2011 HIV/AIDS CARE AND TREATMENT NEEDS ASSESSMENT REPORT

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INTRODUCTION

Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome (HIV/AIDS) remains a major health concern in Colorado with over 400 new cases diagnosed annually in the state. As of June 30, 2011, there were 11,198 living cases of HIV that had been reported in Colorado since the beginning of the epidemic. It is within the purview of the Sexually Transmitted Infection/ Human Immunodeficiency Virus (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 receive the medical care, prevention, and other services they need. Approximately every three years, the HIV Care and Treatment Program at CDPHE conducts a needs assessment of PLWH in accordance with the Health Resources and Services Administration (HRSA) requirements. The results of the needs assessments are used in setting priorities for the allocation of funds; in developing the Statewide Coordinated Statement of Need (SCSN); in assessing the quality of programs; and in implementing plans to address identified needs.

The Planning and Evaluation Unit, in collaboration with the HIV Care and Treatment Program, developed plans for this current needs assessment in early 2011, and data collection began in April of that year. Staff at CDPHE also collaborated with the Ryan White Part A Denver HIV Resources Planning Council in the development of the survey used in this study in order to gather similar information from the Ryan White Parts A and Part B service areas. Three principal areas of inquiry were explored as part of this assessment. In order to better understand issues surrounding undiagnosed HIV disease, one part focused on the reasons that people delay testing for HIV and ideas for improving testing rates among those who are at risk. A second part concentrated on the reasons many PLWH do not receive medical and related services and what is most needed to link more people to care and retain them in care. A third major focus was on the needs identified by PLWH for medical and other related services and the ways and extent to which those needs are being met. The third focus included an assessment of the use of the AIDS Drug Assistance Program (ADAP) as well as the barriers and facilitators associated with accessing needed services. Other topics that were explored in this needs assessment included people's opinions about how to improve the lives of PLWH and about the benefits they have to offer to others if given the opportunity.

METHODS

Three principal methods were used to gather information for this assessment. First, two of the CDPHE STI/HIV Section databases were used to characterize the HIV epidemic in Colorado, as well as the utilization of the ADAP. Aggregate data from the Electronic HIV/AIDS Reporting System (eHARS) compiled by the STI/HIV Section's Surveillance Program were used to provide an updated profile of the HIV epidemic in Colorado, including the number of PLWH with reported CD4 or viral load tests within the previous year. The Care and Treatment Program's pharmacy benefits management database was used to assess inconsistent utilization of the ADAP program. Second, a survey (available in Spanish and English) was sent to PLWH who were enrollees in ADAP both in and outside of the six county Denver Metropolitan Area (DMA) and to clients of AIDS Service Organizations (ASOs) that serve populations outside of Denver. The Denver HIV Resources Planning Council administered the same survey to other persons residing in the DMA. A total of 862 people responded to the survey, either by mail or online. Among the respondents, 595 reported living in the DMA, and another 267 were either living outside of the DMA or omitted their county of residence. The third data collection method used for this needs assessment involved two sets of one-on-one interviews with PLWH. These included: 15 interviews with people who did not receive HIV care, treatment, and related services for a significant period of time, and 12 interviews with people who had an AIDS diagnosis at the time of or soon after their initial HIV diagnosis.

Although this report includes some comparative survey data on people living in and outside of the DMA and interview information from people both in and outside of the DMA, the emphasis of the report is on data captured from people living outside of the DMA. For more detailed information on Denver-based PLWH who participated in the needs assessment, refer to the "Transitional Grant Area (TGA) Ryan White Part A 2011 Needs Assessment Report" (August 4, 2011, available at: *http://dhrpc.org/default/assets/File/PDF's/DHRPC_DataReports_NeedsAssessmentReportFinal_2011.pdf*).

DEMOGRAPHIC PROFILE OF PLWH IN COLORADO AND SURVEY RESPONDENTS

It is difficult to quantify the actual number of people currently living with HIV in Colorado. The STI/HIV Surveillance Program at CDPHE provided the HIV case data used for this study. The Surveillance Program collects reports from laboratories and providers within Colorado, and from health departments across the country that submit reports when PLWH who were first diagnosed in Colorado access care in another state. Given that PLWH frequently move between states and do not necessarily access care right away, no reports are generated for some of those leaving or entering the state. Also, some PLWH who were originally diagnosed with HIV in Colorado may have passed away in other states, the records of which may not get back to the Surveillance Program in Colorado in a timely manner. The data available tend to be less reliable the longer the time elapsed since the original HIV diagnosis if updated reports have not been received.

With these caveats in mind, Table 1 provides the demographic profile of persons diagnosed with HIV in Colorado by June 30, 2011 for whom no death records have been documented. The table does not contain information on people diagnosed in other states. These prevalence data are categorized according to residence inside and outside of the DMA. Other categories include gender, age group, race/ethnicity, birth origin (inside or outside of the U.S.), year of HIV diagnosis, and disease status (either HIV or AIDS). Males, by far, outnumber females living with HIV/AIDS in Colorado (89 percent versus 11 percent); however the proportion of female cases is somewhat higher outside of the DMA (15 percent versus ten percent). The majority (65 percent) of all cases are among people over the age of 44, reflecting the current trend of PLWH living longer. The mean age is 48 and the median age is 49. African Americans are disproportionately represented among Colorado cases, accounting for 14 percent of the cases compared to only four percent of the state's population. What is not shown in Table 1 is the highly disproportionate representation of African American women among female cases, accounting for 32 percent of those cases. Whites are somewhat underrepresented among all cases, accounting for 64 percent of HIV cases and 70 percent of the population, and white women only represent 42 percent of the female cases. Latino cases are more proportionate to the Latino population numbers (19 percent of cases and 21 percent of the population). Latina women accounted for 22 percent of female cases. Surveillance data show that among all living Colorado cases, 44 percent have a documented AIDS diagnosis.

Men who have sex with men (MSM), including those who also have a history of injection drug use (MSM/IDU), have always dominated the epidemic in Colorado, accounting for almost three quarters (73 percent) of the cases. The proportion of the total cases documented as IDU alone has always been lower in Colorado relative to many other states, currently making up eight percent of the total number of cases, compared to approximately 19 percent nationwide. Documented heterosexual (HET) cases represent 10 percent of all cases. This percentage reflects only HIV positive males who report heterosexual sex as their only risk and for whom there is a documented HIV positive female partner. All other males are included in the "Unknown" transmission category. Cases in this category make up nine percent of all Colorado cases. A closer look at those who are included in this “unknown” category shows that males make up 74 percent, African Americans of both genders 20 percent, Latinos 26 percent, and whites only 47 percent.

Table 1: Colorado cases of HIV/AIDS as of June 30, 2011, by geographic location*

	Denver Metro		Non-Denver		All	
	N	%	N	%	N	%
Total	8699	100	2499	100	11,198	100
Sex at Birth						
Male	7816	90	2117	85	9,933	89
Female	883	10	382	15	1,265	11
Age Group						
<15	23	<1	8	<1	31	<1
15 - 19	13	<1	9	<1	22	<1
20 - 24	122	1	41	2	163	1
25 - 34	867	10	250	10	1,117	10
35 - 44	1920	22	561	22	2,481	22
45 - 64	5280	61	1489	60	6,769	60
65 and over	474	5	141	6	615	5
Race/Ethnicity						
White	5575	64	1626	65	7,201	64
Latino	1592	18	481	19	2,073	19
Black	1313	15	307	12	1,620	14
Other	170	2	66	3	236	2
Unknown	49	1	19	1	68	1
Birth Origin						
US Born	7798	90	2247	90	10,045	90
Foreign Born	901	10	252	10	1,153	10
Year of HIV Diagnosis						
Before 1990	2184	25	510	20	2,694	24
1990 - 1995	1979	23	597	24	2,576	23
1996 - 2000	1316	15	442	18	1,758	16
2001 - 2005	1476	17	431	17	1,907	17
2006 - 2011	1725	20	512	20	2,237	20
Unknown	19	<1	7	<1	26	<1
Disease Status						
HIV	4955	57	1324	53	6,279	56
AIDS	3744	43	1175	47	4,919	44
Documented Transmission Category**						
MSM	5828	67	1361	54	7,189	64
HET	808	9	283	11	1,091	10
MSM & IDU	748	9	201	8	949	8
IDU	561	6	287	11	848	8
Perinatal	35	<1	18	1	53	<1
Other	30	<1	14	1	44	<1
Unknown	689	8	335	13	1,024	9

*These figures include all HIV cases diagnosed in Colorado for which no mortality information has been documented.
** All percentages have been rounded to the nearest whole percent and may not equal 100%.

Table 2 displays Colorado incidence data on persons diagnosed with HIV from January 1, 2006, to December 31, 2010. One difference between the more recent data as compared to the prevalence data is that it includes a somewhat higher proportion of female cases (14 percent versus 11 percent). Another is seen in the age groups, with 58 percent of all of the newer cases falling into the 25 to 34 and 35 to 44 year age groups. The mean age of those diagnosed within that five-year period was 40 and the median age was 39. Among race/ethnic groups, African Americans are even more overrepresented at 17 percent (over four times their proportion of the population), and African American females accounted for 44 percent of all female cases (11 times their proportion of the population). The proportion of Latino HIV cases exceeded Latino population proportions by five percentage points at 26 percent, with Latina females at 24 percent of all female cases. Another difference is in the higher proportion of foreign-born cases in the incidence data at 16 percent. Within the documented transmission categories, MSM and MSM/IDU make up a smaller percentage of the total at 69 percent, and IDU alone were down to five percent. Documented heterosexual cases were up to 15 percent and those with unknown risk were up to 12 percent of the incident cases.

Table 2: Colorado cases of HIV diagnosed between 2006 – 2010 by geographic location

	Denver Metro		**Non-Denver**		**All**	
	N	**%**	**N**	**%**	**N**	**%**
Total	1650	100	515	100	2,165	100
Sex at Birth						
Male	1423	86	430	84	1,853	86
Female	227	14	85	17	312	14
Age Group						
<15	14	1	5	1	19	1
15 - 19	5	<1	1	<1	6	<1
20 - 24	95	6	31	6	126	6
25 - 34	499	30	152	30	651	30
35 - 44	484	29	131	25	615	28
45 - 64	509	31	179	35	688	32
65 and over	44	3	16	3	60	3
Race/Ethnicity						
White	842	51	305	59	1,147	53
Latino	435	26	128	25	563	26
Black	312	19	63	12	375	17
Other	61	4	19	4	80	4
Birth Origin						
US Born	1371	83	437	85	1,808	84
Foreign Born	279	17	78	15	357	16
Disease Status						
HIV	977	59	303	59	1,280	59
AIDS	673	41	212	41	885	41
Documented Transmission Category						
MSM	1068	65	287	56	1,355	63
HET	243	15	74	14	317	15
MSM & IDU	92	6	31	6	123	6
IDU	71	4	28	5	99	5
Perinatal	11	1	3	1	14	1
Other	-	-	1	<1	1	<1
Unknown	165	10	91	18	256	12

* All percentages have been rounded to the nearest whole percent and may not equal 100%.

Table 3 shows similar demographic descriptions for the 862 PLWH who responded to the needs assessment survey. When compared to the Colorado prevalence data, those reporting living in the DMA are somewhat underrepresented (69 percent versus 78 percent), as are males (82 percent versus 89 percent), whites (56 percent versus 64 percent), and MSM (63 percent versus 72 percent). Heterosexuals appear to be overrepresented in the survey sample, however much of this difference is due to the transmission category being self-reported on the survey rather than assessed by the documentation of an HIV positive heterosexual partner for males as it is in the surveillance data displayed above.

Table 3: Survey respondents by geographic location

	Denver Metro		Non-Denver		All	
	N	**%**	**N**	**%**	**N**	**%**
Total	595	100	267	100	862	100
Sex at Birth						
Male	491	83	213	80	704	82
Female	102	17	53	20	155	18
No Response	2	<1	1	<1	3	<1
Age Group						
<15	1	<1	-	-	1	<1
15 - 19	1	<1	1	<1	2	<1
20 - 24	10	2	3	1	13	2
25 - 34	49	8	22	8	71	8
35 - 44	154	26	69	26	223	26
45 - 64	331	56	149	56	480	56
65 and over	23	4	11	4	34	4
Unknown	26	4	12	4	38	4
Race/Ethnicity						
White	324	54	156	58	480	56
Latino	135	23	76	28	211	24
Black	84	14	11	4	95	11
Other	35	6	18	7	53	6
Unknown	7	1	2	1	9	1
Birth Origin						
US Born	518	87	227	85	745	86
Foreign Born	77	13	40	15	117	14
Year of HIV Diagnosis						
Before 1990	92	15	41	15	133	15
1990 - 1995	132	22	60	22	192	22
1996 - 2000	101	17	48	18	149	17
2001 - 2005	108	18	50	19	158	18
2006 - 2011	138	23	54	20	192	22
Unknown	24	4	14	5	38	4
Disease Status						
HIV	292	49	133	50	425	49
AIDS	286	48	125	47	411	48
No Response	17	3	9	3	26	3
Transmission Category						
MSM	400	67	148	55	548	64
HET	110	18	65	24	175	20
IDU	32	5	18	7	50	6
Other	40	7	33	12	73	8
No Response	13	2	3	1	16	2

* All percentages have been rounded to the nearest whole percent and may not equal 100%.

Tables 4 and 5 provide further information on the survey respondents, which goes well beyond the data that are gathered through typical HIV surveillance efforts. Given that this sample is made up predominantly of ADAP recipients and clients of ASOs, it can in no way be seen as representative of all PLWH in Colorado as it inherently includes very few people who could be considered as out of care or people with higher incomes who typically do not rely on these services. As shown in Table 4, sixty-eight percent of the survey respondents reported sufficient income and household number data to assess their percent of Federal Poverty Level (FPL), which is $10,890 for an individual and $22,350 for a family of four. PLWH are eligible for ADAP services if their household income is up to 400 percent of FPL. Of those who provided sufficient income information (N=588), 47 percent were under the poverty level, including 20 percent whose income fell below 50 percent of FPL. Fourteen percent earned 200 percent or more of FPL. Among those reporting Denver area residency, 50 percent were at or above FPL and 21 percent were below 50 percent of FPL. Among those outside of the DMA or whose residence was unknown, 60 percent were at or above FPL and 19 percent were below 50 percent of FPL. Only 16 percent of the survey respondents were working full-time, and another 14 percent were working part-time. Forty-two percent reported being retired or on disability. Fourteen percent of those responding to the question reported being homeless sometime within the previous two years, with a higher percentage of the DMA residents reporting a history of homelessness than the non-Denver residents (16 percent versus seven percent). Only two percent claimed to be currently living in a shelter or on the streets. The majority of the survey respondents (58 percent) reported renting the place where they live.

Table 5 displays the respondents’ answers to various health-related questions. When asked how they would describe their physical health, 47 percent rated their health as good and another 15 percent rated it as excellent. The non-Denver residents were somewhat more likely to rate their health as good or excellent than the Denver area residents (65 percent versus 60 percent). Eight percent of the overall sample rated their physical health as poor (seven percent from the DMA and 11 percent from outside the DMA). A smaller percentage of the sample rated their overall mental health as good or excellent (54 percent) than they did with physical health, with the non-Denver residents choosing one of these two ratings more often than the Denver residents (60 percent versus 51 percent). Although only 45 percent of the survey sample reported their overall mental health as fair or poor, 62 percent reported experiencing symptoms of depression in the previous 12 months, 55 percent reported feeling as if they needed help with mental health in the past year, and 63 percent reported having ever been diagnosed with one or more mental disorders such as depression, anxiety, bipolar disorder, obsessive compulsive disorder, or schizophrenia. Over half of the survey sample (52 percent) reported having had a diagnosis of depression. Overall, 58 percent of the survey sample reported that they used alcohol or drugs, with a higher percentage of the Denver area residents reporting some use compared to the non-Denver based respondents (61 percent versus 49 percent). Of those who reported using alcohol or drugs, 39 percent (23 percent of the whole sample) reported feeling that they should cut down on their use in the past 12 months, and 22 percent (13 percent of the total) reported feeling that they needed help cutting down in the past 12 months.

Table 4: Other characteristics of survey respondents

	Denver Metro		Non-Denver		All	
	N	**%**	**N**	**%**	**N**	**%**
All	595	100	267	100	862	100
Household Income*						
No Income in 2010	61	10	17	6	78	9
$8000 or less	133	22	55	21	188	22
$8,001 to $10,400	96	16	34	13	130	15
$10,401 to $20,800	202	34	87	33	289	34
$20,801 to $31,200	52	9	39	15	91	11
$31,201 or more	44	7	30	11	74	9
No Response	7	1	5	2	12	1
Percent of Federal Poverty Level based on number in household						
Less than 50%	84	14	35	13	119	14
60% - 90%	120	20	38	14	158	18
100% - 190%	154	26	76	28	230	27
200% or more	49	8	32	12	81	9
Unknown	188	32	86	32	274	32
Level of Education						
Less than H.S.	69	12	28	10	97	11
High School/GED	248	42	111	42	359	42
Technical school degree	34	6	16	6	50	6
Two-Year degree	70	12	41	15	111	13
Four-year degree	75	13	36	13	111	13
Graduate degree	32	5	15	6	47	5
Other	65	11	16	6	81	9
No Response	2	<1	4	1	6	1
Employment Status						
Employed Full-time	88	15	49	18	137	16
Employed Part-time	89	15	35	13	124	14
Unemployed (looking)	126	21	41	15	167	19
Unemployed (not looking)	39	7	20	7	59	7
Retired/On disability	247	42	119	45	366	42
Other	3	1	-	-	3	<1
No Response	3	1	3	1	6	1
Homelessness in past two years						
Yes	96	16	19	7	115	13
No	488	82	242	91	730	85
No Response	11	2	6	2	17	2
Living Situation						
Renter	350	59	150	56	500	58
Owner	85	14	63	24	148	17
Staying with friends/family	90	15	39	15	129	15
Live in shelter	11	2	-	-	11	1
On streets	7	1	-	-	7	1
Other	45	8	8	3	53	6
No Response	7	1	7	3	14	2

* All percentages have been rounded to the nearest whole percent and may not equal 100%.

Table 5: General health status of survey respondents

	Denver Metro		Non-Denver		All	
	N	%	N	%	N	%
Respondent's self described physical health						
Poor	43	7	29	11	72	8
Fair	191	32	63	24	254	29
Good	266	45	135	51	401	47
Excellent	89	15	37	14	126	15
No Response	6	1	3	1	9	1
Respondent's self described mental health						
Poor	77	13	28	10	105	12
Fair	206	35	77	29	283	33
Good	238	40	125	47	363	42
Excellent	67	11	34	13	101	12
No Response	7	1	3	1	10	1
Respondent experienced symptoms of depression in past 12 months*						
Yes	388	65	145	54	533	62
No	193	32	112	42	305	35
No Response	14	2	10	4	24	3
Respondent felt they needed help with mental health in last 12 months						
Yes	339	57	138	52	477	55
No	252	42	125	47	377	44
No Response	4	1	4	1	8	1
Respondent has had a diagnosis of mental disorder**						
Any Mental Health dx	385	65	157	59	542	63
Depression	318	53	131	49	449	52
Anxiety	209	35	86	32	295	34
Bipolar	102	17	31	12	133	15
Other	56	9	20	7	76	9
OCD	35	6	7	3	42	5
Schizophrenia	20	3	3	1	23	3
Respondent ever drinks or uses drugs						
Yes	**364**	**61**	**132**	**49**	**496**	**58**
No	221	37	131	49	352	41
No Response	10	2	4	1	14	2
Of those that drink or use drugs, respondents felt they should cut down on alcohol or drug consumption in past 12 months (N=496)						
Yes	142	39	50	38	192	39
No	201	55	81	61	282	57
No Response	21	6	1	1	22	4
Of those that drink or use drugs, respondents felt they needed help cutting down in past 12 months (N=496)						
Yes	85	23	24	18	109	22
No	199	55	85	64	284	57
No Response	80	22	23	17	103	21

* All percentages have been rounded to the nearest whole percent and may not equal 100%.

**Respondents selected all that apply, therefore does not sum to 100 percent.

AIDS AT FIRST HIV DIAGNOSIS

Over a third of the 2,154 people (35 percent) diagnosed with HIV from 2006 through 2010 received a diagnosis of AIDS within a year of their initial HIV diagnosis, most of whom received their AIDS diagnosis at almost the same time as they found out they had HIV. These cases are referred to as "concurrent HIV/AIDS" and Table 6 shows the percent of each demographic and risk group that received such diagnoses. Of the 1,846 males diagnosed from 2006-2010, 36 percent had concurrent diagnoses as compared to 32 percent of the 308 females diagnosed during that time. Among MSM, 34 percent had concurrent HIV/AIDS diagnoses and among heterosexual men, 49 percent had concurrent diagnoses. Those under the age of 35 were much less likely to have had concurrent diagnoses compared to those 35 and over (23 percent versus 42 percent). Almost half (47 percent) of those over 45 had concurrent diagnoses. Among race/ethnic groups, whites and African Americans had similar percentages of concurrent diagnoses (32 and 34 percent respectively), and 37 percent of U.S. born Latinos had concurrent diagnoses. However the percentage of Latinos born outside the U.S. with concurrent HIV/AIDS diagnoses was much higher at 56 percent.

Table 6: Percent of all Coloradans diagnosed (Dx) between 2006 and 2010 with concurrent HIV/AIDS diagnoses by demographic, risk, and geographic groups

	Concurrent HIV/AIDS Dx		Non-concurrent AIDS Dx		HIV		Total
	N	%	N	%	N	%	N
All	762	35	122	6	1270	59	2,154
Sex at Birth							
Male	662	36	108	6	1076	58	1,846
Female	100	33	14	5	194	63	308
Age Category							
<25	25	17	6	4	118	79	18
25 - 34	162	25	32	5	453	70	647
35 - 44	228	37	45	7	339	55	612
45 - 64	317	46	37	5	332	48	686
65 and over	30	50	2	3	28	47	60
Race/ Ethnicity by Birth Origin							
White-US Born	359	32	70	6	702	62	1,131
Latino-US Born	143	37	25	7	214	56	382
Black-US Born	79	32	12	5	153	63	244
Other US Born	17	33	3	6	31	61	51
Latino - Non-US born	100	57	3	2	74	42	177
Other - Non-US born	64	38	9	5	96	57	169
Documented Transmission Category							
MSM	453	34	75	6	823	61	1,351
IDU	40	40	10	10	49	50	99
MSM & IDU	38	31	13	11	70	58	121
Male Heterosexual	56	49	7	6	51	46	114
Female Heterosexual	63	31	10	5	129	64	202
Other	2	14	-	-	12	86	14
Unknown	110	44	7	3	136	54	253
County Type of Residence							
Denver Metro	568	35	104	6	970	59	1,642
Non-Denver	194	38	18	4	300	59	512

* All percentages have been rounded to the nearest whole percent and may not equal 100%.

In many ways, the rates of concurrent diagnoses mirror the rates of HIV cases in general, with the highest concentrations in the DMA. Overall, there was only a 3.3 percent difference between the proportions of concurrent diagnoses in the DMA and other parts of the state. However, a closer look shows that some parts of the state have higher proportions of concurrent diagnoses relative to the total number of incident cases than others. An analysis of the proportion of concurrent cases relative to total incident cases using geocoded data from 2007 to mid 2011 was conducted at both the county and zip code level. This time period was chosen because address data were not systematically entered into HARS prior to 2007.The analysis showed that among counties with at least 25 incident cases during that time period, the proportion of concurrent cases ranged as high as 56 percent of the total HIV incident cases. Among zip codes with over 10 incident cases during that time period, the proportion ranged as high as 69 percent.

Figure 1 displays the geographic distribution of the rates of concurrent cases diagnosed between 2007 and mid 2011 by county. Figure 2 shows the proportions of concurrent diagnoses relative to the total number of cases of HIV by county during the same period, excluding counties with less than 25 incident cases. However, it is important to note that among those excluded counties that had at least one incident case during that time period, an average of 41 percent of cases involved concurrent diagnoses. The proportions ranged from zero to 100 percent. This analysis shows Weld County with the highest proportion of concurrent diagnoses at 56 percent, although the incident rate in Weld County is relatively low, accounting for two percent of the total cases in Colorado. Weld is followed by Jefferson with 41 percent concurrent cases and eight percent of the epidemic, Adams with 40 percent concurrent cases and 10 percent of the epidemic, and Boulder with 38 percent of concurrent cases and four percent of the epidemic. Denver County had, by far, the highest number of concurrent diagnoses (N=235), but the proportion of concurrent cases relative to total cases in Denver County was 33 percent, slightly below the state average of 35 percent. Forty percent of all incident cases during that time period were in Denver County.

A similar analysis of the distribution of proportions of concurrent cases by zip code focused only on zip codes with 10 or greater incident cases over the four and a half year period. All of the zip codes with the most reported incident cases during this period (>30 incident cases; range = 32 to 88 cases) were located in the DMA and had proportions of concurrent diagnoses close to or below the state average of 33 percent. Zip codes with the highest proportions of concurrent diagnoses (>40 percent of incident cases) but with incident case numbers less than 30 during the four and a half year period were located in Denver, Jefferson, Adams, El Paso, and Weld counties. A total of 62 zip codes around the state with low HIV incidence had rates of concurrent HIV and AIDS diagnoses of at least 50 percent.

Figure 1:Rates per 100,000 of Colorado incident cases of HIV with concurrent AIDS diagnoses: 2007-2011 by county

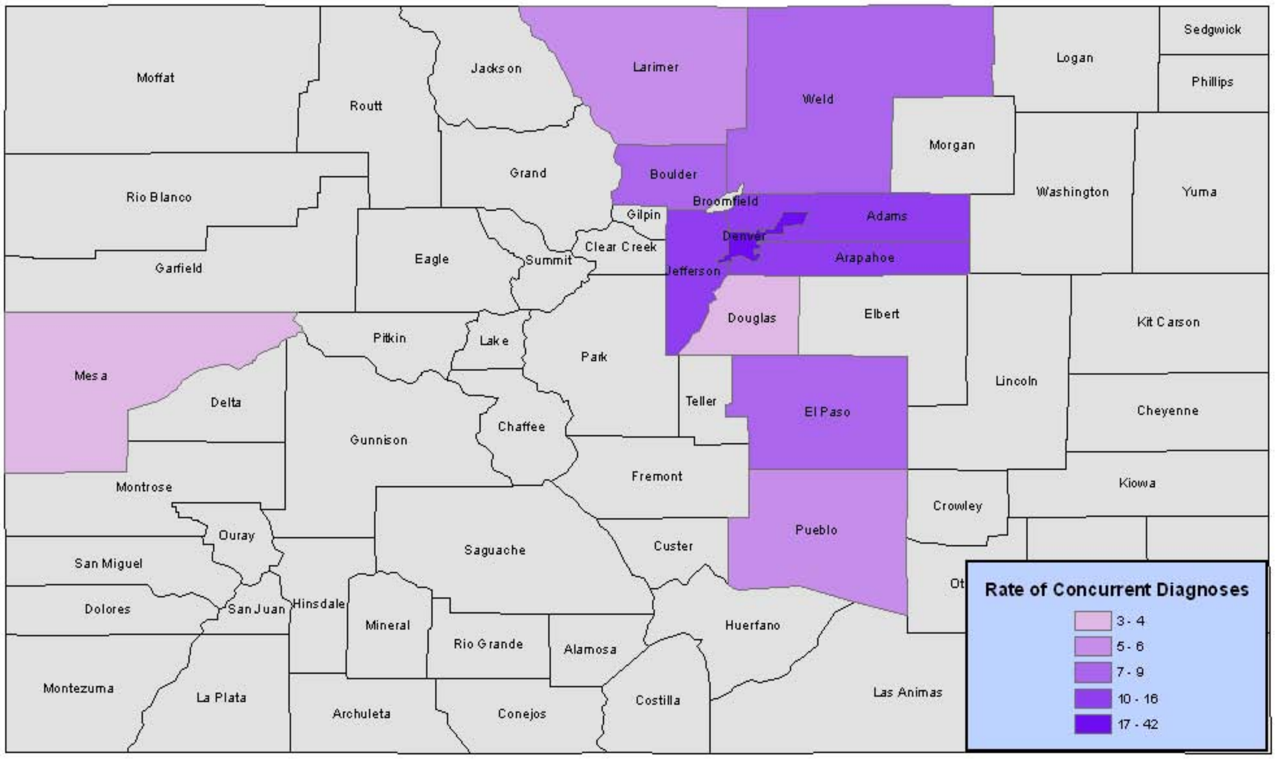
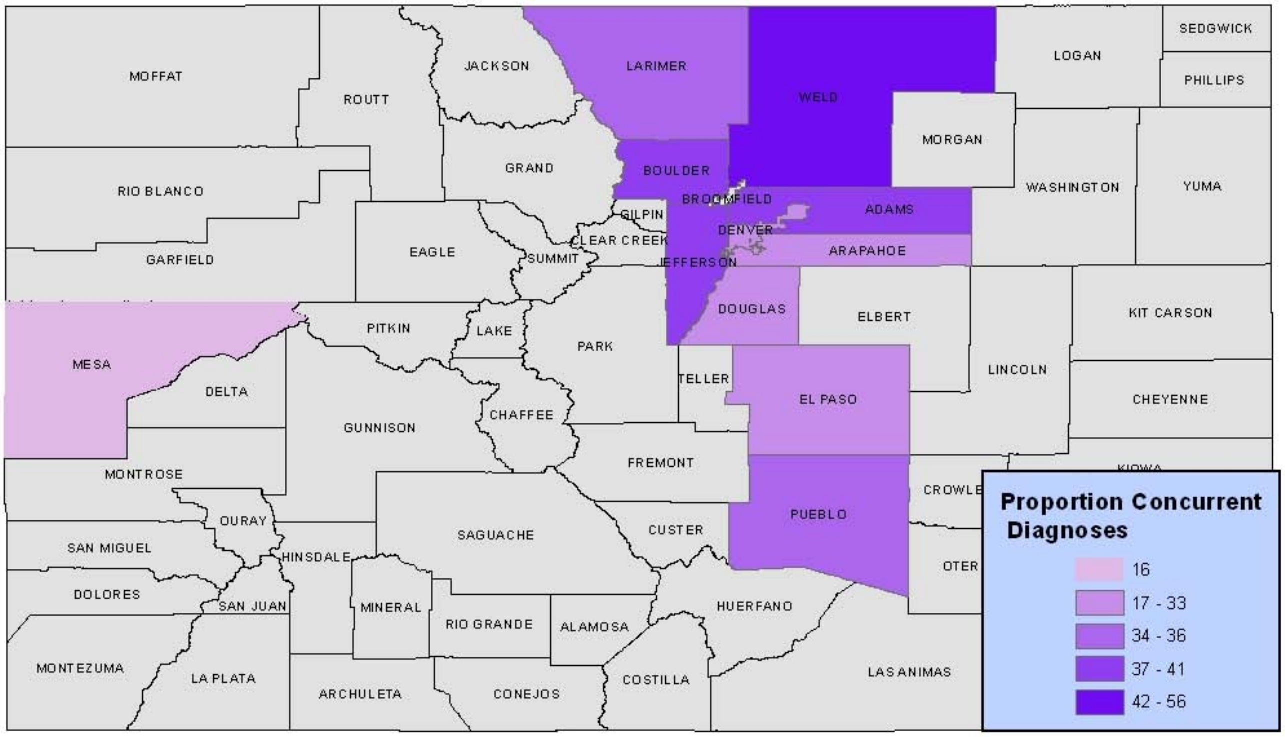


Figure 2:Proportions of Colorado incident cases of HIV with concurrent AIDS diagnoses relative to all incident HIV cases: 2007-2011 by county



Survey respondents who had reported the same calendar year of diagnosis for their HIV and AIDS were considered as having concurrent diagnoses. Note that this could potentially underestimate the number of respondents who had an AIDS diagnosis within 12 months of HIV if they did not occur in the same calendar year. Overall, the sample of survey respondents had a much lower proportion of those with concurrent HIV/AIDS diagnoses than the Colorado epidemic as a whole. Only 22 percent of all survey respondents self-reported having had a concurrent diagnosis. This lower percentage was prevalent throughout all of the demographic categories, not exceeding 25 percent in any category. Among the survey respondents who were diagnosed with HIV between 2006 and 2010, 27 percent had a concurrent diagnosis. Those categories with the highest proportions of people with concurrent diagnoses in that five-year period, immigrants and those over 44 years of age did not exceed 35 percent. There were 15 (two percent) respondents whose diagnoses were only one year apart, some of which could have been classified as concurrent if the month of diagnosis had been collected.

When asked why they decided to test for HIV at the time they were first diagnosed, survey respondents who had concurrent AIDS diagnoses most commonly responded that they did so due to illness (see Table 7). This is especially high given that illness was not one of the choices provided on the survey, and respondents wrote it in under “other”. Responses such as “my doctor suggested it” and “it was offered during a medical visit” were also frequent among this group and could also indicate that many of them were sick at the time. Those who did not have an AIDS diagnosis soon after their initial HIV diagnosis most commonly reported testing because they wanted to know their status, with only 15 percent reporting that it was because their doctor suggested it and 11 percent due to illness. Those without concurrent diagnoses much more commonly responded that they tested because a sexual partner had tested positive than those with concurrent diagnoses (16 percent versus seven percent). This was also the case for those reporting testing because an organization offered it (11 percent versus five percent), suggesting the need for testing to be made available in more venues that people tend to access. There were few differences in the reported reasons for testing between those living in the DMA and those outside of Denver. Five percent of women who did not have concurrent AIDS diagnoses reported testing due to pregnancy, and only two percent tested because it was offered to them by an organization. This compares to 14 percent of MSM and 13 percent of IDU who were offered testing at an organization, suggesting the need to offer testing to women in more places that they are likely to frequent.

Table 7: Top five reasons for testing of survey respondents diagnosed with AIDS in the same year as HIV compared to those who did not have AIDS

Concurrent HIV/AIDS diagnoses (N=190)		**Non-concurrent (different calendar-year) or no AIDS diagnosis (N=655)**	
I became sick*	30%	Wanted to know status	29%
My doctor suggested it	28%	Had unprotected sex	18%
Wanted to know status	16%	Sexual partner tested positive	16%
Offered during medical visit	13%	My doctor suggested it	15%
Sexual partner tested positive	7%	I became sick*	11%
Had unprotected sex	7%	Organization offered it	11%

*Written in as “Other” response
Respondents were asked to mark all that apply. Responses do not sum to 100 percent.

Twelve people who had received an AIDS diagnosis soon after being diagnosed with HIV for the first time participated in one-on-one interviews. All but four had been initially diagnosed with HIV within the 12 months prior to participating in the interview. Four of the interview participants reported never having been previously tested for HIV. Three reported that the last time they tested negative for HIV was between two and six years prior to their HIV diagnosis. Five of the participants reported to have tested negative between three and 12 months prior to their HIV diagnosis. All of this information is based on self-report and would need to be investigated further to document the actual dates of previous negative tests before drawing any conclusions related to the time of progression to AIDS among these participants.

When asked about the reason for testing when they were diagnosed with HIV, nine of the 12 participants were tested because they were extremely ill, with all but one of the nine testing while in the hospital. Those who offered information about their initial CD4 counts said that they were already down to double and single digits when their first laboratory tests were done. Among the other three individuals, one found out he was positive after donating plasma at a time when he needed some quick money. Another tested as part of an annual routine physical, and the third tested after finding out that a partner had tested positive. One of those who tested due to illness said that he had been misdiagnosed for around six months, having received treatment for another condition during that time.

The interview participants were then asked why they had delayed getting tested for HIV. Three of them did not think they were at risk because, as heterosexuals, they thought they did not fit the profile of people who tend to be at risk for HIV. Three gay men who were interviewed spoke of times when they were not routinely tested for HIV because they were in (what they thought) were monogamous relationships. One gay man asked his doctor why he had never tested him and was told that it was because he had children. Two other gay men thought that their doctors had been testing them over the years, but they had not. Three participants said that they had not delayed testing, reporting to have tested negative within the previous several months. When asked what might have encouraged them to test sooner, two people responded that having their doctors talk to them about HIV and offer the tests would have helped. Three others said they would have tested more often if testing were more available and affordable in the areas where they live or if testing were available in more venues with people encouraging them to test. One respondent said that he would have tested sooner if he had more information about HIV and risk behaviors.

In an effort to gain ideas from PLWH about how to increase HIV testing and lower the proportion of people who find out about their diagnoses when they already have advanced disease, these interview respondents were asked for their opinions about increasing testing. Most of their responses fell into two general categories: 1) Increase the availability of testing, and 2) Increase awareness and education about HIV. In terms of increasing availability, several respondents talked about how important it is for doctors to be more proactive about HIV, talking to their patients about risks and making testing available during appointments. Others mentioned the importance of outreach, with friends, PLWH, and outreach workers encouraging people to test and then making testing available in many venues including health centers, bars, colleges, on the streets, and in a mobile van. Two emphasized the importance of having testing available for free, and three others noted that wherever testing was offered, it needed to be discrete given the stigma surrounding HIV. Those who thought it was important to increase knowledge and raise awareness about HIV in order to increase testing offered several different ideas as to the information that would be important to share. Some thought it important for people to understand their risks better. This included: heterosexuals knowing that they could be at risk, gay men in relationships better understanding their partners' risks as well as their own, and gay men who were insertive partners ("tops") knowing they still had risk. Others thought it was important for people to understand that HIV is not a death sentence, and the sooner people find out they are positive, the earlier they can receive effective treatment and also prevent spreading the disease to their sex partners. Two people recommended that HIV testing be mandatory. Two others pointed out that some people just couldn't be encouraged to get tested no matter what one says to them.

PEOPLE LIVING WITH HIV OUT OF CARE

Between July 1, 2010, and June 30, 2011, there were 11,279 Colorado cases which were considered as "living" cases (no death records had been reported) for at least one day during that time. Of those, 4,989 had a reported AIDS diagnosis and 6,290 had an HIV diagnosis. Surveillance data show that 51 percent of Colorado cases were considered to be "out of care." It is difficult to estimate the proportion of the people diagnosed with HIV who are actually living in the state but not receiving medical care and other related services. According to HRSA, a person is considered to be "out of care" when there is no evidence that she or he received a doctor visit or a CD4 or viral load test for a period of at least 12 months. The STI/HIV Section's Surveillance Program at CDPHE consistently tracks these two testing indicators of care as laboratories around the state report them, but they do not track doctor visits. In previous years, according to Colorado Board of Health regulations, only CD4 counts below 500 cells per cubic millimeter of blood or below 29 percent of lymphocytes that are CD4 cells were required to be reported. Non-detectable viral load results did not have to be reported prior to March 2010. Therefore, many of the viral load test results were not sent to CDPHE, especially for people who did not have an AIDS diagnosis. In March 2010, the Board of Health revised its regulations around the reporting of viral load results to include those considered as non-detectable. Due to this change, estimates of the number of Coloradans with HIV who are considered to be in and out of care based on these two indicators is more complete than in years past. However, obtaining a true and more complex assessment of the number of people with HIV in the state who are receiving medical care would need to go well beyond the tallying of the reports of these two laboratory tests.

Table 8 provides a demographic breakdown of people living with AIDS (PLWA) in Colorado who are considered to be in and out of care based on the current criteria. As of June 30, 2011, an estimated 1,697 people with an AIDS diagnosis were considered to be out of care. Among those with an HIV diagnosis, 4,045 were considered out of care. Overall, those with an HIV diagnosis were much more likely to be considered out of care at 64 percent compared to those with an AIDS diagnosis at 34 percent. Among age groups, 33 percent of those under 35 were considered as out of care. Among those 35 and older, 53 percent were considered out of care. Whites (53 percent) and African Americans (52 percent) were more likely to be considered out of care than Latinos (43 percent), and men (52 percent) more so than women (40 percent). Those living in rural areas (53 percent) were somewhat more likely to be out of care than those in the DMA (49 percent) and in other urban areas around the state (48 percent). The documented heterosexual category had 39 percent of persons out of care, the lowest percentage compared to all the other risk groups. Among MSM, 50 percent were out of care, and among MSM/IDU and IDU, 56 percent were out of care. As previously noted, there is less current information available on PLWH who were diagnosed in the 1980s and early 1990s, many of which were men, which could distort this overall picture of PLWH in Colorado who are in and out of care. An analysis of cases diagnosed after 1995 shows 35 percent to be out of care compared to 51 percent of the entire sample. When only these more recent cases are considered, the out-of-care percentage decreases most for the following groups: males (from 52 to 31 percent), whites (from 53 to 32 percent), people 45 and older (from 56 to 34 percent), and the

MSM and MSM/IDU risk groups (from 51 to 33 percent). The difference among other demographic and risk groups was less striking.

Table 8: PLWH in Colorado in and out of care

	In Care	%	Out of care	%	Total
Total	5537	49.1	5742	50.9	11279
AIDS	3292	66.0	1697	34.0	4989
HIV	2245	35.7	4045	64.3	6290
Age Group					
24 and under	174	80.6	42	19.4	216
25 - 34	728	64.8	395	35.2	1123
35 - 44	1391	55.8	1103	44.2	2494
45 and older	3244	43.6	4202	56.4	7446
Race/Ethnicity					
White	3431	47.3	3823	52.7	7254
Latino	1196	57.2	895	42.8	2091
African American	773	47.6	852	52.4	1625
Other	135	54.9	111	45.1	246
Sex at birth					
Female	770	60.3	508	39.7	1278
Male	4767	47.7	5234	52.3	10001
County of Residence at HIV Diagnosis					
Other/Unknown	71	13.2	468	86.8	539
Denver Metro	4298	51.0	4124	49.0	8422
Rural/Frontier	263	46.7	300	53.3	563
Urban	905	51.6	850	48.4	1755
Risk					
MSM	3607	49.9	3618	50.1	7225
HET	669	60.9	429	39.1	1098
MSM & IDU	420	43.9	536	56.1	956
IDU	386	44.5	482	55.5	868
Unknown	399	38.6	636	61.4	1035
Perinatal	38	71.7	15	28.3	53
Other	18	40.9	26	59.1	44
Year of HIV Diagnosis					
Unknown	9	34.6	17	65.4	26
Before 1990	580	21.5	2123	78.5	2703
1990 - 1995	1064	41.0	1532	59.0	2596
1996 - 2000	955	53.9	818	46.1	1773
2001 - 2005	1188	61.9	732	38.1	1920
2006 - 2011	1741	77.0	520	23.0	2261

An analysis of people who were diagnosed with HIV from the beginning of 2007 to mid 2011 shows an overall lower percentage of PLWH considered out of care compared to the entire sample of Colorado cases due, in part, to increased efforts over the last several years to link more people to care upon their diagnosis. Figure 3 shows out of care rates by county for those diagnosed during that time period, showing the highest rates in Denver County. However, as shown in Figure 4, an analysis of the proportions of people out of care by county relative to the total number of incident cases in each county shows Denver County in the middle range at 20 percent, the same as the average of all counties with 25 or more incident cases. Larimer and Douglas counties had proportions above the average at 31 and 29 percent respectively. Eleven other counties had proportions of out of care cases of at least 25 percent and ranging up to 100 percent, however, all were low incidence counties, with 11 or fewer total incident cases during the time period.

Figure 3: Rate per 100,000 of PLWH in Colorado diagnosed between 2007 and 2011 considered out of care by county

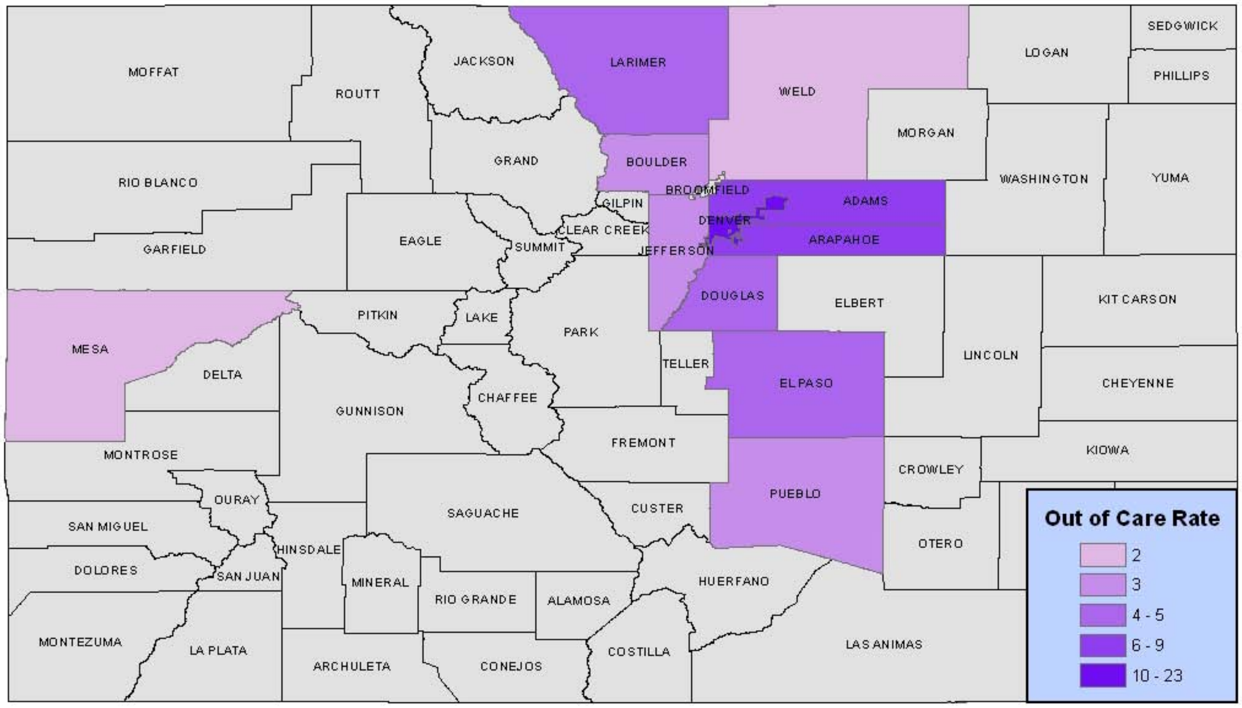
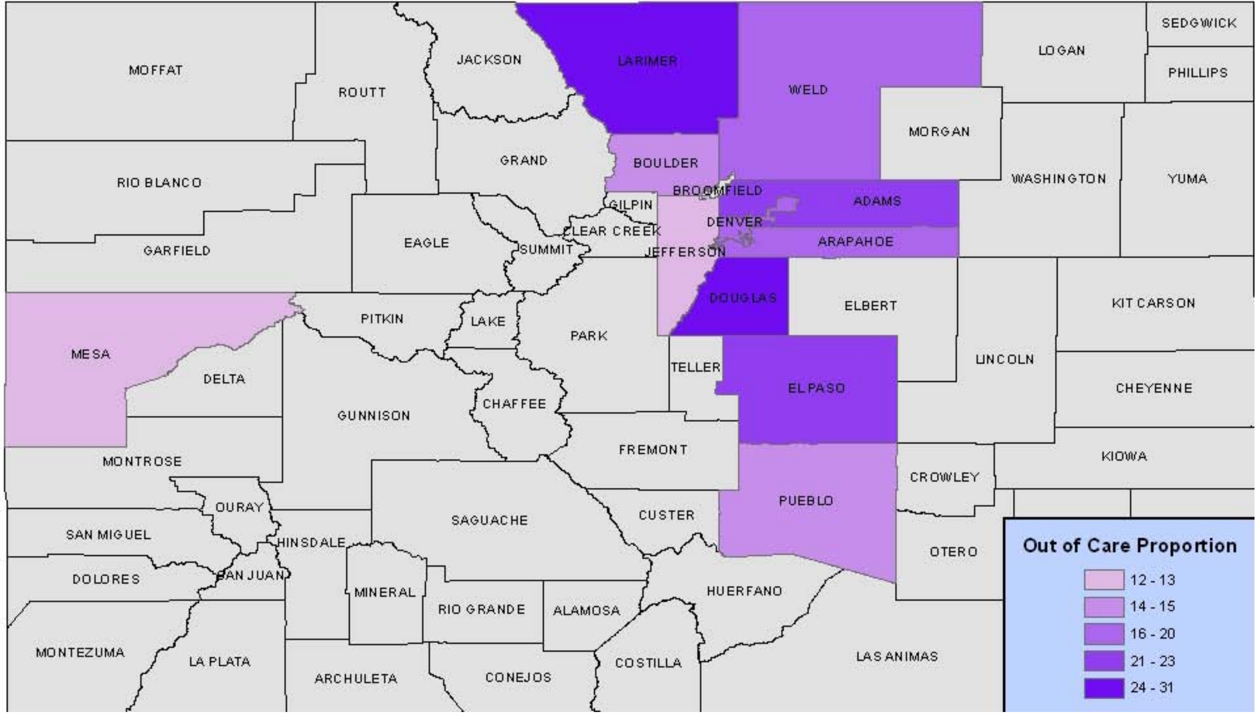


Figure 4: Proportions of Colorado incident cases of HIV considered out of care relative to all incident HIV cases: 2007 to 2011 by county



Several questions included on the survey asked respondents about any experiences they may have had being out of care since their initial HIV diagnosis. Of the 862 survey respondents from throughout the state, 17 percent reported that they went more than a year without receiving medical care after their HIV diagnosis or that they had never received medical services, 18 percent among DMA residents and 14 percent of the non-DMA respondents. When asked if they had ever gone without care for more than 12 months and why, 21 percent indicated that they had at some time been out of care; a reason was provided by 22 percent of DMA residents and 19 percent of non-DMA residents. Forty percent of all respondents stated that they had never gone without care for more than 12 months, and another 39 percent did not respond. Groups of survey respondents that were somewhat overrepresented among those having been out of care include: heterosexuals living in the DMA at 26 percent; women at 24 percent; and people with AIDS at 24 percent. As would be expected, the longer the time period since a person's diagnosis the more likely that he/she would have spent some time out of care. Among this survey sample, 27 percent of those diagnosed with HIV before 2001 had spent more than a year out of care, whereas only 12 percent of those diagnosed since then had been out of care in the past. The majority of the survey respondents are currently receiving HIV care and do not represent all of those living with HIV in Colorado.

Forty percent of all respondents who were ever out of care said it was because they could not afford it. A somewhat higher percentage of respondents from outside of Denver (47 percent) reported this as their reason compared to those living in Denver (36 percent). The next most common response offered by 27 percent of those spending time out of care (29 percent from Denver and 24 percent from out of Denver) was due to insufficient insurance. Table 9 shows the frequency with which each reason was chosen by respondents in Denver and outside of Denver. A higher percentage of respondents from outside of Denver (20 percent versus 11 percent) cited a lack of transportation as a reason for being out of care, and 22 percent of those out of Denver cited poor personal treatment by a provider as their reason compared to only eight percent of the Denver-based respondents (Table 9).

Table 9: Survey respondents' reasons for ever spending more than 12 months out of care. Red indicates high frequency response while green indicates low frequency response.

	DMA N=129		Non-DMA N=50		Total N=179	
	N	%	N	%	N	%
Could not afford it	47	36	23	47	71	40
Insufficient insurance	37	29	12	24	49	27
Did not think I needed care because I wasn't sick	27	21	9	18	36	20
Did not want anyone to find out I had HIV	25	19	9	18	34	19
Too many requirements/too much paperwork	**20**	**16**	5	10	25	14
Did not think medical care would do me any good	**19**	**15**	5	10	24	13
Lack of transportation	14	11	**10**	**20**	24	13
Have never gone without them for that long	14	11	**9**	**18**	23	13
There was no one to help me figure out how to access care	13	10	**10**	**20**	23	13
Poor personal treatment by a provider	10	8	**11**	**22**	21	12
Did not qualify for services	13	10	6	12	19	11
Did not know where to go for medical care	13	10	6	12	19	11
Other	29	22	11	22	40	22

Survey options that were chosen by less than ten percent of respondents included: "I did not want services," "Long wait times for appointments," "A doctor or nurse told me I didn't need medical care," and "No one told me that I needed to get medical care for HIV."

Fourteen percent of the entire survey sample reported not receiving medical or related services for at least one of the following reasons: because the provider did not speak their same language; because of the attitude expressed by the provider, or because of a disability. Overall, 11 percent of the entire sample of survey respondents (10 percent of the Denver sample and 16 percent of the non-Denver sample) cited provider attitude and disrespectful treatment as a reason for not receiving services at some time, compared to two percent because of language differences, and three percent due to a disability (Table 10). A total of 25 people reported being denied some type of related services in the past or receiving highly substandard services from providers because of their HIV status.

Table 10: Survey respondents not receiving care due to language differences, provider attitude, or disability

Reasons for not receiving care	Denver		Non-Denver		All	
	N	%	N	%	N	%
Total	**595**		**267**		**862**	
Ever unable to get services due to one of the following three reasons	70	12	47	18	117	14
Never been unable to get services due to one of the following three reasons	490	82	206	77	696	81
No Response	35	6	14	5	49	6
	N	**% of 70**	**N**	**% of 47**	**N**	**% of 117**
Provider not speaking language	**9**	13	**9**	19	18	15
No	48	69	31	66	79	68
No Response	13	19	7	15	20	17
Attitude expressed by provider	**58**	**83**	**40**	**85**	**98**	**84**
No	5	7	4	9	9	8
No Response	7	10	3	6	10	9
Because of a disability	**19**	**27**	**9**	**19**	**28**	**24**
No	38	54	28	60	66	56
No Response	13	19	10	21	23	20

Survey respondents who had spent time out of care also offered their perspectives on what might have helped them to access care at the time. Among the out of Denver survey respondents who provided their perspectives on this, the most common response was financial assistance and the second most common response was insurance. Emotional or mental health support, better information as to how and where to access services, and better access to transportation were also reported as important needs for accessing care. Having services be more accessible with fewer enrollment requirements was also reported by several survey respondents.

When asked for their suggestions on how to make it easier for PLWH to get and stay in medical and related services, non-Denver survey respondents offered many ideas. Table 13 shows that most commonly, respondents thought that accessing services should be easier. This included: easing the restrictions on who qualifies for services; simplifying the enrollment processes, especially by cutting down on the required paperwork, making the applications easier to understand and complete, offering more enrollment assistance, and having more services available in more places around the state. Secondly, PLWH needed to have good information about what services are available, how to access them, and any changes that may affect their health care. They also mentioned that people needed more information about HIV and about their own personal health. The third most common set of ideas concerned making sure that PLWH had access to affordable health care and medications, including affordable health insurance. Several suggested instituting universal health care as a way of ensuring this access. Fourthly, respondents encouraged PLWH to be more proactive in ensuring that their needs are met. This included ideas such as: educating oneself as to what services are available; fulfilling the requirements to access those services; being honest and following rules; complying with all doctors' directives, including making all appointments and being compliant with medications; keeping providers informed; taking responsibility for one's own health; and advocating for oneself when necessary. The fifth most common suggestion was for PLWH to have access to case management to help them sort out what they need and help them with accessing services. Another common set of suggestions for ensuring access to care concerned providers and staff treating people respectfully. Other suggestions included: ensuring that people had adequate income to meet their needs, providing quality care, providing mental health services; and better access to transportation.

Table 11: Suggestions from Non-Denver survey respondents as to how to make it easier for PLWH to get and stay in medical and related services

Suggestions (N=142)	Number	Percent
Ensure easier access to services and increase availability	49	35%
Provide information on HIV and available services	30	21%
Ensure that heath care is affordable	21	15%
PLWH should comply with medical directives and take charge of their health	19	13%
Ensure PLWH have access to case management	18	13%
Providers/staff should treat PLWH respectfully	11	8%
Ensure adequate income to meet needs	9	6%
Provide quality care	7	5%

As mentioned, fifteen people who had spent substantial time out of care since their initial HIV diagnosis participated in one-on-one interviews in which they described their experiences and needs concerning care. The length of time out of care for these participants ranged from five months to approximately 20 years, with the median time out of care at seven years. Many of them had been in and out of care several times since their HIV diagnoses. About half of these participants reported not getting into care when they first found out they had HIV. The reasons for this varied. Three of the participants said that they did not know where to go or how to go about getting into medical care. Two said that they were reluctant to go on HIV medications. One person referred to his substance abuse problems, one indicated that s/he was running from the law, and two said they were too depressed and in denial to seek medical care. One person cited the cost of care as a reason for not pursuing it right away, and another said it was due to shock and embarrassment.

When asked about reasons they had been out of care at other times since their diagnosis, poverty related issues topped the list. Homelessness and lack of transportation were the most common reasons, as participants spoke of how the overwhelming life issues associated with homelessness, including the time it takes just to meet basic needs, having no place to keep one's drugs, and their inability to get to appointments at scheduled times became major deterrents. Others mentioned that they did not have medical insurance and therefore could not afford care. For some of the participants, mental health issues acted as deterrents to accessing care. These included serious depression, low self-worth, shame, denial, and fear. Several mentioned having had suicidal thoughts. Substance abuse problems were also cited by some as reasons for not being in care at various times since their diagnoses. Almost half of these interview participants indicated they spent some time out of care because they did not feel sick, and therefore did not see any urgency to access care. Others made reference to the amount of “red tape” involved in accessing medical services, which could prove especially problematic for those that had no identification. Additional reasons given by participants for being out of care included: legal problems, difficulties with drug side effects, and not knowing where to access services after moving to another area.

Two of the participants in the interviews were out of care at the time of the interview and said that they had no intentions of pursuing care in the future. One refused to seek care because of how he had been treated by providers at a particular clinic. He had a history of substance abuse and was denied pain medications at the clinic, and he felt highly disrespected during the process. For the other person, his reasons were both political and personal. He had suffered a number of health problems, and he saw no point in prolonging what he considered a substandard life with medications he had found toxic in the past. This was especially the case given that the medications would not cure him. He was also adamantly opposed to taking HIV medications or seeing an HIV doctor because of the huge amounts of money he saw drug makers and doctors earning. He thought that the reason there was no cure for HIV was because there was so much profit to be made in HIV care, and he did not want to contribute to that profit.

Interview participants were also asked a general question about the main reasons some PLWH are not getting the medical and related services that they need. Most commonly respondents cited the stigma that still surrounds HIV, keeping people from accessing care because they are afraid that others will find out about their status. Others responded that a lack of resources keeps some people out of care due to the costs of care, medications, and transportation. Also cited were mental health problems such as depression, which can cause people to not care about their own wellbeing and just give up. Other reasons included: addiction; denial about the severity of HIV; poor accessibility of services, especially outside of Denver; lack of knowledge about what to do or where to go to get services; legal problems; the large amounts of “red tape” involved in accessing care; and disillusionment with providers.

Interview respondents most often cited both better knowledge and support as the main things that would help people access care. The knowledge needed included information about where and how to access care as well as more knowledge about HIV itself. Some suggested how important it would have been to have someone talk to them when they were first diagnosed to offer them support and to ensure that they knew what to expect from the disease and how to access care and related services. The types of support mentioned included having someone to talk to that would be encouraging and who would let them know that HIV was not the “death sentence” it once was. Several people thought it would be especially important to talk to and get encouragement from others living with HIV. Others mentioned the importance of getting emotional support from counselors and doctors. Additional responses to the question about what would help PLWH to access care included: 1) Improved access to services in terms of both closer locations and easier enrollment processes, 2) More life stability including access to housing and transportation, 3) Stronger will on the part of individuals, 4) Treatments that had fewer side-effects, 5) Better access to health insurance, 6) Having HIV stigma addressed so that people were less ashamed to seek care, 7) Getting sick, and 8) Incentives.

ISSUES AND NEEDS OF PEOPLE LIVING WITH HIV

Information about the most important issues faced by PLWH and their most important needs were pursued using several different approaches and three different samples of respondents. One of these approaches consisted of three open-ended questions included on the survey asking respondents what they thought were the most important issues faced by PLWH, what their most important needs were, and what they would recommend to improve the lives of PLWH. Table 12 shows a summary of the responses to these questions from those living outside of the DMA. Another survey question asked respondents what they thought were the three top issues they wanted help with after first learning they had HIV. Table 13 shows the most common responses to this question from both in Denver and out of Denver respondents. Similar questions about important issues and needs of PLWH and needs when first diagnosed were posed to people participating in the interviews, including those who had an AIDS diagnosis soon after their initial HIV diagnosis and those who had spent substantial time out of care since their diagnosis.

Table 12: Most important issues and needs of PLWH and recommendations for improving the lives of PLWH as reported by survey respondents

Most Important Issues Facing PLWH N=230			**Most Important Needs of PLWH N=215**			**Recommendations for Improving Lives of PLWH N=198**		
Issue	**#**	**%**	**Need**	**#**	**%**	**Recommendation**	**#**	**%**
Access to care and medications	122	53%	Medical care and medications	136	63%	Taking responsibility for one's own health	48	24%
Stigma/ discrimination	75	33%	Basic needs (housing, food, income, transport.)	73	34%	Ensure easier access to affordable care and treatment	46	23%
Meeting basic needs (housing, food, income, transportation)	59	26%	Social support/ social interactions	55	26%	Improve people's ability to meet basic needs	35	18%
Mental health issues	41	18%	Acceptance/ address stigma	21	10%	Ensure social support and opportunities for social interactions	22	11%
Staying healthy mentally and physically	24	10%	Good mental and physical health	17	8%	Educate the public and address stigma	18	9%
Lack of social support/isolation	16	7%	Mental health care	12	6%	Ensure access to mental health care	16	8%
Issues around taking medications (including side effects)	11	5%	Quality care	11	5%	Provide updated and understandable information to clients	12	6%

Table 13: Top issues with which survey respondents needed help upon diagnosis with HIV

Top Issues	**Denver Area N=568**		**Non-Denver/Unknown N=253**		**Total N=821**	
Need	**#**	**%**	**#**	**%**	**#**	**%**
Finding a doctor or provider	296	52%	164	65%	460	56%
Getting medications	308	54%	147	58%	455	55%
Emotional support	319	56%	133	53%	452	55%
Information about HIV and how it would affect me	256	45%	99	39%	355	43%
Getting health insurance	141	25%	57	23%	198	24%
Getting laboratory tests	138	24%	56	22%	194	24%
Mental health concerns	135	24%	33	13%	168	20%
Housing/rent assistance	108	19%	29	11%	137	17%
Emergency financial assistance	100	18%	27	11%	127	15%
Getting dental care	100	18%	25	10%	125	15%
Services for other medical conditions	50	9%	21	8%	71	9%
Getting food	51	9%	13	5%	64	8%
Transportation	43	8%	12	5%	55	7%
Other	30	5%	16	6%	46	6%
Substance abuse concerns	31	5%	6	2%	37	5%

Access to Medical Care and Treatment

Access to care and medications was cited as a most important issue by 53 percent of the non-Denver survey respondents and as a most important need by 63 percent. Expressed concerns were predominantly about meeting these medical needs given the high costs of care and medications and the costs of insurance coverage and co-pays that many found difficult to afford. Those who were receiving assistance with medical coverage were concerned about being able to maintain access during hard economic times when cutbacks are common. Others thought that the income caps to receive assistance were too low, preventing them from qualifying and making it difficult to pay for care and meet other expenses. Many who were receiving assistance or who had applied for assistance discussed how cumbersome and complicated the processes often were, involving large amounts of paperwork. Respondents living in some parts of Colorado reported that it could be very difficult to access appropriate care because of the lack of infectious disease doctors in their area, laboratories for testing, or pharmacies that carried the appropriate medications. Other comments included difficulties in making appointments due to job conflicts or having insurance that did not cover all that they needed.

Finding a doctor or provider and getting medications were also among the top responses to the survey question about what people needed most when first diagnosed. Fifty-six percent of the entire sample and 65 percent of the out of Denver sample selected finding a doctor or provider as a top initial need. Additionally, 55 percent of the entire sample and 58 percent of the out of Denver sample selected getting medications as a top initial need. Recommendations from survey respondents around this issue included ensuring people's access to quality and appropriate medical care and medications. For some, quality care included both medical expertise and respectful treatment of patients. Ensuring access most often involved recommendations for lowering the costs of medications, making it easier for working people to qualify for assistance in paying the costs of care and treatment, and simplifying the process of enrolling in programs. Other related recommendations included: having a universal health care system ensuring care and treatment for all PLWH, and having more medications and supplements covered by insurance or ADAP.

Interview participants were provided a much more open-ended forum to discuss their most important issues and needs. Interestingly, access to health care and medications were the least often discussed when participants were asked what PLWH needed most. Only one of the participants who had a history of being out of care mentioned the need for doctors and medications as among the most important when first diagnosed. Most of the interview participants who had concurrent HIV/AIDS diagnoses found out about their diagnoses when they were already very ill, so receiving immediate medical care was more of an issue for them.

Meeting Basic Needs

The second most common set of needs and the third most commonly described issues faced by those with HIV that were reported by the survey respondents concerned the difficulties that many have in meeting their basic needs for housing, income, food, and transportation. The respondents spoke of how struggling to meet such needs made it even more difficult for people to access care services and adhere to treatment regimens, underscoring the need for people to have some stability in their lives to better maintain their health. Additionally, many of the recommendations provided by non-DMA survey respondents for improving the lives of PLWH also underscored the difficulties associated with having HIV and being poor, recommending more widespread assistance in meeting basic needs. Some respondents stressed the need for ensuring better access to housing assistance or more affordable housing. Balancing issues associated with low incomes and access to benefits put some in very precarious positions as several respondents mentioned how small increases in income or benefits could lead to the loss of other benefits or disqualification from assistance programs, which meant an overall loss in income and benefits. Some stressed how they wanted to work and increase their income but feared losing critical benefits, and they emphasized the need for more flexibility within the system making it possible for people to earn more income and still qualify for assistance. One survey respondent mentioned that so often all family resources go toward basic survival needs, leaving nothing for occasional recreation such as seeing a movie. Housing and other basic needs such as financial assistance, food, and transportation were selected as most important issues upon HIV diagnosis more frequently by those living in the DMA than among those living outside of Denver or for whom county of residence was unknown.

Interview participants also considered having stability in their lives and being able to meet basic needs as one of the most important issues for PLWH, especially the need for stable housing. One spoke of how easy it is to give up on everything if a person does not have a place to live. Another talked about how important it is to have a place to go, think, and sort out how things are going and what needs to be done. A third said that if people are worried about where they are going to stay, they will not prioritize taking care of their health and how not having a place to clean up can be demoralizing. One spoke of needing a stable place to store medications properly and not risk having them stolen. Another person summarized the importance of housing stressing that once a person gets housing, other things tend to fall into place. Lack of transportation was also discussed as a barrier to accessing services by both Denver and out of Denver participants, emphasizing the need for bus passes and gas vouchers to help people keep appointments and access pharmacies. Some mentioned how insufficient income can make people have to choose between buying food and other necessities and accessing expensive medications or making co-pays for care. Others mentioned how having HIV may prevent people from working. Several of the interview participants spoke of having serious financial concerns when they were first diagnosed with HIV and needing help accessing both health insurance and income.

Social and Emotional Support

Just over one quarter of the survey respondents emphasized the need for PLWH to have better social and emotional support and more social interactions with others, including others living with HIV. Emotional support was selected by 55 percent of the total survey sample and 53 percent of the out of Denver sample as one of the top issues they needed help with upon diagnosis of HIV, ranking almost equally to finding a doctor or provider and getting medications. Respondents in the 20 - 24 age group selected emotional support as a top issue more often than people over 45 (69 percent versus 50 percent). More Latinos selected emotional support than those from any other ethnic group with 60 percent indicating it was a top issue, compared to 56 percent of African Americans and 48 percent of whites. Respondents stressed how critical social support is to many people who are dealing with HIV and the feelings of fear, loneliness, and rejection that often accompany the disease. Therefore many survey respondents recommended building more social dimensions or provision of social support into the assistance provided to PLWH, including organizing support groups and social events.

Among interview participants who had spent time out of care, the need for support was the most commonly cited. This was especially the case when asked about what they and others needed most when they were first diagnosed with HIV. For some this meant the need to be able to gain support from and to socialize with others with HIV, either as part of support groups or a mentoring program. For others it was about having someone to talk to who they could trust and who could offer them encouragement, reassurance, and hope. Some specified the need for family, friends, and community to offer them support and understanding. Even though many were dealing with serious illness, interview participants who had concurrent HIV/AIDS diagnoses also most often spoke of needing support when they first found out they had HIV. For them this included support from family, partners, doctors, counselors, or just someone who was not judgmental that they could talk to.

Stigma and Discrimination

A third of the survey respondents addressing the question about important issues faced by PLWH mentioned the difficulties associated with HIV-related stigma and discrimination, which they thought was quite prevalent. People talked of being subjected to judgment, bad treatment, and rejection by others, often leading to depression or feelings of anger, isolation, and shame. Many lamented the ignorance of the general public about HIV, expressing unfounded fears about contact with those who are HIV positive. Some reported that they had told very few people about their status due to the stigma. Respondents emphasized the needs for acceptance and to have stigma addressed. Recommendations concerning addressing HIV-related stigma emphasized the need for more education directed to the public about the disease. The powerful impact of stigma on PLWH was also commonly discussed in the interviews with PLWH. In these interviews, participants spoke of others being afraid of them or of having casual contact with them, thinking they might contract the disease. Others spoke of PLWH being denied jobs based on similar misinformation about how HIV is spread. Some described feeling like an outcast and the impact of that on their mental health or of not being able to disclose their status in certain settings for fear of violence. Interview participants also stressed the need for better public information to confront stigma, dispel misinformation, and generate better acceptance and understanding of PLWH.

Mental Health Assistance

The fourth set of issues reported by survey respondents as most important for PLWH centered on mental health. Both dealing with their diagnosis as well as the stigma were said to cause feelings of depression, anxiety, stress, loneliness, isolation, and low self-esteem. Some also discussed problems with the high costs of mental health treatment and the limited number of available options for care. Maintaining good emotional health was considered as a most important need by many of the respondents, and was reported by 20 percent of the survey sample as one of the top three issues they needed help with when first diagnosed. Ensuring access to counseling and other types of mental health care was among the recommendations for improving the lives of PLWH for eight percent of the survey sample. Given that over half of the survey respondents reported having mental health problems, the percentage of those recommending access to mental health care was relatively low. When asked about what issues arose for them when they were first diagnosed with HIV, interview participants who had spent time out of care most often spoke of dealing with depression and related emotions such as fear, disbelief, shame, guilt, and anger, some of which was exacerbated by HIV-related stigma. Several reported needing counseling at the time.

Information

Another important set of needs reported by survey respondents related to information. People stressed that it was important for PLWH to have updated information about HIV in general and about their own personal health, what they needed to do to take care of themselves, and where they could go to access services. The need for information about HIV and how it would affect them ranked fourth among the most important issues survey respondents reported needing help with when first finding out they had HIV, with 43 percent of the entire sample and 39 percent of the out of Denver sample selecting it. Women selected information about HIV much more often than men (52 percent versus 39 percent). Fifty-eight percent of African Americans chose information about HIV compared to 41 percent of Latinos and 39 percent of whites. When asked what they needed most when they first found out they had HIV, the interview participants also discussed the importance of information, ranking it second after the need for support. The types of information people said they needed included information about HIV and how it would affect them, how HIV was no longer a death sentence, and what they needed to do to access services, including some form of case management.

Other Issues, Needs, and Recommendations

Other issues that were less commonly mentioned as being most important by survey respondents included: staying healthy, both mentally and physically, and the difficulties adhering to medication regimens and dealing with medication side effects. Among the recommendations for improving the lives of PLWH, respondents most frequently wrote about what PLWH should do for themselves to maintain their health including: making sure they make it to all of their doctor’s appointments and adhering to their treatment regimens, getting exercise and eating right, keeping a positive attitude, and living a healthy lifestyle. Some mentioned that having affordable access to recreation centers and gyms would help facilitate this process as well as access to nutritious foods. Among interview participants, other issues and needs they discussed included struggling with maintaining one’s confidentiality or deciding who to tell and how they would broach the subject. One person spoke of needing help with disclosure issues. Several participants spoke of developing or worsening substance abuse problems that arose when they found out they had HIV.

MEETING THE NEEDS OF PLWH

Questions were posed to all of the participants in the needs assessment about the HIV care, treatment, and related services that they had been able to access and those they had not been able to access. They were also asked questions about barriers and facilitators to accessing services and about service quality. Two percent of survey respondents indicated that they were not currently receiving HIV care, and two percent did not respond. Of the 822 survey respondents who were in care, 60 percent reported receiving HIV care more than three times in the last 12 months (Table 14).

Table 14: Number of times in-care survey respondents cited receiving HIV care in the past 12 months

	Denver		Non Denver		Total	
	N	%	N	%	N	%
Once	34	6	9	4	43	5
Twice	81	14	32	13	113	14
Three times	93	16	63	25	156	19
More than three times	353	62	144	57	497	60
No Response	7	1	6	2	13	2
Total	568		254		822	

Ninety-six percent of the survey respondents who were currently receiving HIV care reported following up on their doctors' recommendations for laboratory tests, such as CD4 and viral load tests. Ninety-two percent followed up through their doctors recommendations for filling their prescription medications (Table 15). Ninety-one percent reported following through on both recommendations. Four percent of in-care survey respondents indicated that their doctor did not recommend lab tests, prescription medications, or both.

Table 15: Number of in-care survey respondents who reported following through on their doctor's recommendations for laboratory tests and prescription medications

	Denver		Non Denver		Total	
	#	%	#	%	#	%
Total in-care respondents	568	100	254	100	822	100
Respondent followed through on recommendation for lab tests						
Yes	547	96	240	94	787	96
No	2	0	0	0	2	0
Not Recommended	11	2	6	2	17	2
No Response	8	1	8	3	16	2
Respondent followed through on recommendation for prescription medications						
Yes	534	94	226	89	760	92
No	4	1	2	1	6	1
Not Recommended	14	2	13	5	27	3
No Response	16	3	13	5	29	4

Table 16 displays a summary of survey responses to questions concerning the services participants had needed in the previous 12 months and those that they had received. Since such a high percentage of the respondents were currently receiving medical care and HIV medications, the proportion of those reporting needing them and having received them ranged between 91 and 96 percent across the sample. Dental care, however, had a much lower proportion of those reporting needing such care and receiving it, with 34 percent of the DMA respondents and 27 percent of the non-Denver respondents reporting not receiving it in spite of need. Overall, non-Denver residents reported receiving the services they needed more than those in the DMA, in spite of the fact that a higher percentage of respondents out of Denver reported needing the services. This was especially the case for services such as: 1) Case management (21 percent of Denver respondents needing the service did not receive it versus eight percent of non-Denver respondents); 2) Emergency financial services (44 percent in Denver versus 22 percent non-Denver); 3) Transportation (40 percent in Denver versus 22 percent non-Denver); 4) Nutritional counseling or supplements (54 percent in Denver versus 37 percent non-Denver); and 5) Support groups or peer counseling (39 percent in Denver versus 25 percent non-Denver).

Table 16: Number of survey respondents who needed each service by type, and proportion of those that did and did not receive it. *Yellow indicates "unmet" needs, defined as a service needed by more than 25 percent of respondents, which was received by fewer than 75 percent of those that needed it.*

	Denver (N=515)				Non-Denver (N=240)			
	# Needed	% of total	Proportion received	Proportion did not	# Needed	% of total	Proportion received	Proportion did not
Visits to doctors, nurses, and other medical providers	475	92%	0.94	0.06	225	94%	0.96	0.04
Laboratory tests (CD4, viral load, etc.)	470	62%	0.94	0.06	228	95%	0.96	0.04
Help buying the prescriptions you need	399	53%	0.91	0.09	181	75%	0.92	0.08
Dental care	354	47%	0.66	0.34	178	74%	0.73	0.27
Case management	242	32%	0.79	0.21	163	68%	0.92	0.08
Help getting or paying for health insurance	281	37%	0.74	0.26	113	47%	0.73	0.27
Emergency financial assistance (utilities, etc.)	174	23%	0.56	0.44	103	43%	0.78	0.22
Individual or group counseling for mental health	183	24%	0.75	0.25	83	35%	0.81	0.19
Groceries or prepared meals	168	22%	0.68	0.32	81	34%	0.77	0.23
Help getting or staying in housing	157	21%	0.67	0.33	66	28%	0.76	0.24
Transportation to and from medical or other services	143	19%	0.60	0.40	69	29%	0.78	0.22
Nutritional counseling or supplements	129	17%	0.46	0.54	68	28%	0.63	0.37
Support groups or peer counseling	130	17%	0.61	0.39	63	26%	0.75	0.25
Help buying over-the-counter medication	120	16%	0.47	0.53	63	26%	0.56	0.44
Alternative care (acupuncture, herbal remedies, etc.)	96	13%	0.35	0.65	57	24%	0.60	0.40
Education-related services	82	11%	0.56	0.44	33	14%	0.55	0.45
Substance abuse treatment/counseling (out patient)	75	10%	0.79	0.21	25	10%	0.80	0.20
Home health care or other in-home assistance	44	6%	0.57	0.43	26	11%	0.62	0.38
Substance abuse treatment (residential)	34	5%	0.68	0.32	12	5%	0.83	0.17
Child care while accessing medical or other services	17	2%	0.35	0.65	11	5%	0.27	0.73

A closer look at the extent to which certain demographic groups within the survey sample reported needing services and receiving the services they needed shows some substantial differences. Table

17 displays the demographic groups with the most expressed need, defined here as groups in which at least 25 percent needed 12 or more of the services listed in Table 16 above. Respondents ages 25 to 44 had the highest proportion of unmet need (75 percent), followed by MSM/IDU (71 percent), African Americans (67 percent), and people diagnosed from 1990 to 1995 (62 percent). People with a history of IDU (other than MSM/IDU) reported a high number of needs as a group, but a very low proportion of unmet need (20 percent). This was similarly the case for people living in urban areas other than the DMA who reported a high number of needs but a low proportion of unmet need (27 percent). Those making less than 50 percent of FPL reported somewhat fewer needed services than those making 60 to 90 percent of FPL and reported a lower proportion of unmet needs (38 percent versus 57 percent). People diagnosed with HIV between 2006 and 2011 reported a higher number of services needed than those diagnosed between 2001 and 2005, but a lower proportion of unmet need (46 percent versus 58 percent). Those 65 and older reported the fewest number of needs and the proportion of unmet need was zero.

Table 17: Demographic categories that needed at least 12 of the 20 services listed on the survey and their proportion of unmet need.

	N	Total number of services needed by >25% of people	Number of Services Received by >75% that needed it	Services needed by 25% but received by< 75%	Proportion of needs unmet
Ages 25 to 44	236	15	4	11	0.73
< 50% FPL	80	13	8	5	0.38
60%-90% of FPL	132	14	6	8	0.57
African Americans	59	15	5	10	0.67
Females	112	15	9	6	0.40
Other urban (non-Denver)	132	15	11	4	0.27
Heterosexual sex	127	14	6	8	0.57
Needle/Works sharing	25	15	12	3	0.20
MSM/IDU	13	17	5	12	0.71
HIV Dx 1990-1995	168	13	5	8	0.62
HIV Dx 2001-2005	119	12	5	7	0.58
HIV Dx 2006-2011	157	13	7	6	0.46
AIDS Dx	350	14	7	7	0.50

Table 18 provides an overview of the quality ratings respondents gave to the services they received, ranging from A to F. As shown, ratings for medical care, laboratory services, and medication assistance were high both among DMA-based respondents and those from out of Denver. Several of the services accessed by those outside of Denver received somewhat lower ratings such as: 1) Groceries or prepared meals, 2) Transportation services, 3) Support groups or peer counseling, 4) Nutritional counseling and supplements, and 5) Home health care services. Help buying over the counter (OTC) medications had the lowest overall rating among the whole sample that received the service. Table 19 provides a summary of the reasons respondents gave for assigning lower grades to certain services as well as their reasons for not being able to receive certain needed services. Many did not provide their reasons on the survey.

Table 18: Service evaluations from those who received the service in question. *Table shows the proportion of respondents who rated each service received as failing (D or F), Average (C), or above average (A or B). Yellow indicates dissatisfaction, defined as fewer than 70 percent of respondents giving it an above average grade or more than 10 percent giving it a failing grade.*

Service	Denver				Non-Denver			
	N	Failing	Average	Above Average	N	Failing	Average	Above Average
Visits to doctors, nurses, and other medical providers	441	0.0	0.1	0.9	206	0.0	0.1	0.9
Laboratory tests (CD4, viral load, etc.)	432	0.0	0.0	1.0	209	0.0	0.1	0.9
Help buying the prescriptions you need	358	0.0	0.1	0.9	160	0.1	0.0	0.9
Dental care	224	0.0	0.1	0.9	126	0.1	0.1	0.8
Case management	185	0.0	0.1	0.9	141	0.1	0.1	0.9
Help getting or paying for health insurance	203	0.0	0.0	0.9	76	0.1	0.1	0.8
Individual or group counseling for mental health	131	0.0	0.2	0.8	63	0.1	0.1	0.8
Groceries or prepared meals	106	0.1	0.1	0.8	59	0.2	0.1	0.7
Emergency financial assistance (utilities, etc.)	91	0.1	0.1	0.8	74	0.1	0.1	0.8
Help getting or staying in housing	98	0.1	0.1	0.8	48	0.1	0.1	0.8
Transportation to and from medical or other services	84	0.1	0.1	0.8	54	0.2	0.1	0.7
Support groups or peer counseling	75	0.1	0.1	0.9	45	0.2	0.1	0.7
Nutritional counseling or supplements	55	0.1	0.1	0.8	41	0.2	0.1	0.7
Help buying over-the-counter medication	54	0.2	0.1	0.7	33	0.4	-	0.6
Substance abuse treatment/counseling (out-patient)	52	0.0	0.2	0.8	17	-	0.1	0.9
Alternative care (acupuncture, herbal remedies, etc.)	30	0.0	0.1	0.9	31	0.2	-	0.8
Education-related services	41	0.0	0.0	1.0	17	0.2	-	0.8
Home health care or other in-home assistance	22	0.1	-	0.9	15	0.3	0.1	0.7
Substance abuse treatment (residential)	23	0.1	0.3	0.7	9	0.3	-	0.7
Child care while accessing medical or other services	4	-	-	1.0	3	0.3	-	0.7

Table 19: Reason for giving a low grade, or reason service could not be accessed.

Service	Reasons for low grade	Reasons could not get
Visits to doctors, nurses, and other medical providers	Poor quality of care (4), poor provider attitude (3), too far away (2), denied access to doctor (2), if work will lose benefits, too many appointments (1), too costly, no assistance available, scheduling problems	Don't know how to access (2), no insurance (2), can't afford
Laboratory tests (CD4, viral load, etc.)	Poor quality (5), won't give copies, rude staff, scheduling problems	Don't know how to access
Help buying the prescriptions you need	If work will lose benefits (3), insurance slow to pay, restricted by formulary, not available in local pharmacies, long waits	Don't know how to access, can't afford co pays (4), can't get clinic card, no help with non-HIV meds (6), no assistance available (4)
Dental care	Lack of HIV clinics (3), too costly (8), rude staff (2), difficult to access (8), poor care (6), lack of funding (2), long waits, scheduling problems	Don't know how to access (2), no insurance (2), poor case management, can't afford (5), not available (6), don't take HIV patients, not covered (3), only get cheapest care
Substance abuse treatment/counseling (outpatient)	Not gay, lesbian, bisexual, transgender, and questioning (GLBTQ) appropriate	Don't know how to access
Individual or group counseling for mental health, support groups	Difficult to access (4), too costly (2), limited options, no support groups (8), poor quality care (3), poor quality groups (5)	Don't know how to access, not available (6), not in Spanish (3), staff changes, transportation problems, did not push for help, denied access
Nutritional counseling or supplements	Doesn't help, uninformed staff, long waits	Don't know how to access, can't afford (2), not covered, not available (3)
Alternative care (acupuncture, herbal remedies, etc.)		Don't know how to access (3), can't afford (2), not covered (3), never recommended, not available (2)
Help getting or paying for health insurance	No follow up from ADAP (2), high co pays (2), confusing/too much red tape (2)	Don't know how to access, don't qualify (5), lack of funding (2), complicated system, not available (2)
Help getting or staying in housing	Discriminatory	Don't know how to access (2), long wait list (4), can't afford initial costs, don't help with mortgages, not available, don't qualify, staff don't want to help, could not access (4)
Transportation to and from medical or other services	Difficult to access (3), lack of funding (4), not available for other services	Don't know how to access, can't afford (3), insufficient help, not available, no funding
Groceries or prepared meals	Poor quality at food banks (4), sparse supplies (3), limited availability (10), limited funding	Don't know how to access, insufficient benefits, cannot access, denied benefits,
Emergency financial assistance (utilities, etc.)	Long waits, poor quality programs	Don't know how to access (6), no funding (2), did not qualify (7), not available
Help buying over-the-counter meds		Don't know how to access, OTC not covered (5),
Child care while accessing medical or other services		Don't know how to access, not available (2)
Home health care or other in-home assistance	Long waits	Don't know how to access, denied benefits, cannot access (2)
Education-related services		Don't know how to access, can't afford
Case management	Not working for right reasons, not doing their jobs, don't follow up (4), not helpful (3), poor quality (5), limited availability, don't return calls (3), caseloads too large (3)	Don't know how to access, not offered

The Colorado Indigent Care Program (CICP) and Medicare were listed as top sources of payment for medical services both for Denver and outside of Denver survey respondents. ADAP and Bridging the Gap were the top sources of payment for medications. A higher proportion of the non-Denver survey respondents reported using private insurance, personal savings, and family and friends to pay medical expenses than those residing in the Denver Metro area (Table 20).

Table 20: Sources of payment for medical care and for medications

	Denver				**Non-Denver**				**Total**	
	N	**%**			**N**	**%**				
Payment Source Question- No Response	28	5			9	3			**37**	4
Which of the following did you receive assistance from in the past year?	Medical Care N	%	Medications N	%	Medical Care N	%	Medications N	%	Care N (%)	Meds N (%)
AIDS Drug Assistance Program (ADAP)	124	21	440	74	40	15	152	57	164 (20)	592 (72)
Bridging the Gap, Colorado	79	13	170	29	29	11	60	22	108 (13)	230 (28)
Colorado Indigent Care Program (CICP)	234	39	144	24	72	27	39	15	306 (37)	183 (22)
Medicare	202	34	134	23	80	30	46	17	282 (34)	180 (22)
Personal income or savings	96	16	99	17	61	23	59	22	157 (19)	158 (19)
Medicaid	113	19	82	14	62	23	37	14	175 (21)	119 (14)
Family/Friends	40	7	41	7	23	9	31	12	63 (8)	72 (9)
Private health insurance through work	39	7	35	6	37	14	34	13	76 (9)	69 (8)
Individual health insurance plan	33	6	28	5	24	9	22	8	57 (7)	50 (6)
Pharmacy Company Assistance Program	16	3	26	4	8	3	17	6	24 (3)	43 (5)
Other (describe)	24	4	23	4	20	7	11	4	44 (5)	34 (4)
Coverage under a spouse/partner's health insurance plan	11	2	10	2	8	3	7	3	19 (2)	17 (2)
Cover Colorado	10	2	11	2	5	2	4	1	15 (2)	15 (2)
Don't know/not sure	7	1	6	1	8	3	6	2	15 (2)	12 (1)
Veteran's Administration	6	1	5	1	6	2	7	3	12 (1)	12 (1)
Indian Health Services	2	<1	1	<1	1	<1	1	<1	3 (0)	2 (0)

One question posed to survey respondents asked what medications or medical care people were not receiving because they were not covered under their medical plans or because people could not afford them. A total of 170 respondents provided answers to this question, 105 from the DMA and 65 from outside of Denver. Table 21 shows the types of medications that respondents said they were not receiving. Medications for mental health disorders such as depression or anxiety were the most commonly reported by survey respondents statewide, and more frequently reported by DMA residents than by those from outside of Denver (16 percent versus nine percent). Pain medications were also reported as not received more frequently by DMA residents (15 percent versus nine percent). Stomach medications were reported as not received by 14 percent of the Non-Denver respondents and 12 percent of the DMA residents who responded to the question. Medications that were listed by less than four percent of the total survey respondents included cancer medications, eye medications, and drugs for chronic obstructive pulmonary disease, genital warts, gastro esophageal reflux disease, drinking cessation, and smoking cessation, and 30 different types of medications were each mentioned by only one person.

Table 21: Medications reported by survey respondents as ones they could not access

	Total Survey Respondents (N=170)		Denver (N=105)		Non-Denver (N=65)	
	n	%	n	%	n	%
Psych meds	23	14	17	16	6	9
Pain meds	22	13	16	15	6	9
Stomach meds	22	13	13	12	9	14
Nutritional supplements	14	8	9	9	5	8
Blood pressure meds	12	7	9	9	3	5
Sleeping aids	9	5	7	7	2	3
Cholesterol meds	9	5	6	6	3	5
Heart meds	7	4	6	6	1	2
Allergy meds	7	4	5	5	2	3
Erectile dysfunction drugs	7	4	5	5	2	3
HIV meds	7	4	5	5	2	3
Testosterone	7	4	5	5	2	3
Vitamins	7	4	5	5	2	3

Table 22 summarizes responses about care-related services people living outside of Denver reported not being able to access. Dental care topped the list with 32 percent of those who responded to the question reporting this as an unmet need. Eye care ranked second, reported by 23 percent of those responding, and alternative care such as acupuncture and massage was reported by 14 percent.

Table 22: Medical care reported as not received by non-Denver based survey respondents

Out-of Denver only N=65	N	%
Dental care	21	32
Eye care	15	23
Alternative care	9	14
Mental health care	6	9
Other care	6	9
Chiropractor	3	5
Emergency care	2	3
Hearing	2	3
Labs	1	2

Over two thirds of the interview respondents who had been out of care for extended periods of time got back into care because they were sick, most to the point where they needed to be hospitalized. Most then were linked to ongoing care and related services by clinic staff, many of whom facilitated not only access to doctors appointments and medications, but also services such as CICP, Social Security, case management, and counseling. Many of the participants were very complimentary of their doctors and the staff at certain clinics for helping them understand HIV and the care process, linking them to medical care and treatment, helping them to find other needed services, and helping them with the paperwork to enroll in those services. About half of the interview participants received help accessing care and related services from community-based organizations (CBOs) that provide services to the homeless and ASOs. Decreasing substance abuse and improved mental health, including an increased desire to live and an acceptance or diminishing fear of HIV, were also cited by participants as helping them to access care, as were advice from other PLWH, family encouragement, partner support, and better proximity to clinics. One participant said that increasing knowledge about the services available helped him to access care, and another said changes in his income lead to him being eligible for services for which he previously did not qualify.

Interview respondents were also asked about any barriers they faced when trying to get into care, and their answers were quite varied. Three respondents from outside the Denver area spoke of the lack of providers specializing in HIV in their areas. The ones that were available were sometimes not a good fit for the person. Issues related to being homeless or extremely poor caused barriers for three other respondents, including transportation problems in getting to appointments, loss of an acceptable method of identification, and having medications and paperwork stolen. Three others spoke of barriers related to insurance, the high costs of medications when not sufficiently covered by insurance, limitations on covered providers, and high co-pays for doctors' appointments. Two others mentioned the long waits getting in to see a doctor as barriers to care. Other barriers included having trouble adhering to medication regimens and the large amount of paperwork necessary to access care.

All of the people who were interviewed because they already had AIDS at their first HIV diagnosis had accessed care very soon after their diagnosis, and all seemed satisfied with the care they were receiving. Although some expressed having bad experiences with doctors in the emergency departments where they were first diagnosed, most described a very smooth process of getting linked to very good doctors, to medications, and to other needed services such as Medicare, disability benefits, emotional support, and assistance meeting basic needs for food and transportation. Clinic staff in both Denver and Pueblo were cited for their comprehensive approaches to getting the medical and other needs of their clients met, as well as for making follow-up calls to clients when they had not shown up for appointments or to help them access services. Some had received help accessing care and other services from ASOs. Several participants mentioned the good results they have had in their CD4 and viral load counts since accessing medications.

A few respondents did mention some problems in accessing care. Two of these interview participants who had private insurance at the time of their HIV diagnoses had lost their insurance since. One was very concerned about accessing care and meeting living expenses until clinic staff helped to link him to care and disability benefits. The other had to wait six months for insurance after getting a new job, but the ADAP helped him with information and medications. One man with private insurance spoke of paying $6,000 in co-pays, which depleted his savings. Some mentioned the high costs of care and treatment and expressed concerns about ever losing their benefits or for those who are not insured and not receiving similar assistance. One person spoke of a delay of approximately three months after his diagnosis in getting his medication. He was the only respondent who thought that the process of accessing care was somewhat difficult and took too long. Another did not like the counseling he had received from an ASO, and had not tried to seek it elsewhere.

Given that most of the respondents to these particular interviews had good experiences in accessing the care, treatment, and other services they needed, a few did not have any suggestions about how to improve people's access to these services. The majority stressed, however, that even though there are great programs out there, it was important that PLWH have access to information about what services are available and how to access them. Such information could be made available through public information, clinic staff, case managers, doctors, and through support groups. One respondent stressed how difficult it was to get the appropriate information to people who do not want others to know about their status. Some stressed how lost they would have been if they had not received information and assistance. One emphasized the difficulties filling out large amounts of paperwork to qualify for programs if there is no knowledgeable person to help. Two participants spoke of the need for better access to transportation so that people could access help. Others stressed the need to help people acquire basic needs to help them stay in care.

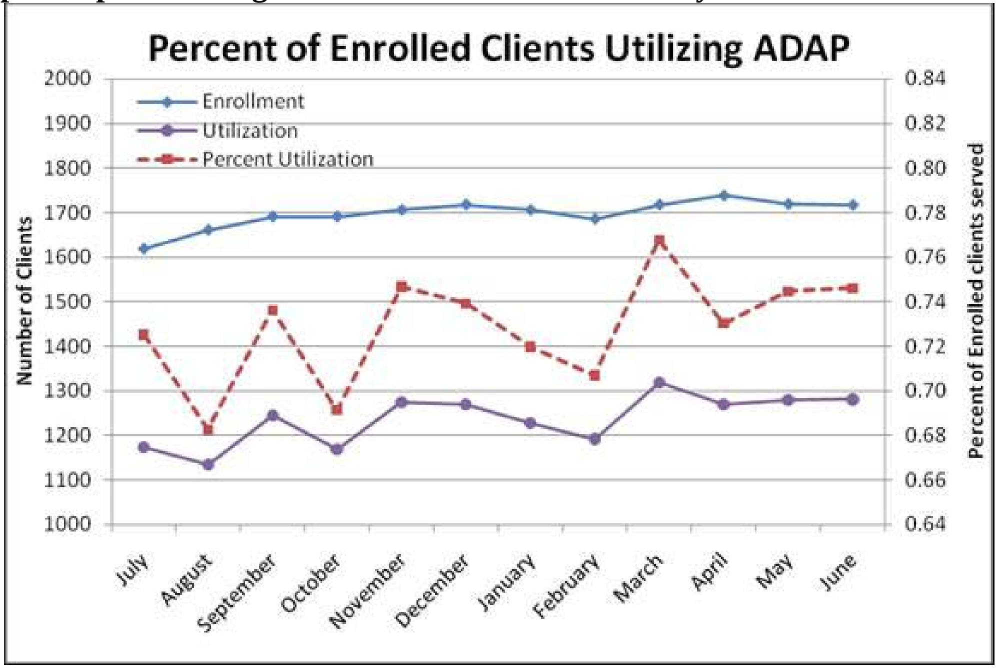
When asked about any unmet needs, over half of the interview respondents said that they had none because they had been so well taken care of by providers. Those who did identify unmet needs described housing assistance, specialty medical care, counseling and support groups, education assistance, opportunities for socializing, and assistance in learning to disclose their HIV status. When asked about needs that are most commonly not met for others, housing was mentioned most frequently by interview participants. Programs for housing assistance were said to be underfunded. Therefore the assistance was limited and the wait lists long. The second most common unmet need was for mental health treatment, counseling and emotional support. A third need that often went unmet was for income, either through a job or disability benefits, which were said to be difficult to get. Several participants talked about how hard it was to get qualified for federal programs such as Social Security disability, Medicare, and the food stamp program. Although several people said that food from food banks was often easy to get, accessing truly nutritious food was said to be difficult. Other needs that were said to often go unmet for PLWH were for HIV and other medications, education, relationships, transportation to appointments, and information on available services. When asked about what services tended to be the easiest and hardest to access, responses ranged substantially and reflect the very different experiences that people have in accessing the medical and other services that they need. Several people made the point that there are services available, but people need to know how to find them which is not always easy.

When asked about what types of people had the hardest time gaining access to the services they need, respondents thought that poor people, especially the homeless had the hardest time. Not being able to afford transportation to appointments was one reason given. One person disagreed saying that the homeless could get everything they need if they are in Denver. Another person thought that it was actually those people who were functional and had jobs that had a harder time because they had to pay for everything, although persons with good incomes and insurance were mostly seen by others as those with the least difficulties accessing what they need. Several interviewees responded that people who are trying to hide the fact that they have HIV from others have the hardest time getting services because they do not want to risk others' finding out if they do access services. People from small towns and people from out of the area were said to have a hard time because they may be the least likely to know about what services are available. One person spoke of those who have not adapted well to their diagnosis and who could not manage to do what needed to be done as having the hardest time. Agreeing with this statement, some added that people who were mature, mentally stable, and with good self-esteem were more likely to be able to accept that they have HIV and take the steps needed to get medical and other services.

USE OF ADAP SERVICES

One component of HIV care is adherence to antiretroviral medications. In addition to the clinical advantage of a client having a consistent regimen, many experts have underlined the importance of ensuring access to anti-retroviral drugs for all PLWH to reduce transmission to others. Information on drug adherence is not readily available for all people in Colorado living with HIV. However, claim information for people on Colorado's ADAP can be used to determine if people who are eligible for this program are readily able to get the medications they need. The number of clients enrolled in ADAP remained relatively stable at around 1,300 during the two-year period examined, however the number of clients who got at least one antiretroviral medication filled fluctuated by as much as 10 percent from month to month. Approximately 27 percent of the enrolled clients did not have antiretroviral prescriptions filled under the ADAP plan in any given month. Figure 5 shows the number of clients enrolled in ADAP, and the number of clients who filled antiretroviral prescriptions each month from July 2010 through June 2011. The secondary axis displays the proportion of enrolled clients who filled such prescriptions each month.

Figure 5: Monthly fluctuations in the number of clients who filled an antiretroviral prescription through the Colorado ADAP from July 2010 to June 2011



Historic data from the pharmacy benefits management database, which houses pharmacy claim data for all Colorado HIV/AIDS drug assistance programs, were used to describe which clients were less likely to access medications consistently so that the ADAP services can be improved to meet all clients' needs. Pharmacy refill data has been shown to correlate with self-reported HIV medication compliance. Additional client risk data were imported from the Colorado eHARS surveillance system (where available), and were used to assess differences between those who consistently used ADAP and those did so irregularly. For simplicity, this assessment included only 2,172 clients for whom there was a claim for at least one of the 11 most frequently prescribed antiretroviral medications filled between January 1, 2009 and December 31, 2010. These drugs account for 63 percent of all ADAP formulary drugs filled and include: Atripla, Isentress, Prezista, Reyataz, Truvada, Kaletra, Norvir, Viread, Combivir, Epzicom, and Viramune.

To classify clients by consistency, the Medication Possession Ratio (MPR) was used which indicates the number of pills for each drug that a patient is prescribed that they have in their possession for each day they are eligible for ADAP during the analysis period.

$$\mathbf{MPR} = \frac{\text{\# of all ARV pills received from ADAP}}{\text{days eligible } \mathbf{x} \text{ \# of ARVs prescribed}}$$

For example, a person who was eligible for the entire analysis period (730 days), who was prescribed two separate drugs, and who received 1,380 pills through ADAP claims would have an MPR of 96 percent. This represents someone who had both prescriptions filled all but one month of the two-year period. For more detailed information on the method and measures used to determine ADAP consistency, see Appendix I.

Of the 2,172 clients, 136 (six percent) only filled each of their prescriptions once during the analysis period. Approximately half of the 2,172 clients were eligible for the entire two-year period, and 1,521 (70 percent) were eligible for at least one full year. Clients, on average, were prescribed two of the antiretroviral medications listed above, and 97 percent were prescribed four or fewer. Two clients were prescribed and filled eight of the 11 drugs analyzed. During the two-year period examined, the median MPR of the 2,172 Colorado ADAP clients was 0.7 meaning clients on average received pills for seven out of every 10 days that they were eligible for ADAP. The quartiles of MPR measurement broke down as follows:

Quartile 4 (most consistent):	MPR > 0.91
Quartile 3:	0.91 ≥MPR > 0.70
Quartile 2:	0.70 ≥MPR > 0.39
Quartile 1 (least consistent):	0.39 ≥MPR

Twenty-nine percent of the ADAP clients included in this assessment used the pharmacy that exclusively delivers prescriptions by mail at least once. Those clients were considerably more consistent than clients who used the other pharmacies, possibly because of the convenience of receiving medication by mail (see Table 23). Many ADAP clients used more than one of the six ADAP pharmacies at some point during the two-year period.

Table 23: Consistency of clients who use each pharmacy

	Quartile 1		Quartile 2		Quartile 3		Quartile 4		All
	N	%	N	%	N	%	N	%	
Mail-service pharmacy	72	15	125	26	154	31	138	28	489
Clinic Pharmacy	459	27	430	26	347	21	447	27	1683

* All percentages have been rounded to the nearest whole percent and may not equal 100%.

Consistency differences across geographic regions were apparent. The difference is likely due to the higher proportion of customers residing outside of Denver who receive prescriptions by mail. Among mail-in pharmacy users, non-Denver clients are slightly more consistent than their Denver counterparts (Table 24). However, for users of other pharmacies, those in Denver appear to be considerably less consistent.

Table 24: Comparison of ADAP consistency based on county of residence for clients who use the mail-service pharmacy and for those who do not

		Quartile 1		Quartile 2		Quartile 3		Quartile 4	
		N	%	N	%	N	%	N	%
Mail-service pharmacy	**Non-Denver**	46	13	92	27	100	29	106	31
	Denver	26	18	33	23	54	37	32	22
Clinic Pharmacy	**Non-Denver**	82	21	77	19	84	21	152	38
	Denver	377	29	353	27	263	20	295	23

* All percentages have been rounded to the nearest whole percent and may not equal 100%.

Overall demographic differences were observed between the four quartiles for consistency. However, mail-service clients, being primarily located outside of Denver, are demographically different from clients of other pharmacies, which likely contribute to the trends seen overall. For this reason, demographic characteristics associated with MPR quartiles were examined separately for customers who used the mail-delivery pharmacy, and those who did not. For the 1,683 customers who did not use the mail-delivery system during this time, there seemed to be lower consistency among certain groups. These included: women, those 25 years of age and younger, African Americans, clients reporting no income, and clients who filled prescriptions for four or more antiretrovirals (Table 25). Groups utilizing ADAP more consistently included those 56 and older, clients who were undocumented, and clients reporting income above 200 percent of the FPL.

Table 25: Demographics of Clinic Pharmacy customers measured by MPR Quartile

	Quartile 1		Quartile 2		Quartile 3		Quartile 4		All	
	N	%	N	%	N	%	N	%	N	%
All	459	27	430	26	347	21	447	27	1683	100
Sex at birth										
Male	348	29	329	27	252	21	273	23	1202	100
Female	80	40	52	26	31	16	37	19	200	100
Age Group										
25 and under	23	43	14	26	7	13	9	17	53	100
26 - 35	99	31	83	26	61	19	72	23	315	100
36 - 45	190	31	172	28	110	18	139	23	611	100
46 - 55	119	22	131	24	135	24	168	30	553	100
56 and older	28	19	30	20	34	23	59	39	151	100
Primary Race/Ethnicity										
White (NH)	162	28	161	28	129	22	127	22	579	100
Latino	120	28	118	27	80	18	118	27	436	100
African American (NH)	116	41	71	25	55	20	38	14	280	100
Other/Unknown	32	28	34	30	20	18	28	25	114	100
FPL										
No Income	219	39	156	28	104	18	87	15	566	100
Below 100%	105	28	99	26	81	21	96	25	381	100
101% - 200%	83	25	97	29	66	20	90	27	336	100
Above 200%	24	18	33	25	33	25	40	31	130	100
Years since enrollment in ADAP										
<2 years	123	28	136	31	104	23	80	18	443	100
2 - 5 years	163	33	130	27	95	19	101	21	489	100
5 - 15 years	137	30	117	25	82	18	126	27	462	100
Unknown/Error	8	42	2	11	3	16	6	32	19	100
Number of Antiretroviral Drugs Prescribed										
One	138	21	141	22	157	24	217	33	653	100
Two	75	26	70	24	56	19	90	31	291	100
Three	143	28	134	27	101	20	127	25	505	100
Four or more	103	44	85	36	33	14	13	6	234	100

* All percentages have been rounded to the nearest whole percent and may not equal 100%.

It should be noted that MPR for clients who filled multiple drugs during the two year period was likely due, in some cases, to the client switching drug regimens during that time. This was not detected in the MPR calculation, and will artificially lower that client's consistency rating. Though the race/ethnicity of ADAP clients differ between men and women, this does not appear to be the cause of the lower consistency of female clients. Women of each race/ethnicity group are slightly less consistent than their male counterparts, suggesting additional barriers to receiving medications for that group.

When consistency of mail-service clients was examined, the only clear differences were between race/ethnicity groups and number of drugs prescribed. This suggests that the convenience of the mail-in pharmacy service may mitigate the effect of gender, age, and economic differences that are seen among the customers of other pharmacies.

Of the 2,172 Ramsell clients assessed, 1,799 (83 percent) were matched to eHARS records to assess client characteristics that are not collected for ADAP program enrollment. These factors potentially associated with ADAP consistency were transmission category, disease status, and time since HIV diagnosis. For these 1,799 there were consistency differences by transmission risk and disease status (Table 26). Clients with MSM recorded as their mode of transmission in eHARS were more consistent than clients in other transmission categories, and IDUs were the least consistent, with only 39 percent having an MPR above the median compared to 55 percent of MSM. Clients with a diagnosis of AIDS were slightly less consistent than those who did not have a diagnosis of AIDS recorded in eHARS. Unlike the demographic differences noted above, these trends were seen in both clients who used the mail-in service and those who did not, indicating additional barriers to consistently filling prescriptions for these clients.

Table 26: eHARS variables potentially associated with MPR quartiles for clinic pharmacy clients

	Quartile 1		Quartile 2		Quartile 3		Quartile 4		All	
	N	%	N	%	N		N	%	N	%
All	461	26	441	25	412	23	485	27	1799	100
Transmission category										
MSM	188	22	211	24	198	23	275	32	872	100
Heterosexual	57	30	47	25	42	22	42	22	188	100
MSM/IDU	46	32	35	24	32	22	33	23	146	100
IDU	38	31	37	30	31	25	17	14	123	100
Other/NIR	132	28	111	24	109	23	118	25	470	100
Disease Status										
HIV	148	23	155	24	159	24	189	29	651	100
AIDS	313	27	286	25	253	22	296	26	1148	100

* All percentages have been rounded to the nearest whole percent and may not equal 100%.

It is important to note that what appears to be inconsistent ADAP utilization based on pharmacy records can actually be a result of a physician directed change in treatment or availability of drugs temporarily from another payment source. Clients who became ineligible for ADAP during the analysis window who subsequently re-enrolled could not be identified as the data only reflected their current eligibility status. In these cases, a client would have appeared to be an inconsistent user of ADAP, but actually could have been consistently receiving medications from another source. Conversely, clients who regularly filled their medications may not necessarily have been adherent. Efforts to better understand these inconsistencies in filling prescriptions among ADAP clients through direct contact with a sample of such clients did not prove fruitful.

The majority of the interview participants who had previously spent time out of care were receiving ADAP services at the time of their interviews. Several others were getting HIV medications through other sources, and a few were not taking any medications. One person was getting his medications through ADAP but did not know it. Those receiving ADAP services had very good things to say about the program, and some thought the enrollment process had gone very smoothly. Some expressed that they had experienced no problems with the program. Several, however, did speak of difficulties qualifying and getting enrolled in the program, especially emphasizing the large amount of complicated paperwork that was involved. Those who had been homeless spoke of difficulties getting together all of the required documents. One spoke of problems in accessing the program because he did not hear back from his case manager at an ASO. About half of the participants who were receiving ADAP said that they had received help from doctors, clinic staff, or case managers in completing the application and enrollment process, which they thought had been critical to their accessing the service. Two people said that they were afraid of the program losing funding and their losing access to medications. One person from an outlying area said that it would be helpful to him if there were more pharmacies that carried his medications, given that he travels within the state often and is not always at home when his medications arrive in the mail. Another thought that it would help if there were more information available about ADAP around the state so that more PLWH would know it is available.

FUTURE CHANGES TO HEALTH CARE IN COLORADO

A final set of survey questions asked about needs and the steps respondents would likely take in the face of future changes to the health care system in Colorado. One question asked if respondents would sign up for Medicaid if rules changed and they were eligible. Another asked if they would sign up for private health insurance if they became eligible. Two follow-up questions asked how much they would be willing to pay for monthly premiums and annual out-of-pocket expenses for office visits, copayments, etc. Denver survey respondents were more likely to say they would be willing to sign up for Medicaid or for private health insurance than non-Denver respondents. A higher proportion of non-Denver respondents said that these questions were not applicable. This is not unexpected based on the higher proportion of non-Denver survey respondents who reported already accessing these services (Table 27). The median amount that respondents from both Denver and out of Denver said they would pay for insurance premiums was $50 a month, and the median out-of-pocket expense they were willing to pay was $200 a year.

Table 27: Survey respondent willingness to sign up for Medicaid or private health insurance if the requirements were to change

	Denver		Non Denver		All	
	N	%	N	%	N	%
Would you sign up for Medicaid?						
Yes	339	57	127	48	466	54
No	80	13	47	18	127	15
Not Applicable	107	18	60	22	167	19
No Response	69	12	33	12	102	12
Would you sign up for private insurance?						
Yes	272	46	100	37	372	43
No	197	33	58	22	255	30
Not Applicable	67	11	76	28	143	17
No Response	59	10	33	12	92	11
What amount would you be willing to pay for a monthly premium?						
	N=224		N=83		N=307	
Median	$50		$50		$50	
Mean	$92		$108		$97	
What amount would you be willing to pay for annual out-of-pocket?						
	N=181		N=63		N=244	
Median	$200		$200		$200	
Mean	$541		$706		$583	

A total of 188 respondents offered explanations for their “yes” or “no” responses to the question about Medicaid. Forty-five percent of those answering that they would sign up for Medicaid said they would do so because they needed the help or to help with the costs of care. Twenty percent said it was so they could access care and treatment, and another 25 percent said they would sign up in order to access better care. Of those responding “no” to the Medicaid question, 31 percent said they did not think they would qualify, including four percent who reported being undocumented. Seventeen percent were receiving Medicare and another twelve percent had private insurance and therefore did not think they would need Medicaid. Ten percent said they did not need it, and six percent said that applying for Medicaid was too complicated. Almost half (48 percent) of the 121 people saying that they would sign up for private insurance, said they would do so only if it was affordable. Another 27 percent said they would do so because they needed the coverage, and 14 percent said they would in order to get better coverage. Of 155 people reporting that they would not sign up for private insurance, 78 percent said that they could not afford it. Another 15 percent said that they already had Medicare, Medicaid, or some other type of coverage and would not need it.

Table 28 shows that there were some significant differences in the demographics of people who said they would sign up for Medicaid and private insurance. Survey respondents with income less than $8,000 (including those with no reported income) were more likely to say that they would sign up for Medicaid and private insurance than those reporting income above $8,000. Survey respondents who were foreign born were more likely to say that they would sign up for Medicaid, but less likely to sign up for private insurance than those born in the U.S.

Table 28: Demographic groups more or less willing to sign up for Medicaid or private health insurance

MEDICAID	Yes	%	No	%	Not Applicable	%	No Response	%	Total
Income $8,000 or less	164	35	17	14	54	33	31	31	266
More than $8,000	298	65	108	86	110	67	68	69	584
Total	462		125		164		99		850
Foreign Born-Yes	67	15	15	12	7	4	15	15	104
Foreign Born- No	395	85	111	88	154	96	85	85	745
Total	462		126		161		100		849
Diagnosis of AIDS	210	46	62	49	96	60	43	48	411
No AIDS Diagnosis	249	54	64	51	65	40	47	52	425
Total	459		126		161		90		836

PRIVATE INSURANCE	Yes	%	No	%	Not Applicable	%	No Response	%	Total
Income $8,000 or less	135	37	73	29	26	18	32	37	266
More than $8,000	234	63	178	71	117	82	55	63	584
Total	369		251		143		87		850
Foreign Born-Yes	39	11	43	17	12	9	10	11	104
Foreign Born- No	328	89	209	83	128	91	80	89	745
Total	367		252		140		90		849
Diagnosis of AIDS	166	46	142	57	62	44	41	50	411
No AIDS Diagnosis	197	54	109	43	78	56	41	50	425
Total	363		251		140		82		836

An open-ended question on the survey asked respondents what they would likely need to make sure they got the most benefit from changes in health care in Colorado had 659 responses (Table 29). Over half of the respondents (52 percent) stressed that they needed an assurance of continued, uninterrupted access to HIV care and treatment including doctor visits, medications, and laboratory testing. For many this meant access to affordable insurance coverage and affordable care and treatment. Many commented on how they were pleased with the coverage, care, and treatment that they currently received, and they wanted to continue receiving them. This included: being able to see the same doctor; continuing to receive ADAP and Bridging the Gap Colorado benefits, continuing to receive Medicaid or Medicare benefits, and no cutbacks in service. Others mentioned that they would need free care and treatment or assistance in paying for insurance premiums, deductibles, and co pays. Still others said that they would need a system that was easy to navigate, with streamlined paperwork required for enrollment, and few restrictions on qualifying for services.
Another 10 percent reported needing improved access to care and treatment. For some this meant full coverage health insurance that would include: care and treatment for HIV and non-HIV related health conditions including dental care and mental health care and treatment, coverage for family members, coverage when traveling outside of one’s county or state, and no restrictions for pre-existing conditions. Others mentioned that they needed more doctor and clinic choices, better quality doctors, and more frequent and easier access to medical appointments. This was especially

the case for those living outside of Denver who also noted the need for more local clinics that could deal with HIV patients. Other suggestions for improvements to care and treatment included: simplified enrollment procedures; fewer income restrictions on benefits allowing people to work; quality care that was not based on income; universal health care; ability to access prescriptions in greater than thirty day supplies; and more ASO locations.

Twenty-two percent of those responding to the question about needs in the face of changes to health care stressed that they would need good information. Most often they reported needing information about the nature of the changes, what the changes imply for their health care, and what they need to do in the face of such changes to ensure their access to care and treatment. Some said they needed to understand what programs and benefits were available to them, have their options explained, and understand which would be most appropriate for their situations so that they could make informed choices. People also wanted information on what they needed to do to gain and maintain access to those programs and benefits. This would include understanding enrollment processes and program requirements. Respondents stressed needing information that was understandable, detailed, and up to date and suggested that it could be delivered through providers, interpreters, the mail, the Internet, and television. Some mentioned needing contact information, and others said they needed to understand both their rights and responsibilities in accessing health care. Another four percent of the respondents stressed that they would need help understanding the health care system and any changes to it as well as assistance in enrolling in programs. Case managers or some other type of informed provider or counselor could provide such assistance.

An additional ten percent of the respondents said that they would not only need access to HIV care and treatment, but access to basic needs as well. These included: income in the form of well-paying jobs, disability benefits, or financial assistance; stable housing and utilities; food stamps or access to food banks; and transportation in the form of bus passes or gas vouchers. Six percent said that they did not know what they would need in the face of changes to the health care system with many saying they would first need to know what those changes would entail.

Table 29: Survey respondents expressed needs in the face of potential future changes to health care in Colorado

Need	Number (N=659)	Percent
Continued access to HIV care and treatment	344	52%
Information	142	22%
Access to basic needs	64	10%
Improved care and treatment	64	10%
Don’t know	41	6%
Case management/guidance	26	4%

GIFTS OF PEOPLE LIVING WITH HIV

One final question asked as part of the interviews with people who had spent time out of care addressed the gifts that PLWH have to offer to others. Their responses fell into three general categories, however, most of the discussion focused on what they could offer to others who were living with the disease. Much of this stemmed from the fact that PLWH could better understand what another person with HIV was going through, especially when they are newly diagnosed. Respondents mentioned that PLWH could offer a sense of hope for those who may be mourning and think their lives are over, and they can remind them that they are not alone. They can give others someone to talk to who can truly understand and with whom they can share experiences.

They can offer others information so that they can better understand the disease and how to cope with the potential related health problems and multiple life issues that often come with it. They can also direct those who are newly diagnosed or out of care to the services and resources they need and teach them how to live a healthier life. Some respondents talked about how much they had learned from other PLWH and how inspirational it was to meet others with HIV who had survived a long time and who have moved on with their lives. A few even spoke of how they had inspired others and how good that felt. One participant who was a recovering addict stressed the importance of people like himself mentoring other addicts with HIV. Overall, the respondents thought that a major gift that PLWH have to offer is a personal touch that people with HIV often do not get from their doctors or other providers. Most of the participants in the interviews talked about how much it would have helped them to be able to talk to someone else who was positive when they first found out they had HIV.

A second set of responses concerning the gifts of those living with HIV focused on their potentially powerful influence in the prevention of HIV and in addressing the stigma surrounding the disease that most thought was still widespread. Consistent with previous prevention and care needs assessments, some respondents spoke about how important it is for PLWH to tell their stories to others, to raise awareness about behavioral risks that some may not know they have or about which they may be in denial. Meeting people with HIV provides others with a better sense of the reality of the disease, and can help them to address misconceptions about risks for HIV and about the people who have it. Such experiences can often help people to have more compassion and be less likely to discriminate against those with HIV.PLWH could also inspire others who may be at risk to seek HIV testing. A third gift mentioned by some participants concerned the volunteer work and fundraising in which many PLWH are involved, helping agencies to better serve the needs of more people. Some said they were glad to have the opportunity to contribute or “give back.”

LIMITATIONS OF THE DATA

Although a wealth of information was gathered through the data collection methods used in this needs assessment, all assessments have limitations, especially those concerning the degree to which the sample of respondents is representative. The sample of participants who completed the survey for this study was predominantly made up of clients receiving ADAP services or services provided by ASOs and should not be considered representative of all PLWH in Colorado. Although interviews were conducted with fifteen people who had spent substantial periods of time out of care, the greatest limitation in this particular study can be seen in the low level of participation of people who were not currently receiving medical care and other related services. This was especially the case among survey respondents living outside of the Denver area. Future needs assessments should place an emphasis on gaining more perspective from people who are not getting the medical care 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. Also, only the information provided by those who responded to the survey and those PLWH who agreed to participate in the interviews could be incorporated in this report. Some who did participate in interviews may have altered their responses out of concern for being judged or jeopardized in some way. Furthermore, approximately three percent of the survey respondents did not provide their county of residence or zip code. Data from these surveys were included with the data on non-Denver residents, making up about nine percent of the non-Denver total. This potentially could have skewed the information somewhat.

The STI/HIV Surveillance Program at CDPHE provided aggregate data used for this study. These data are also inherently limited in that they are dependent on reporting by laboratories and providers within Colorado and by health departments across the country. The surveillance database is not intended to monitor the current locations of Colorado cases, but information is updated as it is received. PLWH frequently move between states and do not necessarily access care when they do or do not access it right away. Therefore, in these cases, no reporting occurs until care is accessed and reports from the new state of residence are sent. Some PLWH who were originally diagnosed with HIV in Colorado may pass away in other states, the records of which may not get back to the Surveillance Program in a timely manner. All of this makes it difficult to have an accurate count of the number of PLWH living in Colorado at any given time. Another limitation stems from the fact that the only consistent indicator that a person is in care is through the reporting of viral load and CD4 tests. Although other indicators of care are available to CDPHE, they are not available for all PLWH living in the state. Additionally, viral load tests for people currently living in the state who were originally diagnosed with HIV in other states are not included in the Colorado statistics. Given these circumstances, current data are not available for a large number of the people considered as Colorado HIV cases, making it especially difficult to assess the total number of people currently living with diagnosed HIV in Colorado and the number of people not receiving HIV care. An additional limitation of the surveillance data is that address data were not systematically entered into HARS prior to 2007.

Data used to assess ADAP utilization were exported from the pharmacy benefit management database. This system is used to track prescription claims paid by all Colorado medication assistance programs. Data from eHARS were linked to pharmacy benefit management database records where possible to include year of HIV diagnosis, disease status, and risk factors, which are not collected in that database. For the purpose of this analysis, ADAP enrollees were not systematically matched to the CDPHE surveillance system, so this information is incomplete. Seventeen percent of the pharmacy benefit mangagement database clients included in this analysis could not be linked to eHARS records, either because they have moved here from out of state and were not in the surveillance records used, or because their name was not reported the same way in both datasets. For consistency and simplicity, these analyses were limited to a two-year period between the beginning of 2009 and the end of 2010 and may not reflect more recent changes in ADAP utilization. Only clients who were taking one of the 11 most commonly prescribed antiretroviral medications during that time were included, so it does not address clients who were enrolled in ADAP and did not use the service, or who were enrolled but only used it for other drugs on the formulary. Justifiable reasons for inconsistent ADAP use, such as a physician directed change in medications or temporary enrollment in a pharmaceutical trial were not readily captured in these data and were not reflected in the measures of consistency.

SUMMARY AND RECOMMENDATIONS

Several themes emerge from a review of the information gathered as part of this needs assessment that relate to the three principal foci of the study. To reiterate, these include: 1) Delays in HIV testing among those who are positive and ways to increase testing; 2) The reasons many PLWH have gone through periods of time when they have not received medical and related services, and what is most needed to link more people to care and retain them in care; and 3) The needs identified by PLWH for medical care and other related services and the ways and extent to which those needs are being met.

The first of these themes centers on the high percentage of those testing positive for HIV in Colorado that are diagnosed with AIDS within 12 months of their HIV diagnosis. Overall, 35 percent of those diagnosed between 2006 and 2010 had a concurrent diagnosis, with certain populations having higher rates than others, such as people over the age of 45, heterosexual men, and Latino immigrants. Certain geographic regions of the state also had higher proportions of their incident cases having concurrent diagnoses. Many of the needs assessment participants were tested for HIV because they were already sick with AIDS-related conditions. Reasons interview participants said that they delayed testing and that others may do so as well included: not thinking that they were at risk; mistakenly thinking that their doctors had been testing them and that the results had been negative; lack of availability of testing, especially outside of the DMA; and lack of overall knowledge and awareness about HIV causing people either not to think of testing or to be afraid of it. Recommendations for increasing HIV testing that emerge from the data include: 1) Promoting testing among at-risk populations, seeking to change norms so that regular testing is more routine; 2) Increasing the availability of HIV testing in more venues that people frequent such as bars, public clinics, service agencies, organizations, on the street, jails, homeless shelters, and college campuses; 3) Offering testing for free; 4) Having doctors talk to their patients about HIV and offering testing; 5) Offering testing in ways that people can pursue it discretely; and 6) Raising awareness about HIV among the general public and high-risk populations so that they better understand their risks and the importance of knowing their status. Although establishing dedicated HIV testing sites in low incidence parts of the state may not be feasible, increased provider and community education is warranted, and providers across the state should be encouraged to conduct more risk assessments and offer HIV testing more routinely.

Another theme of this assessment focuses on the barriers to HIV care and related services that are still faced by many PLWH in Colorado, despite efforts over the last several years to link more people into care. The absence of updated information on many PLWH who were diagnosed in the 1980’s and 1990’s makes it difficult to know the true extent to which people with HIV in Colorado are out of care. However, even when focusing on the more recent cases of people diagnosed since 1995, the data show that 35 percent of the people with diagnosed HIV were not in care as of mid-2011. Survey respondents most commonly cited inability to afford care or insurance as reasons they had been out of care in the past. Other reasons included: not feeling sick and therefore not thinking it necessary; not wanting others to find out about their HIV status; the requirements and paperwork involved in accessing care; lack of transportation; poor treatment by a provider; and not knowing where to go or how to access care. Interview participants offered some of these same reasons for being out of care. Additional reasons offered by them included: poverty and homelessness; reluctance to go on HIV medication; mental health problems; and substance abuse problems.

One principal recommendation for lowering the percentage of PLWH who are out of care is for CDPHE to make significant efforts to follow up on older cases that appear to be out of care, and to evaluate which of those cases reflect needed linkage to care and which may reflect cases that are no longer living or no longer in the state. A second principal recommendation is to increase knowledge about the circumstances influencing why people are out of care and how best to link them to care through expanded research efforts with this population. Another principal recommendation for assuring that more PLWH access HIV care and related services involves people being provided several types of assistance, especially when they are first diagnosed, utilizing a comprehensive approach. These types of assistance include: 1) Providing emotional and social support, including counseling and the opportunity to meet with a peer or peers who are also living with HIV; 2) Providing information about HIV and how it is likely to affect them as well as better information about HIV treatment so that PLWH can better understand the importance of treatment for their own health and that of their partners; 3) Conducting an assessment of care and treatment needs and needs for related services such as help accessing basic needs, mental health support, or substance abuse treatment; 4) Providing active linkage to care including access to affordable and quality care, better information as to how and where to access care, and assistance with enrollment processes; 5) Expanding the availability of quality HIV medical care and other services in more parts of the state and more transportation assistance for accessing services that are far away from where clients live; and 6) Providing active linkage to other needed services based on the assessment, including expanded assistance for accessing housing and other basic needs.

Recommendations for improving services to PLWH who are already accessing care are similar to those identified for those who are not in care. These include: 1) Ensuring continued access to affordable medical care and treatment; 2) Ensuring that people know about the variety of services that are available to them and helping them to make informed choices about what they should pursue; 3) Providing on-going assistance with enrollment processes and helping people to overcome barriers they face in accessing particular services; 4) Conducting further research in order to determine the extent to which PLWH are homeless or at risk for becoming homeless; 5) Providing assistance to help more people find housing and meet other basic needs; and 6) Providing more opportunities for people to find the emotional support they need, including opportunities for support groups and social interactions with other PLWH.

One access-to-care subject that constituted a particular focus of this needs assessment was the use of the Colorado ADAP, a state run program that provides HIV medications to approximately 1,300 Colorado residents in any given month. A large majority of the survey respondents (69 percent) and many of the interview participants reported receiving drug assistance through this program. Most reported high levels of satisfaction with the program, although one critique reflected some people’s desire to have more medications and supplements included in the formulary of available medications. An analysis of the data on patterns of filling prescriptions by enrollees showed a high level of inconsistency in their usage. An effort to gain information from a sample of enrollees to explain these inconsistencies was unsuccessful. Recommendations related to the ADAP include: 1) Continue the effort to understand the inconsistent use of ADAP services through future research efforts, and 2) Increase the amount of adherence counseling conducted by medical providers, clinic staff, and case managers.

Two additional overarching issues emerging from this needs assessment have been highlighted in previous assessments. One concerns the powerful impact of stigma on PLWH. According to participants, stigma affects whether or not people access HIV testing or access treatment if they find out they have HIV. It affects the mental health of PLWH, often making them feel like outcasts, or exacerbating feelings such as shame and guilt. Stigma also affects social interactions as others discriminate against PLWH or keep them at a distance. Participants emphasized the need for the public’s attitude about HIV to change, which would necessitate widespread education about the disease, dispelling myths and challenging stigma and its consequences. The other theme concerns the gifts that some PLWH already offer to others and the huge potential embodied in this population for contributions to HIV prevention and care. A strong recommendation arising from this theme is for providers to incorporate more PLWH in the work that they do, especially acting as peer counselors and peer educators.

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