

Improving Retention and Engagement in HIV Care

INSIGHTS AND LESSONS LEARNED FROM THE OHIO
DEPARTMENT OF HEALTH THREE-YEAR OUT-OF-CARE NEEDS
ASSESSMENT

Sheri Chaney Jones, M.A.
Erin Gerbec, Ph.D.
Elizabeth Pafford, M.P.A.
Jay Seetharaman, B.S., B.A.
Measurement Resources Company

Table of Contents

I. Overview	5
Uncovering PLWHA Needs and Ohio’s System Readiness to Address these Needs.....	6
Year One.....	6
Year Two	6
Year Three	6
Synthesizing the Learnings.....	7
II. Current State of PLWHA in Ohio	9
Engagement in Care	9
Factors Negatively Impacting Engagement in Care	9
Comorbidities and Engagement in Care	10
III. Access, Effectiveness, and Quality of HIV Care	12
Impact on HIV Testing.....	13
Impact on Linkage to Care	14
Impact on Engagement or Retention in Care	15
Impact on Prescribed Antiretroviral Therapy	16
Impact on Achieved Viral Suppression	17
IV. Alignment to Current Best Practices in HIV Patient Care in Ohio.....	19
Cultural Competency and Patient-Centered Care	19
Integrated Care Providers Across the HIV Care Continuum	21
Mental Health Response.....	22
Patient-Led Interaction	23
V. Desired System Response.....	25
Provider Relationships	25
Change Readiness	26
Services, Barriers, and Unmet Needs that Impact Engagement in Care	27
Prioritizing Service Needs	29
VI. Recommendations: Concrete Next Steps.....	31
Strengths.....	31
Barriers.....	31
Lessons Learned.....	32
Recommendations to Increase PLWHA’s Engagement in Care	33
References	36

EXECUTIVE SUMMARY

In HIV medical care, viral suppression is key for improving public health outcomes and for the quality of life for people living with HIV/AIDS (PLWHA). Before viral suppression can be achieved, PLWHA must engage and remain in high-quality HIV care. Over the past three years, The Ohio Department of Health (ODH), Bureau of Health Services, HIV Care Services section, has engaged in a needs assessment to uncover the experience of PLWHA and to identify solutions to increase the rates of PLWHA engaging and remaining in care. Year one sought to identify a clear understanding of the attributes that have predictive value for people not being in care or not remaining in care. Year two continued to examine the predictive factors that prevent PLWHA from entering and remaining in HIV care, as well as examining the relationship between comorbidities and engagement in HIV care. The third year of the study explored Ohio's HIV system of care strengths and the system's readiness to address the inabilities and failures of Ohio's PLWHA to access and stay in HIV care.

Results provide valuable insights into the perceived strengths of the HIV care system which help increase the number of PLWHA engaging and remaining in care. In addition, results identify potential barriers that will need to be addressed for Ohio to improve engagement in care and ultimately achieve greater viral suppression rates.

Current Strengths of Ohio's HIV Care System

- 1. Ohio PLWHA have access to quality HIV-related care.** Nearly all surveyed providers across the state of Ohio agreed that HIV-related services and resources such as medical care, prevention services, testing services, case management, Linkage to Care Specialists, and pharmacies that carry Antiretroviral Therapy (ART) medications and other HIV-related medications are available in their communities.
- 2. The majority of clients who engage in care are achieving viral suppression.** Ohio's Ryan White HIV/AIDS data shows that approximately 8 out of every 10 PLWHA who are engaged in care are virally suppressed. Despite these good outcomes, 20 percent of PLWHA in care are not virally suppressed and this number does not include individuals who are not engaged in care and whose status is unknown.
- 3. With a few exceptions, Ohio providers report effective implementation of best practices in culturally competent care.** Most providers in the year three study reported effective implementation of best practices in culturally competent care. However, clients identified many opportunities for providers to improve the cultural competence of HIV care and support services in the year one and year two studies.

Current HIV Care Barriers to Improved Engagement and Retention in Care

- 1. Community outreach in HIV education is needed.** PLWHA in the year one survey and year two focus groups indicated that lack of HIV education was a significant factor in their decisions to engage in and retain care. Combating stigma, greater HIV education, and improved access to effective HIV testing are greatly needed to prevent new HIV infections and motivate PLWHA to be tested and engage in care.
- 2. Patient-led interaction is needed to engage clients in a culturally competent way.** Clients/patients want their HIV service providers to understand the hardship of living with HIV/AIDS and the physical and emotional fatigue that results. Clients want providers to adopt

patient-led interactions to support them in their present mental state until more barriers to engaging in care are removed for PLWHA.

- 3. Substance abuse and mental health issues are significant barriers to engaging in care.** Client data collected in year one and year two showed that more than 60 percent of PLWHA reported depression. Mental health needs were reported to interfere with PLWHA's motivation and ability to engage in HIV medical care. Substance abuse and mental health issues are a significant barrier to increasing engagement and retention in care of Ohio's PLWHA.

Concrete Next Steps to Improve Engagement and Retention in Care

The following recommendations and concrete next steps were derived from the three-year Out-of-Care Needs Assessment results. These select data-driven recommendations are believed to have the greatest impact on Ohio's HIV care system and clients' willingness to engage in and remain in HIV care.

- 1. Address mental health needs of PLWHA; it is a significant barrier to engagement in care.** All exceptional HIV service providers interviewed described a significant need for mental health assessment and treatment for their HIV clients. Greater understanding of the type and quality of mental health services available to PLWHA throughout Ohio is needed to meet the mental health needs of PLWHA.
- 2. Design marketing campaigns and efforts to change "the face of AIDS" and the stigma of HIV.** Clients specifically stated that stigma is a significant reason they have fallen out of care. HIV service providers in the year three survey rated their community's efforts to address and reduce stigma as effective only 25 percent of the time; combating stigma will likely be an essential and challenging endeavor in changing the HIV care system.
- 3. Invest in cultural competency training and medical CEUs related to compassionate HIV care.** Additional training in culturally competent HIV care is encouraged for Ohio's HIV service providers. Exceptional HIV service providers identified by clients in the year two focus groups were all extremely knowledgeable of how to deliver culturally competent care in their communities, which clients reported as a key reason they stayed engaged in care with that provider.
- 4. Target specific services to improve access and quality of non-HIV support services needed by PLWHA.** Increasing services that have been identified as high client need and low perceived quality ensures that efforts are going towards services that are reported to be needed by a majority of PLWHA. Improving the access and quality of these services is expected to positively influence the population of HIV-positive individuals throughout Ohio and support those who are engaging or retained in care.
- 5. Pursue the Implementation of Integrated HIV Prevention and Care Plan Goals.** The findings of this three-year study align to the Ohio Integrated HIV Prevention and Care Plan 2017-2021. The focus of the Ohio Integrated HIV Prevention and Care Plan is on how Ohio could impact HIV through a common framework that is readily understood by all. Results for the three-year Out-of-Care Needs Assessment support the goals of this initiative.

INSIGHTS AND RECOMMENDATIONS FOR ENGAGING OHIOANS LIVING WITH HIV/AIDS

I. Overview

The first cases of HIV captured the world's attention more than 30 years ago. Since then, nearly 650,000 Americans have lost their lives to AIDS.¹ While HIV transmission rates have been reduced substantially over time and people with HIV are living longer and more productive lives, an estimated 39,500 people in the United States become infected with HIV each year and there are currently more than 1.2 million Americans living with HIV.² In Ohio, there are approximately 22,000 people living with a diagnosis of HIV and/or AIDS and nearly 1,000 new diagnoses are made each year.³ According to the National HIV/AIDS Strategy for the United States, without continued efforts and bold new actions, "we face a new era of rising infections, greater challenges in serving people living with HIV, and higher health care costs."⁴

On July 15, 2010, President Obama released the first comprehensive *National HIV/AIDS Strategy*, which envisions that "the United States will become a place where new HIV infections are rare and when they do occur, every person, regardless of age, gender, race/ethnicity, sexual orientation, or socio-economic circumstance, will have unfettered access to high-quality, life-extending care, free from stigma and discrimination."

The goals of the Strategy are to reduce new HIV infections; increase access to care and improve health outcomes for people living with HIV; and reduce HIV-related disparities and health inequities. In order for this strategy to become a reality, people living with HIV/AIDS must know their status, have access to care, and be actively engaged in their care. Recent research has discovered that, in addition to improving the quality of life of PLWHA, proper medication and treatment can raise CD4 cell counts and reduce viral load counts as well as reduce the likelihood of transmission.^[5-7] These findings elevate the public health benefit to getting all PLWHA in proper care. In Ohio, it is estimated that approximately 40 percent of the PLWHA are currently not actively engaged in care.

To better understand the barriers and factors that are preventing Ohioans living with HIV/AIDS from seeking and consistently engaging in HIV-related care, the Ohio Department of Health (ODH), Bureau of Health Services, HIV Care Services section, contracted with Measurement Resources Company, LLC, to conduct a three-year HIV/AIDS Out-of-Care Needs Assessment study for the Ryan White Part B Program. The goal of the project was to gather data and information necessary to understand the needs of out-of-care people living with HIV/AIDS (PLWHA) and possible solutions and strategies that will help bring this population into care. This report contains the results of a three-year needs assessment and provides data-driven recommendations of how to reduce the number of out-of-care PLWHA and the impact of comorbidities of PLWHA.

Uncovering PLWHA Needs and Ohio’s System Readiness to Address these Needs

Year One

The Out-of-Care Needs Assessment study began in the Spring of 2015 with the goal to examine demographic and other attributes of PLWHA who are consistently in care, intermittently in care, or never in care. Data for the first year Out-of-Care Needs Assessment were collected using a 51-item survey of multiple choice, open-ended, and scaled questions. Inclusion criteria were an HIV or AIDS diagnosis, residency in Ohio, and being 18 years or older. A sample of 363 surveys were collected by partnering with HIV service providers and community organizers who interact with HIV-positive individuals, which resulted in a 5.1 percent margin of error at a 95 percent confidence level.

The goal of year one was to begin to identify a clear understanding of the attributes that have predictive value for PLWHA not being in care or not remaining in care. Survey questions were designed to answer the following research questions:

What factors...

- Prevent PLWHA from seeking care?
- Lead PLWHA to regularly engage in care?
- Put PLWHA at risk of dropping out of care?
- Contribute to PLWHA remaining in care?

Year Two

The second year of the study (July 2015-June 2016) continued to examine the predictive factors that prevent PLWHA from entering and remaining in HIV care. In addition, year two examined the relationship between comorbidities and engagement in HIV care.

PLWHA’s needs and predictive factors of engaging in HIV care were identified through 20 focus groups of 125 PLWHA across Ohio. Comorbidities data were analyzed from the Year One Needs Assessment survey.

Year Three

The last year of the study (July 2016-March 2017) explored the system readiness to respond to the needs of out-of-care PLWHA. An HIV Service Professionals Insight Survey^a was developed to identify the system response to the barriers at each linkage point in the HIV care continuum. The survey results specifically addressed the following four research questions:

- To what extent does the HIV care system in Ohio currently embody best practices in system delivery?
- What is the system’s readiness to reduce barriers to care for PLWHA at each step of the HIV Care Continuum?
- What is the system’s readiness to provide needed services to PLWHA?

^a The survey contained 19 multiple choice, open-ended, and scaled questions. Identical surveys were offered in online and paper-and-pencil formats.

- To what extent are HIV service providers’ attitudes and beliefs aligned with best practices in HIV care?

In this research, the HIV care system is defined as the organizations, nonprofits, and government agencies whose objective it is to provide care and services for Ohioans living with HIV/AIDS. A total of 174 professionals completed the survey, resulting in an estimated^b margin of error of 6.57 percent with 95 percent confidence level. One hundred seventy-three usable surveys were collected from January 2017 through February 2017 across the state of Ohio.

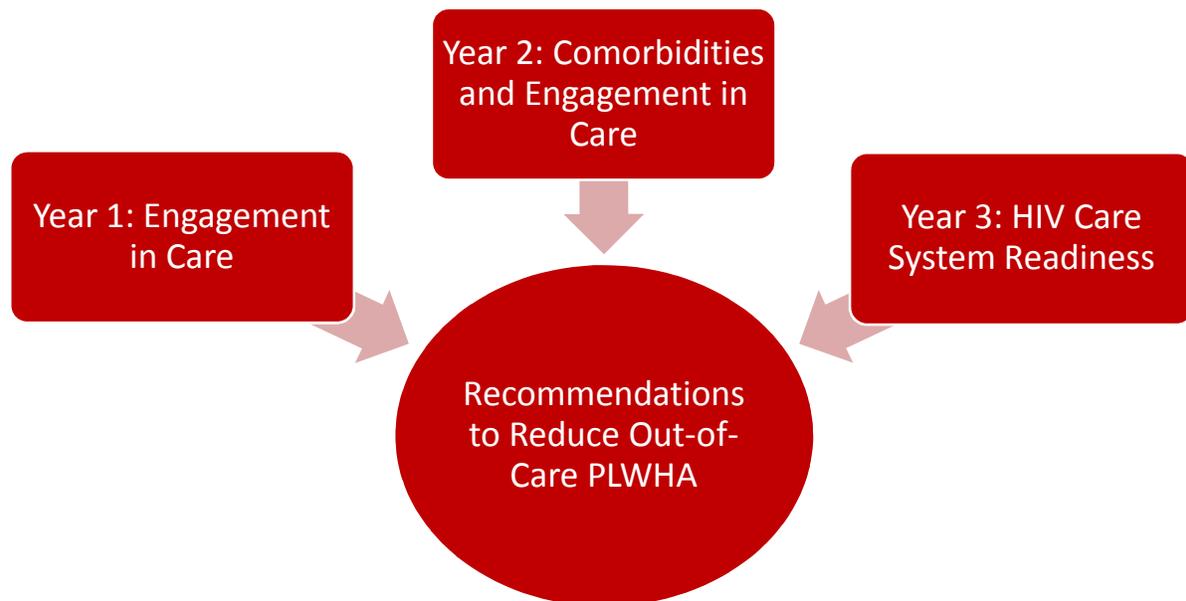
ODH Ryan White program data related to viral suppression and other outcomes was compared against the reported outcomes by the providers.

Synthesizing the Learnings

The results from each year’s needs assessment study are synthesized in this comprehensive report to answer the following questions pertaining to the current state of PLWHA in Ohio.

- What factors contribute to the inability or failures of Ohio’s PLWHA to access and stay in HIV care?
- What are the comorbidities of Ohio’s PLWHA and are there any correlations between comorbidities and the inability or failure of Ohio’s PLWHA to access and stay in HIV care?
- What is the system’s readiness to address the inability and failures of Ohio’s PLWHA to access and stay in HIV care?

Figure 1: ODH Ryan White Part B Out-Of-Care Needs Assessment



^b The survey distribution list of n=797 HIV service providers is known to have duplicates. Due to this imprecision, an official minimum sample size value cannot be calculated.

The report begins with a review of the learnings related to factors that predict engagement in care, then outlines best practices related to engaging individuals in care and Ohio's current effectiveness and quality of this practice. The report concludes with practical actions that Ohio's HIV care system can take to reduce the number of out-of-care PLWHA and the impact of comorbidities on PLWHA.

II. Current State of PLWHA in Ohio

Engagement in Care

Understanding the experiences of PLWHA as well as the complexity of living with a diagnosis of HIV/AIDS is the first step in developing a culturally competent system of HIV care. A goal of the research was to identify the factors which contribute to PLWHA seeking care, engaging in care, and remaining in care. Key themes related to engagement in care and experiences throughout the HIV care continuum emerged. When possible, comparisons were made between those who reported never having a gap in medical care and those who were intermittently out-of-care for six months or more to identify predictors of falling out of care.

Nearly all Ohio's PLWHA who participated in the Needs Assessment studies were participating in care at some level. A sizeable portion also had a previous history of being out-of-care for six months or more. Almost all (99%) of the survey participants reported they currently have an ongoing relationship with at least a primary care physician or an HIV specialist. In addition, most participants reported receiving CD4 and viral load tests and the results of each within the past 12 months. Despite this current engagement, factors influencing the decision to engage or remain in care were identified because of the segments of the population who delayed seeking HIV care and/or had previous gaps in HIV care. In total, 26 percent of survey participants were classified as having a history of being out-of-care for six months or more in the past.

Study results revealed that the majority of PLWHA stayed and engaged in care once they were tested and diagnosed with HIV/AIDS. PLWHA often go years without knowing they are living with HIV/AIDS, which may increase the rate of new infections and delay the time for individuals to engage in care. Almost half the study participants got tested because of getting sick. Another 10 percent got tested because an intimate partner was diagnosed with HIV. Nurses and intimate partners often played a key role in PLWHA's initial linkage to care. Denial was the most common reason for why PLWHA chose not to engage in care after a diagnosis.

Factors Negatively Impacting Engagement in Care

Results from the Year One and Year Two Needs Assessment studies uncovered several factors which influenced PLWHA decisions to engage in care. The factors listed below were the most salient to PLWHA who participated in the research.

Lack of health insurance and financial assistance. Lack of health insurance and financial assistance was a frequently mentioned reason for someone to have delayed care and/or dropped out of care. Getting health insurance was a frequently provided reason for reengaging in care.

Declining health. A commonly mentioned reason that someone delayed care was that they did not feel sick. Many survey participants reported engaging or reengaging in care once they felt ill.

Stigma. Stigma was the primary barrier identified by PLWHA in the focus groups as a reason why one had chosen to not engage in care or had dropped out of care. PLWHA discussed issues related to privacy and fear that others would find out their status as the specific fears related to stigma.

Practical/Structural barriers. Survey participants with a history of being out-of-care were more likely to report difficulty paying for HIV medical care and in receiving returned phone calls for appointments. The

survey participants self-reported this to be the reason for having a gap in care in the previous six months. Other barriers identified by PLWHA included access to transportation, workplace flexibility, addiction, and previous bad experiences with medical providers.

Unmet service needs. PLWHA in the focus groups reported a desire and need for increases in coordination along the continuum of care for HIV-related services. Greater coordination of care would allow for more timely and reliable access to HIV care and wrap-around services (such as housing, transportation, food, etc.) which would help eliminate barriers to staying in care.

The survey identified unmet needs of PLWHA in Ohio regardless of engagement in HIV care. The majority of PLWHA surveyed reported needing the specific services of dental care, mental health care, and food stamps. However, less than 75 percent of those who needed these services reported receiving them.

Lack of culturally competent HIV care. PLWHA in the focus groups discussed a desire for medical and line staff professionals to be more culturally sensitive to those living with HIV and AIDS. PLWHA also desired more peer support services earlier on in their diagnosis to help them navigate and engage in care.

Provider relationships. PLWHA who have never been out-of-care reported significantly more favorable attitudes towards their health care provider and had greater trust with their HIV medical provider than those with a history of being out-of-care. Small to moderate effect size differences ($d = -.25$ to $-.38$) in provider relationship items were found, which was a meaningful difference between the two comparison groups.

Geographic and demographic characteristics. Not all barriers to engaging and remaining in HIV care were experienced at the same rate for all PLWHA. Geographic and demographic characteristics determined if a challenge was experienced and if it was related to engaging in care. For example, African American PLWHA in the focus groups were more likely to have reported not engaging in care due to denial or fear of privacy issues. PLWHA under 30 years old discussed issues related to work flexibility and basic survival needs as reasons they have fallen out of care. Women discussed the need for more family-friendly services, like child care, to help them remain engaged in HIV care. In the survey, PLWHA with a history of being out-of-care were more likely to have spent time under criminal justice supervision and were also more likely to have been diagnosed with AIDS in their lifetime. The cause of the higher rate of criminal justice supervision and AIDS diagnoses cannot be determined by these survey results, so it is unknown whether these outcomes were a result of dropping out of HIV medical care for six months or more or if it was unrelated to the out-of-care period. However, there is a clear pattern of higher rates of these negative outcomes for PLWHA with a history of being out-of-care compared to those without a gap in HIV medical care.

Comorbidities and Engagement in Care

PLWHA reported having higher rates of at least one comorbid condition (86%) than the estimated national average (60%). In Ohio, 67 percent of PLWHA reported having two or more comorbidities. Depression was the most commonly reported comorbidity, which was experienced by more than 60 percent of PLWHA surveyed. High blood pressure was the second highest comorbidity. Mental health issues appear to interfere with PLWHA's motivation and ability to engage in HIV medical care; PLWHA

with a history of being out of care had significantly higher reported rates of mental health disorders compared to those who never had a history of being out of care.

The interaction between HIV, comorbidities related to aging and mental illness, and the effectiveness of medications for other medical diagnoses were the primary concerns for PLWHA. When considering the impact of HIV and other medical diagnoses on one's life, focus group participants reported having to consider the risks and medication side effects they are willing to live with to achieve their optimum health. Some reported making a trade-off between managing their HIV diagnosis and treating other chronic medical diagnoses, such as heart disease and high blood pressure. Many others said their depression and other mental health diagnoses had a significant impact on their decisions to engage in care, especially shortly after their HIV-positive diagnosis.

III. Access, Effectiveness, and Quality of HIV Care

A socio-ecological perspective summarizes the complexities and interactions that impact engagement in care for PLWHA. As shown in Figure 2, there is interplay of individual, relationships, community, health care system, and policy layers that influence one’s processes of engaging in care. Research in years one and two of the Out-of-Care Needs Assessment focused on the individual and relationships levels by connecting with clients directly to better understand their barriers to engaging in care and perceived needs. Research in year three is focused on reaching the service providers of the health care system to better understand the system’s readiness over time, including the system’s ability, willingness, and adaptability, to address the needs of PLWHA.

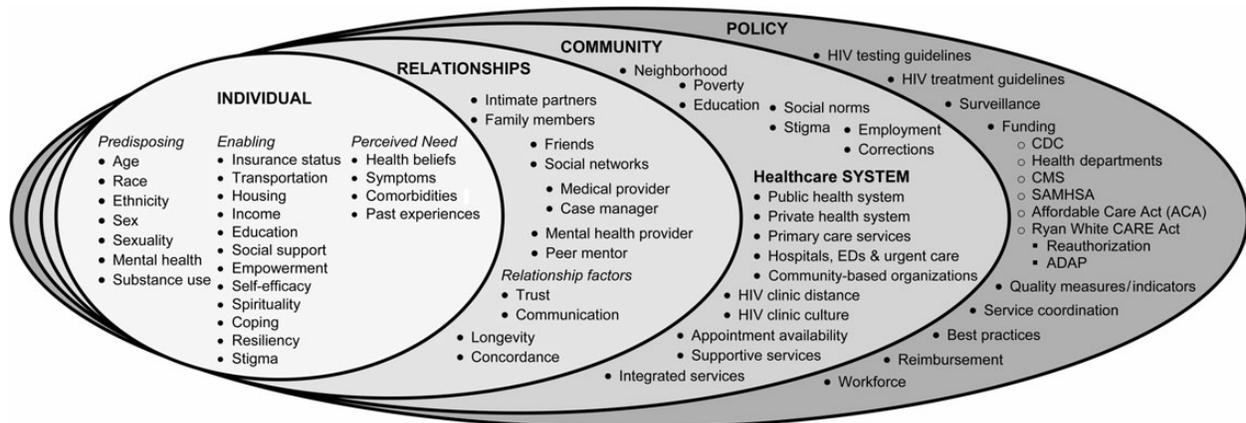


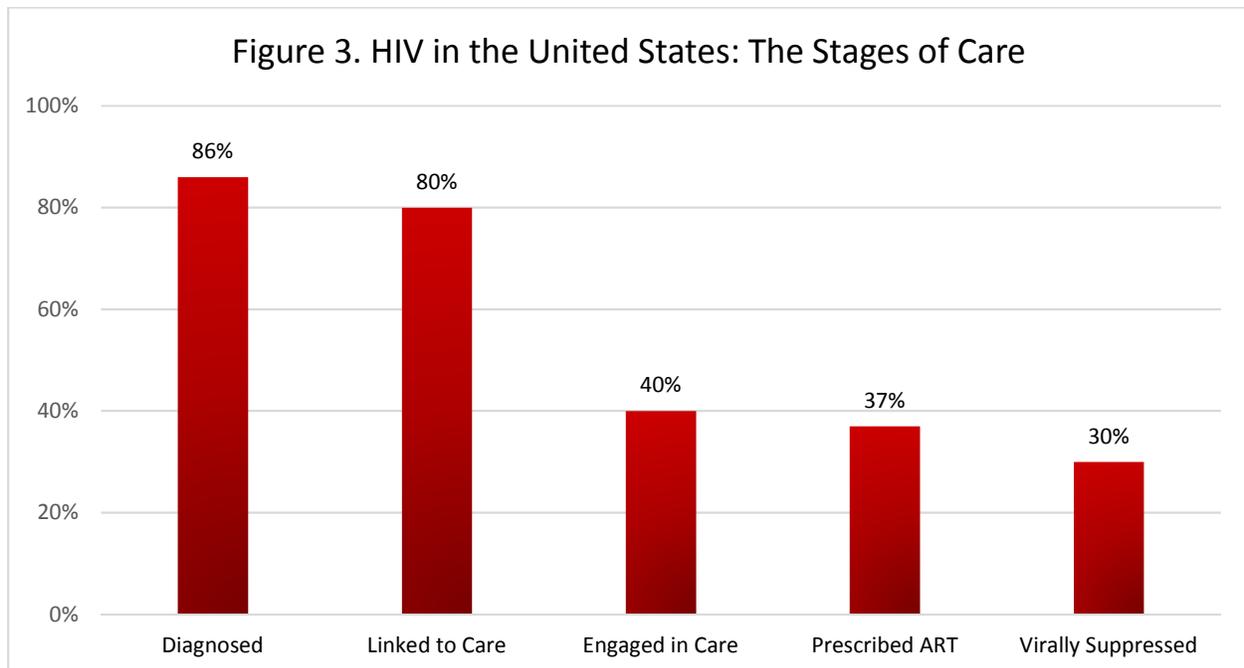
Figure 2. A socio-ecological perspective of factors that influence engagement in care⁸. Predisposing individual factors are identified in the extant literature as those that make someone inclined to specific attitudes or actions that influence engagement in care. Enabling factors, such as health insurance status, are those factors which remove barriers to engaging in care; the removal of enabling factors may reduce one’s likelihood of engaging in care. Perceived needs of the individual, such as individual experiences with HIV medical symptoms and comorbid conditions, are also expected to influence the individual’s engagement in care.

In addition to the socio-ecological perspective displayed in Figure 2, the HIV Care Continuum is a meaningful tool to examine the state of HIV care in a given population at a particular point in time. The HIV Care Continuum provides a framework to document the current system’s strengths as well as to assess the system’s readiness to address the inabilities and failures of Ohio’s PLWHA to access and stay in HIV care. Viral suppression is the ultimate goal of HIV care and the HIV Care Continuum documents several steps required to achieve viral suppression.⁹ The Centers for Disease Control and Prevention (CDC) uses the HIV Care Continuum to track the proportion of people with HIV who are:

- Diagnosed with HIV infection
- Linked to care
- Engaged or retained in care
- Prescribed antiretroviral therapy (ART)
- Virally suppressed^c

^c Current versions of the HIV Care Continuum have combined the final two steps into a single step labeled “virally suppressed” (CDC, July, 2016).

The CDC reports the proportion of people at each step of the continuum and tracks those dropping out at each subsequent stage in the continuum. Figure 3 displays the most recently compiled CDC data of people living with HIV in the United States as they relate to the HIV Care Continuum. This is often called the treatment cascade because of the dropping off at each subsequent step of the treatment process. Of the total population of individuals infected with HIV in the United States, 86 percent are estimated to be diagnosed (have HIV and know it), 80 percent are linked to care, and 40 percent are retained in care. The ultimate percentage of HIV-positive individuals who are virally suppressed in the United States is 30 percent.



Best practices in increasing retention from one step to the next is discussed in the following sections.

Impact on HIV Testing

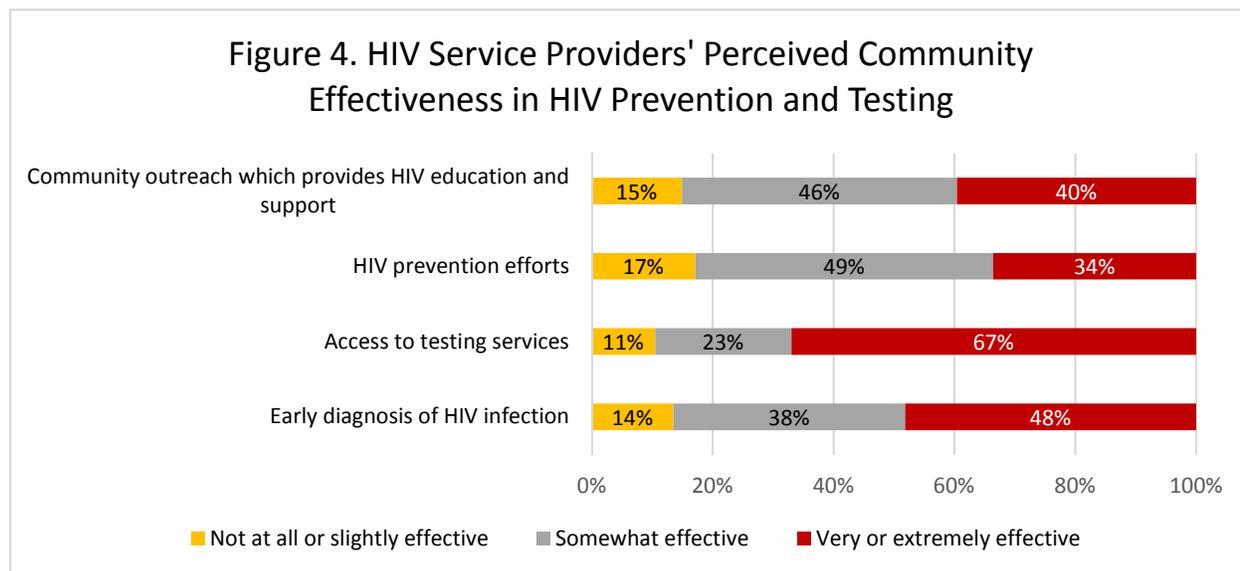
Research on HIV testing and diagnosis have shown that age is a significant factor: younger PLWHA are less likely to have their HIV diagnosed.¹⁰ Specifically, PLWHA between the ages of 18 and 24 years had the lowest rates of HIV diagnosis (49%), while HIV-positive individuals ages 25 to 34 years had the second lowest rates of HIV diagnosis (74%) among all age categories. The testing setting (hospital or community-based site) was not associated with the outcome of viral suppression,¹¹ so there is no recommendation for or against testing in a particular setting. Subsequent steps of the HIV Care Continuum are more influential on achieving viral suppression than the location of where one receives their HIV diagnosis. In general, prevention efforts to discourage HIV infection and encourage diagnosis should be framed with the community culture and value system in mind.¹²

Current State of System Response to HIV Prevention and Testing

PLWHA in the year one Needs Assessment survey and year two focus groups indicated that lack of HIV education was a significant factor in their decisions to engage in and retain care. Some said they delayed engaging in care or remaining in care because they did not realize the severity of the disease. Others said they may have reduced their risky behaviors and engaged in care immediately if they were more

knowledgeable of the health benefits to maintaining viral suppression. **Community outreach in HIV education is needed to prevent new HIV infections and motivate PLWHA to be tested and engage in care.**

Figure 4 summarizes HIV service providers’ perceived community effectiveness of HIV prevention and testing activities from the year three study. Though 99 percent of survey respondents report HIV testing services exist in their community, access to testing services was perceived to be very or extremely effective by only 67 percent of HIV service providers. This is a majority of survey respondents, **yet improved access to effective HIV testing and significant improvements in HIV education are needed.** In addition, **85 percent of survey respondents report having a Disease Intervention Specialist (DIS) in their community, whose quality is rated as excellent by 65 percent of respondents.**



Impact on Linkage to Care

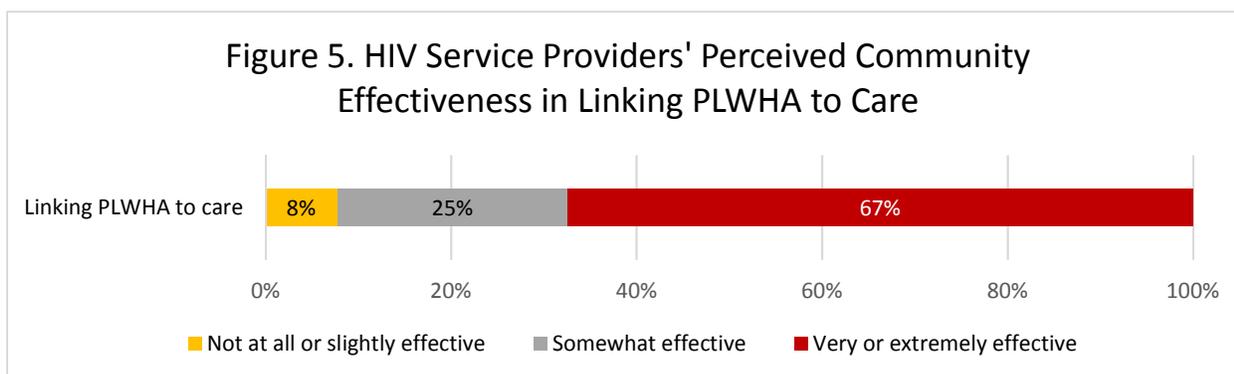
People with HIV are counted as linked to care if they visited a health care provider within three months of learning they were HIV positive. Research on linking the newly diagnosed individual to HIV care has produced consistent evidence. For example, the likelihood of linkage to care in young men who have sex with men (MSM) is increased when the person who provided the HIV-positive test result calls to make the first medical appointment for the individual who tested positive.¹³ Age and sex are significant factors in linkage to care. In general, younger PLWHA are less likely to be linked to care and men are linked to care less often than women. Race is also a factor, as Blacks/African Americans are less likely to be linked to care compared to all other racial groups measured.¹⁴

Case management services have shown meaningful improvements in linkage to care as well. Research has shown an increase in case linkage at six months when *linkage case management* was delivered by community-based organizations and health departments. This was most effective when the patient was more than 25 years of age, Hispanic, stably housed, had not recently used non-injection drugs, attended two or more sessions with a case manager, or was recruited at a study site with HIV medical care collocated on its premises. Patients with these demographics were significantly more likely to have received HIV care in the first six months since HIV diagnosis.¹⁵ In another study, case-managed

participants visited their HIV clinician more often in the first six and 12 months than clients who received more typical passive referrals.¹⁶ Again, certain demographics were more likely to show success, including clients who were more than 40 years of age, Hispanic, and those who had enrolled within six months of their HIV test result. These PLWHA were all more likely to have made two visits to an HIV care provider in this follow-up time. A brief intervention by a case manager was associated with a significantly higher rate of successful linkage to HIV care.¹⁷

Current State of System Response to Linkage to Care

In the year three study, HIV service providers reported HIV-related case management in their community 96 percent of the time; three-fourths (74%) of respondents rated the quality as excellent. However, the community's effectiveness in linking PLWHA to care was a bit lower, with respondents rating their community as very or extremely effective 67 percent of the time (Figure 5). Some PLWHA in the year two focus groups discussed the important role of compassionate nurses who supported their linkage to care. **Nurses and other Linkage to Care Specialists may be effective relationships to leverage in the early days and weeks after a new diagnosis.**



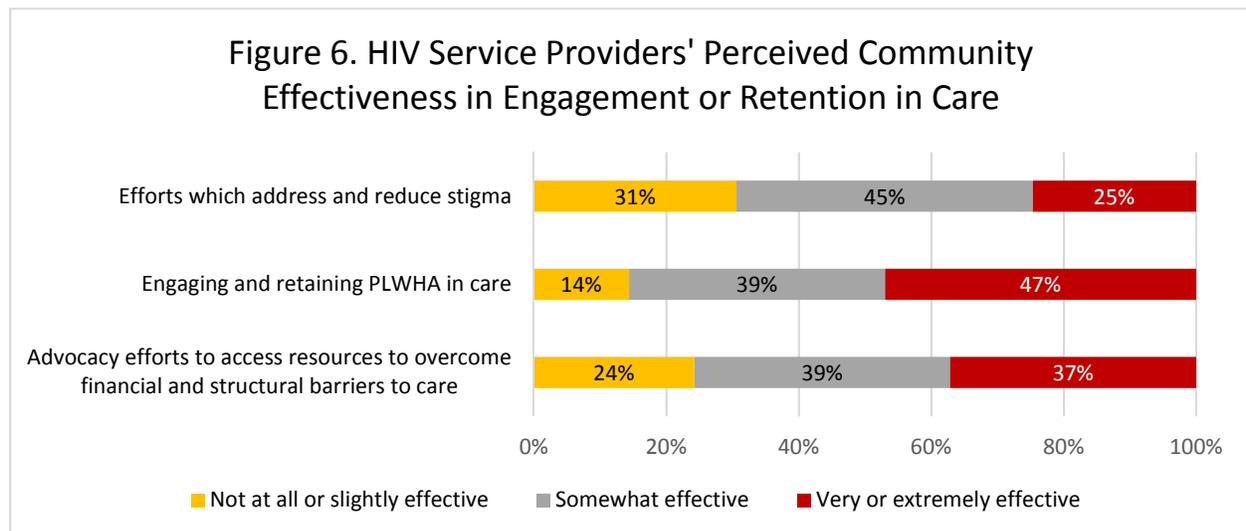
Impact on Engagement or Retention in Care

Several research studies have documented changes to service processes or the removal of barriers that increased engagement or retention in care for PLWHA. For example, a coordinated messaging plan that encouraged patients' clinic attendance was hypothesized to improve client retention. Indeed, adopting clinic-wide messaging about staying in care delivered by HIV medical clinic providers and staff to all clinic patients regarding importance of retention in care had a significant improvement on client retention.¹⁸ Intensive outreach to provide HIV education and support, address stigma, and advocate and access resources to overcome financial and structural barriers to care improved engagement,¹⁹ as did general outreach in promoting engagement in care.²⁰ Improvements were shown in appointment attendance and ART prescription for youth among those who were receiving individualized, intensive medical case management.²¹ Peer navigation also had a significant impact on engagement in care, as peer navigators often share a cultural background with the client and apply a strengths-based approach.²²

Removing barriers has also been shown to improve retention in care. Clients showed improved retention in care, ART adherence, and HIV clinical outcomes when their housing and transportation needs were addressed.^[23,24] Age and sex remain factors at this step of the HIV care continuum, as younger PLWHA and men are less likely to be retained in care.²⁵

Current State of System Response to Engagement or Retention in Care

Year one and year two study participants reported denial, shame, and stigma as key factors that influenced their decision to disengage from HIV medical care. Specifically, focus group participants spoke at length about their experiences with stigma and the deep impact it had on their experience to seek care and remain engaged in care. In the year three study, HIV service providers reported efforts to address and reduce stigma in their communities as only 25 percent effective (Figure 6). Engaging and retaining PLWHA in care is rated higher at 47 percent effective and advocating to help PLWHA overcome financial and structural barriers to care was rated very or extremely effective by 37 percent of survey respondents. Interestingly, more survey respondents rated their community's efforts to address and reduce stigma as not at all effective or slightly effective (31%) than as effective (25%); **combating stigma will likely be an essential and challenging endeavor in changing the HIV system of care.**



The ability to remove specific structural barriers in a specific community was also assessed. **Seventy-three percent of HIV service providers reported that access to safe, affordable housing exists in their community, and 94 percent reported having public transportation. However, the quality of these services was rated as excellent only 21 percent and 30 percent of the time, respectively.**

Impact on Prescribed Antiretroviral Therapy

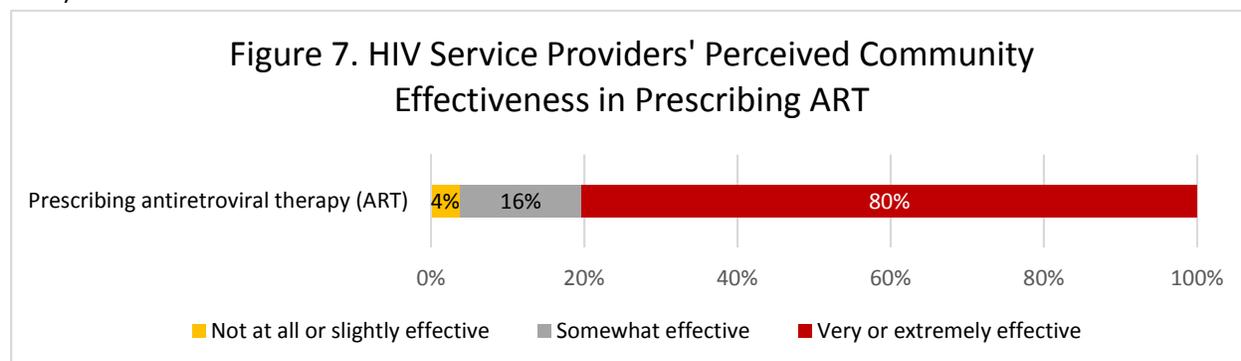
Research on ART prescriptions and medication adherence shows the challenges of maintaining one's ART regimen while experiencing mental health issues. In one study, ART adherence was reduced due to feelings of depression or adverse effects caused by perceived pill burden, including too many pills to take and wanting to avoid side effects.²⁶ These medication adherence barriers were associated with detectable HIV RNA levels 12 weeks later. In other research, women who reported more than 14 mentally unhealthy days per month were less likely to be retained in care during treatment to achieve viral suppression.²⁷

When pharmacy services are combined with medical care sites, there are documented benefits for patients. In one study, integration of specialty pharmacy services with interdisciplinary care at outpatient infectious disease clinics enhanced continuity of care for HIV patients.²⁸ In general, patients diagnosed early on in the progression of their disease who may not have experienced acute symptoms have reduced ART adherence. This can occur when patients begin ART treatment before they are ready to adhere well. There is evidence that patients receiving the Supporting Treatment Adherence Readiness

through Training (START) intervention prior to starting treatment may achieve and sustain treatment readiness and significantly more treatment benefits as a result of greater adherence.²⁹

Current State of System Response to Antiretroviral Therapy Adherence

In the year three study, HIV service providers rated their community's effectiveness at prescribing ART. As shown in Figure 7, 80 percent rated their community as very or extremely effective, the highest rating provided on this scale of community effectiveness in achieving HIV-related outcomes. HIV service providers also reported their agreement that pharmacy services are typically available at medical sites, to which agreement by survey respondents was neutral to slightly positive (average score, 3.60 out of 5.00).



Mental health issues are known to impact ART adherence and PLWHA reported significant mental health challenges in the year one and year two studies. Depression was the most commonly reported comorbidity in the year one study, which was experienced by more than 60 percent of PLWHA surveyed. Mental health issues were reported to interfere with PLWHA's motivation and ability to engage in HIV medical care; PLWHA with a history of being out of care had significantly higher reported rates of mental health disorders compared to those who had never been out of care. HIV service providers in the year three survey reported **mental health services in their communities 91 percent of the time, but only 32 percent were rated as demonstrating excellence and cultural competence. Increased coordination of mental health services and HIV medical care is greatly needed to increase engagement in care and ART adherence.**

Impact on Achieved Viral Suppression

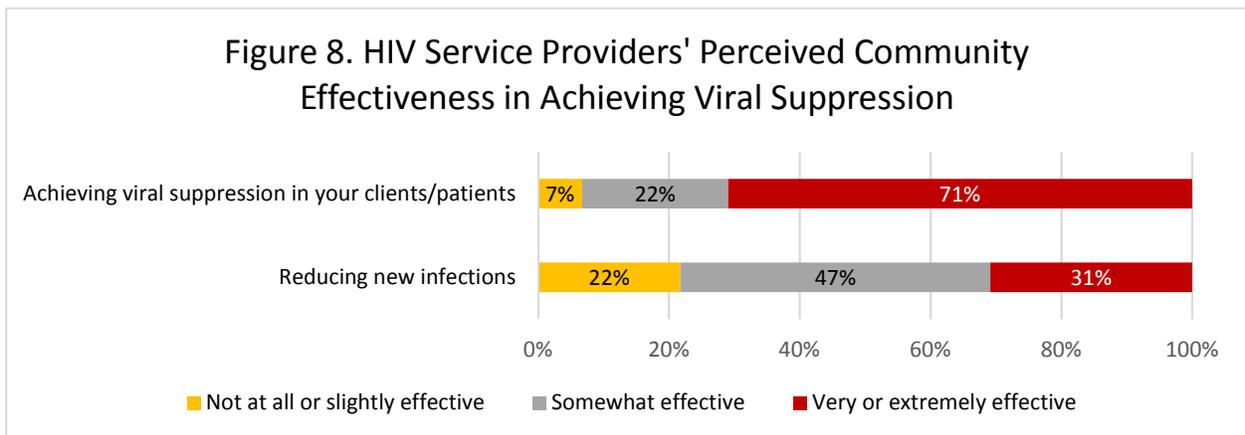
As discussed previously, testing location (hospital or community-based site) does not predict whether PLWHA will achieve viral suppression.³⁰ In one study, a retrospective medical chart review was conducted to determine the relationship between retention in care and viral rebound, meaning the patient's viral load was detectable. The charts of patients who achieved viral suppression were examined at 12 months after viral suppression and the charts were coded for retention in care. The study results showed that retention in care was central to maintaining viral suppression and patients with suboptimal retention in care were far more likely to experience viral rebound than those with optimal retention in care.³¹

Another factor in achieving viral suppression is race, such that Blacks/African Americans are the least likely of any race or ethnicity to demonstrate viral suppression. Although Blacks/African Americans are the least likely among all races and ethnicity (29% demonstrated viral suppression), low levels of viral suppression are also found for Hispanic/Latino PLWHA (31% demonstrated viral suppression) and White PLWHA (32% demonstrated viral suppression).³² Males have lower viral suppression rates than women,

and younger PLWHA have the lowest viral suppression rates of any age, gender, race/ethnicity, or risk group reported.

Current State of System Response to Achieving Viral Suppression

HIV service providers in the year three study rated their community's effectiveness at achieving viral suppression and reducing new infections. **Seventy-one percent rated their community as very or extremely effective at achieving viral suppression in their clients/patients** (Figure 8). Reducing new infections was rated significantly lower at 31 percent. It is curious, however, that the final two stages of the HIV Care Continuum – prescribed ART and achieving viral suppression – produced the most favorable rating from HIV service providers, when it is known that retention in care (47% very or extremely effective) is a precursor to prescribing ART. Perhaps HIV service providers are considering different denominators in their estimates when reporting their perceptions of the HIV system of care, such that 76 percent of providers believe their community is very or extremely effective at achieving viral suppression in those clients/patients who are retained in care, not for the entire population of HIV-positive individuals in their community.



IV. Alignment to Current Best Practices in HIV Patient Care in Ohio

Provider relationships are known to be the significant driver for many PLWHA to remain engaged in HIV medical care; this is supported by research in this three-year Out-of-Care Needs Assessment and published literature in delivering HIV medical care. Certain HIV service providers were named by focus group participants during the year two Out-of-Care Needs Assessment as providing exceptional HIV medical care or service and having a significant influence on the client's decision to engage in care or reengage in care after a period of being out of care. These named providers were interviewed to better understand their approach, methods, patient interaction protocols, programs, and philosophy as it relates to HIV patient care. The goal of the interviews was to document these best practices so Ohio's HIV care system can be assessed for its readiness to implement similar procedures and systems in the future. Interviews with four HIV service providers were conducted, including an HIV tester, Disease Intervention Specialist (DIS), infectious disease physician, and case manager. Their experiences and best practices span the entire HIV Care Continuum.

Cultural Competency and Patient-Centered Care

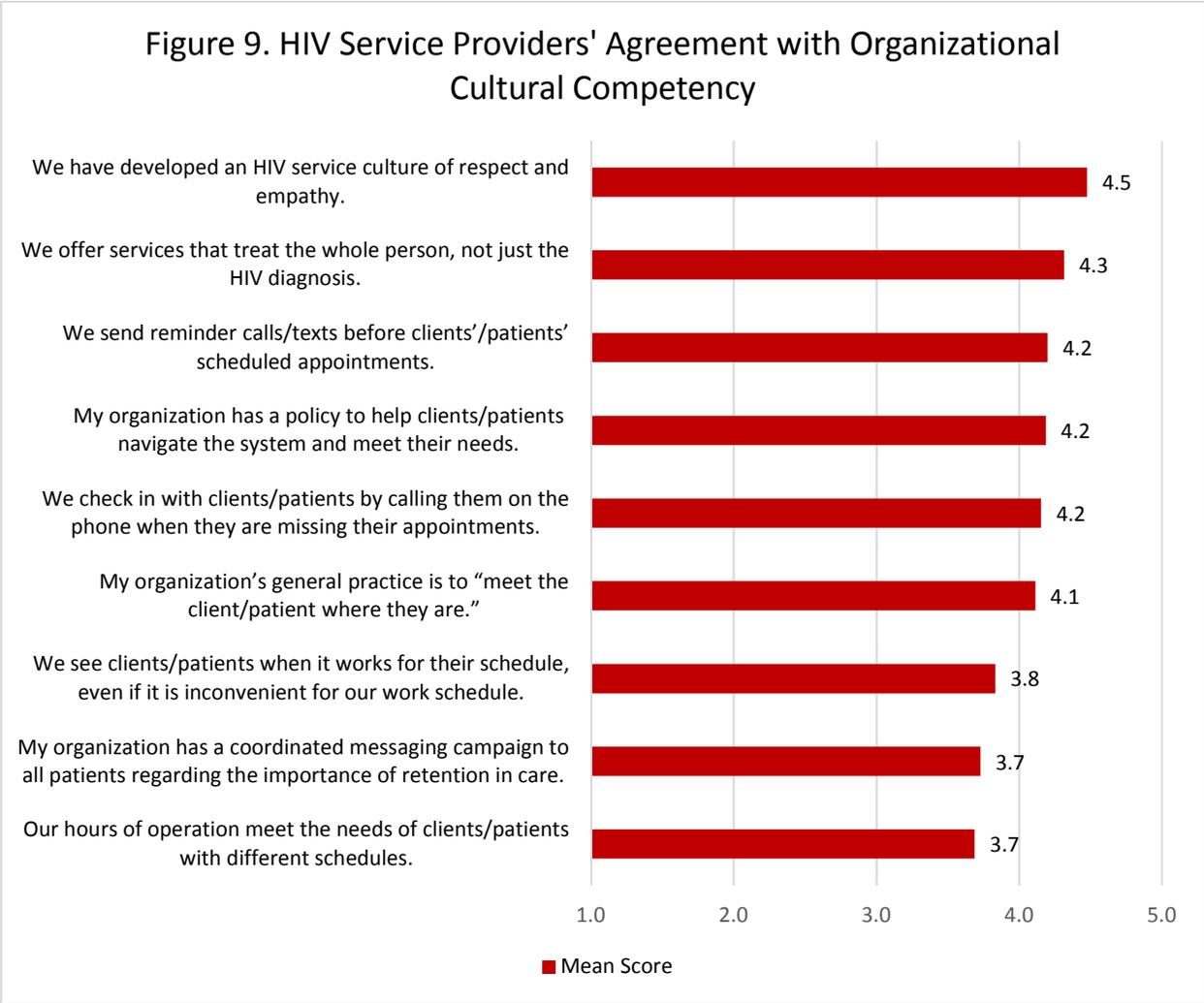
The most common theme among exceptional HIV service providers was HIV care delivered with cultural competency. When asked why their approach is successful, all of the interviewed providers used phrases like "patient-centered care," "meeting clients where they are," "inspiring hope, care, and concern," "acknowledging their emotions," "treating the whole person," and "putting their needs ahead of our timeline." Their objective is for the client to do well now and in the future. This is demonstrated through an intentional culture of respect and empathy.

Culturally competent health care practitioners are those who understand the social and cultural contexts experienced by their patients. Lavizzo-Mourey & Mackenzie³³ define cultural competence as having three components: "(1) an understanding of population-specific health-related cultural beliefs and values, (2) knowledge of disease incidence, prevalence and mortality rates and (3) an understanding of population-specific treatment outcomes."³⁴ Said differently, the culturally competent health care can be defined as the "congruent behaviors, attitudes, and policies that come together to enable systems, agencies and professionals to work effectively in cross-cultural situations"³⁵ to empower care providers to deliver services that are respectful of a patient's culture or identity. Indeed, previous research has shown that cultural competence of care providers can improve HIV patient's care seeking.³⁶ Exceptional HIV service providers said that they provide intensive, whole-person care. The HIV tester and DIS provide linkage to care by scheduling the first medical appointment for the newly diagnosed HIV-positive individual. They always offer to attend the appointment with the client and nearly all clients agree, which is evidence of the rapport and trust the tester and DIS are able to build with the client during an intense and stressful interaction for the client. The infectious disease physician's office motto is: "Patients come first. Everybody is the same." This office provides a flexible, consumer-oriented system that responds to the patient's acceptance level and concerns, such as meeting the client at the back door of the clinic if there is concern of being identified by an acquaintance in the waiting room. The case manager serves a rural area and similarly stated her approach is serving the whole client, not just their HIV care. This is especially important in rural communities where stigma and fear of HIV and diverse sexuality leaves many clients with little or no support network. All of these examples were said

to deepen the relationship and promote trust between the provider and client, ultimately increasing the client’s engagement in HIV medical care.

Current State of System Response to Delivering Cultural Competency and Patient-Centered Care

Cultural competency and patient-centered care concepts articulated in the interviews were developed into statements for all HIV service providers to rate their own organization’s cultural competency in HIV care delivery. Figure 9 summarizes the HIV service providers’ average agreement score for each item. HIV service providers were in highest agreement that their organizations have an HIV service culture of respect and empathy. Flexible hours to accommodate clients/patients with different schedules was rated lowest, though still marginally positive. **Overall, most cultural competency concepts are endorsed by HIV service providers as already present in their organizations. This may present an opportunity to leverage existing attitudes and practices to increase culturally competent HIV medical care that clients/patients would also view as meeting their needs.**



Integrated Care Providers Across the HIV Care Continuum

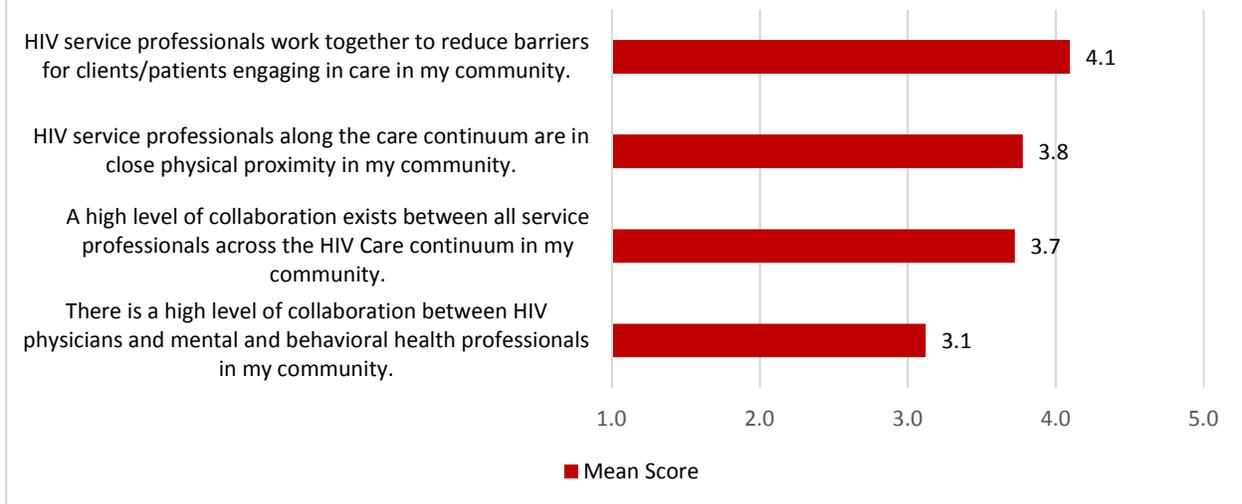
Exceptional HIV care providers agreed that their approaches were successful because they embraced a team approach between service providers at all stages of the care continuum. For example, the DIS and infectious disease physician are co-located in the same building and work together to provide client-centric service. An open appointment in the infectious disease clinic will be made available for the newly diagnosed client, even if it is the same day. The HIV tester walks the client into the clinic to provide a direct introduction to the medical staff. Nurses, social workers, and consumer advocates sit down with the new client to explain health insurance, introduce staff, review symptoms, and complete all requisite paperwork. The infectious disease physician meets with the client to answer questions and order lab work or prescription therapies. The pharmacy is in the clinic, meaning clients who are prescribed ART medications often leave their first appointment with medications in hand.

Service providers in rural counties often do not have as many services under a single roof because of the geographic dispersion of the clients and resources. Therefore, the service network through the HIV Care Continuum is more intentional. The exceptional HIV tester who was interviewed works closely with Ryan White Part B and explained that the Ryan White Part C office is in the same building as the HIV testers' offices. The Ryan White Part B and Part C offices have an excellent relationship. There is great availability between agencies, such that the tester interviewed can call or text a service provider in the Part C office or another regional service provider and receive a prompt response. There is intentional collaboration between agencies. Also, they are accessible to clients. They take client calls that were meant for other agencies, help the client navigate the system and meet their needs, then connect them to the correct person who can best help them. This exceptional HIV tester believed these great relationships with other agencies and service providers reduced the barriers for clients to remain engaged in care.

Current State of System Response to Integrated Care Providers Across the HIV Care Continuum

Clients who participated in the Out-of-Care Needs Assessment desired a more integrated system of care that better aligns to these best practices. **PLWHA specifically requested a coordinated system with streamlined referrals and appointments.** HIV service providers rated their agreement with their community's alignment to these best practices; Figure 10 summarizes their responses to select items. Responses were neutral to agreeable on these best practices in collaborative HIV care, with collaboration to reduce barriers for clients/patients engaging in care rated most favorably. HIV service providers were neither in agreement nor disagreement that their community has a high level of collaboration between HIV physicians and mental and behavioral health professionals. **Despite these modestly favorable perceptions of HIV service providers, PLWHA experience a disjointed system of care that is often difficult to navigate.**

Figure 10. HIV Service Providers' Agreement with Best Practices in Integrated and Collaborative HIV Care



Mental Health Response

All exceptional HIV service providers described a significant need for mental health assessment and treatment for their HIV clients. Depression, anxiety, personality disorders, and/or substance abuse were believed to affect nearly all of their clients. This corroborates the client data collected in previous years of the Out-of-Care Needs Assessment, in which more than 60 percent of PLWHA reported depression, and mental health needs were reported to interfere with PLWHA’s motivation and ability to engage in HIV medical care.

Best practices in mental health assessment and response were described by the infectious disease physician’s clinic. A psychiatric nurse practitioner, counselors, and social workers work together within the infectious disease clinic to treat the mental health needs of the patients. Patients are administered a depression screening tool on the first visit and the results are followed up with counseling service, as needed. The mental health professionals have training and experience specifically in HIV care, which is often lacking in other counseling and behavioral health services utilized by PLWHA. The psychiatric nurse practitioner runs therapy groups in addition to the typical support groups, such as a therapy group for men with personality disorders. One objective of the group is to help these men with personality disorders socialize and be respectful of staff, with the ultimate goal of continuing in their HIV care.

Sometimes the mental health need is less severe. Simply calling clients and reaching out if they are skipping appointments can support their mental health care. A nurse in the infectious disease clinic stated that sometimes the client needs resilience and coping skills that are not developed through normal life events, which can be addressed through counseling and other supportive steps. Every provider in their system takes a holistic approach to mental health. For example, if the dietician is consulted because the client is losing weight, the dietician’s approach to care is to also assess whether the weight loss is caused by depression or other mental illness.

The mental health response in rural areas did not reflect best practices. The exceptional tester and case manager interviewed explained there are no Ryan White mental health providers in their areas,

meaning only clients who could afford self-pay or who were enrolled in Medicaid could access needed mental health treatment. Others travel great distances to access mental health services. Substance abuse is also a significant mental health concern in rural Ohio. There are few mental health treatment options for substance abuse patients who need assistance overcoming their addiction to get into HIV medical care, and participating clients with a history of substance abuse clearly stated in the focus groups that addiction made it nearly impossible to engage in HIV medical care.

Current State of System Response to Mental Health

As previously stated, HIV service providers in the year three survey reported **having mental health services in their communities 91 percent of the time, but only 32 percent were rated as demonstrating excellence and cultural competence.** According to the exceptional HIV service providers, mental health services' existence in a community is insufficient; they must be culturally competent, patient-centered services. Specific, culturally competent practices by mental health professionals were not rated in the HIV Service Professionals Insight Survey because of expected low participation by mental health professionals (counselors or behavioral health specialists comprised less than 5% of the total sample). Greater understanding of the type and quality of mental health services available to PLWHA is needed to meet the mental health needs of PLWHA.

Patient-Led Interaction

The fourth common theme across exceptional HIV service providers was patient-led care. Exceptional providers look for opportunities to shift ownership to clients, while still supporting them and helping them make the best decisions possible. The case manager described how clients were taught that achieving an undetectable viral load is important. Because clients embraced this, they are focused on getting to a specific viral load number and are motivated by seeing that their ART is working. It is why those clients take their medications.

Another way exceptional HIV service providers create a patient-led interaction is to allow unwilling clients to delay their linkage to care. One of the providers described encouraging a newly diagnosed client to get linked to care, but the client's response was, "I'll get to it later." After several phone calls and failed attempts to set up the linkage, the provider replaced the frequent phone calls with monthly check-in calls to see if the client needed other resources or supports. This developed rapport with the client. When the client's personal circumstances changed and the client was ready to get linked to care, the client called the provider to set up an appointment. The client was still engaged in care at the time of the provider interview, even after initially delaying care for nine months.

Another best practice discussed by the exceptional HIV service providers was to avoid "burning bridges" with clients. Letting the client have ownership encourages them to work with the DIS to identify partners and get them tested. There is no judgment or criminalization of the client's HIV status or behaviors from the tester or DIS, which also corresponds with the providers' high cultural competency when serving the HIV-positive population. Similarly, another provider recommended that clients who arrive late to appointments should be seen if possible. Rather than "teaching life lessons" with missed appointments by requiring the client to reschedule, this provider's best practice is to learn about the client's barriers to keeping the appointment and address the barrier. For example, transportation is a common barrier for many of this provider's clients. The client may be relying on a neighbor's car or a bus route to arrive to the appointment. Rather than punishing the client again for their circumstances, the provider will work the client into the day's remaining scheduled appointments to reduce the barrier of

having to return a different day. All the exceptional HIV service providers interviewed found success in responding to patient-led interactions rather than insisting the client adapt to the system.

Current State of System Response to Patient-Led Interaction

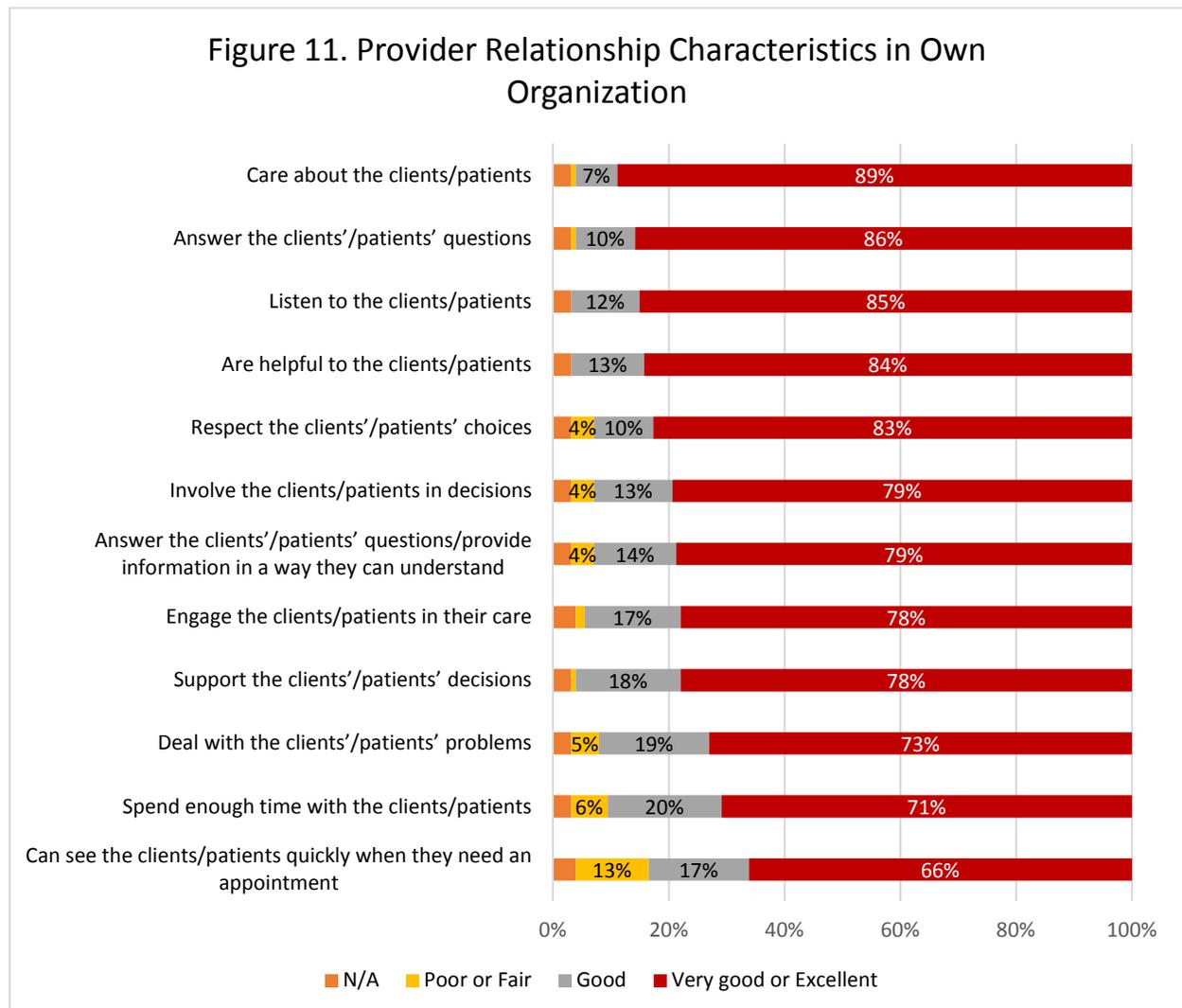
Generally, PLWHA in the year one and year two studies discussed their desire for patient-led interactions as the need for greater culturally competent medical professionals. It was often said that one's basic needs must be met before one can focus on engaging in HIV care. **Clients/patients want their HIV service providers to understand the hardship of living with HIV/AIDS and the physical and emotional fatigue that results from living with the virus.** This may manifest in skipping appointments, missing doses of the prescribed ART, and prolonged hesitancy making a needed phone call to initiate services or benefits. **Until more barriers to engaging in care are removed for PLWHA, the exceptional HIV service providers recommend all providers adopt patient-led interactions to support the client/patient in their present state.**

V. Desired System Response

Creating a system of care that integrates data-driven research with best practices in patient care is expected to significantly advance more PLWHA on the HIV Care Continuum toward viral suppression. Several other learnings about the state of Ohio’s HIV system of care and the PLWHA it serves were discovered in this three-year Out-of-Care Needs Assessment.

Provider Relationships

As previously stated, provider relationships are a critical element of engaging in HIV care. PLWHA who have never been out-of-care reported significantly more favorable attitudes towards their health care provider and had greater trust with their HIV medical provider than those with a history of being out-of-care. Similarly, focus group participants identified a previous bad experience with medical personnel as a key reason they ceased engaging in care. Because provider relationships are important to clients/patients, in the year three survey, HIV service providers rated the quality with which the professionals in their organization exemplify positive provider behaviors. Overall, approximately 79 percent of HIV service providers rate their own organization as exemplifying very good or excellent provider relationship characteristics. As summarized in Figure 11, the mostly favorably rated items



related to caring about the clients/patients and answering the clients'/patients' questions. The lowest rated items, spending enough time with the clients/patients and seeing the clients/patients quickly when they need an appointment, were endorsed as very good or excellent by two in every three HIV service providers. However, when combined with PLWHA's responses to the same items, the results are troubling. When PLWHA completed these items in the year one survey, those with a history of being out-of-care rated their health care provider relationship as neutral to slightly favorable while those who have never been out-of-care rated their relationship as more favorable. This difference was statistically significant at $p < .05$ for every health care provider relationship statement in Figure 11. The largest differences between those who have never been out-of-care and those with a history of being out-of-care were in perceptions of the provider spending enough time with the client and being able to be seen quickly when the client needs an appointment, the two lowest rated items by HIV service providers themselves. This means **HIV service providers in the year three survey rate their own performance lowest on the elements of provider relationships known to show the biggest gap between those who are engaged in care and those who have a history of being out of care.** It cannot be said that low provider relationship characteristics cause PLWHA to fall out of care, however, the relationship between PLWHA's lower provider relationship perceptions and one's history of being out-of-care is a robust finding in this three-year Out-of-Care Needs Assessment and merits further attention.

Change Readiness

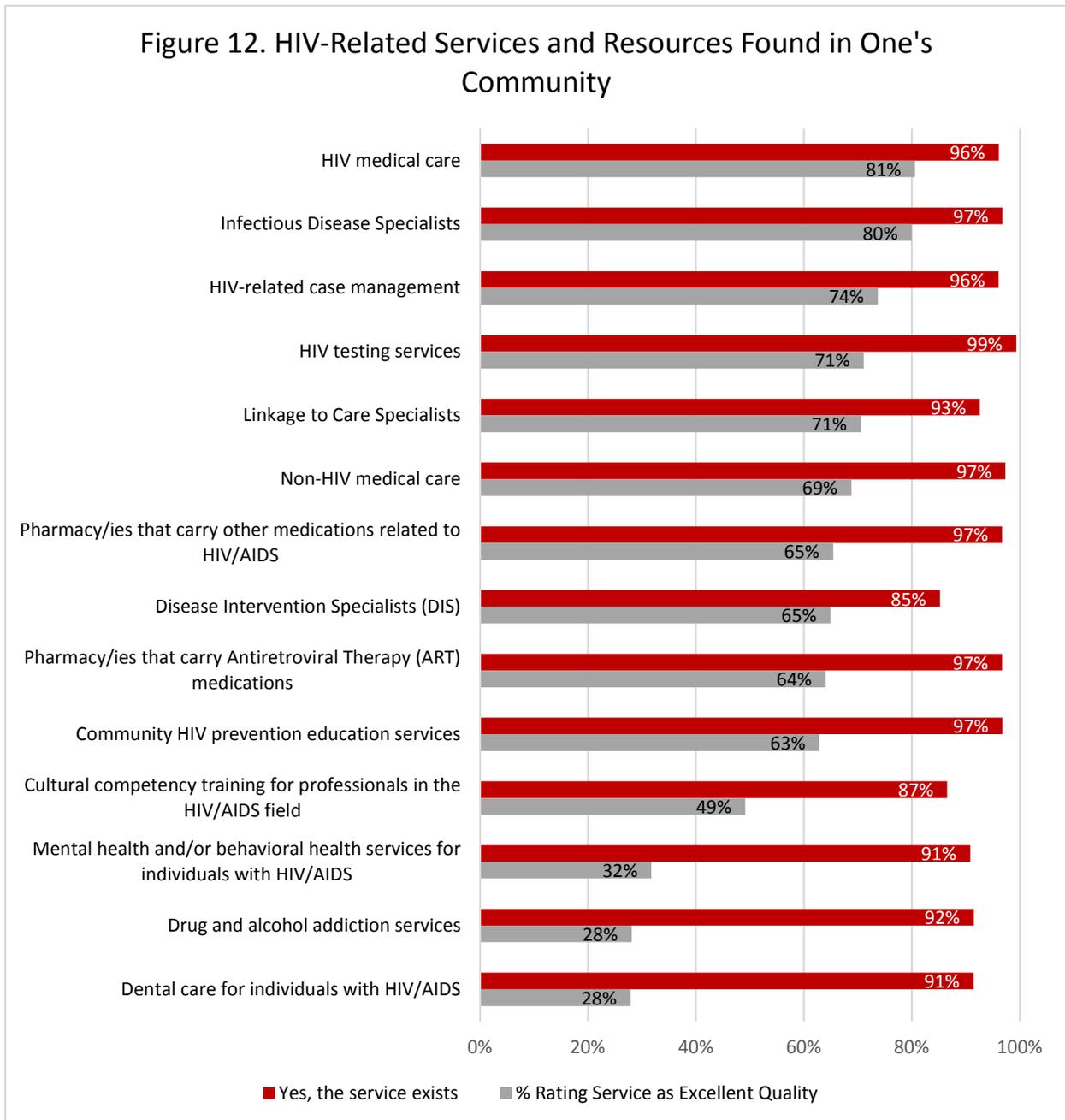
HIV service providers responded to a validated change readiness scale³⁷ by rating the extent of their agreement to making the HIV care system more client-friendly and streamlined with unified planning along the HIV Care Continuum. Overall, survey respondents had a change readiness score that is neutral to slightly favorable (M=3.81 of 5.00). Survey respondents were most agreeable that the HIV care system will benefit from this change. The lowest-rated item, the change will make their jobs easier, was rated neutrally. Interestingly, HIV specialists and/or Infectious Disease physicians who participated in the survey demonstrated the lowest change readiness scores of all the HIV service provider roles represented in the survey.

HIV specialists/Infectious Disease physicians have among the lowest agreement of being change ready and score the lowest on "meeting the client where they are," a component of cultural competency. This may present challenges in modifying the HIV system of care because provider relationships are known to be very important to clients, yet HIV specialists/Infectious Disease physicians are less likely to adopt culturally competent approaches or desire to change the HIV system of care.

Linkage to Care specialists, Case Managers, and Counselors are often the most agreeable or favorable to being flexible to the client, and Linkage to Care specialists were most agreeable to a change to the HIV system of care. It may be beneficial to leverage these HIV service providers to be advocates for changes within the HIV system of care because they are more likely to be currently demonstrating best practices in culturally competent HIV care.

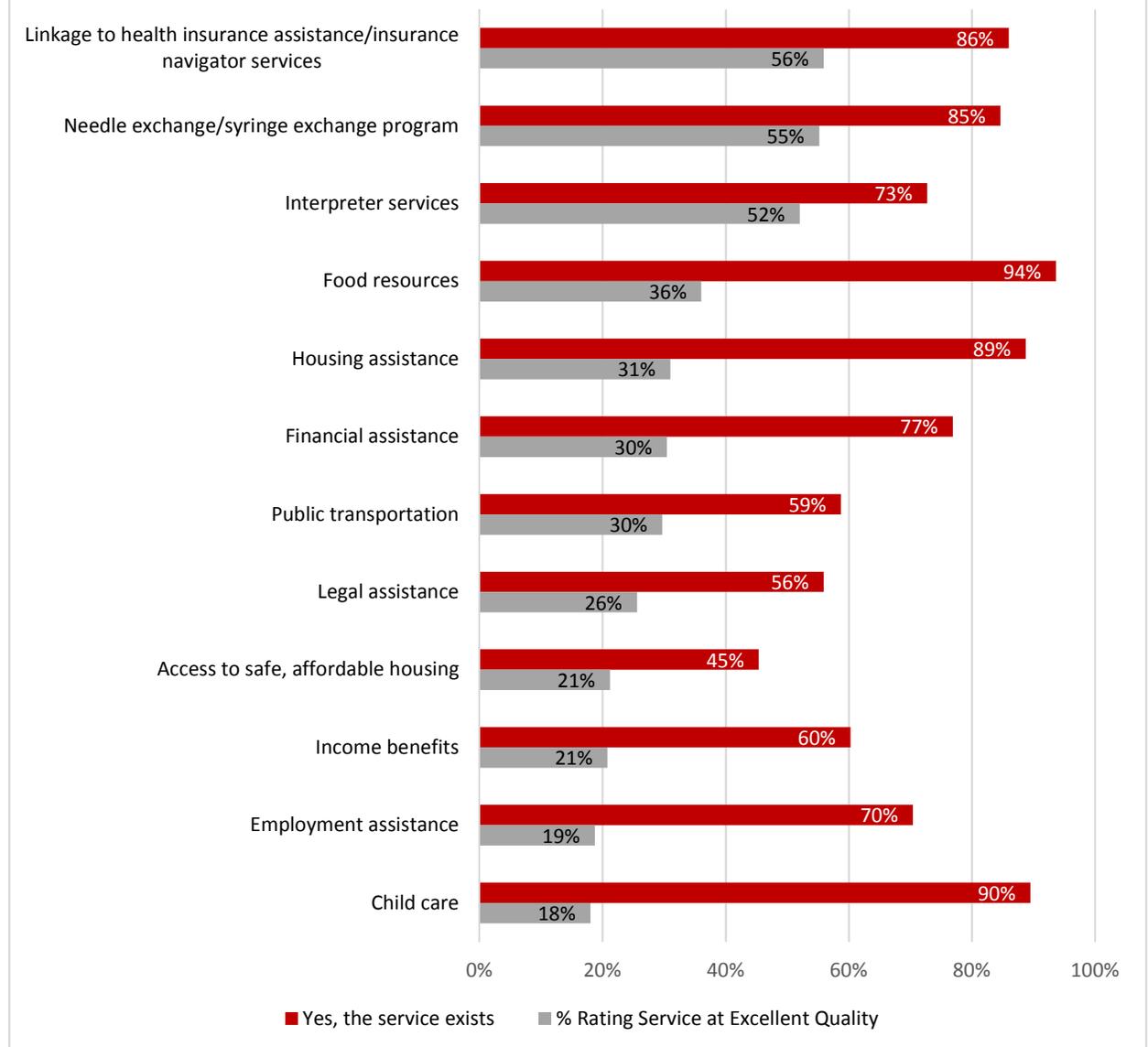
Services, Barriers, and Unmet Needs that Impact Engagement in Care

Figure 12 summarizes the list of HIV-related services and resources found in one's community. HIV service providers first selected whether the service exists in their community. If it exists, they rated the service quality, with excellent quality defined as culturally competent service. As shown in Figure 12, nearly all HIV-related services and resources were rated as present in survey respondents' communities. However, quality varied significantly. Mental health and/or behavioral health services for PLWHA, dental care, drug and alcohol addiction services, and cultural competency training for professionals in the HIV/AIDS field were rated with the lowest quality.



Similarly, Figure 13 summarizes the list of non-HIV support services and resources found in one's community. HIV service providers rated these support services for presence in the community and then for excellent quality with cultural competency. Non-HIV support services were endorsed less frequently for being in all HIV service providers' communities. Service quality varied significantly, with few services endorsed as excellent quality by more than 50 percent of survey respondents. Together, Figures 12 and 13 demonstrate HIV service providers' perceptions of Ohio's HIV system of care. Generally, HIV-related services are perceived to be available in nearly every community of moderate to excellent quality, while non-HIV support services and resources are less available and of low to moderate quality.

Figure 13. Non-HIV Services and Resources Found in One's Community



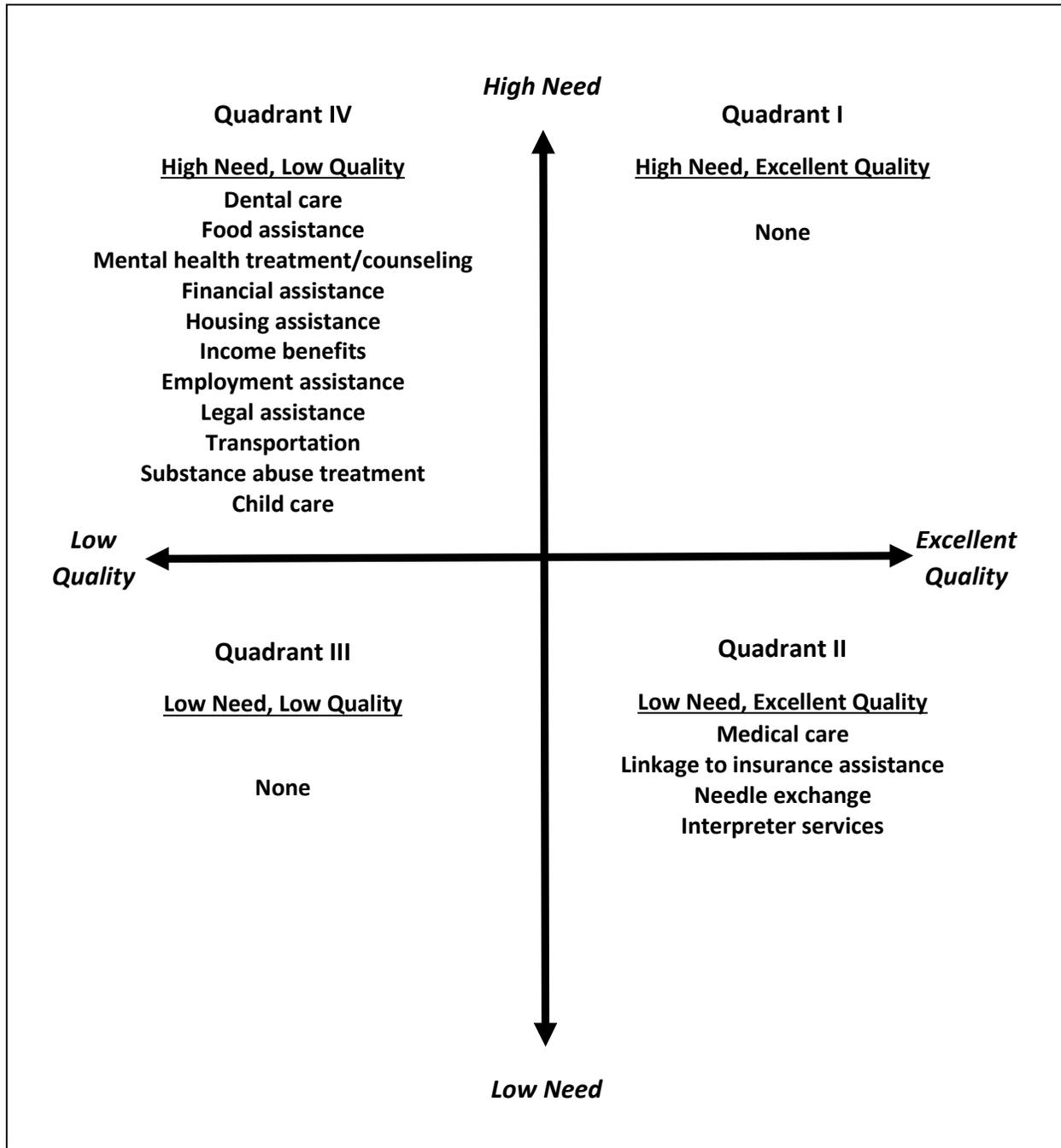
Prioritizing Service Needs

In a well-coordinated system of care, individuals who need a medical or support service would receive that service from a high quality, culturally competent provider. To identify services where access and quality may be a problem for PLWHA, the following matrix was created (Figure 14). This combines the Year 1 Out-of-Care Needs Assessment responses of clients' service needs with the Year 3 HIV Service Professionals Insight Survey quality ratings of the services in their community. The matrix divides services into four quadrants based on the needs and access of the population as well as the quality of the service.

- Quadrant I represents high-need/excellent quality services. These are services where 50 percent or more of the HIV service providers who reported their community providing the service rated it with excellent quality (a score of 4 or 5) and 25 percent or more clients who said they needed the service did NOT receive it.
- Quadrant II represents low-need/excellent quality services. These are services where 50 percent or more of the HIV service providers who reported their community providing the service rated it with excellent quality (a score of 4 or 5) and less than 25 percent of clients who said they needed the service did NOT receive it.
- Quadrant III represents low-need/low quality services. These are services where less than 50 percent of the HIV service providers who reported their community providing the service rated it with excellent quality (a score of 4 or 5) and less than 25 percent of clients who said they needed the service did NOT receive it.
- Quadrant IV represents high-need/low quality services. These are services where less than 50 percent of the HIV service providers who reported their community providing the service rated it with excellent quality (a score of 4 or 5) and 25 percent or more clients who said they needed the service did NOT receive it.

As shown in Figure 14, there are no services in Quadrant I, meaning high-need service needs that are delivered with excellent quality are already being met. When prioritizing where to focus on improving services, Quadrant IV may be an effective starting point. Increasing services in Quadrant IV ensures that efforts are going towards services that are reported to be needed by a majority of individuals. The Year One Client Needs Assessment revealed that dental care, food assistance, mental health treatment, and various other forms of assistance were needed but not received by a significant portion of PLWHA. The Year Three HIV Service Professionals Insight Survey revealed that these same services are of perceived lower quality than other HIV services and social supports. Improving the access and quality of services in Quadrant IV is expected to positively influence the population of HIV-positive individuals throughout Ohio. Quadrant II will not impact as many people, but will improve services where people currently report having low need.

Figure 14. Prioritization of Clients' Service Needs by Perceptions of Service Quality



VI. Recommendations: Concrete Next Steps

Results of the Ohio Out-of-Care Needs Assessment three-year study highlight the current state of Ohio's HIV care system, the experiences of Ohio's PLWHA, and concrete next steps to better meet the needs of clients to increase engagement in HIV care. Participating providers identified key insights into the current practices and climate of service provision to Ohio's PLWHA. Many HIV-related services and community support services that clients report needing are viewed as lower quality by Ohio's HIV providers. There is greater need to adopt culturally competent best practices at all stages of care. Many strengths and barriers to improvement were identified in Ohio's current HIV care system.

Strengths

- 1. Ohio PLWHA have access to quality HIV-related care.** Nearly all surveyed providers across the state of Ohio agreed that HIV-related services and resources such as medical care, prevention services, testing services, case management, Linkage to Care Specialists, and pharmacies that carry Antiretroviral Therapy (ART) medications and other HIV-related medications are available in their communities. In addition, more than 75 percent of all providers rated these services as good or excellent in their community.
- 2. The majority of clients who engage in care are achieving viral suppression.** Ohio's Ryan White HIV/AIDS data and self-reported data from providers in the year three study indicate that approximately 8 out of every 10 PLWHA who are engaged in care are virally suppressed. Survey responses indicate providers perceive the HIV care system is most effective at prescribing antiretroviral therapy and achieving viral suppression in their clients/patients compared to all other HIV-related activities and outcomes. Despite these good outcomes, 20 percent of PLWHA in care are not virally suppressed and this number does not include individuals who are not engaged in care and whose status is unknown.
- 3. With a few exceptions, Ohio providers report effective implementation of best practices in culturally competent care.** Surveyed providers were asked to indicate if their organization conducted a variety of culturally competent best practices and they were also asked to rate the quality of these practices. Most providers agreed that their organization performed these activities and rated them as good or excellent. However, clients identified many opportunities for providers to improve the cultural competence of HIV care and support services in the year one and year two studies.

Barriers

- 1. Community outreach in HIV education is needed.** PLWHA in the year one Needs Assessment survey and year two focus groups indicated that lack of HIV education was a significant factor in their decisions to engage in and retain care. Some delayed engaging in care or remaining in care because they did not realize the severity of the disease. Others experienced rejection from their community due to the stigma of HIV. Combating stigma, greater HIV education, and improved access to effective HIV testing are greatly needed to prevent new HIV infections and motivate PLWHA to be tested and engage in care.

2. Patient-led interaction is needed to engage clients in a culturally competent way.

Clients/patients want their HIV service providers to understand the hardship of living with HIV/AIDS and the physical and emotional fatigue that results from living with the virus. Clients want providers to adopt patient-led interactions to support them in their present state until more barriers to engaging in care are removed for PLWHA.

3. Substance abuse and mental health issues are significant barriers to engaging in care. Client data collected in year one and year two of the Out-of-Care Needs Assessment showed that more than 60 percent of PLWHA reported depression. Mental health needs were reported to interfere with PLWHA's motivation and ability to engage in HIV medical care. Substance abuse and mental health issues are a significant barrier to decreasing the number of out-of-care PLWHA in Ohio.

Lessons Learned

Several learnings throughout the three-year Ohio Out-of-Care Needs Assessment are documented to inform future applied research in Ohio's HIV care system.

- **Increased PLWHA who are out of care would strengthen the conclusions.** Greater representation from PLWHA currently out of care at the time of their participation in the survey or focus group would have strengthened the study. The study relies on self-report and retrospective experiences of those who were out of care for an extended period of time in the past. There is confidence in the results because the rich, qualitative data from focus group conversations corroborates the trends found in the Year One Needs Assessment survey, but statewide trends in quantitative data would have added tremendous value. Stronger conclusions and recommendations to engage PLWHA in care could have been made with a robust sample of actual out-of-care PLWHA.
- **Southeast Ohio is underrepresented by providers and clients.** Greater participation from Southeast Ohio would have improved the understanding of HIV-positive individuals' experiences living with the disease and accessing care in this region. Southeast Ohio is known to be culturally unique from the rest of the state and a resource-poor region, likely with unique needs and challenges to HIV care delivery. More must be known about PLWHA's needs living in Southeast Ohio and how the HIV care system is currently addressing those needs.
- **Leverage local partnerships to access hard-to-reach populations of PLWHA.** Future statewide needs assessments in HIV care would benefit from creating more intentional, strategic partnerships. Many HIV-positive individuals face physical and emotional challenges and wish their status to remain private. This makes it difficult to research the full population of PLWHA in Ohio. Strategic connections between the research team and targeted providers or partnerships may have resulted in greater participation by remote or hard-to-reach populations. For example, future studies might pursue inviting PLWHA for surveys or interviews by partnering with supportive services to access out-of-care PLWHA when they are interacting with their case worker or social service personnel, rather than primarily leveraging relationships with medical facilities. Developing relationships throughout the study was successful, but often not well-timed to invite hard-to-reach populations at the optimal moment.

- **Create an electronic database of HIV service providers.** A database of HIV service providers will be necessary to facilitate change and develop communication plans for changes that occur to the HIV system of care. All data in this study relied on convenience sampling because no such database exists. Random sampling was not possible, therefore mitigating the generalizability of the results to all communities from which the provider responses are attributed.

Recommendations to Increase PLWHA's Engagement in Care

The following recommendations and concrete next steps were derived from the three-year Out-of-Care Needs Assessment results. These select recommendations are believed to have potential for the greatest impact on Ohio's HIV care system and clients' willingness to engage in and remain in HIV care in the near future.

- 1. Address mental health needs of PLWHA; it is a significant barrier to engagement in care.** All exceptional HIV service providers interviewed described a significant need for mental health assessment and treatment for their HIV clients. Nearly all (91%) HIV service providers in the year three survey reported having mental health services in their communities, but only 32 percent were rated as demonstrating excellence and cultural competence. Clients reported substance abuse and mental health issues as significant barriers to their HIV care. Greater understanding of the type and quality of mental health services available to PLWHA throughout Ohio is needed to meet the mental health needs of PLWHA.
- 2. Design marketing campaigns and efforts to change "the face of AIDS" and the stigma of HIV.** Some PLWHA will not engage in care because they are ashamed to walk in the front door of an organization which had "AIDS" in their name or an infectious disease clinic, even if they know it is the best care available to them. Clients in the year two focus groups repeatedly discussed that the true "face of HIV/AIDS" is a healthy-looking person, not a gaunt frame that is typically the stereotype. The stigma is very real to Ohio's PLWHA, especially those in the rural and Appalachian areas. Clients specifically stated that stigma is a significant reason they have fallen out of care. HIV service providers in the year three survey rated their community's efforts to address and reduce stigma as effective only 25 percent of the time; combating stigma will likely be an essential and challenging endeavor in changing the HIV care system.
- 3. Invest in cultural competency training and medical continuing education units (CEUs) related to compassionate HIV care.** Additional training in culturally competent HIV care is encouraged for Ohio's HIV service providers. Overall, most cultural competency concepts are endorsed by HIV service providers as already present in their organizations, though the year one and year two client results suggest the cultural competency is not to the extent that clients/patients would also view it as meeting their needs. This presents an opportunity to capitalize on existing attitudes and practices to increase culturally competent HIV medical care. Exceptional HIV service providers identified by clients in the year two focus groups were all extremely knowledgeable of how to deliver culturally competent care in their communities, which clients reported as a key reason they stayed engaged in care with that HIV provider.

- 4. Target services in Quadrant IV to improve access and quality of non-HIV support services needed by PLWHA.** Increasing services in Quadrant IV (Figure 14, page 30) ensures that efforts are going towards services that are reported to be needed by a majority of PLWHA. The year one client Needs Assessment survey revealed that dental care, food assistance, mental health treatment, and various other forms of assistance were needed but not received by a significant portion of PLWHA. The year three HIV Service Professionals Insight Survey revealed that these same services are of perceived lower quality than other HIV services and social supports. Improving the access and quality of services in Quadrant IV is expected to positively influence the population of HIV-positive individuals throughout Ohio and support those who are engaging in or retained in care.
- 5. Pursue the Implementation of Integrated HIV Prevention and Care Plan Goals.** The findings of this three-year study align to the Ohio Integrated HIV Prevention and Care Plan 2017-2021. The focus of the Ohio Integrated HIV Prevention and Care Plan is on how Ohio could impact HIV through a common framework that is readily understood by all. Results for the three-year Out-of-Care Needs Assessment suggested the following recommended next steps for select Integrated HIV Prevention and Care Plan goals. Some goals were not explicitly supported or opposed by the results of the three-year Needs Assessment and therefore are omitted below.
- **Goal 1: Develop and Implement *Data to Care*.** The results of the three-year study support *Data to Care*, the use of HIV surveillance data as a primary data source to identify HIV-diagnosed individuals not in care. The data support adopting culturally competent best practices at the DIS and Linkage to Care stage to link newly diagnosed PLWHA and engage them before they can fall out of care. Linkage to Care Specialists are among the highest in reported change readiness and may be a good intervention point to support this.
 - **Goal 1A: Create an Ohio Care Continuum.** The need for an Ohio Care Continuum at 95% completeness is strongly supported by the results of the three-year study. HIV service providers surveyed did not know what variables or other HIV success metrics their organization is tracking. Viral suppression statistics throughout the five Ohio regions are nearly uniform and do not align with perceived regional differences in the HIV system of care delivery as expressed by clients or providers. Data to create a state-level continuum-of-care graph would be valuable to illuminate opportunities to engage PLWHA at each step of the care continuum.
 - **Goal 1B: Improve Data Sharing between Programs.** Surveyed HIV service providers mentioned the need for a coordinated system of care with better data sharing capabilities. Improved data sharing is expected to result in better service delivery to PLWHA.
 - **Goal 2: Improve the Implementation of Linkage to Care.** Two in every three surveyed HIV service providers in the year three study rated the Linkage to Care in their community as very or extremely effective, but retention or engagement in care was viewed less favorably (47% rated very or extremely effective). Improvements to implementing Linkage to Care is supported by the data, though new protocols to address strategies for reengagement in care are also recommended.

- **Goal 5: Address Housing Needs for PLWHA in Ohio.** The data strongly support the need to address housing needs for PLWHA in Ohio in all three years of the study. Housing Assistance was rated as a high need to PLWHA in the year one study. PLWHA frequently discussed the need for housing in the year two focus groups, and HIV service providers in year three deemed housing assistance to be a low-quality service in most communities.
- **Goals 7 and 8: Target Health Disparities.** The disproportionate impact of HIV on communities of color and young men who have sex with other men is supported by the data from all three years of the Out-of-Care Needs Assessment. Results of the three-year study highlight an opportunity to adopt culturally competent best practices, specifically at the DIS and Linkage to Care stage to link PLWHA before they fall out of care.

References

1. Centers for Disease Control and Prevention. (2014b). HIV in the United States: At A Glance. Retrieved from <http://www.cdc.gov/hiv/statistics/basics/ataglance.html>
2. Centers for Disease Control and Prevention. HIV Surveillance Report, 2015; vol. 27. <http://www.cdc.gov/hiv/library/reports/hiv-surveillance.html>. Published November 2016. Accessed April 2017.
3. Ohio Department of Health. (2015). *HIV/AIDS Surveillance Epidemiologic Report for Ohio 2015*. HIV/AIDS Surveillance Program. Retrieved from <https://www.odh.ohio.gov/-/media/ODH/ASSETS/Files/health-statistics---disease---hiv-aids/2015-Data-Tables.pdf?la=en>
4. U.S. Office of AIDS Policy. (July 2010). *National HIV/AIDS Strategy for the United States*. <https://www.whitehouse.gov/sites/default/files/uploads/NHAS.pdf>
5. Bangsberg, D. R. (2006). Less than 95% adherence to nonnucleoside reverse-transcriptase inhibitor therapy can lead to viral suppression. *Clinical Infectious Diseases: An Official Publication of the Infectious Diseases Society of America*, 43(7), 939-941.
6. Lalani, T., & Hicks, C. (2008). Does antiretroviral therapy prevent HIV transmission to sexual partners? *Current Infectious Disease Reports*, 10(2), 140-145.
7. Paterson, D. L., Swindells, S., Mohr, J., Brester, M., Vergis, E. N., Squier, C., & ... Singh, N. (2000). Adherence to protease inhibitor therapy and outcomes in patients with HIV infection. *Annals of Internal Medicine*, 133(1), 21-30.
8. Mugavero, M. J., Rivet Amico, K., Horn, T., & Thompson, M. A. (2013). The state of engagement in HIV care in the United States: From cascade to continuum to control. *Clinical Infectious Disease*, 57, 1164-1171.
9. Centers for Disease Control and Prevention. (2016, July). Understanding the HIV Care Continuum. Retrieved August 2016, from National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention: www.cdc.gov/hiv/pdf/library/factsheets/cdc-hiv-care-continuum.pdf
10. Centers for Disease Control and Prevention. CDC Fact Sheet: HIV in the United States: The Stages of Care, 2014. Retrieved August 2016, <http://www.cdc.gov/nchhstp/newsroom/docs/factsheets/hiv-stages-of-care-factsheet-508.pdf>
11. Schranz, A. J., Brady, K. A., Momplaisir, F., Metlay, J. P., Stephens, A., & Yehia, B. R. (2015). Comparison of HIV outcomes for patients linked at hospital versus community-based clinics. *AIDS Patient Care and STDS*, 29, 117-125.

12. Kalichman, S. C., Kelly, J. A., Hunger, T. L., Murphy, D. A., & Tyler, R. (1993). Culturally tailored HIV-AIDS risk-reduction messages targeted to African-American urban women: Impact on risk sensitization and risk reduction. *Journal of Consulting and Clinical Psychology*, 61, 291-295.
13. Hightow-Weidman, L. B., Jones, K., Wohl, A. R., Futterman, D., Outlaw, A., Phillips II, G., Hidalgo, J., & Giordano, T. P. (2011). Early linkage and retention in care: findings from the outreach, linkage, and retention in care initiative among young men of color who have sex with men. *AIDS Patient Care and STDS*, 25, S31-S38.
14. Centers for Disease Control and Prevention. CDC Fact Sheet: HIV in the United States: The Stages of Care, 2014. Retrieved August 2016, <http://www.cdc.gov/nchhstp/newsroom/docs/factsheets/hiv-stages-of-care-factsheet-508.pdf>
15. Craw, J. A., Gardner, L. I., Marks, G., et al. (2008). Brief strengths-based case management promotes entry into HIV medical care: results of the antiretroviral treatment access study-II. *Journal of Acquired Immune Deficiency Syndrome*, 47, 597–606.
16. Gardner, L. I., Metsch, L. R., Anderson-Mahoney, P., et al. (2005). Efficacy of a brief case management intervention to link recently diagnosed HIV-infected persons to care. *AIDS*, 19, 423-431.
17. Gardner, L. I., Metsch, L. R., Anderson-Mahoney, P., et al. (2005). Efficacy of a brief case management intervention to link recently diagnosed HIV-infected persons to care. *AIDS*, 19, 423-431.
18. Gardner, L. I., Marks, G., Craw, J.A., et al. (2012). A low-effort, clinic-wide intervention improves attendance for HIV primary care. *Clinical Infectious Diseases*, 55, 1124-1134.
19. Naar-King, S., Bradford, J., Coleman, S., Green-Jones, M., Cabral H., Tobias, C. (2007). Retention in care of persons newly diagnosed with HIV: Outcomes of the Outreach Initiative. *AIDS Patient Care and STDs*, 21, S40-S48.
20. Hightow-Weidman, L. B., Jones, K., Wohl, A. R., Futterman, D., Outlaw, A., Phillips II, G., Hidalgo, J., & Giordano, T. P. (2011). Early linkage and retention in care: findings from the outreach, linkage, and retention in care initiative among young men of color who have sex with men. *AIDS Patient Care and STDS*, 25, S31-S38.
21. Wohl, A. R., Garland, W.H., Wu, J., et al. (2011). A youth-focused case management intervention to engage and retain young gay men of color in HIV care. *AIDS Care*, 23, 988-997.
22. Bradford, J. B., Coleman, S., & Cunningham, W. (2007). HIV System Navigation: An emerging model to improve HIV care access. *AIDS Patient Care and STDs*, 21, S49-S58.

23. Wolitski, R. J., Kidder, D. P., Pals, S. L., et al. (2010). Randomized trial of the effects of housing assistance on the health and risk behaviors of homeless and unstably housed people living with HIV. *AIDS Behavior*, 14, 493-503.
24. Andersen, M., Hockman, E., Smereck, G., et al. (2007). Retaining women in HIV medical care. *Journal of the Association of Nurses in AIDS Care*, 18, 33-41.
25. Centers for Disease Control and Prevention. CDC Fact Sheet: HIV in the United States: The Stages of Care, 2014. Retrieved August 2016, <http://www.cdc.gov/nchhstp/newsroom/docs/factsheets/hiv-stages-of-care-factsheet-508.pdf>
26. Saberi, P., Torsten, B., Vittinghoff, E., Johnson, M., Chesney, M., & Cohn, S. E. (2015). Barriers to antiretroviral therapy adherence and plasma HIV RNA suppression among AIDS Clinical Trial Group study participants. *AIDS Patient Care and STDs*, 29, 111-116.
27. Blank, A. E., Fletcher, J., Verdecias, N., Garcia, I., Blackstock, O., & Cunningham, C. (2015). Factors associated with retention and viral suppression among a cohort of HIV+ women of color. *AIDS Patient Care and STDs*, 29, S27-S35.
28. Gilbert, E. M. & Gerzenshtein, L. (2016). Integration of outpatient infectious diseases clinic pharmacy services and specialty pharmacy services for patients with HIV infection. *American Journal of Health-System Pharmacy*, 73, 272-278.
29. Wagner, G. J., Linnemayr, S., Ghosh-Dastidar, B., Currier, J. S., Hoffman, R., & Schneider, S. (2016). Supporting Treatment Adherence Readiness through Training (START) for patients with HIV on antiretroviral therapy: Study protocol for a randomized controlled trial. *Trials*, 17: 162.
30. Schranz, A. J., Brady, K. A., Momplaisir, F., Metlay, J. P., Stephens, A., & Yehia, B. R. (2015). Comparison of HIV outcomes for patients linked at hospital versus community-based clinics. *AIDS Patient Care and STDs*, 29, 117-125.
31. Crawford, T. N. (2014). Poor retention in care one year after viral suppression: A significant predictor of viral rebound. *AIDS Care*, 26, 1393-1399.
32. Centers for Disease Control and Prevention. CDC Fact Sheet: HIV in the United States: The Stages of Care, 2014. Retrieved August 2016, <http://www.cdc.gov/nchhstp/newsroom/docs/factsheets/hiv-stages-of-care-factsheet-508.pdf>
33. Lavizzo-Mourey, R. J., & Mackenzie, E. (1995). Cultural competence – An essential hybrid for delivering high quality care in the 1990s and beyond. *Transactions of the American Clinical & Climatological Association*, 107, 226–235; discussion 236–227.

34. Schilder, A. J., Kennedy, C., Goldstone, I. L., Ogden, R. D., Hogg, R. S., & O'Shaughnessy, M. V. (2001). "Being dealt with as a whole person." Care seeking and adherence: the benefits of culturally competent care. *Social Science & Medicine*, 52, 1643-1659.
35. Cross T, Bazron BJ, Dennis KW, et al. Towards a culturally competent system of care. Washington: National Institute of Mental Health, Child and Adolescent Service System Program. 1989;13.
36. Schilder, A. J., Kennedy, C., Goldstone, I. L., Ogden, R. D., Hogg, R. S., & O'Shaughnessy, M. V. (2001). "Being dealt with as a whole person." Care seeking and adherence: the benefits of culturally competent care. *Social Science & Medicine*, 52, 1643-1659.
37. Holt, D. T., Armenakis, A. A., Field, H. S. & Harris, S. G. (2007). Readiness for organizational change: The systematic development of a scale. *Journal of Applied Behavioral Science*, 43, 232-255.