

# Out-of-Care Populations

## OUT-OF-CARE POPULATIONS

“Out-of-care” PLWHA are a critical focus of this needs assessment. Based on the HRSA definition, out-of-care are those PLWHA who have not had CD4 or viral load tests or have not taken antiretroviral medication in the last 12 months. This section presents key findings about all out-of-care PLWHA and seven populations with adequate numbers of out-of-care respondents to allow them to be considered separately. These include out-of-care African-Americans, injecting drug users, Latinos, recently released from jail/prison, other substance users, women and youth.

For the total out-of-care sample and each out-of-care population, key differentiating attributes are reported in order to promote the development of targeted programs. Reasons for being outside the care system are identified as well as general barriers to care and housing-related barriers to care. Minimizing these barriers is critical to effectively linking out-of-care PLWHA with the medical care system, and effective, culturally appropriate communication is critical to developing and maintaining them within the system.

For each population, the 10 most frequently identified service needs and the top 10 unfulfilled service needs are presented. Respondents identified these services either as needed or as needed with the need not being met. It is interesting to note that for all out-of-care populations, primary medical care is among the top 10 service needs and the top ten unfulfilled needs. This indicates that many out-of-care PLWHA may recognize their need for primary medical care, but may not have accessed it due to barriers or possible misinformation regarding the importance of routine medical care. The challenge is to reduce these barriers and effectively communicate with these populations in order to accomplish the goal of bringing them into the care system and maintaining them once they are enrolled in care. Targeted, population-specific interventions should promote success.

## OUT-OF-CARE: TOTAL SAMPLE

The 654 PLWHA participating in the consumer survey include 69% in-care consumers and 31% out-of-care PLWHA. This is consistent with Centers for Disease Control and Prevention (CDC) estimates that approximately one-third of people diagnosed with HIV disease are outside the care system<sup>20</sup>.

<sup>20</sup> "New Bureau Director Emphasizes Steadfast Commitment to Underserved Populations, Accountability." HRSA Care Action, December 2002, pg. 2

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- ⌘ Men and transgendered PLWHA tend to be out-of-care to a greater extent than women.
  - ◆ Transgendered were 2% of in-care PLWHA and more than 8% of out-of-care.
- ⌘ Out-of-care respondents were generally younger than in-care.
  - ◆ Youth age 13 to 24 years tend to be out-of-care. They make up 6% of in-care respondents and 19% of out-of-care. Similarly, PLWHA ages 25 to 34 were 18% of in-care survey respondents, compared to 29% of out-of-care.
- ⌘ Locating out-of-care consumers was more difficult in rural areas, with 12% of in-care respondents coming from outside Harris County, but only 5% of out-of-care from this area.
- ⌘ Out-of-care PLWHA tend to be in better health and diagnosed with HIV more recently than those in the medical care system.
  - ◆ More than 46% of in-care consumers have an AIDS diagnosis and less than 27% of out-of-care consumers report receiving this diagnosis.
  - ◆ 52% of out-of-care consumers were diagnosed between 2000 and 2004 compared to 32% of those in-care.
- ⌘ More than 70% of out-of-care PLWHA report that since being diagnosed, they have never received medical care for HIV.
- ⌘ Out-of-care consumer survey respondents include a larger percentage of uninsured than those in-care, with 81% of out-of-care reporting no insurance compared to 48% of those in-care
- ⌘ Percentages of respondents with a history of IV or street drug use do not vary between in-care and out-of-care. The differences exist, however, among current users. More than 13% of out-of-care respondents report current IV drug use and 26% report current street drug use. This compares to 3% of in-care that report current IV drug use and 8% who report current street drug use.
- ⌘ The 202 out-of-care consumers were asked their reasons for not accessing medical care. The most frequent response was “I do not believe that I need medical care currently, because I am not sick” (47%). Other reasons included:
  - ◆ I do not believe medical care would help (27%);
  - ◆ I do not want to receive medical care (20%);
  - ◆ I was actively using street drugs or alcohol (16%);
  - ◆ I was worried someone would force me to take medication (15%);
  - ◆ They were not open when I could get there (convenient hours) (15%); and
  - ◆ I was worried that someone would find out about my HIV status if I went there (15%).

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⌘ Barriers to care caused by consumers' housing situations were identified. When asked, "Thinking about your housing situation now, do any of the following stop you from taking care of your HIV?", respondents most frequently identified:

- ◆ I'm afraid of others knowing I'm HIV positive (41%);
- ◆ I don't have money for rent (23%);
- ◆ I don't have enough food (18%); and
- ◆ I can't get away from drugs in the neighborhood (14%).

Out-of-care PLWHA most frequently identified unfulfilled service needs include:

Rental Assistance	156	77.2%
Primary Medical Care	138	68.3%
Health Insurance	138	68.3%
Oral Health	125	61.9%
Utility Assistance	122	60.4%
Household Items	119	58.9%
Vision Care	119	58.9%
Food Bank	118	58.4%
Bus Passes	111	55.0%
Housing-Related Services	109	54.0%
Nutritional Supplements	109	54.0%

### OUT-OF-CARE: AFRICAN-AMERICANS<sup>20</sup>

One-third (33.4%) of African-Americans surveyed were not receiving HIV medical care. These respondents presented the following profile:

- ⌘ Younger than in-care African-American PLWHA (41% under age 35 compared to 24% of in-care).
- ⌘ Transmission mode similar to in-care with the following exceptions:
  - ◆ Smaller percentage reporting injecting drug use as their transmission mode (9% vs. 15% for in-care).
  - ◆ Larger percentage reporting commercial sex work as their transmission mode (14% vs. 5% for in-care).
- ⌘ More than 40% are working full-time or part-time. This is double the percentage of in-care African-Americans who are working. Nevertheless, incomes are low

<sup>20</sup> African-Americans comprised approximately 50% of the out-of-care PLWHA participating in the consumer survey (n=109). Little variation exists between responses for the total out-of-care sample and the African-American out-of-care.

and are similar to those of the in-care.

- ◆ Nearly 75% are uninsured, only 8% report receiving insurance through work.
- ⌘ Out-of-care tend to be more recently diagnosed, with 47% diagnosed since 2000 compared to 27% of in-care.
- ⌘ Larger percentages reporting treatment for STI (31%) and TB (12%) in the last 12 months, but other co-morbidities are lower than in-care.
- ⌘ Higher percentage of current IV drug users (11%) and street drug users (26%).
- ⌘ Most frequently identified reasons for being out-of-care included:
  - ◆ I do not believe I need medical care currently because I am not sick (46%);
  - ◆ I do not believe medical care would do me any good (27%);
  - ◆ I do not want to receive medical care (21%);
  - ◆ Financial reasons (20%);
  - ◆ It was too hard to get there (transportation) (19%); and
  - ◆ I was actively using (street drugs or alcohol) (17%).
- ⌘ When asked, “Do any of the following keep you from getting needed HIV medical care?”, the most frequent responses included:
  - ◆ I don’t have a way to pay for it (32%);
  - ◆ No way to get there (28%);
  - ◆ I don’t feel welcome (21%); and
  - ◆ Disclosure to partner (19%).
- ⌘ Barriers to care caused by consumers’ housing situations were identified. When asked, “Thinking about your housing situation now, do any of the following stop you from taking care of your HIV?”, out-of-care African-American respondents most frequently identified:
  - ◆ I’m afraid of others knowing I’m HIV positive (38%);

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- ◆ I don't have money for rent (27%);
- ◆ I don't have enough food (22%); and
- ◆ I can't get away from drugs in the neighborhood (17%).

Out-of-care African-American's ten most frequently identified unfulfilled service needs include:

Primary Medical Care	78	71.6%
Vision Care	69	63.3%
Health Insurance	68	62.4%
Rental Assistance	67	61.5%
Household Items	64	58.7%
Food Bank	62	56.9%
Case Management	60	55.0%
Housing Related Services	60	55.0%
Oral Health	60	55.0%
Utility Assistance	60	55.0%

The ten most needed services mirror these, except the need for bus passes is identified and the need for housing related services is not included.

### OUT-OF-CARE: INJECTING DRUG USERS (IDU)

Injecting drug users (IDU) include consumer survey respondents who currently use or have a history of injecting drugs. They comprise 25% of the survey sample, with one-third being out-of-care, or 56 respondents. Nearly half report current IV drug use.

- ⌘ Race, age, educational attainment, year of HIV diagnosis match the profile of all out-of-care survey respondents.
  - ◆ The gender profile varies from the total sample with nearly 80% of out-of-care IDU identified as male or transgendered.
- ⌘ Only 31% identified injecting drug use as their transmission mode. Another 31% identified heterosexual contact, and 27% reported male to male sex.
  - ◆ Forty percent identified commercial sex work as their transmission mode.
- ⌘ More than two-thirds of out-of-care IDU are unemployed, and 75% earn less than \$5,000 per year. 20% are homeless and almost all (91%) are uninsured.
- ⌘ More than 70% have never received medical care for their HIV disease.

## Injection Drug Users

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- ⌘ Most frequently identified reasons for being out-of-care included:
  - ◆ I do not believe I need medical care currently because I am not sick (54%);
  - ◆ I was actively using (street drugs or alcohol) (41%);
  - ◆ I do not want to receive medical care (29%);
  - ◆ I do not believe medical care would do me any good (27%); and
  - ◆ It was too hard to get there (transportation) (18%).
  
- ⌘ When asked, “Do any of the following keep you from getting needed HIV medical care?”, out-of-care injecting drug users’ most frequent responses included:
  - ◆ I don’t have a way to pay for it (43%);
  - ◆ No way to get there (30%);
  - ◆ Disclosure to partner (25%); and
  - ◆ I don’t feel welcome (23%).
  
- ⌘ Barriers to care caused by consumers’ housing situations were identified. When asked, “Thinking about your housing situation now, do any of the following stop you from taking care of your HIV?”, out-of-care IDU respondents most frequently identified:
  - ◆ I’m afraid of others knowing I’m HIV positive (36%);
  - ◆ I can’t get away from drugs in the neighborhood (31%); and
  - ◆ I don’t have money for rent (23%).

Out-of-care injecting drug users’ most frequently identified unfulfilled needs include:

Primary Medical Care	42	75.0%
Health Insurance	41	73.2%
Oral Health Care	41	73.2%
Rental Assistance	40	71.4%
Housing Related Services	37	66.1%
Bus Passes	33	58.9%
Vision Care	33	58.9%
Utility Assistance	33	58.9%
Shelter Voucher	33	58.9%
Food Bank	32	57.1%
Household Items	32	57.1%

The most needed services are very similar since very few report their needs have been met.

**OUT-OF-CARE: LATINOS**

Latinos comprised 22% of the survey sample, and 27% of these people, or 41 respondents, were out-of-care.

- ⌘ Out-of-care Latino consumer survey participants have the same gender and age profiles as those receiving HIV medical care.
- ⌘ With 55% working either full or part time, out-of-care Latinos are employed to a greater extent than both in-care Latinos and other groups of out-of-care consumers.
  - ◆ Despite working, 87% are uninsured.
- ⌘ Out-of-care Latinos were relatively newly diagnosed with HIV. Almost all were diagnosed after 1995, and 73% were diagnosed between 2000 and 2004.
- ⌘ After diagnosis, 83% of the out-of-care never received HIV medical care, and 33% reported they were not referred for services.
- ⌘ Few out-of-care Latinos were treated for co-morbid conditions in the last 12 months. Co-morbidities identified included current IV drug use (18%), current street drug use (30%) and homelessness (15%).
- ⌘ Most frequently identified reasons for Latino PLWHA being out-of-care included:
  - ◆ I do not believe I need medical care currently because I am not sick (54%);
  - ◆ I do not believe medical care would do me any good (29%);
  - ◆ I was worried someone would force me to take medication (17%);
  - ◆ I was actively using (street drugs or alcohol) (17%); and
  - ◆ I was worried someone might find out about my HIV status if I went there (17%).
- ⌘ Barriers to care caused by consumers' housing situations were identified. When asked, "Thinking about your housing situation now, do any of the following stop you from taking care of your HIV?", nearly 70% of Latino respondents identified "I'm afraid of others knowing I am HIV positive."
- ⌘ Other barriers were identified with the question, "Do any of the following keep you from getting needed HIV medical care?", the most frequent responses included:
  - ◆ I don't have a way to pay for it (42%);
  - ◆ Fear of being deported (42%); and
  - ◆ I can't get services because of immigrant/legal status (27%).

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Out-of-care Latino's ten most frequently identified unfulfilled needs include:

Health Insurance	28	68.3 %
Oral Health	25	61.0%
Primary Medical Care	22	53.7%
Utility Assistance	21	51.2%
Bus Pass	20	48.8%
Rental Assistance	20	48.4%
Vision Care	18	43.9%
Household Items	18	43.9%
Client Advocacy	18	43.9%
Food Bank	18	43.9%

Top service needs mirror these unfulfilled needs.



**OUT-OF-CARE: RECENTLY RELEASED**

PLWHA who were recently released from jail or prison are those who report being in jail or prison during the past year. They comprise 17% of the survey sample, and 72% of these respondents were not receiving medical care.

- ⌘ Out-of-care recently released include a smaller percentage of women and a larger percentage of whites than other out-of-care populations.
  - ◆ Women account for 25% of out-of-care recently released, and transgendered are 13%.
  - ◆ Nearly 30% were white and 11% were Hispanic.
  
- ⌘ More than 26% report commercial sex work as a transmission mode. Nearly 80% were diagnosed since 1995, with 41% diagnosed since 2000.
  - ◆ One-third were diagnosed with HIV while in jail or prison, but almost 80% have not gotten HIV medical care.
  
- ⌘ Eighty percent are unemployed, and almost all have incomes below \$10,000 per year. In addition, 92% are uninsured.
  
- ⌘ Co-morbidities treated in the last 12 months include STI (28%) and hepatitis C (20%).
  - ◆ Seventy percent report a history of street drug use, with 46% currently using street drugs and 27% currently using IV drugs.
  - ◆ Fifteen percent are homeless.
  
- ⌘ Most frequently identified reasons for being out-of-care included:
  - ◆ I was actively using (street drugs or alcohol) (35%);
  - ◆ I do not believe I need medical care currently because I am not sick (33%);
  - ◆ I do not believe medical care would do me any good (27%); and
  - ◆ I do not want to receive medical care (23%).
  
- ⌘ When asked, “Do any of the following keep you from getting needed HIV medical care?”, the most frequent responses included:
  - ◆ I don’t have a way to pay for it (33%);
  - ◆ No way to get there (31%);
  - ◆ I don’t feel welcome (23%);
  - ◆ Disclosure to partner (23%); and
  - ◆ People don’t understand my culture (23%).

**Recently Released**

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⌘ Barriers to care caused by consumers' housing situations were identified. When asked, "Thinking about your housing situation now, do any of the following stop you from taking care of your HIV?", out-of-care recently released respondents most frequently identified:

- ◆ I'm afraid of others knowing I'm HIV positive (40%);
- ◆ I don't have money for rent (25%); and
- ◆ I can't get away from drugs in the neighborhood (25%).

Out-of-care recently released ten most frequently identified unfulfilled needs include:

Rental Assistance	38	79.2%
Primary Medical Care	37	77.1%
Health Insurance	36	75.0%
Housing Related Services	33	68.6%
Oral Health	31	64.6%
Bus Passes	31	64.6%
Utility Assistance	31	64.6%
Household Items	31	64.6%
Shelter Vouchers	30	62.5%
Food Bank	29	60.4%

The ten most needed services mirror these, except the need for support groups is identified and the need for household items is not included.

**Recently Released**

**OUT-OF-CARE: OTHER SUBSTANCE USERS**

Other substance users include consumer survey respondents who currently use or have a history of using street drugs, such as cocaine, poppers, inhalants, etc. Injecting drug users, however, are not included. These PLWHA comprise one-quarter of the survey sample, and of these 27% are not receiving HIV medical care. In addition, nearly half of out-of-care substance users report current street drug use.

- ⌘ Out-of-care substance users are younger than the survey sample and other out-of-care populations, with two-thirds under 35 years of age. More than 68% are African-American and only 4% are Latino.
- ⌘ Fifty percent report being infected via heterosexual contact, and 30% include commercial sex work as a transmission mode.
- ⌘ Substance users went farther in school than other out-of-care populations, with 57% graduating from high school or attending some college. Nevertheless, 52% are unemployed, and incomes are low, with three-quarters reporting earning below \$10,000 per year.
  - ◆ 80% are uninsured.
- ⌘ Most frequently identified reasons for being out-of-care include:
  - ◆ I do not believe I need medical care currently because I am not sick (30%);
  - ◆ I do not believe medical care would do me any good (30%);
  - ◆ I do not want to receive medical care (23%);
  - ◆ Financial reasons (23%);
  - ◆ They were not open when I could get there (convenient hours) (23%);
  - ◆ I was worried someone might find out about my HIV status if I went there (23%); and
  - ◆ I was worried someone would force me to take medication (23%).
- ⌘ When asked, “Do any of the following keep you from getting needed HIV medical care?”, the most frequent responses included:
  - ◆ I don’t have a way to pay for it (39%);
  - ◆ No way to get there (32%); and
  - ◆ I don’t feel welcome (30%).

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⌘ Barriers to care caused by consumers' housing situations were identified. When asked, "Thinking about your housing situation now, do any of the following stop you from taking care of your HIV?", out-of-care substance users' respondents most frequently identified:

- ◆ I'm afraid of others knowing I'm HIV positive (55%);
- ◆ I don't have money for rent (39%);
- ◆ I don't have enough food (30%); and
- ◆ I can't get away from drugs in the neighborhood (20%).

Out-of-care substance users' ten most frequently identified unfulfilled service needs include:

Household Items	32	72.7%
Rental Assistance	32	72.7%
Nutritional Supplements	31	70.5%
Utility Assistance	31	70.5%
Food Bank	30	68.2%
Primary Medical Care	29	65.9%
Health Insurance	28	63.6%
Case Management	27	61.4%
Buddy/Companion	27	61.4%
Home Delivered Meals	26	59.1%

The ten most needed services are similar, but they include van transportation and bus passes, both of which are being met to some extent. In both cases, 31 consumers identified the need, and 24 (55%) report these needs are not being met.

**OUT-OF-CARE: WOMEN**

Women comprise 37% of the survey sample. This is one of the largest sub-populations under study. Twenty-nine percent, or 68 women, are out-of-care.

- ⌘ Out-of-care women are working to a greater extent than other out-of-care populations, and incomes are somewhat higher than other groups.
  - ◆ Forty percent are unemployed;
  - ◆ Twenty percent have incomes greater than \$15,000 per year, including 13% reporting incomes greater than \$30,000; and
  - ◆ 32% have some type of insurance, with the most frequent being Medicaid.
  
- ⌘ Out-of-care women are more recently diagnosed than other out-of-care populations, with 52% diagnosed since 2000, and a total of 85% diagnosed after 1995.
  
- ⌘ Thirty-five percent of out-of-care women entered the HIV medical care system and dropped out. This compares to 29% of all out-of-care respondents.
  
- ⌘ Eleven percent of women have been treated for an STI in the past year, and 10% have been treated for hepatitis C. Seven percent of women are current injecting drug users and 27% are current street drug users.
  
- ⌘ Most frequently identified reasons for being out-of-care included:
  - ◆ I do not believe I need medical care currently because I am not sick (47%);
  - ◆ I do not believe medical care would do me any good (28%);
  - ◆ Financial reasons (25%); and
  - ◆ It was too hard to get there (transportation) (24%).
  
- ⌘ When asked, “Do any of the following keep you from getting needed HIV medical care?”, the most frequent responses included:
  - ◆ No way to get there (37%);
  - ◆ I don’t feel welcome (21%); and
  - ◆ Disclosure to partner (19%).

Out-of-care women also identified transportation as a barrier to HIV medical care through their responses to the question: “In the past 12 months, how many medical appointments have you missed because of transportation problems?” More than 20% of respondents report missing one to five appointments, and 28% report missing five or more appointments.

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⌘ Barriers to care caused by consumers' housing situations were identified. When asked, "Thinking about your housing situation now, do any of the following stop you from taking care of your HIV?", out-of-care women respondents most frequently identified:

- ◆ I'm afraid of others knowing I'm HIV positive (47%); and
- ◆ I don't have money for rent (21%).

Out-of-care women's ten most frequently identified unfulfilled service needs include:

Primary Medical Care	42	61.8%
Rental Assistance	42	61.8%
Health Insurance	41	60.3%
Vision Care	39	57.4%
Bus Passes	39	57.4%
Utility Assistance	39	57.4%
Taxi Voucher	38	55.9%
Household Items	37	54.4%
Van Transportation	37	54.4%
Food Bank	36	52.9%

The ten most needed services mirror these, except the need for OB/GYN and oral health are identified and the need for household items and van transportation are not included.

**OUT-OF-CARE: YOUTH**

Youth, respondents age 13 to 24 years, are only 10% of the total survey sample, but nearly 60% are out-of-care. This is a relatively small sample of 39 out-of-care youth.

These youth are predominantly male (67%), and 10% are transgendered. Whites comprise a larger percentage than other out-of-care populations, 31%. African-Americans are 41%, and Hispanic/Latinos are 23%.

- ⌘ Most frequently identified reasons for being out-of-care included:
  - ◆ I do not believe I need medical care currently because I am not sick (49%);
  - ◆ I do not believe medical care would do me any good (36%); and
  - ◆ I was actively using (street drugs or alcohol) (23%).

Out-of-care youth’s ten most frequently identified unfulfilled service needs include:

Food Bank	31	79.5%
Health Insurance	30	76.9%
Primary Medical Care	29	74.4%
Medical Case Management	29	74.4%
Utility Assistance	28	71.8%
Household Items	28	71.8%
Rental Assistance	26	66.7%
Nutritional Supplements	26	66.7%
Housing Related Services	26	66.7%
Oral Health	25	64.1%

The ten most needed services mirror these, except the need for bus passes is identified and the need for oral health care is not included.

