.pdf>.

<sup>2</sup> Table 1: Annual Estimates of the Population of Metropolitan and Micropolitan Statistical Areas: April 1, 2000 to July 1, 2006. *2006 Population Estimates*. U.S. Census Bureau, Population Division. Accessed 20 February 2008 from <http://www.census.gov/population/www/estimates/CBSA-est2006-annual.html>.

<sup>3</sup> HIV/STD Surveillance, Colorado Department of Public Health and Environment. Accessed 23 October 2007 from <http://www.cdphe.state.co.us/dc/HIVandSTD/surveillance.html> .