

2008 HIV/AIDS CARE AND TREATMENT NEEDS ASSESSMENT REPORT

**Susan Luerssen, PhD
Bryan Knepper, MPH
George Ware, MS**

**Research and Evaluation Unit
STI/HIV Section
Colorado Department of Public Health and Environment
4300 Cherry Creek Drive South
Denver, Colorado 80246**

January 2009

For further information about the data summarized in this report call Susan Luerssen (303-692-2792) or George Ware (303-692-2762). For more information about HIV care and treatment in Colorado call Bob Bongiovanni (303-692-2703).

Introduction

HIV/AIDS remains a major health concern in Colorado with approximately 400 new cases diagnosed annually. As of mid-year 2008, 10,619 people with an HIV diagnosis were reported to be living in Colorado. It is within the purview of the STI/HIV Section at the Colorado Department of Public Health and Environment (CDPHE) to ensure, to the extent possible, that people living with HIV (PLWH) in the state are receiving the medical care, prevention, and other services they need. Following requirements imposed by the Health Resources and Services Agency (HRSA), the HIV Care and Treatment Program at CDPHE conducts a needs assessment with PLWH approximately every three years. The results of the needs assessments are then used in setting priorities for the allocation of funds, developing a comprehensive plan, assessing the quality of programs, and designing implementation plans to address identified needs.

The Research and Evaluation Unit in collaboration with the HIV Care and Treatment Program developed plans for this current needs assessment in September of 2008 and data collection began soon after. Three principal areas were explored as part of the assessment. The first concerned people's access to medical care and related services, including reasons why some people are not receiving such services. The second area focused on issues of retaining people in care. The third focus area identified people's opinions about the quality of medical care and other services that they have received and their suggestions for improving those services. Other related topics explored as part of the needs assessment included: the most important issues faced by PLWH, their most important needs, the gifts and assets of PLWH that are or could be utilized in improving people's lives, and people's visions of what Colorado would be like if it were an ideal place for PLWH to live.

Methods

Four principal methods were used to gather information for this assessment. First, aggregate data compiled by the CDPHE STI/HIV Section Surveillance program was used to provide a current profile of the HIV epidemic in Colorado, including the number of PLWH reported to have received CD4 or viral load tests within the previous year. Second, short and long versions of a survey (both available in Spanish and English) were sent to PLWH who were enrollees in the AIDS Drug Assistance Program (ADAP) or clients of AIDS Service Organizations (ASO) that serve populations outside of Denver. The shorter version of the survey was made available to people living in the Denver Metropolitan Area (DMA), and the longer version was provided to those living in other parts of Colorado. Persons residing in the DMA were sent the abbreviated survey to avoid duplicating the work of the Denver HIV Resources Planning Council that had conducted a needs assessment with PLWH earlier in 2008. A total of 412 people responded to the shorter version of the survey either by mail or on-line. Another 269 persons responded to the survey for persons living outside of the DMA. All survey respondents were receiving or had recently received some type of HIV care-related services. The third data collection method used for this needs assessment involved conducting five focus groups with 43 clients of ASOs in various parts of the state including Boulder, Fort Collins, Grand Junction, Colorado Springs, and Pueblo. Additionally, interviews were conducted with seven PLWH who were or had previously been "out of care," meaning that they were not accessing medical or other services related to their HIV infections. Finally, three people with extensive experience working with PLWH who were out of care were interviewed as key informants.

Coloradans In and Out of Care

As of June 30, 2008, 10,619 people were reported to be living with HIV in Colorado. Of those, 4,507 had a reported AIDS diagnosis. It is difficult to estimate the proportion of people diagnosed with HIV who are receiving medical and other related services in the state. The STI/HIV Section's Surveillance Program is only able to consistently track two indicators of care among reported cases: the results of CD4 and viral load tests reported to the CDPHE by laboratories and medical providers. However, according to Colorado Board of Health regulations, only CD4 counts below 500 or 29 percent are required to be reported to CDPHE. Therefore, many of the test results are not reported, especially for people who do not have an AIDS diagnosis. The state of Colorado considers a person to be "out of care" when there is no evidence that s/he received a CD4, viral load test, or anti-retroviral therapy for a period of 12 months. Given that CDPHE does not receive complete information on these indicators, out of care estimates for HIV and AIDS cases are by nature inaccurate. However, out of care estimates for people with a reported AIDS diagnosis are likely to be somewhat more accurate given that the case definition for AIDS includes a CD4 count below 200 or less than 14 percent, and, therefore, all tests that are conducted are required to be reported. Table One provides a demographic breakdown of people living with AIDS (PLWA) in Colorado who are considered to be in and out of care based on these criteria. According to this estimate, 1,748 PLWA in Colorado may be out of care. The highest percentages of people out of care are seen among injection drug users (IDU) (including men who have sex with men [MSM] with a history of IDU), people over the age of 49, people living in rural counties, and people diagnosed with HIV before the year 2000.

Table One: People Living With AIDS in Colorado With and Without Reported CD4 or Viral Load Test in the Previous Year

Category	Group	Tested		Not Tested		Total	
		n	%	n	%	n	%
Gender	Male	2,426	60%	1,591	40%	4,017	89%
	Female	333	68%	157	32%	490	11%
Race/Ethnicity	Black	397	58%	286	42%	683	15%
	Latino	600	66%	307	34%	907	20%
	White	1,704	61%	1,112	39%	2,816	62%
	Other	58	57%	43	43%	101	2%
Age Group	< 15	2	67%	1	33%	3	0%
	15 – 19	2	100%	0	0%	2	0%
	20 – 29	131	76%	41	24%	172	4%
	30 – 39	527	66%	274	34%	801	18%
	40 – 49	1,216	62%	746	38%	1,962	44%
	50 – 59	677	57%	505	43%	1,182	26%
	> 59	203	53%	179	47%	382	8%
Missing	1	---	2	---	3	0%	
Risk Group	MSM	1,784	63%	1,056	37%	2,840	63%
	MSM/IDU	239	59%	166	41%	405	9%
	IDU	241	54%	202	46%	443	10%
	HRH	300	64%	168	36%	468	10%
	NIR	171	57%	131	43%	302	7%
	Other	24	49%	25	51%	49	1%
County	Adams	157	70%	68	30%	225	5%
	Arapahoe	262	59%	180	41%	442	10%
	Boulder	110	62%	67	38%	177	4%
	Denver	1,487	62%	914	38%	2,401	53%
	El Paso	171	58%	125	42%	296	7%
	Fremont	69	58%	50	42%	119	3%
	Jefferson	173	61%	111	39%	284	6%
	Larimer	55	60%	36	40%	91	2%
	Pueblo	46	61%	30	39%	76	2%
	Weld	43	64%	24	36%	67	1%
	Other DMA (2 Counties)	32	64%	18	36%	50	1%
	Rural (43 Counties)	153	55%	125	45%	278	6%
Missing	1	---	0	---	1	0%	
Year of Diagnosis	1985 - 1989	30	33%	60	67%	90	2%
	1990 - 1994	341	44%	436	56%	777	17%
	1995 – 1999	724	54%	605	46%	1,329	29%
	2000 – 2004	795	63%	465	37%	1,260	28%
	2005 - 2007	749	81%	178	19%	927	21%
	2008 (through 6/30)	120	97%	4	3%	124	3%
Total		2,759	61%	1,748	39%	4,507	100%

Survey Results

A total of 681 PLWH responded to one of the two versions of the survey distributed for this needs assessment, including 412 people responding to the shorter version and 269 to the longer version. Given that the survey was only distributed to people who were enrolled in ADAP or who were clients of ASOs, all of those responding to the survey would be considered to be receiving services, or “in care”. Therefore, survey results do not include responses from people “out of care” and should not be considered as representing their views. Table Two provides a general demographic comparison of the overall epidemic in Colorado and the survey respondents. Table Three provides a more detailed demographic profile of the people responding to both the longer and shorter versions of the survey.

Table Two: Demographic Comparison of Coloradoans Living With HIV/AIDS and Survey Respondents

Category	Care and Treatment Survey Respondents						Current Colorado Statistics					
	Total		AIDS Diagnosis		No AIDS Diagnosis		Persons Living with HIV/AIDS		Persons Living With AIDS		Persons Living with HIV	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
Total	681		299		359		10,613		4,511		6,102	
Sex												
Male	561	82.74%	234	79.05%	310	86.35%	9,474	89.27%	4,023	89.20%	5,451	89.30%
Female	113	16.67%	62	20.95%	49	13.65%	1,139	10.73%	488	10.80%	651	10.70%
Unknown/Other	7	1.03%	3	1.00%	1	0.28%	-	-	-	-	-	-
Total	681		299		359		10,613		4,511		6,102	
Race												
White-Not Hispanic	386	57.31%	161	40.57%	218	60.87%	6,999	65.95%	2,815	62.40%	4,184	68.60%
Black-Not Hispanic	86	13.01%	46	20.49%	37	10.60%	1,497	14.11%	679	15.10%	818	13.40%
Hispanic	158	23.10%	55	28.69%	78	21.20%	1,847	17.40%	918	20.40%	929	15.20%
Asian/Pacific Islander	7	1.46%	4	2.05%	4	1.36%	86	0.81%	40	0.90%	46	0.80%
American Indian/Alaska Nat.	5	3.51%	2	4.92%	4	3.26%	86	0.81%	41	0.90%	45	0.70%
Multiple Races- Not Hispanic	16	1.61%	10	4.10%	6	2.73%	31	0.29%	18	0.40%	13	0.20%
Unknown/Other Race	23	3.38%	-	-	-	-	67	0.63%	-	-	67	1.10%
Total	681		278		347		10,613		4,511		6,102	
Age at HIV Diagnosis												
13-24	80	13.02%	40	14.34%	40	11.80%	1,202	11.33%	185	4.00%	1,057	17.20%
25-44	438	70.79%	198	70.97%	240	70.80%	7,774	73.25%	3,330	73.80%	4,444	72.80%
45-64	96	15.40%	40	14.34%	56	16.52%	1,542	14.53%	962	21.30%	580	9.50%
65 Years and Older	4	0.79%	1	0.36%	3	0.88%	55	0.52%	34	0.80%	21	0.30%
Other	4	0.59%	2	0.67%	2	0.55%	-	-	-	-	-	-
Missing	59	8.66%	18	6.02%	20	5.54%	-	-	-	-	-	-
Total	681		299		361		10,573		4,511		6,102	

Table Three: Demographic Profile of Survey Respondents (N=681)

Category	Frequency	Percent
<u>Gender</u>		
Male	561	82.38%
Female	113	16.59%
Transgender M to F	4	0.59%
Did not answer	3	0.44%
Total	681	
<u>Current Age</u>		
13-24	12	1.76%
25-44	261	38.33%
45-64	360	52.86%
65 Years and Older	28	4.11%
Did not answer	20	2.94%
Total	681	
<u>Race</u>		
White-Not Hispanic	386	57.31%
Black-Not Hispanic	86	13.01%
Hispanic	158	23.10%
Asian/Pacific Islander	7	1.46%
American Indian/Alaska Native	5	3.51%
Multiple Races- Not Hispanic	16	1.61%
Did not answer	23	3.38%
Total	681	
<u>Sexual Orientation</u>		
Heterosexual/Straight	188	27.62%
Homosexual/Gay or Lesbian	417	61.23%
Bisexual	45	6.61%
Other	12	1.76%
Did not answer	19	2.79%
Total	681	
<u>Income</u>		
<\$8,000	187	27.46%
\$8,001 - \$10,400	135	19.82%
\$10,401 - \$20,800	201	29.52%
\$20,801 - \$31,200	68	9.99%
>\$31,200	58	8.52%
Did not answer	32	4.70%
Total	681	

Category	Frequency	Percent
<u>Education</u>		
Less than High School	71	10.43%
High School/GED	272	39.94%
Technical School Degree	72	10.57%
Four-Year College Degree	89	13.07%
Two-Year College Degree	34	4.99%
Graduate Degree	49	7.20%
Other	75	11.01%
Did not answer	19	2.79%
Total	681	
<u>Colorado Region</u>		
North Central	36	5.29%
Northeast	42	6.17%
Not Valid/Missing	37	5.43%
Out of Area	3	0.44%
South	131	19.24%
Transitional Grant Area	390	57.27%
West	42	6.17%
Total	681	
<u>Country of Origin</u>		
USA	585	85.90%
Outside of USA	86	12.63%
Did Not Answer	10	1.47%
Total	681	
<u>Diagnosis</u>		
AIDS	299	43.91%
HIV	361	53.01%
Did not answer	21	3.08%
Total	681	
<u>Served Time in Jail Since Diagnosis</u>		
Yes	123	18.06%
Less than One Month	48	39.02%
One Month to One Year	34	27.64%
More than One Year	41	33.33%
No	540	79.30%
Did Not Answer	18	2.64%
Total	681	

In addition to the responses to the demographic questions summarized above, additional information was gathered from the respondents to the longer version of the survey. The first set of questions asked for information on people's living situations, including any experiences they may have had with homelessness in the previous two years, their current housing situations, and the physical conditions and levels of safety in the places where they live. These responses are summarized in Table Four. Approximately nine percent of the respondents to the longer survey had considered themselves to be homeless at some time during the previous two years. None reported

being homeless at the time they were responding to the survey, although 22 percent considered their housing situation to be temporary. Close to 85 percent rated their housing conditions and the level of safety of their residences as excellent or good.

Table Four: Housing and Living Conditions (N=269)

	Frequency	Percent
<u>Homeless in the Past Two Years</u>		
Yes	24	8.92%
No	239	88.85%
Did Not Answer	6	2.23%
<u>Current Living Situation</u>		
Permanent Housing	202	75.09%
Temporary Housing	59	21.93%
Homeless	0	0.00%
Institution	3	1.12%
Did Not Answer	5	1.86%
<u>Physical Conditions of Residence</u>		
Excellent	129	47.96%
Good	99	36.80%
Fair	31	11.52%
Poor	6	2.23%
Did Not Answer	4	1.49%
<u>Level of Safety of Residence</u>		
Excellent	149	55.39%
Good	79	29.37%
Fair	30	11.15%
Poor	6	2.23%
Did Not Answer	5	1.86%

Table Five provides general information about issues related to substance use and mental health, including people’s assessments of their experiences and their need for services related to these issues. Approximately 17 percent of the respondents reported that they thought they should cut down on their use of alcohol or drugs; however, only eight percent reported needing help cutting down on their substance use. Over half of the sample (52 percent) reported not using alcohol or drugs at all. Although 60 percent of the sample rated their emotional health as excellent or good, 58 percent reported having feelings of sadness, low self-esteem, loneliness, or shame that significantly affected their normal activities in the previous 12 months. Close to 49 percent reported needing help dealing with emotional issues. Sixty percent of those responding to the longer survey reported having been diagnosed with a mental illness.

Table Five: Substance Use and Mental Health (N=269)

<u>Should Cut Down on Use of Alcohol/Drugs</u>	<u>Frequency</u>	<u>Percent</u>
Yes	46	17.10%
No	73	27.14%
Don't Use	141	52.42%
Did Not Answer	9	3.35%
Total	269	
<u>Needed Help Cutting Down on use of Alcohol/Drugs</u>		
Yes	22	8.18%
No	81	30.11%
Don't Use	124	46.10%
Did Not Answer	42	15.61%
Total	269	
<u>Description of Overall Emotional Health</u>		
Excellent	48	17.84%
Good	114	42.38%
Fair	83	30.86%
Poor	20	7.43%
Did Not Answer	4	1.49%
Total	269	
<u>Symptoms of Depression in past 12 Months</u>		
Yes	157	58.36%
No	106	39.41%
Did Not Answer	6	2.23%
Total	269	
<u>Needed Help Dealing with Emotional Issues in Past 12 Months</u>		
Yes	131	48.70%
No	129	47.96%
Did Not Answer	9	3.35%
Total	269	
<u>Told by a MH provider that had any of following conditions</u>		
Depression	126	46.84%
Anxiety	91	33.83%
Bipolar	36	13.38%
Obsessive Compulsive	13	4.83%
Schizophrenia	2	0.74%
Other	17	6.32%

Three open-ended questions asked for respondents' opinions about: 1) the most important issues faced by PLWH; 2) the most important needs of PLWH; and 3) ways to improve the lives of PLWH. These questions were not included in the shorter version of the survey. A large number of people filling out the survey did not respond to these open-ended questions.

Table Six displays the categories of responses offered by the 164 people who responded to the first question about important issues. Two of the most frequent responses concerned people's access to HIV medications and to medical care. Issues were raised about the cost and availability of care and treatment as well as about the quality of care. People living outside of the Denver area expressed particular concern about the lack of availability of quality medical care in their areas. The high costs and limited level of coverage of insurance plans were also discussed, along with the requirements for accessing insurance and medical assistance plans that many found problematic. Another set of topics that were raised most commonly concerned the high degree of stigma and discrimination surrounding HIV and the difficult experiences faced by PLWH as a result. Respondents cited problems in their jobs, with housing, with family and friends, and with partners that could be quite painful. Some mentioned having been victimized or fearing possible victimization. Due to stigma and discrimination, a number of respondents expressed fear of their confidentiality being breached. Issues related to financial matters and meeting basic needs were also commonly discussed, including difficulties accessing jobs and income, appropriate housing, transportation, and healthy food. Additionally, respondents frequently discussed the importance of issues related to their emotional well-being. These included: 1) emotional disorders such as depression, anxiety, fear, loneliness, and shame; 2) the need for support, compassion, and acceptance; 3) and access to mental health services.

Table Six: Most important issues faced by PLWH (N=164)	Frequency	Percent
Issues concerning health status, health care, and treatment		
Access to medication (including cost)	58	35.37%
Access to medical care (including cost and quality)	53	32.32%
Access to health insurance	26	15.85%
Staying healthy	19	11.59%
Difficulties with service requirements	5	3.05%
Finding a vaccine/cure; research	4	2.44%
Access to dental care	4	2.44%
Drug side effects/complications	3	1.83%
Access to supplements; alternate care	2	1.22%
Social concerns		
Discrimination; poor treatment; stigma; victimization;	53	32.32%
Confidentiality	8	4.88%
Partners/dating/relationships	8	4.88%
Disclosing status; confiding in people	7	4.27%
Issues related to basic needs		
Poverty; financial issues; jobs; meeting basic needs	34	20.73%
Access to appropriate housing	13	7.93%
Access to transportation	9	5.49%
Appropriate nutrition	8	4.88%
Issues concerning mental health		
Depression; anxiety; stress; feelings of isolation and shame	19	11.59%
Need for emotional support; compassion; acceptance	17	10.37%
Access to mental health care	11	6.71%
Fear; insecurity about future	9	5.49%
Happiness; quality of life	3	1.83%
Personal acceptance of diagnosis	2	1.22%
Other Issues		
Need for HIV education; information	7	4.27%
Accessing other services; knowing about them	7	4.27%
Substance use/abuse	2	1.22%
Need for legal assistance	2	1.22%

Health and health care issues topped the list of most important needs of PLWH (Table Seven). These included access to quality care and treatment in the areas where people live, the importance of staying healthy, and better access to related services. The second most discussed needs concerned people's ability to earn income and meet their basic needs, including those for good nutrition, adequate housing, and transportation. The third set of needs emphasized the importance of emotional well-being, including: needs for support from friends, family, and others around them; access to mental health care; and support from other PLWH. Social needs, especially the need for social acceptance and the absence of stigma and discrimination, were also commonly emphasized as being most important to the respondents.

Table Seven: Most important needs of PLWH (N=152)	Frequency	Percent
Needs related to health, health care, and treatment		
Access to medications	97	63.82%
Access to medical care	88	57.89%
Insurance	15	9.87%
Dental care	12	7.89%
Staying healthy	9	5.92%
Exercise	7	4.61%
Alternative care; supplements	5	3.29%
Case management	4	2.63%
Quality medical services available locally	4	2.63%
Health care for non-HIV problems; preventive care	3	1.97%
Fewer restrictions for services	2	1.31%
Access to basic needs		
Good nutrition; food;	47	30.92%
Financial support; income; jobs	40	26.32%
Housing/shelter	35	23.03%
Transportation	10	6.58%
Job training/education	4	2.63%
Needs related to mental health		
Emotional/social support/understanding	29	19.08%
Mental health care/counseling	26	17.11%
Peace of mind; stress free; happiness; positive attitude	9	5.92%
Support among PLWH; support groups	9	5.92%
Faith; spiritual needs	3	1.97%
Social needs		
Acceptance/respect; no discrimination	11	7.24%
Companionship; social connection; acceptance	9	5.92%
Privacy; maintaining confidentiality	5	3.29%
Being safe; disclosure	3	1.97%
Public education	2	1.31%
Other Needs		
Health information; HIV education; updates	11	7.24%
Substance abuse treatment	3	1.97%
Outreach programs	2	1.31%
Legal assistance	2	1.31%

Table Eight summarizes respondents' recommendations for improving the lives of PLWH. These included service recommendations as well as recommendations to other people living with HIV. Increasing access, lowering costs, and improving quality were among the most common suggestions related to health and health care. Altering the requirements involved in accessing services was also commonly mentioned including decreasing the amount of "red tape" involved and lessening restrictions as to who can receive services. Other service recommendations included ideas related to: improving access to mental health services and support groups; increasing access to income, good nutrition, appropriate housing, and transportation; increasing funding for HIV-related programs and expanding and improving services such as HIV education and prevention programs; and better advertising of available programs. Recommendations around meeting social needs

concerned addressing social stigma and discrimination, improving social support, and providing more opportunities for PLWH to socialize with each other. Recommendations to PLWH included: trying to live a normal, happy, and healthy life; eating well, getting exercise, and avoiding substance use; taking medications as prescribed and keeping regular doctor's appointments; and accessing the other services that are available to them.

Table Eight: Recommendations to improve lives of PLWH (N=183)	Frequency	Percent
Recommendations about health care and treatment services		
Increase access to medical care	26	14.21%
Improved treatment by doctors (personal and medical)	12	6.56%
Lower drug prices and care costs	12	6.56%
Improve service requirements; less red tape	10	5.46%
Provide/improve medical services locally	10	5.46%
Lower insurance prices; improved coverage	6	3.28%
Find a cure	5	2.73%
Expand medical services offered	4	2.19%
Improve access to and quality of case management	4	2.19%
Recommendations to PLWH		
Live a normal, healthy life; lower stress; keep a positive attitude	19	10.38%
Eat nutritious foods	16	8.74%
Seek regular medical care; take medications	12	6.55%
Exercise	11	6.01%
Access ASO services and related services	5	2.73%
Use protection; be safe	4	2.19%
Don't use drugs and alcohol	3	1.64%
Get educated; get involved; educate others	2	1.09%
Advocate for yourself	2	1.09%
Recommendations concerning mental health services		
Improve access to counseling/mental health care	14	7.65%
Organize support groups	6	3.28%
Recommendations for basic needs services		
Improve access to financial/job/education assistance	13	7.10%
Improve access to appropriate housing	10	5.46%
Improve access to transportation	7	3.83%
Other program recommendations		
Increase HIV education for PLWH	12	6.55%
Increase funding for/access to HIV organizations/services	8	4.37%
Improve knowledge of available programs	8	4.37%
Increase prevention programs (including outreach)	6	3.28%
Provide client-centered services	2	1.09%
Ensure that service providers are compassionate	2	1.09%
Provide client-centered services	2	1.09%
Increase access to legal assistance for PLWH	2	1.09%
Recommendations around meeting social needs		
Educate the public; Address stigma	11	6.01%
Ensure social support	9	4.92%
Provide opportunities for socializing among PLWH	5	2.73%

As mentioned above, three topics formed the principal foci of the needs assessment survey. These included: 1) access to HIV care and treatment and related services; 2) retention of PLWH in those services; and 3) the quality of those services. Table Nine summarizes responses from the longer survey (n=269) about how long it took for the respondents to first begin receiving HIV-related medical services after their initial diagnosis. Almost two-thirds (62 percent) began receiving services within the first two months, and 85 percent by the end of six months. Close to eight percent went more than a year without receiving services. Only one percent of the survey respondents reported never receiving medical services. Once again, given that the survey was distributed to clients of ASOs and people receiving prescription and insurance assistance, this sample is not representative of all people living with HIV in Colorado.

Table Nine: Time Between Diagnosis and When Began Receiving Services (N=269)

	<u>Frequency</u>	<u>Percent</u>
1 Month	124	46.62%
2 Months	42	15.79%
3-6 Months	61	22.93%
6-12 Months	16	6.02%
More than One Year	21	7.89%
Have Not Received Med Services	2	0.75%
Did Not Answer	3	1.13%
Total	269	

Table Ten, however, shows that 20 percent of the longer survey sample had gone without CD4 and viral load tests for more than a year at some time since their diagnosis. Twenty-two percent of the sample had gone more than a year without seeing a doctor since their diagnosis, and 22 percent had gone without HIV medications. Just over one third claimed to never have gone without seeing a doctor and receiving laboratory tests, and 47 percent claimed to never have gone without medications. Table Eleven summarizes the reasons people gave for going without services for more than 12 months since their diagnosis. Affordability and lack of insurance were the two most cited reasons for going without medical care for more than a year.

Table Ten: Longest time without receiving medical services (N=269)						
	Doctor Visits		Laboratory Tests		HIV Medications	
	#	%	#	%	#	%
Went < One Year	117	43.49%	116	43.12%	68	25.28%
Went > One Year	58	21.56%	54	20.07%	58	21.56%
Never Without Services	91	33.83%	91	33.83%	127	47.21%
Did Not Answer	3	1.12%	8	2.97%	16	5.95%
Median Time Without Services (Months)	6 months		6 months		7 months	

Table Eleven: Reasons for Going without Medical Services (N=269)

	<u>Frequency</u>	<u>Percent</u>
Could not afford it	55	20.45%
No health insurance	46	17.10%
Other	29	10.78%
Fear my privacy would not be respected	21	7.81%
Did not qualify for services	18	6.69%
Did not know where to go	17	6.32%
Lack of transportation	17	6.32%
Did not want services	13	4.83%
Insufficient insurance	13	4.83%
Poor personal treatment by provider	11	4.09%
No services available	10	3.72%
Low quality of available services	10	3.72%
Long wait times for appointments	9	3.35%
Too many requirements	7	2.60%
Too much paperwork	4	1.49%

Table Twelve shows that 91 percent of the entire survey sample (n=681) had received CD4 laboratory tests and 94 percent had received viral load tests within the previous 12 months. Less than two percent reported not having a CD4 test within the previous 12 months or to have never had a test. Only one percent of the sample reported not having a viral load test in the previous 12 months, and no one reported having never received such a test. Table Thirteen shows that 69 percent of the entire sample had seen a case manager at an AIDS service organization in the previous 12 months. Twelve percent reported not seeing a case manager in the previous year, and another 9 percent reported that they had never seen a case manager.

Table Twelve: Time since receiving last CD4 and Viral Load Tests (N=681)

<u>Time Since last CD4 Test</u>	<u>Frequency</u>	<u>Percent</u>
0-6 Months Ago	618	90.75%
7 months ago-one year ago	22	3.23%
More than one year	10	1.47%
Never had a CD4 Test	2	0.29%
Do not Know/Do not Remember	19	2.79%
Did Not Answer	10	1.47%
Total	681	

<u>Time Since last Viral Load Test</u>	<u>Frequency</u>	<u>Percent</u>
0-6 Months Ago	621	91.19%
7 months ago-one year ago	21	3.08%
More than one year	7	1.03%
Never had a Viral Load Test	0	0.00%
Do not Know/Do not Remember	22	3.23%
Did Not Answer	10	1.47%
Total	681	

Table Thirteen: Time Since Seeing a Case Manager at an AIDS Service Organization (N=681)

<u>Last Time Met With Case Manager</u>	<u>Frequency</u>	<u>Percent</u>
< 3 months	279	40.97%
3-6 months	128	18.80%
7 months - 1 year	60	8.81%
> 1 year	83	12.19%
Never	62	9.10%
Do Not Know/Do Not Remember	50	7.34%
Did Not Answer	19	2.79%
Total	681	

Respondents to the longer survey were asked about people that were helpful to them in getting medical and other services related to HIV. Table Fourteen summarizes their responses to this question, with ASO staff and health care providers reported most often as being helpful. Table Fifteen summarizes the types of health insurance people have, with the majority reporting Medicare and Medicaid as their insurers. Seventeen percent reported having no health insurance.

Table Fourteen: People Helpful in Accessing HIV-Related Services (N=269)

<u>Helpful in Getting HIV Services</u>	<u>Frequency</u>	<u>Percent</u>
AIDS Service Organization Staff	193	71.75%
Doctor/Health Care Provider	134	49.81%
State Health Department Staff	61	22.68%
Family Member	46	17.10%
Local Health Department Staff	42	15.61%
Friend	40	14.87%
Community-Based Organization Staff	31	11.52%
Person Living With HIV	31	11.52%
No One Helped Me	15	5.58%
Other	14	5.20%
Religious/Faith-Based Organization	11	4.09%

Table Fifteen: Kind of Health Insurance (N=269)

	<u>Frequency</u>	<u>Percent</u>
Private	55	20.45%
Medicaid	60	22.30%
Medicare	95	35.32%
Veteran's Administration	10	3.72%
None	46	17.10%
Other	41	15.24%

As part of the long survey, respondents were asked about health and other related services that they had needed in the previous 12 months. They were then asked which of the services they reported needing they had received during the previous 12 months. Table Sixteen summarizes the responses,

with doctor visits, laboratory tests, and prescriptions ranking as the most needed and most received. Fifty-eight percent of survey respondents reported needing doctor visits during the past 12 months and about 94 percent of those also reported that they received this service. Forty-six percent of respondents reported needing help buying prescriptions during the previous year. However, only 85 percent of those who reported needing this service also received it. Other services that were reported as being needed by at least 15 percent of the sample but were frequently not received included: 1) dental care; 2) help accessing health insurance; 3) help accessing housing; 4) groceries/meals assistance; 5) emergency financial assistance; 6) transportation assistance; and 7) mental health counseling.

Table Sixteen: Access to Needed Services

Service Category (N=269)	Needed Service*	Received Service**
	No. (%)	No. (%)
Doctor visits	156 (58.0)	146 (93.6)
Laboratory tests	157 (58.4)	143 (91.1)
Help buying prescriptions	123 (45.7)	104 (84.6)
Dental care	116 (43.1)	91 (78.4)
Substance abuse treatment (outpatient)	14 (5.2)	10 (71.4)
Substance abuse treatment (inpatient)	5 (1.9)	3 (60.0)
Individual/group mental health counseling	42 (15.6)	34 (81.0)
Nutritional counseling or supplements	35 (13.0)	26 (74.3)
Alternative care	20 (7.4)	14 (70.0)
Help accessing health insurance	65 (24.2)	48 (73.8)
Help accessing housing	45 (16.7)	38 (84.4)
Transportation assistance	42 (15.6)	33 (78.6)
Groceries/meals assistance	70 (26.0)	60 (85.7)
Emergency financial assistance	49 (18.2)	37 (75.5)
Help buying over the counter medication	29 (10.8)	16 (55.2)
Support groups/peer counseling	23 (8.6)	17 (73.9)
Child care while accessing services	3 (1.1)	2 (66.7)
Home health care	11 (4.1)	7 (63.6)
Legal assistance	22 (8.2)	14 (63.6)
Education-related services	10 (3.7)	7 (70.0)
Case management	92 (34.2)	88 (95.7)
Other	5 (1.9)	5 (100.0)

Note:*Needed Service: Number and percent of people out of all long survey respondents (N=269) that reported needing the service in the past year

**Received Service: Of persons reporting needing a service, the number and percent of those that received the service

Survey respondents also evaluated the services they had received with grades of A (excellent), B (good), C (average), D (poor), or F (failing). The results of this evaluation are summarized in Table Seventeen. Services that received the highest number and percentage of lower evaluation scores included: 1) dental care; 2) groceries/meals assistance; 3) mental health counseling; 4) nutritional

counseling/supplements; 5) help accessing health insurance; 6) help accessing housing; 7) transportation assistance; and 8) emergency financial assistance.

Table Seventeen: Evaluation of Services*

Service Category	Received Service (No.)	Evaluation	
		A or B No. (%)	C, D, or F No. (%)
Doctor visits	146	134 (91.8)	12 (8.2)
Laboratory tests	143	135 (94.4)	8 (5.6)
Help buying prescriptions	104	96 (92.3)	8 (7.7)
Dental care	91	75 (82.4)	16 (17.6)
Substance abuse treatment (outpatient)	10	9 (90.0)	1 (10.0)
Substance abuse treatment (inpatient)	3	2 (66.7)	1 (33.3)
Individual/group mental health counseling	34	28 (82.4)	6 (17.6)
Nutritional counseling or supplements	26	20 (76.9)	6 (23.1)
Alternative care	14	10 (71.4)	4 (28.6)
Help accessing health insurance	48	41 (85.4)	7 (14.6)
Help accessing housing	38	31 (81.6)	7 (18.4)
Transportation assistance	33	25 (75.8)	8 (24.2)
Groceries/meals assistance	60	42 (70.0)	18 (30.0)
Emergency financial assistance	37	28 (75.7)	9 (24.3)
Help buying over the counter medication	16	12 (75.0)	4 (25.0)
Support groups/peer counseling	17	15 (88.2)	2 (11.8)
Child care while accessing services	2	2 (100.0)	0 (0.0)
Home health care	7	7 (100.0)	0 (0.0)
Legal assistance	14	5 (35.7)	9 (64.3)
Education-related services	7	4 (57.1)	3 (42.9)
Case management	88	80 (90.9)	8 (9.1)
Other	5	4 (80.0)	1 (20.0)

Note:

*Evaluation of Services: Letter grade assigned to the service by survey respondents who reported both needing and receiving the service

For each service that respondents evaluated as a C, D, or F, and for each service that survey respondents reported needing but not receiving, they were asked to provide reasons for their responses. Table Eighteen provides a summary of their comments.

Table Eighteen: Categories of Comments from Respondents Not Satisfied With Services Received	
Service	Evaluation Summary
Doctor Visits	<ul style="list-style-type: none"> ▪ Doctor does not spend enough time; not thorough, attentive, or concerned ▪ Difficulty setting appointments; long waits for appointments ▪ Disrespectful treatment; discriminatory treatment ▪ Available doctors do not know enough about HIV ▪ Long waits in doctors' offices ▪ Too costly without adequate insurance ▪ Reluctant to provide medications or marijuana for pain
Laboratory Tests	<ul style="list-style-type: none"> ▪ Incompetence of laboratory staff ▪ Too costly without adequate insurance
Help buying prescriptions	<ul style="list-style-type: none"> ▪ Prescriptions and co-pays too costly without adequate insurance ▪ Income levels for assistance eligibility too low ▪ Not aware of assistance available ▪ Non-HIV medications not covered
Dental Care	<ul style="list-style-type: none"> ▪ Too costly without adequate insurance; assistance very limited ▪ Limited availability of dental programs for PLWH statewide ▪ Long waits for appointments ▪ Disrespectful treatment; discriminatory treatment
Substance Abuse Treatment	<ul style="list-style-type: none"> ▪ Treatment counselors do not understand experiences of users ▪ Limited gay-specific treatment statewide ▪ Inappropriate/ineffective treatment
Individual/Group Mental Health Counseling	<ul style="list-style-type: none"> ▪ Too costly ▪ Limited availability of mental health services ▪ Inappropriate/ineffective services
Nutritional Counseling or Supplements	<ul style="list-style-type: none"> ▪ Too costly ▪ Limited availability of assistance statewide
Alternative Care	<ul style="list-style-type: none"> ▪ Too costly and not covered by insurance or assistance programs
Health Insurance Assistance	<ul style="list-style-type: none"> ▪ Long wait to get assistance ▪ Limited coverage associated with assistance plans ▪ Limited availability of assistance; income requirements too low ▪ Limited awareness of assistance available
Housing assistance	<ul style="list-style-type: none"> ▪ Difficult to get assistance; long waiting list; limited assistance available ▪ Housing provided is inadequate or substandard
Transportation assistance	<ul style="list-style-type: none"> ▪ Assistance unavailable in many parts of the state ▪ Assistance insufficient to adequately subsidize costs ▪ Lack of transportation assistance prevents some from accessing services
Groceries/Meals assistance	<ul style="list-style-type: none"> ▪ Difficulties accessing sufficient food vouchers ▪ Food banks not available in many parts of the state ▪ Low quality of food at food banks; low level of nutrition; small selection
Emergency Financial Assistance	<ul style="list-style-type: none"> ▪ Limited programs available to help with utilities ▪ Income requirements too low for some to qualify ▪ Some do not know how to access assistance

Help buying over the counter medication	<ul style="list-style-type: none"> ▪ Assistance unavailable or unable to access assistance ▪ Lack of knowledge of assistance programs
Support Groups/Peer Counseling	<ul style="list-style-type: none"> ▪ Available groups unhelpful (e.g. “cliquish” “bitch sessions”, depressing) ▪ Groups not available in all areas or for all populations
Child care assistance	(No comments)
Home health care	<ul style="list-style-type: none"> ▪ Not available in all areas
Legal assistance	<ul style="list-style-type: none"> ▪ Not available
Education-related services	<ul style="list-style-type: none"> ▪ Not available
Case management	<ul style="list-style-type: none"> ▪ Staff turnover causes breaks and inconsistency in service ▪ Do not provide adequate information about available services and how to access services ▪ Limited availability in parts of the state
Other	<ul style="list-style-type: none"> ▪ Need more education to the public to address stigma and discrimination ▪ Many services not available in outlying areas ▪ Lack of funding for services ▪ Requirements to access services prevent many from getting help

Several questions asked of the entire survey sample focused on respondents’ use of three programs coordinated by CDPHE staff, including the AIDS Drug Assistance Program (ADAP), the Bridging the Gap Colorado (BTGC), and insurance assistance. Just over 72 percent of the survey respondents were enrolled in ADAP, 25 percent were enrolled in BTGC, and 26 percent were receiving insurance assistance. Table Nineteen summarizes use of the ADAP program and enrollees responses to customer satisfaction questions concerning access, retention, and quality of services. Table Twenty summarizes responses to similar questions about the BTGC program, and Table Twenty-one concerns insurance assistance programs. Overall, approval ratings on the ADAP and BTGC programs were very high. Only a few respondents mentioned difficulties with ADAP enrollment requirements and coverage, and a small number reported that they did not know about the BTGC program or said that it was difficult to find out about. Insurance assistance was rated somewhat lower with around 10 percent of respondents disagreeing with statements that it was easy to find out about the assistance, easy to enroll in the program, and easy to continue in the program.

Table Nineteen: PLWH Receiving Medications from ADAP Pharmacies (N=681)

	Frequency	Percent
Yes	493	72.39%
No	132	19.38%
Do Not Know	18	2.64%
Did Not Answer	38	5.58%
Total	681	

It is easy to find out about the ADAP services that are available. (N=493)

Agree Strongly		Agree		Disagree		Disagree Strongly		Did Not Answer		Total
#	%	#	%	#	%	#	%	#	%	
325	65.92%	128	25.93%	19	3.85%	8	1.62%	13	2.64%	493

The process of getting enrolled in ADAP was easy. (N=493)

Agree Strongly		Agree		Disagree		Disagree Strongly		Did Not Answer		Total
#	%	#	%	#	%	#	%	#	%	
328	66.53%	121	24.54%	16	3.65%	7	1.42%	19	3.85%	493

Once a person is enrolled in ADAP it is easy to continue on the program. (N=493)

Agree Strongly		Agree		Disagree		Disagree Strongly		Did Not Answer		Total
#	%	#	%	#	%	#	%	#	%	
356	72.21%	93	18.86%	16	3.25%	5	1.01%	23	4.67%	493

Because of the ADAP program, I am able to receive the prescription HIV medications I need.

Agree Strongly		Agree		Disagree		Disagree Strongly		Did Not Answer		Total
#	%	#	%	#	%	#	%	#	%	
445	90.26%	38	7.71%	1	0.20%	1	0.20%	8	1.62%	493

I am satisfied with the help I receive from the ADAP staff. (N=493)

Agree Strongly		Agree		Disagree		Disagree Strongly		Did Not Answer		Total
#	%	#	%	#	%	#	%	#	%	
411	83.37%	60	12.17%	5	1.01%	4	0.81%	13	2.64%	493

I am satisfied with the ADAP pharmacy network where I pick up my medications or have them mailed to me. (N=493)

Agree Strongly		Agree		Disagree		Disagree Strongly		Did Not Answer		Total
#	%	#	%	#	%	#	%	#	%	
412	83.57%	61	12.37%	11	2.23%	3	0.61%	6	1.22%	493

Table Twenty: PLWH Enrolled in the BTGC Program (N=681)		Frequency	Percent
Yes		168	24.67
No		376	55.21
Do Not Know		77	11.31
Did Not Answer		60	8.81

It is easy to find out about these gap services. (N=168)										
Agree Strongly		Agree		Disagree		Disagree Strongly		Did Not Answer		Total
#	%	#	%	#	%	#	%	#	%	
90	53.57%	60	35.71%	7	4.17%	1	0.60%	10	5.95%	168

The process of getting enrolled in this program was easy. (N=168)										
Agree Strongly		Agree		Disagree		Disagree Strongly		Did Not Answer		Total
#	%	#	%	#	%	#	%	#	%	
102	60.71%	46	27.38%	5	2.98%	0	0.00%	15	8.93%	168

Once a person is enrolled in the gap coverage program is easy to continue on the program. (N=168)										
Agree Strongly		Agree		Disagree		Disagree Strongly		Did Not Answer		Total
#	%	#	%	#	%	#	%	#	%	
108	64.29%	37	22.02%	2	1.19%	2	1.19%	19	11.31%	168

Because of this program, I am able to receive the prescription HIV medications I need. (N=168)										
Agree Strongly		Agree		Disagree		Disagree Strongly		Did Not Answer		Total
#	%	#	%	#	%	#	%	#	%	
137	81.55%	17	10.12%	1	0.60%	0	0.00%	13	7.74%	168

I am satisfied with the help I receive from the staff. (N=168)										
Agree Strongly		Agree		Disagree		Disagree Strongly		Did Not Answer		Total
#	%	#	%	#	%	#	%	#	%	
123	73.21%	30	17.86%	2	1.19%	0	0.00%	13	7.74%	168

I am satisfied with the gap coverage network where I pick up my medications or have them mailed to me. (N=168)										
Agree Strongly		Agree		Disagree		Disagree Strongly		Did Not Answer		Total
#	%	#	%	#	%	#	%	#	%	
128	76.19%	23	13.69%	3	1.79%	1	0.60%	13	1.91%	168

Table Twenty-One: PLWH Receiving Insurance Assistance (N=681)										Frequency	Percent
Yes										180	26.43%
No										379	55.65%
Do Not Know										56	8.22%
Did Not Answer										66	9.69%
It is easy to find out about the insurance support that is available. (N=180)											
Agree Strongly		Agree		Disagree		Disagree Strongly		Did Not Answer		Total	
#	%	#	%	#	%	#	%	#	%		
98	54.44%	58	32.22%	14	7.78%	3	1.67%	7	3.89%	180	
The process of getting enrolled for insurance assistance was easy. (N=180)											
Agree Strongly		Agree		Disagree		Disagree Strongly		Did Not Answer		Total	
#	%	#	%	#	%	#	%	#	%		
99	55.00%	51	28.33%	18	10.00%	3	1.67%	9	5.00%	180	
Once a person is enrolled in insurance assistance it is easy to continue on the program. (N=180)											
Agree Strongly		Agree		Disagree		Disagree Strongly		Did Not Answer		Total	
#	%	#	%	#	%	#	%	#	%		
108	60.00%	40	22.22%	11	6.11%	5	2.78%	16	8.89%	180	
Because of the insurance assistance program, I am able to receive the prescription HIV medications I need. (N=180)											
Agree Strongly		Agree		Disagree		Disagree Strongly		Did Not Answer		Total	
#	%	#	%	#	%	#	%	#	%		
138	76.67%	20	11.11%	3	1.67%	2	1.11%	17	9.44%	180	
Because of the insurance assistance program, I am able to receive the medical services I need. (N=180)											
Agree Strongly		Agree		Disagree		Disagree Strongly		Did Not Answer		Total	
#	%	#	%	#	%	#	%	#	%		
129	71.67%	27	15.00%	6	3.33%	3	1.67%	15	8.33%	180	
I am satisfied with the quality of the medical services that I receive through the insurance assistance program. (N=180)											
Agree Strongly		Agree		Disagree		Disagree Strongly		Did Not Answer		Total	
#	%	#	%	#	%	#	%	#	%		
129	71.67%	27	15.00%	8	4.44%	1	0.56%	15	8.33%	180	
I am satisfied with the help I receive from the insurance assistance staff. (N=180)											
Agree Strongly		Agree		Disagree		Disagree Strongly		Did Not Answer		Total	
#	%	#	%	#	%	#	%	#	%		
122	67.78%	34	18.89%	5	2.78%	3	1.67%	16	8.89%	180	

Two final open-ended questions were posed to the survey respondents. The first asked respondents for their ideas for improving people’s ability to receive services or continue receiving services for as long as they need them. The last question asked for any other information they would like to share. One set of suggestions most commonly offered by survey respondents concerned the need for funding to provide more services throughout Colorado. This included more availability of quality and affordable clinics, doctors, and laboratory services, especially outside of Denver, and better

access to affordable and adequate health insurance. These suggestions also included enhanced transportation assistance to help people access services as well as better availability of related services such as housing assistance, mental health services, HIV education, job training, legal assistance, food banks, and vision and dental care. Another set of suggestions emphasized the need to loosen requirements, especially income requirements, for accessing services and to simplify or streamline the processes and the necessary paperwork involved in enrolling in programs. A third set of suggestions centered around improving case management and other assistance to help people know about available services for which they qualify and to help people navigate the service system and complete the requirements so that they can access what they need. People emphasized the need for knowledgeable and conscientious caseworkers that were client centered and respectful. Also commonly suggested was an increased effort to improve the visibility of programs so that PLWH are more aware of the services that are available.

When asked about other things they would like to express, many survey respondents took the opportunity to express their appreciation for many of the services they had accessed and the agencies providing those services. These included the ASOs and the caseworkers from those organizations, ADAP, and the providers at two Denver area hospitals. In other cases they reiterated some of the concerns reflected in the suggestions described above, including: concern about the lack of services and lower quality services outside of Denver; difficulties in finding out about available services; problems qualifying for services; problems with insurance coverage; long waits to access services; concerns about confidentiality breaches; and disrespectful treatment and stigma. They mentioned a number of service needs, most commonly the need for transportation, food, housing, dental care, and alternative treatments.

Focus Group and Interview Results

A total of 43 people who are living with HIV took part in focus groups at ASOs in Ft. Collins, Boulder, Grand Junction, Colorado Springs, and Pueblo. Seven PLWH who were currently or had previously been out of care participated in one-on-one interviews, and three key informants working with people who were out of care also participated in interviews. Table Twenty provides a brief description of focus group and interview participants' characteristics (excluding the key informants).

Table Twenty-Three: Interview and Focus Group Participant Demographics (N=50)							
	NCAP	BCAP	WestCAP	SCAP	Posada	Interviews	Total
Race/Ethnicity							
African American	1	0	0	2	0	7	10
Latino	2	3	1	2	1	0	9
White	9	2	7	2	7	0	27
Mixed Race	0	1	0	0	0	0	1
Other	0	0	1	1	1	0	3
Gender							
Male	10	5	8	7	7	5	42
Female	2	1	1	0	2	1	7
Transgender	0	0	0	0	0	1	1
Sexual Orientation							
Gay/Lesbian	7	4	6	7	5	2	31
Bisexual	0	0	0	0	2	2	4
Straight	5	2	3	0	1	3	13
Other	0	0	0	0	1	0	1
Age Group							
Under 25	0	0	1	0	0	1	2
25 – 34	1	1	0	1	0	2	5
35 – 44	2	2	1	3	3	1	12
45 – 54	6	3	3	2	5	3	22
55 and Older	3	0	3	1	1	0	8
Unknown	0	0	1	0	0	0	1
Totals							
Total	12	6	9	7	9	7	50

Most Important Issues of PLWH. A number of topics were discussed as part of the interviews and focus groups, and very rich, in-depth information was drawn using these qualitative approaches. Two topics that were discussed were also included as open-ended questions in the longer version of the survey, the responses to which are summarized above. These concerned the most important issues and needs of PLWH, both of which vary significantly for different individuals.

One of the principal issues discussed by interview participants concerned the difficulties they faced due to the stigma surrounding HIV and the types of discrimination that result from such stigma. Shame was one by-product that was mentioned. Participants also discussed the high level of ignorance about HIV on the part of society at large and how it is and is not transmitted, which feeds the stigma and discrimination. They cited incidences with family members, friends, co-workers, landlords, doctors, and others in which people avoided or feared casual contact with them. Fear of rejection, of losing jobs or not being considered for jobs, and of being treated poorly kept many of the participants from disclosing their HIV status to others or caused them to be very selective about whom they told. Another issue mentioned by interview respondents concerned just how overwhelming having HIV can be, causing a high level of stress. Other issues discussed included the importance of staying healthy and of not exposing others to HIV. The three key informants working with people who are out of care also mentioned stigma as an important issue faced by PLWH as well as the many problems people face in trying to access the services they need. These problems related to the limited availability of services relative to the need and the rules, regulations,

and large amount of necessary paperwork that often exempted people from services or made applying for services confusing or overly cumbersome.

The focus group participants addressed a large number of issues faced by themselves and others they know who are living with HIV. Issues related to people's emotional well-being were commonly discussed. These included experiences with depression and suicidal thoughts, loneliness, lack of support, fear, and shame along with the emotional impact accompanying social stigma, discrimination, and even victimization. Other issues including difficulties meeting basic needs, especially if they were relying on public assistance, having to miss work to get to appointments, and disclosing HIV status to family, friends, employers, and others. Most commonly, focus group participants discussed difficulties that they faced in accessing the services they need as well as the quality of services as principal issues faced by PLWH. Both of these topics are discussed in more detail below.

Most Important Needs of PLWH. When asked about the most important needs of PLWH, interview respondents mentioned those associated with income and meeting basic needs (including housing, food, and transportation) as well as access to medical care, medications, and case management. However more of the discussion centered around social and emotional needs. Several mentioned the need for someone to talk to that would listen to them and value who they are as people or someone who could help lead them in the right direction such as a mentor. Three participants mentioned the need to be able to socialize with other PLWH including within support groups. One person also mentioned the importance of accepting one's situation and then using one's experiences to teach others. When asked what they needed or what others often need soon after diagnosis, PLWH who had been out of care discussed the importance of stability in their lives including the ability to access basic needs such as income, housing, food, and transportation. Knowledge of how to access services, information about HIV, substance abuse treatment, effective and supportive case management, medical care, and a variety of options for insurance coverage and care were also mentioned. Again, the interview participants most commonly discussed social and emotional needs as being most immediate, such as those for companionship, support, people with whom they can comfortably share personal information, help dealing with shame and stigma, counseling or other mental health services, moral support, and safe places to go to be around other PLWH. One person stressed the importance of maintaining confidentiality. Another talked about the importance of having a counselor that can relate to their culture and their situation. A third person mentioned the importance of getting involved in outreach or other gratifying work.

The three key informants interviewed for this study discussed a number of important needs of PLWH. Basic needs such as income, housing, food, job assistance, and transportation were included in one set of responses, with all three emphasizing people's need for proper identification and help getting identification cards so they can access services. They also emphasized people's needs for effective substance abuse and mental health services that people could access on demand with minimal "red tape". Such services should include access to: in-patient treatment, counselors, or mentors that people can talk to that will listen to them and understand their situations. They stressed the need for people to be connected to others, be nurtured, and feel a sense of belonging. All of the key informants also emphasized the need for people to be "stabilized", with basic needs met and substance abuse and mental health needs addressed, before they can substantively deal with HIV. One key informant emphasized "health literacy" and the need for advocacy to help people to connect with the right agencies and services, to understand how to navigate the service system, to understand what their diagnosis means and the seriousness of it, to understand the importance of

being healthy and taking care of themselves, and to better communicate with doctors and other services providers. The two other key informants emphasized the need for good case management, better access to health insurance, better knowledge about the services that are available, and providers who follow-up with people and make efforts to retain them in care. They also discussed needs for job assistance, housing, food and other basic needs, and adequate substance abuse and mental health treatment. One stressed that mental health problems are the most overlooked even though they can play a major part in whether or not people get other needs met, including medical care.

Focus group participants also emphasized the needs of PLWH to receive help dealing with emotional or mental health issues such as depression, anxiety, and loneliness. The need for better access to mental health treatment, including counseling, was especially highlighted as was having other people to talk to, including others living with HIV, and help facing the reality of having HIV. A second set of needs discussed by focus group participants involved the ability to access the services they need. This included the need for case management, advocating for oneself, learning about the medical care and other resources available, learning about service regulations and how to navigate what can often be a very confusing service system, and help setting up appointments. Other needs expressed included financial assistance, spiritual services, and finding doctors who are understanding and who care about their well-being.

Reasons People are Not Receiving Services.

When the interview participants were asked about the reasons they had spent time out of care, six of the seven discussed how addictions had played a major part in their ability to seek or continue in care. In most of these cases, their drug use had been either initiated or exacerbated by finding out they had HIV. All mentioned how difficult it was to deal with their diagnoses, some claiming to have been in denial or needing to avoid thinking about it. For some depression, anxiety, shame, and feeling overwhelmed caused them to “just give up” or “hibernate”. A number of these respondents discussed how having HIV was just one among many very difficult life circumstances they were dealing with. Aside from the addictions, these included a history of childhood sexual abuse, poverty, homelessness, loss of relationships, and lack of a supportive social network. Several respondents mentioned not being able to afford care. One person did not seek care because the only affordable option for care was with an employer. Another could not cope with feeling like a “charity case” if services were accessed. Two people mentioned being influenced by conspiracy theories about HIV and HIV medications that impeded their ability to trust care providers. Several mentioned fear of confidentiality being breached and the consequences of such a breach if they accessed care. One mentioned feeling that CDPHE’s efforts to bring people into care were sometimes overly aggressive, which acted as a barrier. When these same respondents were asked why other PLWH may not be receiving the services they need, they offered many of the same reasons given for their own lack of accessing care including denial, fear of others finding out, inability to accept that they have HIV, substance abuse, mental health problems, and need for stability. Stigma was another common response. Several people mentioned that difficulties with knowing where and how to access services, lack of availability of services, and complicated service regulations kept some people away. Other responses included ignorance about HIV and its seriousness, lack of transportation, language issues, fear of deportation, and disrespectful treatment by providers.

Given that the three key informants had extensive experience working with people who had been out of care, they offered a number of reasons for why people may not receive services. One of these informants emphasized the interconnectedness of people's life problems. Substance abuse, mental health problems, poverty, homelessness, and how people deal with an HIV diagnosis are highly interrelated, and this complex of difficult life circumstances can overshadow efforts to take care of one's health. He emphasized the importance of helping people become stable before trying to get them into medical care or expecting them to stay in care. This would include helping people address their substance abuse and mental health problems, find stable housing, and obtain a sufficient amount of food. Lack of money and lack of proper identification were also important factors keeping people from qualifying for or paying for care. This key informant also emphasized problems within the service system as important factors affecting access to care. Overall there are not enough services to meet the needs of everyone with HIV. Some agencies have requirements and regulations surrounding access to services that keep people away, such as complicated enrollment procedures, rules about not providing housing assistance for former felons or substance abusers, or maximum income requirements that are too low. The key informant described little flexibility or creativity in the system that could facilitate access. Disrespectful or judgmental treatment on the part of providers can also be an issue. The other two key informants discussed how having jobs and children meant that scheduling and keeping appointments can be very difficult. For people with some income, accessing care can be too expensive if they do not qualify for some assistance programs or have adequate health insurance. They explained that some people do not access care because of stigma and discrimination, and they do not want people to know about their infection, including family members, friends, ex-spouses, and employers. Other reasons offered were substance abuse, poor mental health, denial, fear of abuse, lack of identification or legal documentation, trauma, or the fact that people do not feel sick and do not see the need to get into care.

Responses from the focus group participants on why people are out of care were very similar to those described above, including substance abuse and mental health problems that keep people from seeking care, stigma, fear of confidentiality breaches, difficulties of accessing care ("too many hoops to jump through"), high costs of care, and not knowing where and how to get help. A number of participants stressed how going into care means facing the realities of having HIV that some do not want to face, so they avoid going until they get sick. One person mentioned distrust of the government and fear of being on the government "list" of people known to have HIV.

Access to Services. Participants in the interviews and focus groups were asked to discuss a number of issues related to accessing the services they need. Interview participants who had been out of care but who had eventually accessed some type of services were asked what had helped in that process. One person said he was able to get SSDI and medical care very quickly because he was so sick with AIDS related illness when he was first diagnosed. He thought the process may have been easier for him because people thought he probably would not live very long. Two people were helped by agency staff from health departments and a local community-based organization. A psychologist contracted by a health department was helpful to another participant in sorting out emotional barriers that kept him from accessing care. Others claimed to be assisted and motivated to get into care by self-education, anxiety over not knowing the details of one's condition, and helping others by acting as mentors. When the interview respondents were asked about services that they needed but did not receive, aside from health care they discussed problems getting appropriate housing, job assistance, transportation, and counseling.

Other topics related to access to services that were discussed by interview and focus group participants concentrated on the types of people the participants thought had the hardest and the easiest time getting the help they need and on which services were the most difficult and easiest to access. One interviewee stressed how people have to really want help. Two others stressed the importance of being connected to the right providers and agencies through outreach, emphasizing that those without advocates had the hardest time getting services. One person stressed that it was easiest for those who are well off and who have insurance, while another thought that people without insurance could access more help because they were not bound by restrictions that were part of many insurance policies. Others who were said to have the hardest time were people of color (especially those who are not comfortable in predominantly white agencies), people who are homeless, and those who are mentally and physically challenged. The services that interview participants thought were the hardest to get were substance abuse treatment services that were comprehensive and that lasted long enough to make a difference. One person said that all services are easy to access if you really want them.

All three of the key informants thought that undocumented immigrants had the hardest time getting the help that they need given that there were only a limited number of clinics and other agencies that served their needs. They also stressed that the services that were the most difficult to access were those that imposed the most requirements on people and had the most restrictions on who was eligible for services. Substance abuse treatment services and mental health services were seen as scarce relative to demand, which meant that many had to be put on waiting lists. One key informant also pointed out that people without social networks and advocates and people with substance abuse and mental health problems had the hardest time accessing services. Key informants who were staff at CDPHE thought that the services offered by CDPHE were the easiest to access. They thought clinical services for the undocumented were the most difficult to access. Other access issues pointed out by the key informants included: 1) barriers associated with agencies hours of operation, making it difficult for working people to make appointments; 2) the lack of Spanish speaking providers; 3) poor communication about the services that are available; 4) the need for bus passes (rather than tokens) to facilitate people accessing multiple services at various locations; and 5) the need for universal access to case management so more people could be linked to the help they need.

Focus group participants commonly discussed how people of color, people who are poor, undocumented immigrants, and people without health insurance had the hardest time getting the services they need. Some people stated that agencies can be discriminatory based on personality, how a person looks or carries him/herself, how he or she communicates and their degree of assertiveness, or how sick a person looks. One person thought that there was no discrimination, and that everyone had the same access to assistance. Another person stressed that people in the military had good access to services. One thought that people with children had an easier time getting what they need. When asked about the services that are hardest and easiest to access, adequate housing was mentioned most as being difficult. Another mentioned as difficult was the opportunity to connect with others and share experiences. One person stated that no services were easy to access. There was disagreement among participants in the focus groups about access to public assistance programs such as Social Security, SSI, SSDI, Medicaid, Medicare, and food stamps with some stating that access was easy and others saying it was difficult. The same was true in terms of transportation assistance and case management. Getting adequate medical care was definitely seen as difficult for people living outside of Denver. ADAP was said to be easy to get, but accessing the Bridging the Gap Program was seen as somewhat confusing by a few participants.

To focus group participants, qualifying for assistance for those with even small incomes proved to be problematic, with some saying that having a job or savings meant that they could not get some types of assistance. Complicated enrollment processes and regulations around who can qualify for services had also proved daunting for many. High co-pays and high costs of insurance, prescription medications, medical care, and alternative care were also problematic for some as were long waits to get housing assistance or mental health care. Overall lack of funding for programs was a major barrier to accessing sufficient assistance for PLWH, especially outside of Denver. This affected basic needs related services such as food banks, housing, emergency financial assistance, and transportation. Limited availability of affordable mental health and substance abuse treatment services and vision and dental care meant that those needing immediate assistance confronted very long waiting lists. Participants mentioned that in some parts of the state such services were not available at all.

Access to quality medical services outside of Denver proved to be a main focus of discussion in the focus groups. There were a very limited number of clinics and medical staff that were considered as sufficiently competent to treat people with HIV, and those that were could not adequately serve the number of clients in need, or they required types of insurance and co-pays that many could not afford. People had trouble traveling the long distances to get to appointments and to get laboratory work done, and they often had difficulties getting prescriptions filled. Consequently many traveled to Denver for their medical care, which they said was time consuming and expensive. One other issue that proved problematic for interview and focus group participants concerned people's ability to access assistance paying for non-HIV prescription drugs, over the counter drugs, and nutritional supplements. Another was the lack of confidentiality associated with accessing services. People participating in the focus group in Pueblo unanimously agreed that a number of the problems they faced accessing services were exacerbated by the fact that there was no longer an ASO office in Pueblo.

Focus group participants were also asked about issues surrounding continuation of services. Retention of doctors in areas outside of Denver and client overload for some doctors were reasons offered as to why people may not continue to receive services. High co-pays and cumbersome requirements and paperwork were also mentioned as were cost of living adjustments on some services that could lead to people no longer qualifying for other services. One person mentioned survivors' guilt as a reason why some people may drop out of care.

Quality of Services. Those interview participants that had accessed medical services spoke highly about the quality of the services they received at two Denver area hospitals. In particular, they were appreciative of the way they were treated as people, saying that staff members were straightforward, challenged them to take care of themselves, and followed up with clients when they did not show up for services. They stressed that they liked the team approach that these clinics took to care and how they offered integrated services (e.g., medical, mental health, nutrition, etc.). One person also mentioned liking the assistance they offered with transportation, their respect for his autonomy, and their expressions of concern for his well-being. Additionally, participants expressed appreciation for the help they received from ADAP and the ADAP staff. Medical services that people found unsatisfactory were those received in emergency rooms, saying staff tended to neither explain what they were doing nor listen to patients.

When asked about the quality of other related services, interview respondents, all of whom lived in the Denver area, were complimentary of several agencies for: their efforts to link people to medical

care, substance abuse treatment, and mental health care; providing places for people to socialize; providing respectful treatment and needed services for the homeless; providing HIV-related education; and assistance with food, clothing, and transportation. Although the participants were overall appreciative of the services they received from ASOs, they also had a number of complaints. One particular agency was cited for its unfriendly atmosphere, lack of client-centered approaches to case management, poor accessibility, long waits for appointments, difficulties surrounding housing assistance, and lack of diversity in staff. Several participants expressed that they had problems in their dealings with CDPHE. Two people expressed having a very negative reaction to what they saw as overly aggressive efforts by staff to contact them in their homes or where they work or by what they considered insincere offers of assistance. One person discussed the lack of diversity of staff, and another criticized the lack of flexibility in and diversity of the services and options for care offered to clients. One did, however, mention that the counselor to whom he was referred was very good and very helpful, and another found the book of resources he was given to be very helpful.

As mentioned above, all of the focus groups were conducted outside of the Denver area, and an overall sentiment dominating the discussions in these groups concerned the lack of quality services in the areas where people lived. Many of the available doctors were said to not have sufficient expertise in HIV. The few clinics that participants cited as good were all said to have more clients than they could adequately accommodate. Many participants claimed to travel to Denver to get medical care and were satisfied with that care, although they lamented having to travel so far. A number of the participants were receiving care from doctors from a Denver area hospital who would travel to their areas on a regular basis, and they claimed to be very satisfied with the care offered by these doctors. ADAP also received a very favorable rating among focus group participants. However some were not so complimentary of local pharmacy services and laboratories. Most of the participants offered favorable assessments of the ASOs serving their area, stating that they were normally very helpful in providing a number of services. However, most thought that the funding provided to these agencies was insufficient to adequately meet people's needs, and a few mentioned that the amount of assistance available was diminishing over time. High staff turnover at the ASOs was cited as one reason for inconsistency in the quality of services. The participants who were least satisfied were those living outside of the cities in which these agencies were located. People were more critical of the government assistance programs upon which many relied for basic subsistence such as Social Security, SSI, HOPWA, and food stamps. The complaints focused on the number of requirements and cumbersome amount of paperwork involved in accessing services, the small amount of benefits provided, and the limited amount and poor quality of subsidized housing available.

Ideas from focus group participants for improving services included: 1) having more PLWH working at agencies that provide HIV-related services; 2) increased funding to provide a better range of services; 3) simplification of enrollment processes and enhanced assistance with enrollment; 4) improved access to mental health services; 5) improved transportation services and better agency locations that can be accessed by public transportation; 6) improved local pharmacy services with greater availability to appropriate medications; 7) more respectful treatment from agency staff; 8) more client-centered services; 9) more provision of social events and opportunities for diversion; 10) better availability of case management; 11) multiple services provided in one location and streamlined processes for accessing these multiple services; and 12) improved communication about available services. Pueblo participants strongly encouraged the opening of a

local ASO office, and others living outside the cities suggested that the ASOs do more outreach to their areas.

Gifts of PLWH. Very important discussions took place around the issues of the assets of people living with HIV and the gifts they can and often do offer to others. Responses fell into two general categories. One concerned what PLWH could do for each other, and the other focused on what they could do for society as a whole. Interview and focus group participants discussed how people who had been living with HIV for a while could act as mentors, helping those more recently diagnosed to navigate service systems and access the medical and other services they need. They could reinforce the importance of taking care of oneself and taking medications; educate them about HIV and how best to live with it; prepare them for the future; help them with personal issues concerning family, friends, and partners; and ensure them that there is hope. They could form support groups and organize group activities such as developing a community garden or a communal business. Roles they could play in educating others would be to help bring public attention back to HIV; to make people more aware of what HIV is and how it is and is not transmitted; to encourage people to adopt safer behaviors so they will not contract HIV; and to challenge stereotypes, stigma, and discrimination. PLWH could also speak in schools and at community events, and serve on boards and committees to influence HIV-related policy and programming.

One of the key informants expanded on these same themes, emphasizing that PLWH who are willing to be open about their infection can talk to their peers, promote prevention through education and fun activities, and challenge stigma. They could draw other people with HIV into agencies, feed them, make them feel welcome, assess their needs, and connect them to community in a way that is not judgmental. They could help people with histories of trauma and help them sort out how this history is playing out in their lives, and they could help people deal with stigma. They could ask the right questions and be role models, showing people how to take care of themselves and how to challenge themselves and appreciate any small successes associated with behavior change.

Colorado as the Ideal Place for PLWH.

One final question posed to interview and focus group participants and to the key informants centered on what Colorado would be like if it were the ideal place for PLWH to live. Interestingly, very little of these discussions focused on medical care. Most of the interview participants focused on the importance of taking care of people's emotional well-being. This included widespread access to mental health care and substance abuse treatment, peer counseling, mutual support, places for PLWH to socialize, and societal acceptance. Counselors and conscientious case managers would be available to people upon diagnosis to help people process the information and to begin connecting them to needed services. Advocates would help people to navigate service systems. Related to this was a vision of an environment free of stigma and discrimination. This would involve educating the public via talks and outreach by PLWH, announcements made by famous people, and open discussions and education in churches, work sites, schools, and the media. A third set of responses concerned an environment in which people's basic needs are met, especially those related to housing and income. Two of the interviewees saw an ideal Colorado as a place where people could access comprehensive services, preferably in one location. For one, these services would include substance abuse treatment and the development of life skills, education, healthy relationships, better self-esteem, confidence building, job skills, and managing one's finances. Another interview participant emphasized the need for a more equitable distribution of funding with

more services offered by a diverse set of agencies. This would make services such as housing programs and case management available to a broader range of people who would have more choices about the agencies upon which they rely.

One of the key informants agreed that in an ideal Colorado, more resources would be available for PLWH, and they would be better distributed among agencies. He also stressed the need for CDPHE to better collaborate with communities and for PLWH to be seen as valuable and more involved in decision-making processes.

Focus group participants described a very similar vision of an ideal Colorado as the interview participants. They most often mentioned that an ideal environment would include efforts to challenge stigma and discrimination and educate the public about HIV to promote tolerance, compassion, and understanding. This would involve expanded public information in the media and schools resulting in an overall increase in knowledge about HIV. Equally discussed was a state in which services were expanded, more equitably distributed, and more diverse in order to meet the diverse needs of the PLWH population. These services would include quality and affordable medical care available to all people throughout the state. It would also include improved case management that was client-centered and available to everyone, more comprehensive education on HIV for PLWH, services for those “affected” by HIV, and better advertising of available services. Adequate and equitable access to basic necessities such as housing, food, and income were also part of the vision of an ideal Colorado, as was an environment in which people’s emotional and social needs were met. This would include access to quality mental health care and substance abuse treatment, support groups, opportunities for positive social interactions, entertainment, and social acceptance. In several groups people talked about the potential benefits associated with having multiple, interrelated services available in one location.

Limitations of the Data

Although a wealth of information was drawn through the data collection methods used in this needs assessment, a study such as this, by nature, will have limitations, especially those concerning the degree to which the sample of respondents is representative of the population as a whole. The sample of participants in this study was drawn largely from among clients receiving ADAP services or services provided by ASOs and should not be considered representative of all PLWH living in Colorado. The greatest limitation in this particular study was the low level of participation of people who were not receiving medical and other related services. Various efforts to engage more out of care PLWH in the study were unsuccessful. Therefore the sample of participants in this study likely over represents people who can be considered “functional”, meaning they have been able to access services and were able to fill out the survey or participate in the interviews and focus groups. Future needs assessments should place a particular emphasis on gaining more perspective from people who are not getting the medical and other assistance they need. People who were better off financially and who had private health insurance were also underrepresented given that they would likely not have received a survey sent to ADAP and ASO clients or been invited to participate in a focus group. Also, only the information provided by those who responded to the survey and those ASO clients who agreed to participate in the focus groups could be incorporated in this report. Another limitation related to the representativeness of the sample is that all of the participants in the one-on-one interviews were African Americans. Similar in-depth information is not available from people of other racial or ethnic groups.

Conclusion and Recommendations

Four general themes emerge from a review of the information gathered as part of this needs assessment that relate to the principal foci of access to medical care and related services, retention in services, and quality of services. One theme concerned the availability of sufficient and appropriate services statewide. Overall, participants in this study were generally satisfied with the quality of the medical care they received, but accessing such services was very problematic for some people, especially those living outside of the Denver area. There were relatively few clinics and doctors that people thought had the expertise to provide quality care for PLWH outside of Denver. Providers in which people had confidence had large patient loads, which meant that many patients had to wait for long periods of time for an appointment. Many of the PLWH who lived along the Front Range and even some from Western Colorado came to the Denver area to access care. This obviously posed a greater outlay of time and expense than would seeing a local provider. Although people were very pleased with the medical care provided by Denver-based doctors who visited their areas, such doctors were clearly not available at all times or in cases of emergency. Some people expressed difficulties associated with being able to get their prescribed HIV and other medications at local pharmacies, and some questioned the quality of the laboratory tests that were conducted outside Denver as well. Many of the participants in the focus groups complimented the services they received from the local ASOs and programs such as ADAP as well as the staff at those agencies, but some people thought that the number of services had declined over time. Staff turnover at ASOs affected continuity of assistance, especially in case management services. Food assistance appeared to be declining, and subsidized housing programs were said to be difficult to access due to strict eligibility requirements and long waiting lists. The housing provided was at times considered substandard. Transportation assistance was a huge need for those living outside Denver to access services, but transportation assistance was also said to be diminishing. Public transportation was not available to those living outside of cities. Overall, people who did not live in the cities where ASOs were located expressed having the hardest time getting medical care and other services such as mental health and substance abuse treatment, accessing food and transportation assistance, and receiving sufficient case management services. ADAP clients generally thought the program was excellent at providing access to HIV medications, but many said they had trouble getting other prescription medications, over-the-counter drugs, and nutritional supplements that were not covered by ADAP. Recommendations for improvement included: 1) better HIV-related training for doctors, nurses, and other medical, pharmacy, and laboratory staff throughout the state; 2) an increase in the number of Denver-based doctors visiting other parts of the state; 3) an increase in funding for areas outside of Denver, resulting in improved availability of services; 4) further transportation assistance such as gas vouchers, bus passes, and shuttles; 5) satellite offices of the ASOs; and 6) agencies providing multiple, integrated services in one location. A less specific recommendation was to increase the availability of housing, mental health, and substance abuse services in more parts of the state.

A second theme concerned various problems people had in accessing available services or sufficient services to meet their needs. One common problem was associated with eligibility requirements for services. People thought the maximum amounts of income or savings they were allowed to have to qualify for assistance was too low. People with lower paying jobs who did not have insurance through their jobs often made too much to qualify for assistance but too little to pay for what they needed, especially medical care, medications, and medical insurance. Even some who had

Comment [GW1]: What areas are you referring to?

insurance found difficulties in getting medical services paid for due to restrictions that were part of their plans or due to high co-pays. Some had to choose between keeping or getting a job and getting the services they needed. In other instances people did not qualify for needed services, particularly housing assistance, because they had histories of incarceration or substance abuse. Others did not qualify for many services because they were undocumented immigrants. Not having identification often kept people from getting medical care, housing, jobs, or any type of financial assistance. Another common access issue that was discussed had to do with how confusing and cumbersome the service system could be, involving a large amount of paperwork that some have trouble completing. Government programs such as Social Security, SSI, SSDI, food stamps, and HOPWA were especially noted for how difficult they were to access and for continuing to meet their requirements. Finally, many of the participants thought that it was difficult to know what services were available to people because communication about these services was very limited. General recommendations around these issues included: 1) universal access to care; 2) more flexibility in the service system around eligibility requirements; and 3) raising of income limits that affect eligibility. Somewhat more specific recommendations included: 1) better collaboration between government agencies, affected communities, and community-based organizations; 2) better advertising of available services; 3) an increase in advocacy and case management to help people know what services are available and how to access them, including “walking” people through the process; and 4) an increased use of peer mentors that can explain these processes to people and “show them the ropes”.

A third theme concerned the importance of stability in people’s lives if they are going to access and continue to receive the help they need. Many people living with HIV have multiple, interrelated issues and critical problems that can overshadow the importance of HIV. Mental health problems are often overlooked or downplayed, and many people do not get the help they need. Some of these problems stem from histories of trauma and neglect and others from getting an HIV diagnosis. Other problems range from serious disorders such as clinical depression and bipolar disease to feelings of low self-esteem, loneliness, and shame, all of which can affect people’s ability to get the care they need. Substance abuse is also a key factor that prevents people from being able to take care of themselves and seek assistance. If people do not have adequate housing or sufficient food for themselves and their families, these issues can take priority over dealing with HIV. Among participants in this study, housing was seen as especially critical in helping people get jobs, access services, take HIV medications, and feel good enough about themselves to seek out what they need to be healthy and safe. Transportation to get to services was also seen as critical. Some participants also mentioned how overwhelming an HIV diagnosis can be, causing some to want to deny that they have it or downplay its seriousness. Recommendations for improving stability included: 1) improved access to an array of substance abuse treatment and mental health services that are available to people on demand; 2) multiple services offered through single agencies in single locations; 3) improved access to housing programs that have fewer eligibility restrictions; 4) improved access to advocates and case managers to help people understand and negotiate service systems; 5) ready access to counselors upon diagnosis who can assess people’s needs, help people to process the information they are receiving, help them to better understand the meaning of their diagnosis, and link them to appropriate assistance; and 6) peer mentors and support groups that can help people to know they are not alone, to know what to expect in terms of having HIV, and to give them hope.

A final theme emerging from the survey responses, interviews, and focus groups concerned the environment surrounding those living with HIV. Stigma surrounding HIV and the associated

discrimination were primary topics raised by a large number of study participants. Stigma influenced: 1) feelings of shame, low self-esteem, loneliness, and depression; 2) fear of losing jobs, friends, partners, custody of children, housing, and close relationships with family members; 3) feelings of social isolation and of being shunned or treated like a pariah; and 4) fear of violence. Some were so affected by the stigma that they kept the information about their HIV status from everyone or almost everyone in their lives. Many participants mentioned that people will often not access HIV-related services, including medical care or even HIV testing, because they are afraid that people will find out about their status or that they might be at risk. Others, however, were very open about having HIV and were much more able to put the stigma and discrimination in perspective and not let it significantly limit their lives. Participants lamented what they saw as widespread ignorance about HIV on the part of society as a whole. This ignorance included people not understanding how HIV is transmitted and therefore avoiding casual contact with PLWH. This could have painful effects when people, including family members, did not want to be around or want their children to be around PLWH, or share meals with them. It also affected the ability of PLWH to find and maintain steady intimate partnerships. Participants also discussed people's misconceptions about the "types" of people who get HIV and why, which fostered many harmful stereotypes. Recommendations for addressing stigma focused on a number of types of public education to improve people's knowledge about HIV and to challenge HIV-related discrimination and stereotypes. Suggestions included: outreach in schools, workplaces and at public events; increased media coverage; and the use of celebrities to raise awareness. Many participants saw a large role for PLWH in these public information efforts to not only raise awareness, but also to challenge stereotypes, increase compassion and empathy for PLWH, and encourage prevention among those who may be at risk for HIV.