HIV and Housing Instability in Central Florida

INTERIM REPORT

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NOTE: DRAFT REPORT. NOT FOR DISTRIBUTION. COMMENTS WELCOME TO DR. AMY DONLEY AT AMY@DW-CONSULTING.COM.
Introduction

According to the Centers for Disease Control (CDC), 1.1 million people in the United States are living with HIV. Of those, the CDC estimates that 1 in 7 are unaware of their condition. In the State of Florida, over 100,000 people are living with diagnosed HIV. Florida also leads the country in the number of new HIV infections. The current study is focused on five Florida counties - Orange, Osceola, Seminole, Lake, and Brevard – which together comprise the Ryan White Central Florida region. In those five counties a total of 14,815 individuals are living with diagnosed HIV according to 2015 Florida Department of Health data (11,454 in Orange, 771 in Osceola, 893 in Seminole, 519 in Lake, and 1,178 in Brevard).

While advancements in medical research have made HIV much more treatable than it once was, HIV is still a major public health concern. People living with HIV must be proactive about their medical care and their medication regimen to assure that they can live a full life and not succumb to the disease. One thing that can make doing this more challenging is dealing with homelessness or housing instability.

Homelessness is defined as “lacking a fixed, regular or adequate nighttime residence.” While federal definitions vary, for the purpose of this this study this includes residing in a motel and doubling up with friends or family because no other options are available. Precariously housed refers to individuals “who (1) have not leased, owned, or occupied permanent housing within the past 2 months; (2) have experienced persistent housing instability (i.e., two moves or more during the preceding 2 months); and (3) are not expected to change their housing status at any point in the near future. People fleeing domestic violence are also considered unstably housed if they do not have the resources and support to obtain other permanent housing.
In the State of Florida in 2016, 529 people identified as homeless and living with HIV in the annual Point in Time Count. This number reflects only those who have been diagnosed, who admitted their diagnosis, and who were counted during the Point in Time survey efforts. Estimating the number of precariously housed individuals living with HIV is much more difficult as no count of the population exists.

The five counties included in this study cross homeless agency boundaries so estimates for the number of homeless people living with HIV who were counted in the 2016 Point in Time counts have been used from the three distinct jurisdictions. The number identified in Orange, Osceola, and Seminole counties (which comprise one Continuum of Care (CoC) area) was 69. One homeless person living with HIV was counted in the CoC which includes Lake County (in addition to Citrus, Hernando, and Sumter Counties) and zero were counted in the Brevard CoC count. Therefore the total number of homeless individuals living with HIV in the five county area according to Point in Time Count data is 70. This is certainly an undercount. The National Alliance to End Homelessness estimates that as many as 3.4% of homeless people are living with HIV. This number from the Point in Time counts also does not include those who are precariously housed which is difficult to estimate (estimates of the total population who must “couch surf” in a given year is 1.65%).

Given the information available, the total number of people living with HIV in the region and experiencing homelessness or housing instability is not known. A reasonable guess would be at least 748.¹ The purpose of the current study is not to attempt to conduct an actual census of

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¹ Total number living with HIV in the five county region (14,815) times 5.05 percent (the percentage of homeless people estimated to be living with HIV + 1.65% (the number of individuals that are estimated to “couch surf” every year).
everyone who is impacted by housing instability and homelessness, but rather to survey as many people as possible to better understand how housing instability impacts people living with HIV in the region and their ability to manage the condition.

Methods
On behalf of the Ryan White Planning Council, Dr. Amy Donley of DW Consulting has been conducting in-depth surveys with individuals who are HIV+ and are homeless or precariously housed. (See Appendix for survey questionnaire). The survey takes approximately 15-30 minutes to complete, although some interviews have taken over an hour. The survey is administered face to face or on the telephone. To date, 37 have been conducted in person while the remaining 28 have been done over the phone. Respondents are given a $10 Walmart gift card as a thank you for participating. Data collection began in February 2017 and will continue through the end of 2017. All surveys conducted to date have been entered into SPSS to allow for statistical analysis of quantitative measures. All qualitative data were coded for themes.

Recruitment
To recruit participants for this study, several methods have been used. To begin the recruitment efforts, we constructed a database of potentially relevant agencies (HIV services, healthcare, housing, emergency shelter, etc.). The Ryan White Planning Council contacted these agencies and asked them to share a flyer with their staff and clients which provided information about the study. Members of the Planning Council also distributed the flyers through the agencies they represent as well as other contacts. DW Consulting

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2 We would like to extend a sincere thank you to Miracle of Love and Executive Director Angus Bradshaw for donating the gift cards for this study. Without their generosity, this research would not have been possible.
called and emailed agencies from the database to ask for their participation as well. In addition, Dr. Donley visited many agencies in person to meet with staff and case managers to explain the project and drop off flyers.

More specific recruitment efforts have also been made. For example, Aspire has made accommodations on several dates for interviews to be conducted on site at one of their locations in downtown Orlando. The Healthcare Center for the Homeless reviewed their case files for people who meet the study criteria. Their staff contacted these individuals and asked if they would like to participate and if they would agree to have their contact information released to DW Consulting. Contact information for those who said yes was provided to us and all were contacted. Case managers at Project Response in Brevard County told all of their clients about the study and contact release forms were provided for those who were interested in participating.

Although multiples methods of recruitment have been used throughout the duration of the project (and continue to be used), recruitment has still been a challenge. A major challenge is that HIV is still stigmatized and many people may be reluctant to speak about their experiences with someone that they have not established rapport with. Among those who are willing, many who qualify for the study rely on government phones and thus often do not have minutes available to make or take calls.

**Results**

The current sample consists of 65 individuals who are HIV+ and are homeless or precariously housed. As shown in Figure 1, the majority of the sample is homeless (80%) while the remaining 20% are precariously housed.
This research study covers a five county area: Orange, Osceola, Seminole, Lake, and Brevard. As shown in Figure 2, the majority of respondents currently reside in Orange County which is not surprising as Orange County has more resources available for people living with HIV and in need of stable housing, as compared to the other counties.
Some general demographics of the sample are provided in Table 1. The majority of the sample is male. The mean age is 49.3 years. Over half of the ample is Black/African American (56.9%), while approximately a third are White (32.2%). The sample is relatively well-educated with over three quarters having a least a High School diploma or GED, however nearly one quarter (23.1%) have less than a High School education.

Table 1. Demographics N=65

<table>
<thead>
<tr>
<th>Percentage*</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
</tr>
<tr>
<td>Mean</td>
</tr>
<tr>
<td>Median</td>
</tr>
<tr>
<td>Range</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
</tr>
<tr>
<td>Male</td>
</tr>
<tr>
<td>Female</td>
</tr>
<tr>
<td><strong>Race</strong></td>
</tr>
<tr>
<td>White</td>
</tr>
<tr>
<td>Black/ African American</td>
</tr>
<tr>
<td>Hispanic/Latino</td>
</tr>
<tr>
<td>Asian</td>
</tr>
<tr>
<td>Bi/Multi Racial/Ethnic</td>
</tr>
<tr>
<td><strong>Education</strong></td>
</tr>
<tr>
<td>Less than High School</td>
</tr>
<tr>
<td>High School Diploma/GED</td>
</tr>
<tr>
<td>Some College</td>
</tr>
<tr>
<td>AA Degree</td>
</tr>
<tr>
<td>BA Degree or Higher</td>
</tr>
</tbody>
</table>

*Unless otherwise noted

**Housing and Homelessness**

Table 2 provides more information on the current housing situations of the participants. The majority are currently residing in a homeless shelter or transitional housing facility (67.7%).

Over thirteen percent (13.8%) are residing in their own place, however they have not been there for longer than 2 months, may have to move in the near future, or do not find it affordable and thus fit the definition of precariously housed.
Table 2. Current Housing Situation

<table>
<thead>
<tr>
<th>Place you rent/own (name is on lease or mortgage)</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Permanent supportive housing for formerly homeless people</td>
<td>1.5</td>
</tr>
<tr>
<td>Homeless shelter/transitional housing program</td>
<td>67.7</td>
</tr>
<tr>
<td>Place not meant for habitation (street, homeless camp, car, park, etc)</td>
<td>6.2</td>
</tr>
<tr>
<td>Hotel/motel</td>
<td>3.1</td>
</tr>
<tr>
<td>With someone (friend or family member) (not on the lease)</td>
<td>4.6</td>
</tr>
<tr>
<td>Other</td>
<td>3.1</td>
</tr>
</tbody>
</table>

Those who are currently homeless report being homeless this time on average for a little over 14 months (range is 1 week to 6 years). All respondents who are or have ever been homeless report on average that they have spent 2 and half years of their life homeless (range 2 months to 7 years).

People who are not currently in stable housing were asked if they have sought help from housing agencies. Slightly less than half had with the most common agencies being Aspire, HOPWA, Miracle of Love, and the Center for Multicultural Wellness and Prevention3.

Of those who said they have worked with an agency in trying to secure stable housing, over half are still working with a case manager and waiting. Three people report the agency they contacted cannot find a housing program to help them, 2 others have been denied for felony convictions. Three people report that housing has been found and they are simply waiting to move in.

For respondents who are currently in more stable housing, we asked if they would have to leave in the near future. Only one person said that they did not believe they would have to leave. Four people said yes and the remaining 6 were unsure. When asked if they had resources to move

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3 Other agencies were: Homeless Services Network, Orlando Housing Authority, Cocoa Beach Housing Authority, Project Response, Section 8 Office, Zebra Coalition, Centaur, and Agape.
somewhere else if they had to, all stated that they do not. Additionally, the majority (61.5%) of people currently in more stable housing situations do not consider their place to be affordable.

Table 3 shows how long respondents have been in their current housing situation. As the majority of respondents are in a homeless shelter or transitional program, it is not surprising that few have been in their current housing location for a long period of time. Over half have been at their current location for less than 6 months.

Table 3. Length of Time in Housing Situation

<table>
<thead>
<tr>
<th>Duration</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than one month</td>
<td>18.5</td>
</tr>
<tr>
<td>1-2 months</td>
<td>21.5</td>
</tr>
<tr>
<td>More than 2 months – less than 6 months</td>
<td>21.5</td>
</tr>
<tr>
<td>6 months – 1 year</td>
<td>20.0</td>
</tr>
<tr>
<td>More than a year</td>
<td>18.5</td>
</tr>
</tbody>
</table>

If respondents stated that they have been living in their current housing situation for less than 2 months, they were asked where they lived prior to where they are currently. As shown in Table 4, most commonly these participants were living in a place not meant for habitation (46.2%), most typically on the streets.

Table 4. Previous Housing Situation

<table>
<thead>
<tr>
<th>Housing Situation</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Place you rent/own (name is on lease or mortgage)</td>
<td>7.7</td>
</tr>
<tr>
<td>Permanent supportive housing for formerly homeless people</td>
<td>--</td>
</tr>
<tr>
<td>Homeless shelter/transitional housing program</td>
<td>7.7</td>
</tr>
<tr>
<td>Place not meant for habitation (street, homeless camp, car, park, etc)</td>
<td>46.2</td>
</tr>
<tr>
<td>Hotel/motel</td>
<td>11.5</td>
</tr>
<tr>
<td>With someone (friend or family member) (not on the lease)</td>
<td>19.2</td>
</tr>
<tr>
<td>Other</td>
<td>7.7</td>
</tr>
</tbody>
</table>
HIV

We asked respondents detailed questions about their HIV diagnosis. We began by asking when they were diagnosed. The earliest diagnosis among respondents was in 1983 while the most recent was in 2017. The median for date of diagnosis is 2000.

We also asked how the participants originally learned that they were HIV+. As shown in Table 5, the most common way respondents found out was by going to a testing facility specifically to be tested. In these instances respondents typically reported that they became aware that a previous sexual partner had become infected.

Table 5. How Participants were Diagnosed with HIV

<table>
<thead>
<tr>
<th>Method of Diagnosis</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Went to a testing facility specifically to be tested</td>
<td>38.5</td>
</tr>
<tr>
<td>Found out while receiving medical care for another issue</td>
<td>27.7</td>
</tr>
<tr>
<td>Tested at home</td>
<td>--</td>
</tr>
<tr>
<td>Other(^4)</td>
<td>33.8</td>
</tr>
</tbody>
</table>

We also asked respondents about their current and past lab numbers. Specifically we asked about viral load and CD4 cell count. Sixty percent (60%) stated that they are currently undetectable. Over a quarter of respondents (27.7%) do not know their current viral load.

Over half of the respondents (59.4%) do not know their highest viral load. Of those that do the range was 480 to several million. Nearly half of the respondents (47.7%) do not know their current CD4 cell count (of those that do the range is 37-1500).

Although many respondents do not know their current lab numbers, the majority (89.2%) are currently taking Anti-Retroviral Therapy.

\(^4\) For those who selected “other,” most were tested while incarcerated either at entry, during incarceration, or upon release (13). Five (5) were informed after donating blood plasma, one (1) was tested at a nightclub, one (1) went to a mobile unit, one (1) received a letter from the health department while incarcerated, and one (1) does not remember.
The 10.8% who are not currently taking ART have stopped fairly recently (all in 2017 except for one in 2016). The most common reason people have stopped taking it is a change in location (becoming homeless on the streets) or a change in healthcare providers. All said they plan on taking it again soon.

The majority also have regular HIV related medical visits. Over 9 in 10 (92.3%) report having had at least two HIV related medical visits at least 3 months apart in the past year. Nearly all (95.4%) of these participants have had lab work done at these visits. Among those who have not had at least two visits, 83.3% have had at least one visit. Only one person has not sought any HIV related medical visits in the past year.

Participants were also read a list of statements about HIV management and asked if they

Strongly Disagree (1), Disagree (2), Agree (3), or Strongly Agree (4) with each statement (Table 6). Overall the participants agreed with all five statements. However over one in ten (12.3%) disagree with the statement, “I am successfully managing my HIV.” Nearly one in ten (9.2%) also disagree with the statement, “I am comfortable asking for help in the management of my HIV” which shows that some people still face stigma in trying to manage their HIV.

Table 6. HIV Management

<table>
<thead>
<tr>
<th>Statement</th>
<th>SD</th>
<th>D</th>
<th>A</th>
<th>SA</th>
<th>DK</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am successfully managing my HIV</td>
<td>1.5</td>
<td>10.8</td>
<td>41.5</td>
<td>46.2</td>
<td></td>
</tr>
<tr>
<td>Managing my HIV is one of my top priorities</td>
<td>--</td>
<td>3.1</td>
<td>43.1</td>
<td>53.8</td>
<td></td>
</tr>
<tr>
<td>I believe HIV can be well managed with proper medication</td>
<td>--</td>
<td>1.5</td>
<td>43.1</td>
<td>53.8</td>
<td>1.5</td>
</tr>
<tr>
<td>I believe there is a substantial risk to my health if I do not take action to manage my HIV</td>
<td>--</td>
<td>--</td>
<td>49.2</td>
<td>50.8</td>
<td></td>
</tr>
<tr>
<td>I am comfortable asking for help in the management of my HIV</td>
<td>1.5</td>
<td>7.7</td>
<td>41.5</td>
<td>49.2</td>
<td></td>
</tr>
</tbody>
</table>
Healthcare

Respondents were asked about where they receive the majority of their healthcare and they were also asked to assess the quality of the care they receive. As shown in Table 7, the modal response was the County Department of Health.

Table 7. Where Participants Receive Health Care

<table>
<thead>
<tr>
<th>Health Care Center for the Homeless</th>
<th>3.1</th>
</tr>
</thead>
<tbody>
<tr>
<td>County Health Department</td>
<td>41.5</td>
</tr>
<tr>
<td>Private Primary Care Doctor</td>
<td>16.9</td>
</tr>
<tr>
<td>Other Hospital/Urgent Care</td>
<td>3.1</td>
</tr>
<tr>
<td>Other5</td>
<td>33.8</td>
</tr>
<tr>
<td>Not Currently Receiving Health Care</td>
<td>1.5</td>
</tr>
</tbody>
</table>

Overall the respondents rate their healthcare they receive highly with over three quarters (79.7%) saying the care they receive is “excellent” or “good” (Figure 3).

![Figure 3. Assessment of Health Care Received](image)

The majority of respondents (58.5%) stated that they do not face any barriers in accessing healthcare. Among those that do face barriers, the most common were lack of transportation barriers.

5 The “other” responses were: OIC (10), AHF (5), Bliss (2), Comprehensive Healthcare (2), Project Response (2), and the VA (1).
(33.3%), lack of insurance (25.9%), and being unaffordable (18.5%). Other barriers that were mentioned included stigma, lack of time, difficulty in finding providers, issues with the time it takes to get medications through pharmacies, feeling tired, being treated poorly by staff, and not being able to return to a provider because of an unpaid missed appointment fee.

In terms of health insurance, over half (52.3%) do not have any insurance. Among those that do, one person has private insurance, another has insurance through the VA, and the remaining participants have Medicare, Medicaid, or both.

**Housing Stability and HIV**

Although the majority of respondents are obtaining medical care, well over half (69.2%) of respondents believe that their housing situation has impacted their ability to manage their HIV. Those that stated that their housing situation is not having a negative impact on their ability to manage their HIV were then asked, “Do you think if your housing was more stable your ability to manage your HIV would increase?” Seventy percent (70%) of the respondents stated that yes, more stable housing would increase their ability to manage their HIV.

Respondents were asked to provide some detail on how their lack of stable housing is impacting their ability to manage their HIV. The most common reasons given were difficulty in keeping medications and taking them properly, lack of regular sleep, lack of a clean environment, and the stress of not having a stable place to stay. Here is a sample of some of their responses:

“It’s really hard being homeless. It’s hard to make appointments. I let Ryan White lapse when I was having to go back and forth trying to find a place to stay. It’s been very stressful.”

“Being homeless takes away your will to move forward. A person on the street doesn’t even have a toilet. I thought about throwing a brick through a car to go back to jail. You never know what you’re going to do next. It impacts the mindset of a person.”

“When I was on the streets I was losing medicine and not keeping consistent doctor’s appointment. It impacted my weight. I lost a lot.”
“With instability you can’t take the meds like you are supposed to. Finding somewhere to stay is more important.”

“People would steal the meds or I’d lose them and I was always sick when in shelters.”

“I was working day labor and had 2 doctor’s appointments in one month. I had to take days off and I lost the job. I couldn’t tell a construction boss I have HIV.”

“Not having stable housing makes it more stressful and stress kills T cells.”

“A lack of stable housing and moving has caused breaks in my meds because of having to get new healthcare when I move.”

“I’m stressed, I get depressed, and I miss appointments.”

**Other Medical Issues**

Respondents were asked about their health beyond their HIV diagnosis. As shown in Figure 4, the majority rate their health as excellent or good (67.2%).

![Figure 4. Current health self assessment](image)

Although the self health assessment ratings were generally quite high, over half (53.6%) of the respondents reported going to the emergency room at least once in the past twelve months (Mean = 1.53, range 0-6 times) and a majority have abused drugs or alcohol in their lives (64.6%). Of those 72.3% have been treated for drug or alcohol abuse (not at least once in the past year). A
majority (53.8%) have been treated for mental health issues in their lifetime and 21.5% have been taken to the hospital against their will.

We also presented respondents with a list of medical conditions and asked if they have been diagnosed with them. As shown in Figure 5, approximately one-quarter have been diagnosed with high cholesterol (24.6%) and/or high blood pressure (26.2%). However, by far the most common diagnoses were depression (69.2%) and anxiety (55.4%).

![Diagnosed Medical Conditions](image)

Figure 5. Diagnosed Medical Conditions

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6 “Other” medical conditions included psychiatric conditions such as schizophrenia, bipolar disorder and paranoia, Hepatitis C, renal disease, syphilis, and herpes.
The survey questionnaire contained a modified depression identification scale. This scale was administered to all respondents regardless of whether they stated they have been diagnosed with depression. The scale asks for respondents to state how often they have experienced different emotions or behaviors in the past two weeks.

As shown in Table 8, over half of the respondents report feeling down, having trouble falling or staying asleep or sleeping too much, and feeling tired at least several days in the past two weeks.

Table 8. Depression Scale

<table>
<thead>
<tr>
<th>Condition</th>
<th>Not at All</th>
<th>Several Days</th>
<th>More Than Half the Days</th>
<th>Nearly Every Day</th>
</tr>
</thead>
<tbody>
<tr>
<td>Little interest or pleasure in doing things</td>
<td>55.4</td>
<td>23.1</td>
<td>7.7</td>
<td>13.8</td>
</tr>
<tr>
<td>Feeling down</td>
<td>36.9</td>
<td>35.4</td>
<td>7.7</td>
<td>20.0</td>
</tr>
<tr>
<td>Trouble falling/staying asleep or sleeping too much</td>
<td>44.6</td>
<td>10.8</td>
<td>7.7</td>
<td>36.9</td>
</tr>
<tr>
<td>Feeling tired</td>
<td>43.1</td>
<td>16.9</td>
<td>9.2</td>
<td>30.8</td>
</tr>
<tr>
<td>Poor appetite or overeating</td>
<td>66.2</td>
<td>6.2</td>
<td>6.2</td>
<td>21.5</td>
</tr>
<tr>
<td>Feeling bad about yourself</td>
<td>61.5</td>
<td>13.8</td>
<td>9.2</td>
<td>15.4</td>
</tr>
<tr>
<td>Trouble concentrating</td>
<td>60.0</td>
<td>9.2</td>
<td>7.7</td>
<td>23.1</td>
</tr>
<tr>
<td>Moving slowly or being excessively fidgety</td>
<td>70.3</td>
<td>4.7</td>
<td>9.4</td>
<td>15.6</td>
</tr>
</tbody>
</table>

In sum, while the self-health assessments were generally high, overall respondents are dealing with a myriad of other physical and mental health conditions that their housing situation often exacerbates.

Another section of the questionnaire asked about other social service needs. Respondents were read a list of social services and asked if they currently need assistance. As shown in Figure 6, over half of the respondents (52.6%) stated they need help with budgeting or credit repair (credit repair being the most salient issue for most). Transportation was the second most cited need with 40% of respondents stating they need help with transportation. Many did report that they did not need help with this as they had already received help via bus passes from some local agencies.
Over half (52.8%) report that they have sought help for at least one of the needs they reported. Of those 59.3% stated that they are in the process of receiving help, 53.8% state they have been assigned a case manager at the agency, and 42.3% said they have been told about housing opportunities that may be available for them. For those that have not sought help, the most common reason givens were not having the time, focusing on other more pressing needs like healthcare and housing and not knowing what services are available.

**Income**

A major cause of homelessness and housing instability for the participants, and for people in general, is the lack of adorable housing. As shown in Table 9, nearly half of the participants are disabled (46.2%) and only a little over 1 in 10 (10.8%) work at least part time, making affordable housing difficult to come by.
Table 9. Employment Status

<table>
<thead>
<tr>
<th>Status</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Working Full Time</td>
<td>6.2</td>
</tr>
<tr>
<td>Working Part Time</td>
<td>4.6</td>
</tr>
<tr>
<td>Not Working and Not looking for Work</td>
<td>13.8</td>
</tr>
<tr>
<td>Not Working but Currently Looking for Work</td>
<td>24.6</td>
</tr>
<tr>
<td>Not Working due to Disability</td>
<td>46.2</td>
</tr>
<tr>
<td>Retired</td>
<td>4.6</td>
</tr>
</tbody>
</table>

Close to half receive disability (43.1%), but generally state that it is not enough to afford housing outside of permanent supportive housing programs or programs that only take a set percentage of your income. For the entire sample, the monthly take home pay is low. The most common monthly take home pay is actually zero dollars with 42.9% of the sample stating that they do not make any money currently. Among those with some take home pay, the range is $400-$1600 per month with the modal response being $735, the typical disability benefit. It is not surprising that well over three quarters of the sample (83.9%) do not consider themselves to be financial stable. While 12 people state that they have never been financially stable, most recall a time when they were.

Conclusion

Through these interviews with 65 individuals living with HIV and experiencing homelessness or housing instability, it is clear that the lack of housing stability is leading to difficulties that are negatively impacting their health. While the vast majority are having regular checkups with lab work and taking ART, a majority are struggling with depression and anxiety as well as stress and a host of other medical conditions. Most report taking breaks with their ART as a result of their housing instability as housing instability makes it difficult to store or take medication properly. It also leads to depressive symptoms which make finding the motivation to make health a priority difficult.
Appendix: Survey Questionnaire

County __________________ #_____

Thank you for taking the time to speak with me. I am a researcher working with DW Consulting and we are conducting interviews with HIV+ individuals in five Central Florida counties to determine peoples’ health outcomes and housing stability levels. While I know your name, I will not be entering it in this interview questionnaire so all of your responses will be anonymous. Some of the questions are quite personal so we want to make that clear in the beginning. We will be analyzing all of the data together to produce a report for the Ryan White Planning Council so they can effectively serve HIV+ individuals. It takes about 10-15 minutes and you will receive a $10 gift card for participating.

May I continue?

- Yes
- No

If yes, great, thank you, now to determine if you are eligible to participate in this study I need to clarify a few things.

First have you received an HIV+ diagnosis?

- Yes
- No (If no terminate interview- explain that they study is only for HIV+ individuals).

OK and second, I need to know about your housing history.

**Housing History**

What is your primary current housing situation? Are you living in a …

- Place you rent/own (name is on lease or mortgage)
- Permanent supportive housing for formerly homeless people
- Homeless shelter/transitional housing program
- Place not meant for habitation (street, homeless camp, car, park, etc)
- Hotel/motel
- With someone (friend or family member) (not on the lease)
- Other: ____________________________

How long have you been living there?

- Less than a month
- 1-2 months
- More than 2 months- less than 6 months
- 6 months – a year
- More than a year
If less than a month or 1-2 months… Where were you staying before that?

- Place you rent/own (name is on lease or mortgage)
- Permanent supportive housing for formerly homeless people
- Homeless shelter/transitional housing program
- Place not meant for habitation (homeless camp, street, car, park, etc)
- Hotel/motel
- With someone (friend or family member) (not on the lease)
- Other: ____________________________

And how long were you staying there?

- Less than a month
- 1-2 months
- More than 2 months- less than 6 months
- 6 months – a year
- More than a year

If Place you rent/own (name is on lease or mortgage) or staying with someone (friend or family member) (not on the lease).

Do you believe you will have to leave this place in the next two months?

- Yes
- No
- Unsure

If yes or unsure, do you have the resources to find another place to live when/if you have to leave this place?

- Yes
- No
- Unsure

If yes, where are you planning on moving to? __________________

If no or unsure, where do you think you will go? _______________________

If Place you rent/own (name is on lease or mortgage) or staying with someone (friend or family member) (not on the lease).

Do you consider this place to be affordable?

- Yes
- No
- Unsure
What is your monthly rent/mortgage payment? _______________

If the individual has no history of housing instability or homelessness and no known future housing instability, discontinue interview.

If literally homeless (3,4,5),

How long have you been homeless THIS TIME? _____ (in months)
And how long have you been homeless in your life? _______ (in months)

If precariously housed or literally homeless,

Have you sought assistance in obtaining stable housing?

• Yes
• No
• Unsure

If yes, what agencies have you gone to? (check all that apply)

• Homeless Services Network
• HOPWA
• Other(s) ______________

If yes, what was the outcome of going to that agency? (Ask per agency based on what they select)

Agency_________ Outcome: ________________________________________________
Agency_________ Outcome: ________________________________________________
Agency_________ Outcome: ________________________________________________

If no, why haven’t you? ___________________________________________________

For everyone:

Is there anything you would like to add about your housing situation?
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

HIV

Now I want to talk about your HIV diagnosis. And again I would like to remind you that your name is not attached to this survey.
First, when were you diagnosed with HIV? ___/____ Month/year

How did you find out that you have HIV?

• Went to a testing facility specifically to be tested
• Found out while receiving medical care for another issue
• Tested at home
• Other ______________________________________

Are you currently receiving antiretroviral therapy (ART)?

- Yes
- No
- Other ________________________________

If no, Have you ever started antiretroviral therapy (ART)?

- Yes, when? _______________________________________________________________
- No
- Other ________________________________

If yes, How long have you been consistently taking ART? _____ (in months)

What is your last known viral load? __________________ Date: ________________ DK

What was the highest your viral load has been? ________________ Date: ________________ DK

What was the lowest your viral load has been? ________________ Date: ________________ DK

What was your last known CD4 T lymphocyte (CD4 cell) count and/or percentage?

________________ Date: __________________ DK

What was the lowest your CD4 cell count/percentage has ever been?

________________ Date: __________________ DK

What was the highest your CD4 cell count/percentage has ever been?

________________ Date: __________________ DK

Do you think that your housing situation is impacting your ability to manage your HIV?

• Yes
• Maybe
• No
• Cant Say, DK

If yes or maybe, can you tell me how it is impacting your ability to manage your HIV?

______________________________________________________________________________

______________________________________________________________________________

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If no or can’t say, DK, do you think if your housing was more stable your ability to manage your HIV would increase?

- Yes
- Maybe
- No
- Cant Say, DK

Medical Care

In the past 12 months, have you been to two or more HIV related medical visits, at least three months apart?

- Yes
- No
- Unsure

If no, have you had one HIV related medical visit?

- Yes
- No
- Unsure

If yes to either of the above…did you have lab work done at the visit(s)?

- Yes
- No
- Unsure

In the past 12 months, how many times have you been to the emergency room? ____ (enter number)

Where do you primarily go to receive health care?

- HCCCH (1)
- County Health Department (2)
- Private primary care doctor (3)
- Other hospital or urgent care center (specify name) (4) ____________________
- Other (5)________________
- Not currently receiving health care (6)

Overall, how would you rate the health care services you receive?

- Excellent
- Good
- Fair
- Poor
- Very Poor
Do you feel there are any barriers to receiving medical care for your HIV?

- Yes
- No

If yes, What are the barriers you face to receiving medical care for your HIV? (Check all that apply)

- Affordability/Cost
- Lack of Insurance
- Transportation
- Time restraints
- Stigma
- Other: ________________________________________

Now I’m going to read you a list of statements, please tell me if you strongly disagree, disagree, agree, or strongly agree with each statement.

<table>
<thead>
<tr>
<th>Statement</th>
<th>SD</th>
<th>D</th>
<th>A</th>
<th>SA</th>
<th>DK, Cant say, etc (volunteered)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am successfully managing my HIV</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Managing my HIV is one of my top priorities</td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I believe HIV can be well managed with proper medication</td>
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<td></td>
</tr>
<tr>
<td>I believe there is a substantial risk if I do not take action for the management of my HIV</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>I am comfortable asking for help with the management of my HIV</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Overall how would you rate your current health?

- Excellent
- Good
- Fair
- Poor
- Very Poor

Social Services

Now I want to ask you about any problems you may be currently experiencing and if you have had any contact with agencies to address these problems.

I'm going to read you a list of services please tell me if you currently need assistance with any. (Check all that apply)

- Budgeting/financial literacy/credit repair
- Obtaining food
- Help obtaining EBT/Food stamps
- Domestic violence services
- GED/Adult Education
- Individual or family counseling
- Job training/Job readiness training
- Legal services
- Transportation
- Other (Specify need) _________________

Have you sought assistance for any of these areas that you mentioned?
- Yes
- No

**If yes**, what agencies have you gone to in the past year? (Enter in each agency)

Per agency- are you actively getting help there? Do you have a case manager or another staff person assigned to help you? Have you told someone from this agency about your housing situation?

Service: _______________________ Agency: ______________________________
Help: Yes No Case Mgr/ Other Staff Assigned: Yes No Told about Housing? Yes No
Service: _______________________ Agency: ______________________________
Service: _______________________ Agency: ______________________________
Help: Yes No Case Mgr/ Other Staff Assigned: Yes No Told about Housing? Yes No
Service: _______________________ Agency: ______________________________
Help: Yes No Case Mgr/ Other Staff Assigned: Yes No Told about Housing? Yes No
Service: _______________________ Agency: ______________________________
Help: Yes No Case Mgr/ Other Staff Assigned: Yes No Told about Housing? Yes No
Service: _______________________ Agency: ______________________________
Help: Yes No Case Mgr/ Other Staff Assigned: Yes No Told about Housing? Yes No

If **yes** to Have you told someone from this agency/ any of these agencies about your housing situation?, Did they offer assistance in acquiring housing?
- Yes
- No

If yes, Which agencies? ___________________________________________________
If yes, what was/were the outcome(s)? ____________________________________________

If no to Have you sought assistance for any of these areas that you mentioned?, why haven’t you sought assistance? (Do not read – code responses as appropriate)

- I do not know about the services that are available
- The services are offered at inconvenient times
- The services that I need are not available
- It takes too long to get services; there is a waitlist
- The services are too expensive
- I’m not eligible
- There are problems with staff at the agencies (e.g., poor customer service)
- I don’t have transportation to the services I need
- Not Sure

Ok we are getting towards the end!

Other Medical

Now I want to ask about other health conditions you may have. I’m going to read a list of conditions and please tell me if you have been diagnosed with any of them.

- High Cholesterol
- Diabetes
- High blood pressure
- Emphysema/COPD
- Heart Disease
- Ulcers
- Cancer
- Liver disease
- Strokes
- Neuropathy
- Asthma
- Depression
- Anxiety
- PTSD
- Other ____________________________

Per condition 1:

Are you receiving treatment for this.  Yes  No

Are you prescribed medication (if appropriate)  Yes  No

Do you take the prescribed medication as directed?  Yes  No
Do you believe _____ is currently being managed?  Yes   No
Per condition2: Condition: ________________
Are you receiving treatment for this.   Yes   No
Are you prescribed medication (if appropriate)  Yes   No
Do you take the prescribed medication as directed?  Yes   No
Do you believe _____ is currently being managed?  Yes   No
Per condition3: Condition: ________________
Are you receiving treatment for this.   Yes   No
Are you prescribed medication (if appropriate)  Yes   No
Do you take the prescribed medication as directed?  Yes   No
Do you believe _____ is currently being managed?  Yes   No
Per condition4: Condition: ________________
Are you receiving treatment for this.   Yes   No
Are you prescribed medication (if appropriate)  Yes   No
Do you take the prescribed medication as directed?  Yes   No
Do you believe _____ is currently being managed?  Yes   No
Per condition5: Condition: ________________
Are you receiving treatment for this.   Yes   No
Are you prescribed medication (if appropriate)  Yes   No
Do you take the prescribed medication as directed?  Yes   No
Do you believe _____ is currently being managed?  Yes   No

Over the last 2 weeks, how often have you been bothered by any of the following problems?

<table>
<thead>
<tr>
<th>Statement</th>
<th>Nearly every day</th>
<th>More than half the days</th>
<th>Several days</th>
<th>Not at all</th>
</tr>
</thead>
<tbody>
<tr>
<td>Little interest or pleasure in doing things</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Feeling down, depressed, or hopeless</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Trouble falling or staying asleep, or sleeping too much</td>
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<tr>
<td>Feeling tired or having little energy</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poor appetite or overeating</td>
<td></td>
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</tr>
</tbody>
</table>
Feeling bad about yourself—or that you are a failure or have let yourself or your family down

Trouble concentrating on things, such as reading the newspaper or watching television

Moving or speaking so slowly that other people could have noticed. Or the opposite—being so fidgety or restless that you have been moving around a lot more than usual

Have you ever abused drugs or alcohol, or been told you do by a professional?  
Yes  No

Have you ever been treated for drug or alcohol abuse?  
Yes  No

If YES, HOW MANY TIMES IN THE PAST YEAR?  
___

Are you currently or have you ever received treatment for mental health issues?  
Yes  No

Have you ever been taken to the hospital against your will for mental health reasons?  
Yes  No

Now just a few demographic questions and we will be done.

What is your gender?

• Male
• Female
• Transgender Male-to-Female
• Transgender Female-to-Male
• Other __________________________________________

What is your racial or ethnic identity?

• White
• Black or African American
• Hispanic/Latino
• American Indian or Alaska Native
• Native Hawaiian or Other Pacific Islander
• Asian
• Bi- or multi-racial
• Other [DO NOT ASK, ONLY USE IF VOLUNTEERED.] (SPECIFY)

______________________
How old are you? ___

What is the highest level of education that you have received?

- Less than high school (1)
- High school degree or GED (2)
- Some college (3)
- Associate's degree (4)
- Bachelor's degree or higher (5)

If less than high school, what is the highest grade you completed? ____

Do you currently have medical insurance?

- Yes
- No

If yes, what insurance plan(s) do you have? ______________________

Are you currently working?

- Yes, full time (more than 30 hours per week)
- Yes, part time
- No, and not currently looking for work
- No, and currently looking for work
- No, and not currently able to work due to disability
- No, I'm retired

If yes full or part time, how long have you been working at your current job? ___ (in months)

If no, not currently looking for work or no, currently looking for work, when is that last time you held a position where you worked at least 20 hours per week? __/__ (month/year)

Do you currently receive disability?

- Yes
- No

If yes, when did you begin receiving disability? _____/____ Month/year

If no, is it pending?  Yes  No

After taxes and other deductions, what is your current monthly take home pay? ____________
(Legal employment/disability/other federal cash payment-retirement income/etc.)
Do you consider yourself to be financially stable?

- Yes
- No
- Unsure

If no, When is the last time you would say you were financially stable? <(Enter year) _______
(or record “never” if response given.>

Is the anything else you would like to tell me that I haven’t asked about?  Yes  No  (Record on back if yes)

Ok last thing- I need to get your name and address to mail you your gift card. I write this information in a notebook that is not attached to the results of this survey to maintain confidentiality.