

APPROACHES TO STRENGTHEN LINKAGE-TO-CARE REFERRAL NETWORKS FOR YOUTH LIVING WITH HIV

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## **ABSTRACT**

Hanna Kiros Tesfasyone: Approaches to Strengthen Linkage-to-Care Referral Networks for Youth Living with HIV  
(Under the direction of Byron Powell)

New initiatives are needed to help foster better collaboration among health agencies and providers to ensure youth living with HIV are linked to care. This dissertation examines how several inter-agency HIV programs came together to address the fragmented LTC referral process. I examine their attempt to establish a formal HIV LTC referral network between health departments, the criminal justice system, and agencies that oversee HIV testing, promote community health, and deliver medical care. My conclusions explain barriers to partnership and strategies to overcome them. Barriers included a lack of collaboration between health sites primarily due to co-location of HIV testing and care services, an absence of a culture of collaboration within the organization and in the community, competition-focused federal funding requirements for program implementation, health sites' inability to utilize HIV surveillance data to swiftly locate youth out of care and link them to youth-friendly services, poor staff selection to spearhead the LTC referral network, and a non-cooperative approach between health sites to engage agencies in the community to join the LTC referral network. Key strategies to overcome these barriers include: use of coalitions made up of diverse stakeholders to support LTC referral networks; inter-agency capacity-building support to staff to provide youth-friendly services; leadership involvement on daily decisions, and partnership advocacy in the community.

I dedicate this dissertation to my loving family: Kiros, Weini, Teddy, Jeremy and Stinky.

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## LIST OF ABBREVIATIONS

AIDS	Acquired Immunodeficiency Syndrome
AMTU	Adolescent Medicine Trial Unit
ART	Antiretroviral Therapy
ASO	AIDS Service Organizations
ATN	Adolescent Medicine Trials Network
COH	Commissioner of Health
C2P	Connect to Protect
CDC	Centers for Disease Control and Prevention
CFR	Code of Federal Regulations
DIS	Disease Intervention Specialist
DOC	Department of Correction
HD	Health Department
HIPAA	Health Information Portability and Accountability Act
HIV	Human Immunodeficiency Virus
HRSA	Health Resources and Services Administration
IRB	Institutional Review Board
ISF	Interactive System Framework
LGBTQ	Lesbian, Gay, Bisexual, Transgender, and Queer
LTC	Linkage-to-Care
MOH	Ministry of Health
MOU	Memorandum of Understanding
MSM	Men Who Have Sex with Men
NCC	National Coordinating Center
NHAS	National HIV/AIDS Strategy
NIH	National Institutes of Health
PEACOC	Project for the Enhancement and Alignment of the Continuum of Care for HIV-Infected Youth

PEPFAR	President’s Emergency Plan for AIDS Relief
PHA	Public Health Authority
PHI	Protected Health Information
PI	Principal Investigator
PLWH	People Living with HIV
PrEP	Pre-Exposure Prophylaxis
RWD	Ryan White Part D
SMAIF	Secretary’s Minority AIDS Initiative Fund
VL	Viral Load
YLWH	Youth Living with HIV

## **CHAPTER 1: BACKGROUND AND SPECIFIC AIMS**

### **Background**

In the United States, the number of Black and Latinx youth living with HIV (YLWH) continues to rise in part due to the national health care system's unsuccessful linking of YWLH to medical care (Kasedde et al., 2013; Zandoni & Mayer, 2014). Since the early years of the epidemic, several points of care have emerged throughout the United States to provide medical and social services for people living with HIV (PLWH) (Rosenberg, 2010). Many of these points of care existed before the epidemic's onset and were then reorganized to provide HIV-related services (Rosenberg, 2010). These points of care, or agencies and organizations, include the following: hospitals, AIDS service organizations, federally qualified health centers, community clinics, academic medical centers, community service organizations, emergency departments, criminal justice systems, health departments, and social service agencies. As the number of HIV-related service providers has grown, so too has concern about the growing chasm between public health systems (e.g. testing agencies) and medical care systems (e.g. hospitals, community clinics, federally qualified health centers), lack of coordination among agencies, and unnecessary duplication of effort (Rier & Indyk, 2006; White House Office of National AIDS Policy, 2015). This confluence of issues has led to low rates of PLWH getting linked to medical care (Philbin et al., 2014; Rier & Indyk, 2006). According to the Centers for Disease Control and Prevention (CDC), approximately 20 percent of the 1.2 million PLWH in the U.S. are undiagnosed; 33% of whom are not in routine care (CDC, 2015).

In recent years, funding agencies have prioritized the need for coordination among different points of care to provide medical and nonmedical services to PLWH by mandating organizations to develop systematic linkage-to-care (LTC) protocols. In 2010, the White House Office of National HIV/AIDS Policy introduced the National HIV/AIDS Strategy (NHAS), a detailed plan to reduce the HIV epidemic in the United States (White House Office of National AIDS Policy, 2010). In 2015, a revised NHAS plan specially called for a less fragmented health care system (White House Office of National AIDS Policy, 2015). Specifically, NHAS called for efforts to "...adopt

structural approaches to reduce HIV infections and improve health outcomes in high-risk communities...” (Goal 3, Step 3b) and to “...increase the coordination of HIV programs across federal government and between federal agencies, state, territorial, tribal, and local governments...” (Goal 4, Step 4a) (White House Office of National AIDS Policy, 2015). The 2015 NHAS set an additional goal: 85% of patients are referred to appropriate care within 90 days of their HIV diagnosis (White House Office of National AIDS Policy, 2015). According to CDC’s 2015 National HIV Prevention Progress Report, which is aligned with NHAS LTC goal, the linkage to HIV medical care was 82.1% and remained stable across age, race/ethnicity, and transmission risk subgroups- with the exception of a 4% decline among 13-24 years old (CDC, 2015). Moreover, the report called on the HIV community to develop protocols and strategies for ensuring linkage to HIV medical care among young people, especially Blacks (CDC, 2015). Research has shown that LTC is not a straightforward process with only 66% of identified YLWH LTC (Philbin et al., 2016). Often research depicts progress from HIV testing to LTC and engagement in care as one stop, thus, there is little written on the role of getting PLWH from the HIV testing site to their first medical appointment known as LTC.

ATN research results showed the important role timing plays in the initial step from referral of YLWH to getting linked to medical care. Specifically, research findings revealed that YLWH linked to their first medical appointment within 28 days of referral to medical care had a higher likelihood of being engaged in care than those referred after one year (Philbin et al., 2016). Similarly, individuals linked to care on the same day as referral and within 21 days of referral had a higher likelihood of being engaged in care than those linked between 22-42 days after referral (Philbin et al., 2016). Thus, these research findings reveal that organizations focused at the early stage of the referral process had an influence on YLWH adherence to appointments. Research also showed that youth are more likely to get LTC if YLWH are referred to a youth-friendly clinic (Philbin et al., 2016). These research results support the 2020 NHAS call for newly diagnosed PLWH to be linked to medical care within one month of their diagnosis (White House Office of National AIDS Policy, 2020).

The above results demonstrate the important role timing plays in LTC, suggesting the need for both a LTC infrastructure such as an LTC referral network that consists of close collaborations between different agencies to facilitate the referral process. Progress has been made in getting PLWH LTC through interventions at the individual and clinic levels but not at the systems level (Gardner et al., 2005; Menon et al., 2016). Individual-level

interventions mostly focus on case management, which is a time-limited interaction that assists PLWH to schedule appointments to access care for mental health, substance use, housing, financial, and other social services (Gardner et al., 2005). Clinic-level interventions have focused mostly on increasing the prevalence of HIV tests and then providing PLWH a list of available medical care organizations to receive care (Menon et al., 2016). Until recently only a few empirically sound studies focused on system level approaches (Boyer et al., 2015), specifically studies showcased systems level approaches by developing LTC referral networks (Anaya et al., 2015; Bernard et al., 2016; Gilman et al., 2012; Kinsky et al., 2015; Mitchell et al., 2015; Philbin et al., 2014; Simonsen et al., 2015; Tanner et al., 2013).

The recent studies have attempted to develop LTC referral networks between health departments, testing agencies, community agencies, medical agencies, and other agencies in traditional and nontraditional health care system. The goal of LTC referral networks is to achieve these common goals: Identifying PLWH in the community, getting youth linked to appropriate medical and nonmedical care, and ensuring that PLWH are engaged in medical care (J. D. Fortenberry et al., 2017). Developing interventions at the systems level, such as improving HIV LTC referral networks is vital to achieve the NHAS minimum goal of 85% of patients referred to care (Mugavero et al., 2013). Thus, a need exists to study how communities attempt to create LTC referral networks for YLWH that creates continual coordination among health departments, community service agencies, and medical care agencies to ensure YLWH stay healthy, routinely receive care, maintain a low viral load, and reduce further transmission (Philbin et al., 2016; Tanner et al., 2013).

### **Specific Aims**

To recommend a viable way to fulfill the NHAS goal, I researched real-life examples of how agencies developed LTC referral networks for YLWH. Also, I evaluated barriers in achieving such networks and strategies to overcome them. Collaboration between the CDC, the HRSA, the Adolescent Medicine Trials Network ([ATN], an HIV clinical research network), and the National Institutes of Health (NIH) resulted in three HIV service delivery partnerships between Adolescent Medicine Trial Units (AMTU) here-in-after referred to as the CDC/NIH sites and Ryan White Part D (RWD) sites that came together to develop a LTC referral network. The Project for the

Enhancement and Alignment of the Continuum of Care (PEACOC) was implemented over a three-year period from 2013 through 2016.

I examined the implementation of one of PEACOC's goals: to develop a LTC referral network between two HIV service delivery units that collaborate to form partnerships with one another and with other community partners (e.g., health departments, testing agencies) to strengthen the surrounding HIV service delivery system's LTC referral network (J. D. Fortenberry et al., 2017). Each of PEACOC's three LTC referral networks required a formal memorandum of understanding (MOU) between agencies to detail the partnership's LTC referral process (J. D. Fortenberry et al., 2017). The federal agencies' expected outcome for the CDC/NIH-RWD partnership was to promote an increase in referral rates, faster linkages to medical and non-medical care, allow for a more thoughtful matching of youth's needs with a youth-friendly agency in the community, and reduce duplication of effort among agencies (J. D. Fortenberry et al., 2017).

I used a multiple case study design to conduct an in-depth evaluation of PEACOC's HIV LTC referral networks (Stake, 2006). I chose a multiple case study design because case studies provide more nuanced understanding of the project. Moreover, several case studies allow researchers to examine of how contextual factors influenced implementation of the project. I defined each case as a LTC referral network—there are a total of three cases. Each case summarizes the staff's individual experiences in the LTC referral network. Each case (i.e., LTC referral network) is in a different state.

The dissertation's secondary data analysis utilized interview data to conduct a qualitative content analysis to create new knowledge from raw unordered data, as well as examined individual cases in a systematic manner. There are enough similarities in each network to conduct a cross-case analysis of barrier data across all three cases. Review of partnership-related documents provided valuable foundational information on LTC referral network development, as well as validate and supplement findings found in the analysis of secondary data found in the interview data.

According to John W. Creswell, the key to developing a good case study research involves a description of the case (Creswell, 2016). Thus, in aim 1, each case study provided a description of the LTC referral network. Aim I included the following layout: background information about the PEACOC program, description of the HIV LTC landscape, description of the two agencies (the RWD and the CDC/NIH sites), staff's roles and responsibilities, the

CDC/NIH-RWD partnership's approach to community engagement to expand the LTC referral network, and key partnerships targeted to join the LTC referral network.

Aim 2 examined barriers to establish the LTC referral network, and strategies used to overcome barriers. In addition, I conducted a cross-case analysis to better understand similarities in barriers across partnerships. Aim 1 and Aim 2 results coupled with literature findings were used to develop my plan for change to improve the LTC referral networks (Stake, 2006). In conclusion, my dissertation aims are the following:

Aim 1: Describe the linkage-to-care referral networks utilized in three HIV service delivery partnerships;

Aim 2: Identify barriers to a partnered approach to establish a LTC referral network, and examine strategies used to overcome barriers; and

Aim 3: Create an action plan (plan for change) to implement LTC referral networks

### **Aim 1 Overview**

Although LTC is a crucial initial step in the HIV continuum of care, relatively little is known about how to effectively implement formal LTC referral networks in the United States. Not having a formal youth-specific LTC referral network has been a systematic barrier for youth to access care that meets their needs (J. D. Fortenberry et al., 2017; Magnus et al., 2012). Moreover, the term LTC referral network is generic for a process that is very complex because it requires a lot of coordination among several agencies and the implementation of a network takes a variety of approaches (Christopoulos et al., 2011; Christopoulos et al., 2013; Khosla et al., 2016; Tanner et al., 2013). Therefore, I conducted research to examine the characteristics for the development of a LTC referral network, especially for YLWH.

My dissertation sought to understand how agencies lay the foundation for the LTC referral network specifically designed to ensure that YLWH are LTC. An examination of the various approaches and characteristics of the LTC referral network could guide the development of future partnerships focused on YLWH. In addition, my findings may create an opportunity for HIV-focused agencies to become more interconnected to improve youth's ability to initiate their medical care and non-medical care services.

To accomplish aim 1, I used a multiple case study design to conduct a descriptive, qualitative data analysis to examine how each CDC/NIH-RWD partnership formed to expand its local LTC referral network. Also, I identified



issues that influenced the type of relationship between the CDC/NIH site and the RWD site to approach expanding their communities' LTC referral network (Yin, 2014). Understanding this level of detail can provide unique information about what to expect when creating linkages between agencies (Cross et al., 2009). A descriptive, multiple case study analysis provides useful information for practitioners and policymakers, enabling a deeper understanding of developing LTC referral networks in different contexts.

Case study data came from transcripts of qualitative interviews with partnership program staff who created and implemented the LTC referral network and the data was triangulated with partnership-related documents (Community Impact Plan). The methodology for data coding will follow qualitative content analysis (Forman & Damschroder, 2007). Using NVivo Version 12, I applied qualitative content analysis to conduct inductive and deductive coding. Figure 1 (Conceptual Framework) in Chapter 3 was used to code the a priori themes found in transcript data and partnership-related documents.

Lastly, my research shifts the responsibility of LTC referrals from youth to the HIV service delivery system. This approach is similar to system-change initiatives that target entities, not people, to make changes in programs, practices or policies, and shape the community landscape to promote improved health outcomes (Boyer, et al., 2016; J. D. Fortenberry et al., 2017). System-change interventions are greatly needed because Black and Latinx YLWH experience daily barriers getting LTC due to the hallmarks of health disparities, such as racism, marginalization, unequal power, and differential resources (Boyer et al., 2016; J. D. Fortenberry et al., 2017). Therefore, such system-change interventions—e.g., developing a strengthened LTC referral network among agencies in the HIV service delivery system—are needed to identify ways to alleviate health disparities for YLWH.

## **Aim 2 Overview**

My research into the factors that inhibit LTC partnerships will help service delivery agencies address challenges towards developing close partnerships. I used a multi-case study design to capture these factors for case studies in three states. It is possible that each city experienced similar barriers and employed similar strategies to overcome the barriers. To illustrate these similarities in barriers, I used a cross-case analysis to provide information that federal agencies, practitioners, and researchers could use to consider before implementing their own LTC referral networks.

Case study data came from the transcripts and partnership-related document (Community Impact Plan). Qualitative content analysis was used as the methodology for data coding (Forman & Damschroder, 2007). Using NVivo Version 12, I applied qualitative content analysis to conduct inductive and deductive coding. Use of theory in studies can help identify factors that predict the likelihood of implementation success and help develop better strategies to overcome barriers, thereby strengthening the understanding and explanation of how and why implementation succeeds or fails (Damschroder et al., 2009). Thus, barrier codes followed the a priori codes identified in the literature review, Organizational Readiness Framework and Interactive Systems Framework (Scaccia et al., 2015; Wandersman et al., 2008). In addition, I used inductive coding to identify barriers and the strategies providers utilized to overcome barriers.

I examined barriers to the LTC referral network from the perspective of persons who provide HIV care services, a perspective that has rarely been described in the literature (J. D. Fortenberry, Martinez et al., 2012; Gilman et al., 2012). Practitioners have knowledge about referral barriers based on their extensive service provision to YLWH (J. D. Fortenberry et al., 2012). Currently, there exists a knowledge gap in strategies used to overcome partnership barriers to establish formal LTC referral networks. As health care agencies undertake improving LTC rates in their communities, they will benefit from a documentation of strategies that enable successful collaborations among different sectors in health care or within the HIV subsector. Moreover, documenting how partnerships create and implement strategies to overcome barriers offers opportunities for improving the science and practice of partnerships to improve the HIV LTC referral networks. My conclusions may help future partnerships realize the NHAS goal of 85% LTC referral rate within 90 days of an individual's HIV diagnosis.

### **Aim 3 Overview**

My action plan is based on the results of my cross-case analysis and literature review of best practices implemented after 2016 to support the LTC referral network. My action plan, in its final form, will bring a set of approaches to jump start efforts and/or improve implementation of LTC referral networks. For the sites that have already embraced the value of improving the LTC referral network, my action plan provides additional rigor to the decision-making process to use specific strategies to implement LTC referral networks.

## **CHAPTER 2: NARRATIVE LITERATURE REVIEW**

### **A Disorganized HIV Service Delivery System**

After the first case of HIV was diagnosed in 1981 but before antiretroviral medications were introduced in 1987, clinicians were aware of HIV but unable to treat it (Rosenberg, 2010). Due to HIV's rapid spread and lack of treatment options, agencies capable of providing services to PLWH were in short supply. Grassroots agencies—called AIDS service organizations (ASOs)—which were independent of the traditional health care system, arose to fill this void and became the default treatment centers and social service providers for PLWH (Rosenberg, 2010).

As the HIV epidemic expanded in the mid-1990s, so did AIDS research and medical treatment options. Once treatment options were available, the government began to fund ASOs in earnest, which in turn led to the establishment of many new ASOs (Rosenberg, 2010). As the HIV service network continued to grow, so did its complexity, increase in the number of organizations serving PLWH, and its disorganization among all the agencies. Providers, patients, and funding agencies had difficulty staying abreast of this rapidly changing network of ASOs, which caused redundancies in care.

### **Obstacles to More Unified Coordination**

Almost 40 years later, this disorganization among the loosely connected network of HIV service providers persists and continues to impede delivery of services to PLWH. PLWH often receive little external assistance to navigate this complex system. This can result in the interruption of care or worse: no care at all. As stated previously, one challenge to effective service coordination is the number of agencies that patients must negotiate to access HIV care. But what does this care system look like? HIV/AIDS service delivery system is comprised of the following key provider groups: testing agencies, hospital-based clinics, academic medical institutions, outpatient clinics at local health departments, community health centers, federally qualified health centers, private clinics, emergency departments, school clinics, inpatient clinics in criminal justice systems, and community-based agencies. Also, there are health care facilities within non-health care institutions—such as correctional centers,

homeless shelters, or religious agencies—that provide HIV care to their HIV-positive clients who may be difficult to reach through the traditional health care system (Anaya et al., 2015; Simonsen et al., 2015; Stewart et al., 2016).

Providing comprehensive medical care to PLWH requires getting PLWH linked to medical and nonmedical care that meet their specific needs; however, agencies within these categories usually offer only a few specialized services and may serve only one or more specialized target groups (e.g., men who have sex with men [MSM]) (Philbin et al., 2014). For example, one clinic might provide HIV medication services only, while another may offer inpatient care, mental health counseling, case management, and support groups. Therefore, there is a need to forge a LTC referral network among multiple agencies to get PLWH linked to the agency that best meets their specific needs. Continual coordination among entities to ensure that no duplication of effort occurs constitutes the need for an LTC referral network. Tanner et al. (2013) showed that developing a LTC referral network requires a high degree of coordination among the several agencies involved in the partnership (Tanner et al., 2013). Moreover, Tanner et al. (2014) highlighted the importance of creating integrated systems of care to ensure that regardless of where PLWH are referred from, they are referred to a clinic that best meets their medical and non-medical needs (Tanner et al., 2014).

The HIV research community has called for a more comprehensive initiative to develop LTC referral networks (Philbin et al., 2016; Rier & Indyk, 2006). Moreover, newly diagnosed individuals living with HIV have expressed the value in having a health care system that takes ownership of matching the individual to primary care providers who meet that person's needs (Christopoulos et al., 2013). Although there is a need for a more unified coordination, Rier & Indyk (2006) opine that forming partnerships to strengthen the LTC referral network will only occur once providers recognize their inter-dependence to be able to benefit from each other and to provide encompassing care that can meet the needs of PLWH (Rier & Indyk, 2006).

### **Federal Government Wants to Strengthen Referral Networks**

The lack of a coordinated system among providers has become such a massive issue in recent years that now the federal government has called on agencies/providers to strengthen the LTC referral process by establishing LTC protocols. Strong LTC referral networks are necessary to achieve optimal health outcomes for PLWH and to reduce the transmission of HIV in the United States (J. D. Fortenberry et al., 2012). In 2009, with the

realization of uncoordinated services between public health agencies (e.g., health departments and HIV testing agencies) and medical care agencies, the United States Congress reauthorized the Ryan White HIV/AIDS Program, which placed a greater emphasis on ensuring that PLWH receive access to medical care (Gilman et al., 2012). The statute specifically required Ryan White grantees develop plans to identify undiagnosed PLWH, make them aware of their HIV status, and provide them access to medical treatment (Gilman et al., 2012).

In 2010, the White House released its first National HIV/AIDS Strategy (NHAS), a five-year plan that details principles, priorities, and actions to guide the national response to the HIV epidemic in the United States of America (White House Office of National AIDS Policy, 2010). The NHAS focused on the lack of coordination throughout the HIV service delivery system, from national to local levels (White House Office of National AIDS Policy, 2010). In response, in 2011, the CDC released a new five-year grant opportunity for health departments—Comprehensive HIV Prevention Programs for Health Departments—to ensure cooperation and coordination of services between testing agencies and medical care facilities (Gilman et al., 2012).

Further actions by the federal government aimed at increasing HIV focused interagency cooperation can be found in Executive Order No. 13,649, which President Obama issued in 2013 (*Executive Order No. 13649, 78 Fed. Reg. 43057*, February 19, 2013). The Executive order called on federal funded health agencies to draft action plans that increase interagency cooperation and thus strengthen the LTC referral network. This is aimed to ensure that clients go through the sequential steps in the HIV care continuum. In the HIV care continuum, the patient progresses as follows: 1) Diagnosis of HIV infection, 2) Linkage-to-care, 3) Retention-in-medical care, 4) Receipt of antiretroviral treatment (ART), and 5) PLWH achieve viral load suppression. Moreover, the White House Office of National AIDS Policy, in its 2015 NHAS, tasked HIV health service providers to coordinate with each other to improve LTC rates (White House Office of National AIDS Policy, 2015). In addition, the White House Office of National AIDS Policy, for the first time, formally recognized YLWH as a population at-risk of not receiving medical care and recommended, in the NHAS, a coordinated national response to the HIV epidemic for this vulnerable population (White House Office of National AIDS Policy, 2015). To follow this edict, we need a deeper understanding of how agencies develop formal LTC referral networks that specifically target YLWH.

## **Youth Living with HIV Suffer from Lack of Oversight and Assistance**

Studies in the United States have shown that there are significant health disparities by age along the HIV care continuum (Horberg et al., 2015; Zandoni & Mayer, 2014). HIV data show that YLWH aged 13-29 years are dropping off at each stage along this continuum (Zandoni & Mayer, 2014). Zandoni & Mayer (2004) study showed that only 41% of YLWH (13-29 years of age) are aware of their diagnosis, 25% are linked to medical care, 62% are lost to care within 12 months of their diagnosis, 57% are retained in care, and only 6% are virally suppressed (Zandoni & Mayer, 2014). The decrease in regular medical care visits, as YLWH move along the HIV care continuum, also meant that only 6% of YLWH achieved viral suppression (Zandoni & Mayer, 2014).

There is a greater need to develop the LTC referral networks for YLWH. Navigating care in the disjointed health care system is often even more challenging for YLWH since they generally have less experience with the health care system (J. D. Fortenberry et al., 2017). Unfortunately, agencies typically do not provide a hands-on approach to guide YLWH through the HIV health care system, so they often “slip through the cracks”. Even in the hospital setting, where there may be an organized coordination of care, accessing services is effectively still the sole responsibility of YLWH (Tanner et al., 2014). This can result in the failure of timely LTC (Tanner et al., 2013). In addition, for some adolescents, the desire to hide sexual or drug-related activities from parents or family may overpower the fact that they must receive treatment. These YLWH might not seek parental or family support to help them access care because they fear rejection or punishment. Young sexual minorities (gay, lesbian, transgender, etc.) are most likely not to access ART treatment or not remain in ART treatment for such reasons (J. D. Fortenberry et al., 2017).

For these youth, delayed onset of HIV specific medical care typically means YLWH start ART later and adhere to it less closely (Kasedde, et al., 2013; Philbin et al., 2016). Only 76% of YLWH aged 18-24 years have ART prescription, which often leads to increased viral load and transmission risk for this age group (Hall et al., 2012). According to CDC in 2013 only 26% of YLWH aged 18 to 24 years had suppressed viral loads, defined as < 200 copies per ml, meaning that their infection is controlled at level where they can stay healthy and active and that their risk of passing HIV to other is significantly reduced (CDC, 2013). Philbin et al. (2016) showed that YLWH with shorter time intervals between diagnosis and LTC (within 21 days of referral) are more likely to sustain long-term engagement with HIV medical care; individuals who stayed engaged in care had more timely viral load suppression

(Philbin et al., 2016). These research findings underscore the need to focus national attention on strengthening the LTC referral network for YLWH. Thus, establishing a formal LTC referral network among the numerous agencies within a local HIV service delivery system would ensure that HIV-positive sexual, racial, and ethnic minority youth receive care in a timely manner and remain in medical care (J. D. Fortenberry et al., 2017).

### **Specific Need for Partnerships to Form LTC Referral Networks**

The basic need for getting YLWH linked to medical care through a strong LTC referral network is clear, however, information on steps taken to foster interagency partnerships is minimal. This growing field has become more prominent given the focus on federal agencies through the NHAS document first developed in 2010. The NHAS focused on increasing the number of YLWH that are LTC, and increasing federal funds that are allocated to improve the LTC referral network. Contrary to requests from NHAS, the field for attempting to implement a formal process to connect several agencies to strengthen their communities' LTC referral networks is relatively new. Literature on HIV LTC referral networks is minimal, most likely because funding for this initiative first became available in 2009. In addition, the limited literature on LTC referral networks is perhaps likely documented in internal interagency material that is not available to the public. Lastly, the majority of LTC referral networks published consists of very few agencies coming together.

The number of studies describing barriers to LTC referral process has increased since 2012. A review of the current literature (which is sparse) revealed that LTC referral networks vary considerably in the number and type of agencies involved and in the type of interorganizational partnerships implemented—testing agency and health departments, health department and one medical care site, criminal justice system and medical care site, emergency department and medical care site, and collaboration between agencies with different foci (e.g., nutrition, medical, housing) (Anaya et al., 2015; Bernard et al., 2016; Gilman et al., 2012; Kinsky et al., 2015; Mitchell et al., 2015; Philbin et al., 2014; Simonsen et al., 2015; Tanner et al., 2013). Relatively little is known about how to effectively implement the LTC referral networks in the United States, but in general, coordination will require the health departments, the community agencies, and the medical care agencies come together to coordinate services (Philbin et al., 2016; Tanner et al., 2013). The implementation processes to develop a LTC

referral network varies by locale, so insights from practitioners may help policymakers propose better steps to implement LTC referral systems for PLWH (Khosla & Zachary, 2016).

### **LTC Barriers at the Systems, Organization, and Individual Levels**

A review of the literature on the barriers to establishing a LTC referral network is intended to shed light on the literature that explores a phenomenon that is more than likely occurring in almost every organizational setting attempting to implement the LTC referral network across the United States but has not been thoroughly evaluated. Literature from outside the United States were outside the scope of this review. I identified eight empirical studies that used qualitative methods to examine barriers to implementing a formal LTC referral network. Bernard et al. (2016) and Tanner et al. (2013) conducted qualitative interviews to examine partnership initiatives between local health departments' HIV testing agencies and primary care clinics (Bernard et al., 2016; Tanner et al., 2013). Simonsen et al. (2015) and Mitchel et al. (2015) conducted qualitative interviews to examine a LTC referral network between criminal justice system and primary care clinics (Mitchell et al., 2015; Simonsen et al., 2015). Anaya et al. (2015) conducted qualitative interviews to examine a LTC referral network between a primary care clinic run by the US Department of Veterans Affairs and three city or county shelters (Anaya et al., 2015). Philbin et al. (2014) conducted qualitative interviews to examine a comprehensive LTC referral network that aimed to increase coordination among service providers to facilitate access to care (Philbin et al., 2014). Similarly, Kinsky et al. (2015) conducted qualitative interviews to examine LTC referral networks between three or more medical and non-medical agencies in geographically and institutionally diverse settings (Kinsky et al., 2015). Lastly, Gilman et al. (2012) conducted qualitative interviews to examine the LTC referral networks—between hospital emergency departments, health departments, and primary care clinics—that were implemented in geographically and institutionally diverse settings (Gilman et al., 2012).

I drew from the ecological framework to explore the multi-level factors affecting linkage-to-care referral networks. The ecological framework is a common model to explain HIV interventions using the proposed three levels: 1) Systems, (2) Organization, and (3) Individual. I found the ecological framework useful as it assumes that linkage-to-care is influenced by multiple levels and clearly identifies barriers at each level.



## Systems Level Barriers

Previous studies have identified inter-agency competition and misunderstanding of external policies as system-level barriers (Kinsky et al., 2015; Philbin et al., 2014; Tanner et al., 2013).

*Interagency Competition.* Federal funding rules typically require agencies to link HIV clients to care in order to receive continued funding. In fact, Philbin et al. (2014) showed that continued government funding was tied to the number of patients assisted (Philbin et al., 2014). While this funding requirement is arguably necessary, its implementation has led to competition for patients and, thus, an unwillingness to share patient information or refer patients to other agencies for care (Kinsky et al., 2015; Philbin et al., 2014; Tanner et al., 2013). Therefore, this style of funding can inhibit partnerships that aim to improve the LTC referral network (Philbin et al., 2014). As a potential solution, Tanner et al. (2013) suggests that health departments provide central coordination for LTC services to avoid service fragmentation (Tanner et al., 2013).

*Misunderstanding of External Policies.* Another critical barrier to implementing a formal LTC referral network is the misunderstanding in how to properly share personal health information or protected health information (PHI) with other health care agencies to facilitate better LTC (Kinsky et al., 2015; Philbin et al., 2014; Tanner et al., 2013). Some leading HIV law experts argue that public health authorities (PHAs) established with the expressed purpose of preventing or controlling disease may legally be sent patient data at the aggregate level (i.e., number of PLWH receiving care at the agency); this is commonly referred to as de-identified PHI or granting full PHA (i.e., first and last name of person living with HIV). However, having an agency grant another agency PHA is based on each agency's legal team's interpretation of PHA (O'Connor & Matthews, 2011). Tanner et al. (2013) showed that there were local and state health departments in some jurisdictions that hesitated exchanging PHI with medical care agencies based on their interpretation of PHA (Tanner et al., 2013). The external policies focused on provider-patient privilege, yet provider-to-provider privilege does not clearly explain how the law applies to agencies working together to strengthen LTC referral networks.

This misunderstanding of external policies that safeguard PHI has hindered sharing such information in many jurisdictions. For instance, Philbin et al. (2014) reported that the lack of ease in exchanging client information between testing agencies, health departments, and clinics has been attributed to misunderstanding of the Health Information Portability and Accountability Act (HIPAA) privacy rule. One solution to the

misunderstanding of PHI was when the agencies agreed to clients' sign a client release form granting an agency to share PHI with another agency (Philbin et al., 2014).

### **Organization Level Barriers**

Organization-level barriers that have been identified in the literature include availability of resources, complexity, compatibility, and organizational culture (Anaya et al., 2015; Gilman et al., 2012; Kinsky et al., 2015; Mitchell et al., 2015; Simonsen et al., 2015).

*Availability of Resources.* A lack of resources (e.g., financial, physical space, time) has hindered several LTC partnership attempts (Anaya et al., 2015; Kinsky et al., 2015; Simonsen et al., 2015). For example, Simonsen et al. (2015) tried to establish the LTC referral network between the system and primary care clinics (Simonsen et al., 2015). Unfortunately, the criminal justice system was reluctant to establish a referral process with primary care clinics because it would be responsible for the costs of HIV testing and care (Simonsen et al., 2015). This is likely one example of many where the inadequate funding for PLWH in correctional institutions significantly hindered the formation of the LTC partnership.

*Human Resources.* In the community at large, HIV provider shortages (most likely due to lack of funding and other resources) also considerably limit the ability of support agencies to refer patients to health care agencies within the community (Kinsky et al., 2015). Kinsky et al. (2015) showed a shortage of staff and expertise was a barrier to forming the LTC partnerships (Kinsky et al., 2015). The study revealed partnerships require considerable time and an array of expertise to engage PLWH, support the collaborative process, and perform administrative activities (Kinsky et al., 2015). Moreover, the Kinsky et al. (2015) article highlighted that staff typically harbor concerns over the main job responsibilities and the job responsibilities they will have to do to maintain partnerships (Kinsky et al., 2015).

*Complexity.* Complexity of the LTC referral network can also hinder the implementation of a partnership (Anaya et al., 2015; Mitchell et al., 2015). Complexity is the perceived difficulty of implementation reflected by these quantitative and qualitative factors: duration, scope, radicalness, disruptiveness, centrality, intricacy, and number of steps required to implement (Damschroder et al., 2009). In this context, complexity centers on the difficulty of implementing LTC referral protocols with other agencies and modifying institutions' LTC policies. For

example, Anaya et al. (2015) showed that the line of communication created to inform partners to perform the LTC process with other agencies led to additional steps that staff had to follow, which ultimately created more work, though more patients were served (Anaya et al., 2015).

*Compatibility.* Another barrier to the formation of partnerships is the compatibility of the new LTC referral process to the agency's existing patient workflow patterns and systems (Anaya et al., 2015; Gilman et al., 2012). While some agencies welcome the LTC referral network, others view collaboration as unrealistic, taxing, or outside of their job description (Anaya et al., 2015). For instance, one interviewee noted the following: "We're good at providing shelter services. It's not our place to get involved outside of that" (Anaya et al., 2015).

Anaya et al. (2015) also noted that scheduling difficulties between agencies with differing hours of operation may be an important impediment to vulnerable patients (Anaya et al., 2015). Though coordinating clinic hours may be difficult, Anaya et al. (2015) recommended that it is at least imperative agencies have a mutual understanding of a client's medical needs and barriers to care (Anaya et al., 2015). Unfortunately, scheduling difficulties may be one especially prominent barrier for vulnerable populations who need walk-in or same-day appointments to reduce the chance of becoming lost to medical care.

*Organizational Culture.* In order to form a LTC referral network, all agencies involved in the LTC partnership must understand each other's mission and organizational culture—i.e., norms, values, and basic assumptions about the partnership itself (Kinsky et al., 2015; Mitchell et al., 2015). Kinsky et al. (2015) noted that agencies that fail to embrace internal culture of collaboration between departments, or intraorganizational collaboration, also fail to achieve an interagency collaboration (Kinsky et al., 2015). Thus, organizational culture of collaboration is a key factor in partnership formation (Kinsky et al., 2015; Mitchell et al., 2015).

*Implementation Climate.* The agency's implementation climate can be another barrier to achieving the LTC referral network (Gilman et al., 2012). In this context, implementation climate is a stakeholder's capacity for change, shared receptivity of involved individuals to participate in the intervention, and the extent to which the use of that intervention will be expected, supported, and rewarded within the stakeholder's organization (Damschroder et al., 2009). Gilman et al. (2012) showed that a lack of staff buy-in and feedback during the early planning and implementation stages of the referral network between an HIV testing agency and a medical care clinic challenged staff's support for and participation in the LTC referral network (Gilman et al., 2012). Staff's

resistance to adopt the new LTC referral process within the network stemmed from the agency's attempts to integrate new responsibilities into staff's existing clinical responsibilities (Gilman et al., 2012).

### **Individual Level Barriers**

Staff themselves can thwart the successful formation of referral networks. Individual level barriers identified in the literature include unclear roles or division of responsibilities, perceived priority of the partnership, relative advantage, and leadership (Anaya et al., 2015; Gilman et al., 2012; Kinsky et al., 2015).

*Unclear Roles or Division of Responsibilities.* Kinsky et al. (2015) and Anaya et al. (2015) emphasized how staff's unclear roles or division of responsibilities has a direct impact on inter-agency LTC outcome data (Anaya et al., 2015; Kinsky et al., 2015). For example, unclear division of responsibility created delays in getting an individual newly diagnosed with HIV to medical care because staff at the testing agency did not know it was their responsibility to connect PLWH to another agency (Anaya et al., 2015).

*Relative Priority.* Another factor that hindered staff's decision to participate in the LTC referral network is the priority of that partnership among responsibilities that already exist (Anaya et al., 2015; Gilman et al., 2012). In this context, relative priority is defined as staff's perceived importance of the network. In the study conducted by Anaya et al. (2015), one of the interviewees explained that "this initiative was an opportunity we needed to explore, because we had not yet been able to provide services in the shelters...but we just had not scheduled this sort of thing and we hadn't prioritized these kinds of efforts" (Anaya et al., 2015).

*Relative Advantage.* Relative advantage is the extent to which staff view the LTC referral process with another agency as better or worse than working independently to maintain a client in the HIV care continuum (Mitchell et al., 2015). In one example of low-relative advantage, Mitchell et al. (2015) found that staff saw so few HIV-positive inmates released into the community during the course of the study that a new LTC referral network with medical care institutions was not considered advantageous to improving clients' LTC (Mitchell et al., 2015).

*Leadership.* An agency's leadership has a lot of influence on how staff view the priority of the initiative compared to their other responsibilities. Lack of leadership support for the LTC referral network can effectively prevent its formation (Gilman et al., 2012; Kinsky et al., 2015). Since leaders face competing priorities and tight deadlines, it can be challenging to convince leaders to prioritize the partnership formation. Of course, general lack

of leadership can also hinder partnership development (Gilman et al., 2012). Partnerships have the best chance of success when someone within the agency champions the cause (Kinsky et al., 2015).

### **Strategies to Overcome Barriers**

Addressing these barriers is essential to improving LTC (Kinsky et al., 2015; Philbin et al., 2014). Unfortunately, studies have not collected data on what strategies providers have taken to address these barriers. In one study, Philbin et al. (2014), content analysis did indicate that a temporary substitute for fixing structural barriers (e.g., hospital/government policies and practices) may help mollify individual barriers (e.g., paying for patient transportation to the clinic or assisting with other vital needs that may cause patients to deprioritize the medical care system) (Philbin et al., 2014). While these individual-focused efforts are necessary to support LTC, system-level solutions will be essential to achieve goals set by the NHAS (Philbin et al., 2014).

Kinsky et al. (2015) also discussed barriers and gave suggestions on strategies to overcome them; however, these suggestions are not based on providers' perspectives (Kinsky et al., 2015). Thus, addressing barriers using insight from providers remains an area ripe for further inquiry and a logical next step for research. Using information from providers as the basis for designing strategies that tackle barriers to forming partnerships is necessary to meet the HIV care goals set by NHAS.

### **Conclusion**

Interagency collaboration is a widely known and reliably measured concept shown to improve patient outcomes in different areas of research and practice, such as mental health, internal medicine, and chronic care (Tomizawa et al., 2017; Bookey-Bassett et al 2016 and Havyer et al., 2014). Though underdeveloped, the collaborative work across service setting has shown to be beneficial in the implementation of HIV prevention services (Purcell et al, 2016). In 2010, the National HIV/AIDS Strategy requested the HIV community utilize the interagency collaboration concept to connect several agencies to strengthen the HIV referral network. However, interagency collaboration to improve LTC rates is still a relatively new concept. Moreover, the HIV published literature often fails to consider the instrumental role coordination of agencies helps in ensuring YLWH have access to care. In addition, the empirical studies that examine HIV LTC referral networks are clinic based, however, youth are usually disengaged from the medical system and are community found at community-based agencies. Thus,

there is a need to create linkages with community service agencies to maximize engagement of YLWH in the medical care system (Philbin et al., 2016; Tanner et al., 2013). Creation of a formal LTC referral network will foster agencies to make their collective interest in YLWH, rather than the interest of the single agency, when determining where to connect YLWH to services.

Although we have begun to understand barriers to the formation of these networks, we must do more research to identify and overcome barriers to establishing a formal LTC referral network that targets YLWH. Grounded in qualitative data, researchers in this field examined barriers towards implementing a LTC referral network from the perspective of persons who provide HIV care services. The literature presented 12 specific barriers to such connections: competition, misunderstanding of external policies, organization's availability of resources, complexity, compatibility, organizational culture, unclear roles or division of responsibilities, lack of partnership experience, perceived relative priority of the partnership, implementation climate, relative advantage, and leadership (Anaya et al., 2015; Bernard et al., 2016; Gilman et al., 2012; Kinsky et al., 2015; Mitchell et al., 2015; Philbin et al., 2014; Simonsen et al., 2015; Tanner et al., 2013). Moreover, existing literature lacks generalizable information about how organizations implement strategies to overcome these barriers. As health care agencies undertake improving LTC rates in their communities, they will benefit from documentation on strategies that enable successful collaboration among different agencies to improve the LTC referral process. Therefore, there is a need for more research that examines the design and implementation of LTC referral networks, barriers to implementation and strategies used to overcome implementation barriers.

In addition, to better understand the LTC referral network that brought about barriers, it is instrumental to study the whole process of creating linkages. Specifically, research is needed to explore the information pertaining to collaboration between agencies—e.g., how agencies have presented themselves within the community, relationships and collaborations formed to establish networks, frequency of interactions, and duration of interactions. Such research will enable better interpretation of barriers to forming LTC referral networks in communities.

To meet this research need, this dissertation seeks to provide a better understanding of how agencies in a community come together to promote faster linkages to care, increase rates of these linkages, allow for a more thoughtful matching of YLWH to a health care institution, and reduce duplication of effort among agencies—

especially between overlapping care networks so that the agencies involved can collaborate, rather than compete, with one another. My dissertation aims are to 1) Describe the LTC referral networks in Sites A, B and C; 2) Identify barriers to establishing the LTC referral networks and document strategies that have successfully overcome these barriers; and 3) Develop an action plan to guide health care professionals with approaches to establish or expand LTC referral networks in in their communities.

## **CHAPTER 3: RESEARCH DESIGN AND METHODOLOGY**

### **Research Design**

My dissertation sought to provide an understanding of three HIV LTC referral networks that target YLWH aged 12–24 years approached building partnerships with community agencies to facilitate a referral process with health facilities. Specifically, case studies will shed light on barriers encountered and solutions to overcome those barriers. My dissertation employed a multiple case study design, in which each HIV LTC referral network is a case (Stake, 2006). A multiple case study design is useful in understanding how contextual factors affect implementation of the referral network (Stake, 2006). Moreover, while single case study designs lead to valuable insights, most multiple case study designs lead to stronger research designs because they enable researchers to identify similarities between cases (Yin, 2014). Aims 1 and 2 (see below) used a multiple case study design. Aim 3 were based on cross-case analysis results and published articles that have similar program objectives as my dissertation.

Aim 1: Describe the linkage-to-care referral networks utilized in three HIV service delivery partnerships;

Aim 2: Identify barriers to a partnered approach to establish a linkage-to-care referral network, and examine strategies used to overcome barriers; and

Aim 3: Create a plan for change to implement linkage-to-care referral networks

### **Important Features of the Linkage-to-Care Program**

My dissertation examined the LTC program sponsored by the Secretary’s Minority AIDS Initiative Fund (SMAIF) and overseen by the CDC, NIH, HRSA, and ATN, large multi-site research network, to address racial and ethnic disparities among YLWH aged 12–24 years. The ultimate goal of the project was to identify newly diagnosed YLWH and those lost to medical care—and get them linked to medical care within six weeks (42 days) of diagnosis. The LTC program was a national, multisite effort on HIV linkage and reengagement into medical care—over a three-year period from 2013 through 2016. Before PEACOC, there were three protocols sequentially



implemented from 2009 through 2013 to address low rates of linkages for YLWH, with PEACOC protocol as the final CDC, ATN, HRSA, and NIH collaboration to attempt to address the problem. The PEACOC project had multiple interventions implemented in the protocol, therefore, my dissertation only examined a part of a bigger evaluation. Specifically, I examined the partnership between two HIV related health care units to improve the LTC referral network.

PEACOC selected three agencies funded by HRSA's Ryan White Part D (RWD) program. The RWD program main focus is to support women, infants, children, and youths living with HIV. HRSA selected RWD sites through a noncompetitive process, which resulted in the selection of HRSA RWD sites in four cities across the United States. The PEACOC project also had 14 AMTU sites funded by CDC and NIH to continue the 2011 Strategic Multisite Initiative for the Identification, Linkage, and Engagement in Care of Youth with Undiagnosed HIV infection (SMILE 2) protocol. In the SMILE 2 protocol, the AMTUs here-in-after called the CDC/NIH site were charged with providing a wide array of youth-specific services in multidisciplinary clinical environments with well-established adolescent medicine clinicians and staff with experience providing HIV care. In addition to HIV services, the CDC/NIH sites were tasked with building relationships with the community to focus on addressing HIV prevention, care and treatment efforts, and develop an LTC referral network for YLWH through the community mobilization coalition known as Connect to Protect (C2P) coalition.

At the time PEACOC launched in 2013, the project was considered innovative and timely given the recent publication of the first NHAS. Expectation of PEACOC's LTC referral network was to link geographically dispersed and often disconnected agencies to the limited number of youth-friendly HIV specialty care facilities available in most communities (J. D. Fortenberry et al., 2017). In addition, sometimes agencies work in silos because they compete to enroll HIV positive clients to their own institution; therefore, projects are needed to better understand how similar HIV service delivery facilities collaborate to reduce competition through a partnered approach in their respective communities. PEACOC sought to develop a formal LTC referral network by mandating that a RWD site pair with a CDC/NIH site to expand the LTC referral networks that the CDC/NIH site began in 2011. The CDC/NIH-RWD collaboration was overseen by National Coordinating Center (NCC) to provide technical assistance to implement PEACOC program at each site and facilitated cross-sharing of best practices to implement the project.

The underlying justification for the CDC, ATN, HRSA and NIH to pair an RWD site with a CDC/NIH site were the following:

- Anything one agency can do; two agencies can do better.
- Connecting partners that share similar vision and services will lead to improved linkages in care and engagement in care of YLWH.
- Partnership between two similar agencies will reduce service duplication to get YLWH linked-to-care and will address the lack of cross-agency coordination between similar HIV service delivery agencies funded by different federal government agencies.
- Partnership will allow for the transfer of best practices to improve linkages and engagement of YLWH.
- Partnership will address the NHAS goal to improve coordination of care.

Activities to facilitate the CDC/NIH-RWD collaboration to expand the LTC referral networks in their respective cities included all of the following (J. D. Fortenberry et al., 2017):

1. Representation of the RWD site and the CDC/NIH site at coalition meetings
2. Community engagement with local agencies
3. Joint effort to identify and enroll four YLWH into medical care each month
4. The CDC/NIH site sharing best practices working with YLWH
5. Matching youth to most appropriate services that meet their needs
6. Joint approaches to addressing local barriers to HIV-related care for YLWH

### **Data Collection**

My dissertation analyzed secondary data of 15 de-identified interview and partnership-related document data from three CDC/NIH-RWD partnerships. I was also involved in the primary data collection of the data for the PEACOC ATN 28 study. In October 2015, the Principal Investigator for PEACOC ATN 128 study informed CDC, NIH, ATN, and HRSA leadership team that I would like to examine paired CDC/NIH-RWD partnerships in the PEACOC ATN 128 study for my dissertation. I was granted permission to revise the interview guide to address my specific dissertation aims because the sites had already received approval from their local institutional review board (IRB) institutions to examine non sensitive descriptions of the work-related effects of the partnership during the

implementation of PEACOC as it related to interactions with other community partners, and potential effects on health outcomes for patients (i.e., linkage-to-care, engagement-in-care, and retention-in-care activities).

### **Study Participant Sample**

In the PEACOC project, there were six agencies paired into three dyadic partnerships (CDC/NIH-RWD) working together to expand their LTC referral networks. Because the CDC/NIH site and the RWD site were tasked with engaging service providers to increase coordination, each site was given a minimum expectation to coordinate services with one another and attempt to coordinate with the local health department. Each site consisted of a Principal Investigator, LTC Coordinator, and LTC Supervisor funded by CDC-NIH-HRSA-ATN to develop and implement the PEACOC LTC referral network; therefore, interviews were only done for those positions for my dissertation.

The LTC Coordinator's primary function was to promote collaboration among agencies in the community and be the point person for YLWH; thus, all the LTC Coordinators were interviewed for the dissertation. The responsibilities of each Principal Investigator and LTC Supervisor were flexibly adapted to fit site-specific needs; therefore, at some sites, Principal Investigators and/or LTC Supervisors were not sought for an interview because they were known to have minimal involvement in developing formal LTC referral networks. In addition, due to limited HRSA funding at the RWD Site A, the Principal Investigator also assumed the responsibilities of the LTC Supervisor. It should be noted that there were several elements to PEACOC that were not examined in this dissertation; therefore, just because personnel at one site had minimal involvement in the development and implementation of the LTC referral network does not mean that the personnel had minimal involvement in other elements of PEACOC.

There were a total of 18 participants known to be directly involved in the implementation of the LTC referral networks. The participants were selected through purposive sampling to capture their perspectives implementing the partnerships, inclusive of the three-turnover staff (first LTC Coordinator in Site C, first LTC Supervisor in Site A, and first LTC Coordinator in Site B). I interviewed turnover staff from Site A and Site C; however, I was unable to get a response from the first Site B LTC Coordinator to participate in the interview. Fortunately, the replacement LTC Coordinator began shortly after the first one left; therefore, any information

missing as a result of the transition is minimal. In total, 83% (n = 15) of the participants agreed to participate in the interview. Table 1 provides the study participants interviewed at each site.

Digital recordings of the semi-structured interview data was collected from February 2016 through March 2016 nearing the end of the three-year PEACOC ATN 128 project period of May 2016. Due to the geographic spread, all the interviews were conducted over the phone. At the start of the telephone interview, participants were read an oral consent script that provided information about the risks and benefits of participation in the study. At the end of the interview, all respondents were thanked for their time and asked if they could be contacted for follow-up questions; all participants who agreed to the interview also agreed to the follow-up request.

Average interview length was 93 minutes (range was 37–173 minutes). There are a few extended in-depth interviews because of some study participants elaborating on their answers. Moreover, one CDC/NIH site participant spoke for 173 minutes due to her in-depth involvement with ATN's protocols since 2009 and her involvement in creating and implementing the project—possibly requiring a more time-intensive analysis yet a richer data set.

I transcribed—word for word, including indications of emotion, such as an exclamation point—all audio recordings in September 2016. I compared the transcripts to the audio recordings three times to ensure that the transcription was accurate and to immerse myself in the data (Forman & Damschroder, 2007). Each transcript was marked with the date of the interview, site number, participant title, duration of interview, and my initials as the interviewer. All the interviews were logged on the Digital Voice Recording Tracking and Destruction Log. No personally identifying participant information appeared on the transcripts because I stripped the information of participant names and stakeholder names and replaced it with the person's title in the organization. After all interviews were transcribed and quality assurance was completed, I destroyed all audio recordings in September 2016.

**Table 1: List of Study Participants Interviewed at Each Site**

Site A ID	Position	Geographic catchment area	Duration of interview
CDC/NIH	LTC Coordinator	Northern State	93 Minutes
CDC/NIH	Former LTC Supervisor	Northern State	116 Minutes
RWD	LTC Coordinator	Northern State	112 Minutes
RWD	LTC Principal Investigator/LTC Supervisor	Northern State	59 Minutes

Site B ID	Position	Geographic catchment area	Duration of interview
CDC/NIH	LTC Coordinator	Southern State	73 Minutes
CDC/NIH	LTC Supervisor	Southern State	173 Minutes
RWD	LTC Coordinator	Southern State	79 Minutes
RWD	LTC Supervisor	Southern State	87 Minutes
RWD	LTC Principal Investigator	Southern State	89 Minutes

Site C ID	Position	Geographic catchment area	Duration of interview
CDC/NIH	Former LTC Coordinator	Western State	87 Minutes
CDC/NIH	Current LTC Coordinator	Western State	85 Minutes
CDC/NIH	LTC Supervisor	Western State	80 Minutes
RWD	LTC Coordinator	Western State	90 Minutes
RWD	LTC Supervisor	Western State	148 Minutes
RWD	LTC Principal Investigator	Western State	37 Minutes

### **Process for Developing Aim 1 Questions in the Interview Guide**

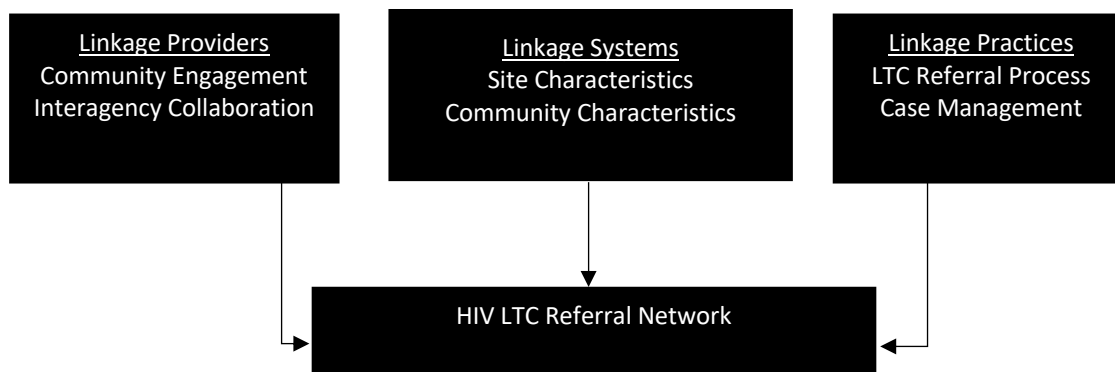
Published literature on the steps taken to foster interagency partnerships is minimal. According to John W. Creswell a description of the case is paramount to developing a strong case study. Aim 1 helps the HIV community understand the complexity of the case studies barriers towards establishing a LTC referral network. Understanding this level of detail can provide unique information about what to expect when creating linkages between agencies. A descriptive analysis provides useful information on each case studies HIV linkage-to-care landscape, description of the CDC/NIH and RWD sites' services, staff's roles and responsibilities, the CDC/NIH-RWD partnership's approach to community engagement to expand the LTC referral network, and key partnerships targeted to join the LTC referral network. The elements to examine were conceived in part by in-depth interviews

with site staff during implementation of the earlier linkage-to-care protocols and later the elements were refined in partnership with ATN Principal Investigator.

Thus, aim 1 interview guide captured more fully the process for developing and implementing an LTC referral network. Before revising the interview guide, I conducted a narrative literature review in December 2015 to examine articles that looked at the process for developing HIV LTC referral networks. The literature search utilized PsycINFO and CINAHL databases from January 1996 to December 2015. Although the interview guide was developed before the dissertation narrative literature review, the dissertation narrative literature review did not lead to the identification of new themes not examined in the interview guide. The entire interview guide can be found in Appendix A.

The PEACOC protocol chooses to focus on improving the following domains: linkage organizations, linkage system, and linkage practices. All three domains are independent variables and serve to better understand the HIV LTC referral network implemented between the CDC/NIH site and the RWD sites. Since all of those domains were examined in the dissertation, I designed a conceptual framework that shows that all of those independent domains influence implementation of the HIV LTC referral network. The conceptual framework can be found in Figure 1. A brief narrative description of each domain can be found below.

**Figure 1: Conceptual Framework for the LTC Referral Network's Key Elements**



**Linkage Providers:** The domain consists of a network of providers that includes the CDC/NIH site and the RWD site and their partner agencies. The features that will be evaluated are the following:

- Community engagement, defined as the extent of dialog with the target community and targeted HIV-positive youths. For example, how the CDC/NIH-RWD partnership impacted existing relationships and collaborations in the community and how the partnership was perceived in the community.
- Interagency collaboration, defined as how the CDC/NIH-RWD partnership situated and presented itself organizationally within the community.

**Linkage Systems:** This domain includes the way the LTC referral network is implemented at the CDC/NIH site and the RWD site before and during the project. Specific features of the network that were assessed are the following: Site characteristics— this is defined as an overview of the organization services and expertise in the community.

- Community characteristics—this is defined as a description of the LTC referral network landscape before the PEACOC project. An examination on preexisting relationships with the health department and community agencies and in turn, how these relationships influenced approaches to integrate RWD funded clinic into the partnerships.

**Linkage Practices:** This domain includes the way the LTC referral network is implemented in each CDC/NIH site and the RWD site and how the comprehensive LTC referral network is adapted to fit local needs. Specific features that will be examined are the following:

- Case management—this is defined as bidirectional consultation of YLWH services to meet youth’s needs or bidirectional referral of nonmedical and medical services between the CDC/NIH site and the RWD site.
- LTC Referral Process—this is defined as providing unique information about the site’s referral process for linking YLWH to care.

### **Interview Guide Questions for Aim 1**

Aim 1 interview questions determined the type of relationship the CDC/NIH site and RWD site had with one another to strengthen the LTC referral network. Findings were used to illustrate the processes taken by similar institutions to strengthen LTC referral networks in their communities. The specific topic areas contained in the semi-structured interview guide were the following:

- (1) Background information—participant involvement in HIV initiatives, their role and responsibilities in the project, history of collaboration with partner site and community agencies
- (2) Interviewees' general thoughts about essential facilitators and barriers to establishing and maintaining partnerships
- (3) Planning phase—understanding the CDC/NIH and RWD sites decision-making process to enter partnership
- (4) Formation phase—understanding what contextual factors influenced how they would partner
- (5) Community engagement—approach for reaching out to the community to join the referral network
- (6) Community partners—experiences working in a partnership to collaborate with the local health department and community partners
- (7) LTC landscape before PEACOC program with an examination on preexisting relationships with the health department and community agencies and in turn, how these relationships influenced approaches to integrate RWD funded clinic into the partnerships
- (8) Referrals for linkage-to-care—description of the process of linking clients to care within their institution and in the community before and after implementation of the new LTC referral network, as well as an example of a client referral case to the partner site to understand challenges and successes referring clients to the partner site
- (9) Unanticipated positive or negative effects of partnering that impacted the institution's implementation of the LTC referral process
- (10) Communication (e.g., mode of communication with one another, decision to communicate in this mode, and communication strategy for informing the community about the partnership)
- (11) Evaluation—in what ways did the partnership meet the needs of youth living with HIV in the community (e.g., improved access to services, reduced wait times), how will outcomes attributed to the partnership be distributed to stakeholders



## **Process for Developing Aim 2 Questions in the Interview Guide**

When I designed my dissertation, my eventual goal was to translate the process of how organizations implement a LTC referral network from one locale to another locale; therefore, I considered the intervention (i.e., LTC referral network) to be an innovation that should be diffused. With this perspective, I searched for frameworks that referenced the diffusion of innovation theory (Rogers, 2010). At the time of developing my interview guide, I believed that the Organizational Readiness Framework was the most appropriate framework to investigate organizational factors that facilitate or hinder the implementation of a LTC referral network and tied in all the factors found in the Diffusion of Innovation Theory (Scaccia et al., 2015). Briefly, the organizational readiness framework posits that successful implementation of an innovation is a function of the organization's motivation, general capacity, and innovation-specific capacity (Scaccia et al., 2015).

Since the Organizational Readiness Framework only depicted factors within an organization to adopt an innovation, I needed to include a framework that examined factors outside of the organization. Fortunately, the organizational readiness framework was adapted from the Interactive System Framework (ISF). I utilized the ISF to help to explain the processes by which external factors influence the introduction of an innovation into communities (Wandersman et al., 2008). Briefly, the ISF is comprised of the following external factors: funding, macro policy, climate, existing research and theory (Wandersman et al., 2008). Thus, the Organizational Readiness Framework and ISF Framework were used to inform interview questions for aim 2 interview guide (Scaccia et al., 2015; Wandersman et al., 2008).

## **Interview Guide Questions for Aim 2**

The following topic areas were examined in my interview guide to address aim 2:

1. Organization's collective perceptions of the advantages and disadvantages of collaborating (OR framework)
2. Stakeholder's perception of their organization's culture working with agencies to link and retain HIV-positive youths (ISF framework)
3. Leadership's perception of the partnership (OR framework)

4. Staff's knowledge, skills, and abilities working with HIV-positive youths within their institution and their view of their partner's knowledge, skills, and abilities working with HIV-positive youths (OR framework)
5. Organizational structure to implement the partnership (OR framework)
6. Interorganizational collaboration between the CDC/NIH site and the RWD site, as well as with partner agencies in the community (e.g., HIV testing agencies and youth-serving agencies) (ISF framework)
7. Program champion for partnership activities (OR framework)
8. Relative advantage for the partnership (OR framework)
9. Compatibility of the partnership strategies within their own institution (OR framework)
10. Complexity of the partnership (OR framework)
11. Understanding how competition for client referrals impacted partnership (ISF framework)
12. Community observability of the partnership (ISF framework)
13. Institutional priority of the partnership's activities (OR framework)

#### **Partnership-Related Document**

This study also involved a review of a partnership-related document that helped to enhance the confidence in the interpretation of findings in the transcript. Specifically, I reviewed each agency's Community Impact Plan that was obtained from the HRSA archives. The Community Impact Plan describes the accomplishments and successes of each element of the PEACOC protocol, provides detailed goals for the future, and methods needed to achieve that purpose. Important features of the Community Impact Plan that are examined are presented in the data extraction form that follows.

#### **Community Impact Plan Data Extraction Form**

<b>1. Background Information</b>	
Location	
Agency (RWD, CDC/NIH, or CDC/NIH-RWD joint submission)	
<b>2. Central Questions to examine from the Community Impact Plan</b>	
Describe the HIV incidence in your community (for youth).	Notes: Summary:
Describe your local LTC referral network landscape before the PEACOC program was implemented.	Notes: Summary:

Was LTC standard practice or not?	Notes: Summary:
Was there an oversaturation of LTC programs?	Notes: Summary:
What did LTC look like for your target population of youth?	Notes: Summary:
What did data sharing look like between key LTC systems in your community?	Notes: Summary:
What were the major LTC gaps (especially for youth)?	Notes: Summary:
Describe local design and implementation of the PEACOC Program.	Notes: Summary:
Who did you identify as main partners and how did that evolve over time?	Notes: Summary:
How did your program work with the state/local health department to enhance local LTC efforts for youth (e.g., public health authority, data sharing, etc.)?	Notes: Summary:
How did your program work with local testing agencies and why	Notes: Summary:
How did this approach support the needs of your community?	Notes: Summary:
What key sectors did your program target to enhance youth LTC locally?	Notes: Summary:
What challenges/barriers did you confront as you established your local program? How did you overcome these barriers/challenges?	Notes: Summary:
What key sectors did your program target to enhance youth LTC locally?	Notes: Summary:
What key sectors did your program target to enhance youth LTC locally?	Notes: Summary:
How will close out of the SMILE Program impact your community and your site ( <i>e.g., LTC process, testing efforts, community events, engagement and retention of clients</i> )?	Notes: Summary:

### Aim 1 Analysis

My goal for aim 1 analysis was focused on a descriptive qualitative case study. The case was the LTC referral network in the different locations in order to identify practical approaches to implement the LTC referral network. My dissertation sought to understand how agencies lay the foundation for a LTC referral network specifically designed to ensure YLWH are linked to care. An examination of the various approaches and characteristics of a LTC referral network could guide the development of future partnerships focusing on coordination of referral processes for YLWH.

Aim 1 of my dissertation involved a within-case analysis. The methodology for data coding utilized qualitative content analysis (Forman & Damschroder, 2007). Qualitative content analysis's central feature is that it is a rule-guided method to systematically categorize textual data (Forman and Damschroder, 2007). Qualitative content analysis is a sound choice for case studies as it allows you to create new knowledge from raw and unordered data (Forman & Damschroder, 2007). Qualitative content analysis was divided into three phases: immersion, reduction, and interpretation. The a priori themes (i.e., deductive approach) will be derived from the conceptual framework found in Figure 1. Data collected through a review of the transcripts and the partnership-related documents was imported into the data management tool, NVivo Version 12.

### **Within-Case Analysis**

For each case, a within-case analysis—a technique to treat each individual case study as a separate study—entails giving an overview of the partnership's creation and evolution of the LTC referral network in each city. Qualitative content analysis was divided into three phases: immersion, reduction, and interpretation.

*Immersion phase:* The purpose of the immersion phase was to engage with the data to get a better understanding of the dataset before I rearranged it into discrete units of analysis (Forman & Damschroder, 2007). I did this by first reading the transcripts several times. Second, I wrote thoughts that are triggered when reading the data; this process is known as “free association” and can be used toward my inductive codes. Lastly, I created memos to capture my initial thoughts and potential new themes.

*Reduction phase:* The purpose of the reduction phase was to reduce the amount of raw data to that which was relevant to answer my aims and then developed a systematic approach to index the data (transcripts and memos) into salient text segments that were reorganized into analytically meaningful categories (Forman & Damschroder, 2007). In the reduction phase, I developed codes to provide the classification system to reorganize data in a way that facilitated interpretation and enabled me to organize and retrieve data by categories that were analytically useful to the study and aided in interpretation.

For aim 1 I tried to format each case study by providing the following sequence of information: examination of the HIV LTC landscape in the city, description of the RWD and the CDC/NIH sites, staff's roles and responsibilities in the LTC program, and the CDC/NIH-RWD partnership approach to community engagement.

## **Aim 2 Analysis**

Aim 2 of my dissertation involved two phases: within-case analysis and cross-case analysis. The methodology for data coding of secondary data followed qualitative content analysis (Forman & Damschroder, 2007). The priori themes to identify barriers were derived from Organizational Readiness Framework and ISF. Also, I used inductive coding to identify barriers as well as strategies used to overcome barriers. I performed a descriptive, qualitative data analysis of transcripts and the Community Impact Plan using NVivo Version 12. The process to conduct within-case analysis was similar as aim 1.

### **Conceptual Framework Used for Reduction Phase:**

For my dissertation, coding of secondary data involved deductive codes using a priori themes from the Organizational Readiness Framework and the ISF and identified inductive codes using qualitative content analysis. The ISF was used in the interview guide to examine contextual factors in the environment that the sites may have potentially experienced during the implementation of the LTC referral network, such as funding, macro policy, and external climate. The Organizational Readiness Framework, which examines factors within the organization was also used as a guide to ask interview questions that examined barriers to implementation. Aim 2 analysis also used inductive coding to capture the unique factors that inhibit the implementation of a LTC referral network and strategies used to overcome barriers.

In addition, during the immersion phase, inductive codes (i.e., NVivo codes) that come from analytical insights, emerging during immersion phase, were incorporated into the codebook used in the reduction phase. Codebook development is an iterative process; therefore, the codebook was revised in an iterative fashion to refine or even eliminate a priori codes and include emerging codes found in the immersion phase, known as “preliminary coding.” According to Forman and Damschroder (2007), the development of 20–40 codes is the norm (Forman & Damschroder, 2007). Coding consists of reading through text, highlighting the passages that may be potentially important to my aims, and writing notes in the margins about the concept. Next, I read several transcripts to find descriptions of different uses of the concept. The fundamental elements that a codebook contains are (1) Name of element; (2) An abbreviated label for the code; (3) Hierarchical position of that code in the coding framework, known as “node type,” which can either be designated as parent node (high-level code) and

how it relates to child node(s) (subcode to parent node); (4) A description of the code that includes a clear definition; and (5) Example quotes that further illustrate the correct use of that code, along with a notation of the transcript and line numbers where the quote is located in the data set.

*Code agreement in reduction phase:* In addition to my own coding, I asked a HIV global public health professional to independently code a subset of the transcripts in Nvivo Version 12 in order to minimize subjectivity that is inherent in a project that I oversaw and the design of the dissertation. The second coder coded 27% of all key informant interview transcripts, which is aligned with the standard qualitative data analysis standard of 25% of transcripts coded for validity (MacPhail et al., 2016). The second coder used my draft code book to code the transcripts. Next, we compared coding of transcripts to determine if any of the codebook definitions needed to be refined based on the second coder's interpretations of the categories. I ran a coding comparison query and got an intercoder reliability (ICR) of .53, which is considered satisfactory since an average .4-.6 ICR is considered acceptable. Moreover, an .53 ICR is impressive given there were more than 30 codes used to code the entire text (MacPhail et al., 2016). A closer look at the coding shows that the second coder and I were in agreement with much of the coded text but just didn't have the exact word for word section coded, which led to a lower ICR. For instance, a few times the second coder included the question text segment along with the answer text segment in the coded section. Lastly, the second coder was instrumental in helping me develop the final code book by identifying emerging codes, collapse codes, and removing codes. The final codebook located in Appendix B has a total of 33 codes. I used a structured codebook that included code definitions and examples in order to ensure replicability of the research process. I then used the final code book to analyze all of the barriers and strategies used to overcome barriers in all the key informant interview transcripts and Community Impact Plan.

*Interpretation phase:* While there is no clear line between data analysis and interpretation, the main purpose of the interpretation phase was to reflect on the raw data found in the coding reports and memos that captured my initial thoughts. This was followed by further reorganizing and synthesizing the data and analyzing it by writing descriptive and interpret summaries. The summaries usually include the main points obtained from reading the report, quotations selected to provide evidence for those points, and an interpretive narrative at the code level.

*Data display in interpretation phase:* Data display is defined as an organized, compressed assembly of information in matrices, models, charts, and/or networks that permits an easiness to draw conclusions from the data (Forman & Damschroder, 2007). For my dissertation, I filled in a matrix template shown in Table 2 for my cross-case analysis of barriers. A cross-case analysis was taken to evaluate the content and magnitude of similarity in barriers. The template provided an overview of each barrier—specific barriers arrayed horizontally across the top and the site arrayed vertically. Each cell in the matrix was filled in with text that summarizes the characteristics of that barrier.

**Table 2: Data Display Matrix of Similarities in Barriers Across Cases**

Case ID	Barrier X	Barrier Y	Barrier Z
Case 1			
Case 2			
Case 3			

Once I completed my matrix, I drew preliminary conclusions that communicated what the data meant. Then I verified conclusions by finding evidence that supported my conclusion and ‘negative cases’ that refuted my conclusion. I also looked for alternative themes and conclusions that ‘fit’ the data better throughout the interpretation process (Padgett, 2011).

#### **Disclosure of Research Bias**

I was a member of the NCC, the central administrative entity that oversaw the sites’ implementation of the study. The NCC’s role was to monitor, support, and provide guidance to the sites involved in the project. Specifically, my role as the PEACOC National Coordinator was to ensure fidelity to the research protocol and to facilitate project implementation across all RWD sites. During the implementation of PEACOC, I emphasized the importance of collaboration between the CDC/NIH site and the RWD site at my monthly calls with the sites; however, the CDC/NIH-RWD partnership approaches were ultimately made between the partner sites. At the time of initiation and during the execution of activities in 2013 and 2014, I did not plan to use the study for my dissertation. Thus, I feel that the partnership initiatives at each site happened organically, with my role providing guidance on partnership collaboration, but never forcing collaboration. I believe there is no research bias as I am

no longer funded for the study, study results do not impact future funding for the organizations examined in my dissertation, and the results do not impact my career or financial situation.

### **Institutional Review Board and Confidentiality Issues**

According to code of federal regulations (CFR) from the US Department of Health and Human Services Office of Human Research Protection, specifically 45 CFR 46.102, an activity that is a systematic investigation designed to develop or contribute to generalizable knowledge is considered research. If the research involves obtaining information about living individuals and involves an investigator's intervention or interaction with individuals, it is considered research involving human subjects; however, if the information obtained is not individually identifiable and does not involve investigator intervention or interaction with individuals, then it is not human subjects' research. Each agency used 45 CFR 46.102 to justify that implementation of PEACOC and data collection for qualitative interviews were not human subjects' research.

The leadership team used 45 CFR 46. 10(B)(1) and (2) to get IRB approval to grant them a waiver for obtaining a signed consent form to participate in the interviews—collecting verbal consent was satisfactory. Leadership's justification for verbal consent instead of written consent was based on having no risk of breach of confidentiality and fully protecting the privacy of staff at each agency. Therefore, no private information was collected from study participants. The data collected from the interviews is now considered secondary data. University of North Carolina at Chapel Hill IRB granted utilization of the data to conduct secondary data analysis. Data analysis of aim 1 and aim 2 only occurred once I received University of North Carolina at Chapel Hill IRB approval of my dissertation proposal.

### **Potential Risks**

No compensation was provided to the respondents. Therefore, the only primary risk in this dissertation is the potential breach of confidentiality. Steps have been taken to reduce the risk of breaching interviewees confidentiality. First, I took an IRB 2016 human subject's training, which taught me the rules to not divulge, make public, or make known to unauthorized persons any specific details of personal information. Second, electronic copies of the interview transcripts have been stored without personal identifiers on my Johns Hopkins password-protected desktop computer. Third, the list that links the participants to their transcripts is stored separately from



the transcripts. Fourth, no individual data collected during the interviews will be shared with any of the study participants. Lastly, specific cities have been removed to protect providers identity.

### **Potential Benefits**

Agencies that wish to engage in similar partnerships will benefit from the knowledge gained through this study. Understanding the factors that inhibited partnerships to develop a LTC referral network can help future partnerships achieve outcomes more quickly. Also, more data on negative experiences could lead to a stronger partnership because agencies are motivated when they know up front what challenges lay ahead and still agree to collaborate to develop the LTC referral network. The community benefit is also a potential benefit. The community may benefit from increased integration of services, decreased service duplication, and improved service utilization by HIV-positive youths. Indirect benefits include greater social cohesion, greater sense of community awareness of agencies strengths and weaknesses, expanded networks of communication and collaboration, and improved cross-cultural communication. The intended long-term beneficial outcome to the community is reduced rates of HIV acquisition and transmission among HIV-positive youths by expanding their access to medical care.

## **CHAPTER 4: SITE A RESULTS**

### **Aim 1 Introduction**

In 2010, leadership at the CDC, the NIH, and a clinical research network came together to fund the CDC/NIH site, located in the Site A, to implement the former LTC program to promote seamless testing, disclosure, and immediate LTC of YLWH. The former LTC program was beneficial for the CDC/NIH site as they had the funding for a dedicated LTC Coordinator. The other unique benefit of the former LTC program was implementing formal data-sharing agreements with key agencies located in Site A to ensure YLWH were tracked through the HIV continuum of care.

In 2013, the Secretary's Minority AIDS Initiative responded to the need for strong linkage-to-care in Site A, particularly among the YLWH; thus, the Secretary's Minority AIDS Initiative provided full financial support for a Federal sponsored partnership between the CDC, the NIH, the HRSA, and a clinical research network. Together, the CDC, the NIH, and the CDC/NIH developed a cooperative agreement known as "the LTC program." This was a partnership between a HRSA selected HIV clinic and the CDC/NIH site. The HRSA selected a HIV clinic it funds through a mechanism called the Ryan White Part D program. Hereafter, I refer to this site as the RWD site. This CDC/NIH-RWD partnership lasted from 2013 to 2016. The LTC program's primary purpose was to expand the partnerships established in the former LTC program put in place by the CDC/NIH site in Site A. The CDC/NIH-RWD partnership decided to target their efforts to establish a partnership with the Site A Department of Corrections (Site A DOC) to establish continuity of care for YLWH released from the Site A DOC.

This case study seeks to provide leadership within the Site A DOC and provide a clear example of how the CDC/NIH and RWD sites made an effort to develop the LTC referral process with Site A DOC and the challenges they encountered. The case study's first aim provides a comprehensive understanding of the collaboration between the CDC/NIH and RWD sites to enhance the existing LTC program. Specifically, aim 1 examines the HIV linkage-to-care (LTC) landscape in Site A, description of the two HIV clinics (the RWD and the CDC/NIH site), staff's

roles and responsibilities on the LTC program, the CDC/NIH-RWD partnership approach to community engagement, and the CDC/NIH-RWD partnership with Site A DOC. The first aim is followed by the second aim to examine the implementation barriers and strategies to overcome those barriers.

### **Site A Characteristics**

Site A remains the epicenter of the HIV epidemic in the United States, with more PLWH than in any other city in the United States. Blacks and Latinx youth were disproportionately affected, making up 80% of those new infections. Young Black and Latinx men are particularly struck by the HIV epidemic, making up 69% of youth living with HIV. Among males, young men who have sex with men (MSM) represent 88% of new HIV infections among youth. Unfortunately, the trends reflecting race, gender, and sexual risk factors during the LTC program's lifetime remain consistent in 2020.

The Site A criminal justice system has a population of about 12,500 inmates. Demographically, the criminal justice population mirrors that of Site A communities hit hardest by the HIV epidemic, Black and Latinx men. Given that most criminal justice detainees return to their communities, criminal justice system settings can present an opportunity for public health interventions and allow clinicians to engage YLWH. However, continuity of care following release remains a challenge.

### **CDC/NIH Site Overview**

The CDC/NIH site based in Site A was established in 1987 to provide HIV prevention, care, and treatment services. The CDC/NIH site serves as a local and national resource for those living with HIV. The CDC/NIH site provides all youth with free HIV counseling and testing, medical care, psychosocial care, the opportunity to join support groups, and to participate in appropriate clinical research.

Even though the CDC/NIH site is part of a hospital, during the life of the LTC program it operated independently and somewhat insulated itself from the hospital leadership. The CDC/NIH site is well known in the community due to its lasting presence for over 30 years. According to one interviewee, the CDC/NIH site which ran the former and the current LTC program missed out on beneficial opportunities to collaborate with the CDC/NIH hospital due to CDC/NIH PI not interested in having regular communication with CDC/NIH hospital leadership:

So, it was kind of like we were a CBO, which was fine, but we were like our own little CBO with like 30 people as opposed to like this pretty powerful institution in Site A, which is interesting. Moreover, now that I sit in the Office of Community Population Health for the whole system so now, I am interacting with system-wide people and leadership all the time, and I see the benefit of [the hospital].

Lastly, the CDC/NIH site only sought to establish partnerships with agencies located in Site A as they only wanted to focus their efforts on clients from Site A. Moreover, the CDC/NIH staff didn't understand the importance of youth having the option to receive services in another Site A.

### **RWD Site Overview**

The RWD site was established in 1995 to provide HIV prevention, care, and treatment services. Specifically, the RWD site offers health education, HIV/STI testing services, and counseling to youth (ages 12-24) with youth-serving agencies. The RWD site also provides comprehensive medical care, psychosocial care, and case management services to YLWH. Moreover, the RWD site is staffed by highly experienced and specially trained health care professionals who are passionate about delivering culturally sensitive and age-appropriate services to youth.

The RWD site works with cities, states, and local community-based organizations (CBOs) to provide a cohesive care system and continuously develop innovative new care models. The RWD site was excited to partner with the CDC/NIH site to strengthen the LTC referral process throughout the geographic catchment area. Before the LTC program, the RWD site staff had many work responsibilities; they did not have the time or the finances to hire a designated person to develop community partnerships to expand the LTC referral network. Thus, the LTC program was an opportunity to hire an LTC Coordinator to expand partnerships and intentionally strengthen the LTC referral process.

Lastly, the RWD site was open to seeing youth regardless of where they lived in Site A. The RWD site believed that YLWH need flexible geographic options for receiving care because youth are generally migratory and fear stigma from their peers. Thus, youth are often more comfortable receiving services far away from where they live.

## **LTC Program Staff Roles and Responsibilities**

The LTC program's federal agencies expected the LTC Coordinator to build community partnerships to expand the LTC referral network and engage with YLWH through in-person meetings, text messages, and phone calls. The LTC Coordinator provided YLWH with appointment reminders and connected them to social services (i.e., housing, financial, and medical insurance assistance). Moreover, the federal agencies expected the LTC Coordinator to offer intense case management services such as personally pick up clients at their homes. The federal agencies also expected the sites to hire a RWD LTC Supervisor and Principal Investigator (PI) to support the Coordinator to enhance the LTC referral network.

The CDC/NIH site had three employees on the LTC program: The Supervisor, the PI, and the Coordinator. The CDC/NIH LTC Supervisor organized outreach events, identified new agencies, and established new partnerships in Site A. The CDC/NIH PI had minimal daily involvement in these activities but had to approve formal partnerships. The CDC/NIH Coordinator linked and retained YLWH to care and coordinated social services. The CDC/NIH Coordinator responsibility was maintaining the existing 50 partnerships developed through the former LTC program.

The RWD site staff responsibilities were different, as they had only two employees assigned to this program due to limited HRSA funding. The RWD site merged the Supervisor and the PI's responsibilities into just one role named the RWD PI. Both the RWD PI and RWD Coordinator ventured into the community to establish partnerships. The RWD Coordinator had done HIV community outreach before this program and was also heavily involved in HIV community activities. Therefore, the RWD Coordinator capitalized on previous work experience to expand partnerships to strengthen the LTC referral network.

In conclusion, the roles and responsibilities were significantly different between the RWD and the CDC/NIH sites. For example, out of necessity, the RWD PI was responsible for taking on multiple roles, while at the CDC/NIH site, their role was more rigidly defined. At the CDC/NIH site, only one employee, the CDC/NIH Supervisor, regularly ventured into the community. In contrast, at the RWD site, the PI and the Coordinator went out into the community. The geographic coverage was different for both sites; the CDC/NIH site only targeted partners on one of Site A's area while the RWD site targeted partners throughout the remaining area of Site A. The

RWD site's geographic coverage led the RWD PI and the RWD Coordinator to better understand ground-level needs across Site A to develop strategic partnerships to expand the LTC referral network.

### **CDC/NIH-RWD Partnership's Strategic Approach to Community Engagement**

The CDC/NIH-RWD partnership approach with organizations in the community to expand the LTC referral network was a "divide and conquer" approach. The CDC/NIH site directed the partnership into a "divide and conquer" community engagement approach for two reasons: 1) YLWH sometimes did not want to go to care clinics in a different neighborhood from where they lived, 2) Each neighborhood had sufficient numbers of agencies to reach out to. One staff member explained the justification for the "divide and conquer" approach:

Site A has so many agencies and hospitals everywhere that people have many options, so a lot of times, you will not have people from one area of Site A going to another location of Site A, or you won't see people from one neighborhood to another neighborhood. For the most part, people focus on their neighborhood because each neighborhood have many services and options for primary care, so there are many partners that can be made in our neighborhood that you don't need to go to another [neighborhood] to make partnerships. For our partnership, there are a limited number of agencies that we have in common.

The CDC/NIH site already had many partnerships in one neighborhood of Site A and didn't see the need to expand to more partnerships outside the neighborhood. A CDC/NIH staff member stated they did not inform their existing partner agencies about the collaboration with the RWD site because they wanted to maintain being the agencies primary referral site:

With people that we sort of have regular contact with and regular referrals from, my sense is that we didn't seem to speak about the partnership that much because they were referring youth to us...We sort of didn't take that task of letting our existing partners know because they are our primary referrals, so we will keep on reaching out to them the way we always have.

However, the RWD site approached community engagement differently. The RWD site highlighted their collaboration with the CDC/NIH site to community agencies to garner more interest. For example, a staff member stated:

When you talk about partnerships in Site A, everybody is like yeah, yeah, partnership, partnership, everybody talks about that, that is like an old song already. But this collaboration was different; this was a very different approach because here we are talking about two significant institutions, two hospitals in two different neighborhoods coming together and even presenting together and their funders work together; it was a very different approach. So, when I presented this collaboration to community partners, everybody loved it.

In general, both agencies were confident that they could expand the LTC referral network with community agencies without collaborating. However, both agencies believed that they needed each other to show a "united front" with large government institutions. A staff member said, "I think [the CDC/NIH site] were helpful in knocking on the door with us with these larger governmental structures, like the Department of Health and Department of Corrections." Therefore, the CDC/NIH and the RWD sites presented the partnership as a "united front" to the Site A DOC to determine where YLWH were referred for medical care once released from criminal justice system.

#### **CDC/NIH-RWD Partnership with Site A DOC**

Efforts to investigate where YLWH inmates receive medical care after release from criminal justice system began in the fall of 2014. The CDC/NIH-RWD partnership shared that YLWH in Site A criminal justice system are offered medical care and treatment through the Site A DOC. However, a continuation of medical care upon release from criminal justice system remains a challenge, especially for those who were not engaged in medical care before their incarceration. The CDC/NIH-RWD partnership presented a valid case to the Site A Department of Health (Site A DOH) as to why direct and timely access to the HIV surveillance data for newly detected HIV infections among youth is vital. The RWD site observed that the Site A DOC did not record linkage-to-care for Site A DOC-released youth. This begged the question, where did YLWH receive care after being released from criminal justice system? After meetings and an exchange of data with the Site A DOH, the RWD site learned that YLWH were not receiving consistent medication or medical care once released from the criminal justice system. Thus, the RWD site concluded direct and timely access to YLWH would have helped youth transition to medical care in the community and ultimately save lives.

Moreover, inmates are released daily without a schedule and often released at unusual hours, preventing them from meeting medical care providers right away. The particular timing of releases negatively impacts how the HIV health care system can deliver services to individuals released from the criminal justice system, especially vulnerable minority YLWH. Thus, the CDC/NIH-RWD partnership's main focus was creating a better LTC referral process for youth released from Site A criminal justice system.

The two objectives of the CDC/NIH-RWD partnership concerning YLWH released from criminal justice system were: 1) Develop a more structured LTC referral process and 2) Successfully refer youth to youth-friendly clinics. In the long term, the CDC/NIH-RWD partnership hoped the city would develop a more formal LTC referral process that could be sustained even after federal funding for the LTC program ended. The RWD site identified the impetus for the partnership to address the issue.

In regards to objective 1, the RWD site encouraged the CDC/NIH site to partner together to establish an LTC referral process with the criminal justice system because the RWD PI believed two large agencies in Site A coming together to create an LTC referral process with the Site A DOC would be better than just the RWD site reaching out to the Site A DOC.

Regarding objective 2, at the beginning of the LTC program, the Site A DOC leadership did not place a high priority on linkage to a youth-friendly clinic. The CDC/NIH site found it challenging to get a meeting in place with the Site A DOC staff. The CDC/NIH staff said, "We were unsuccessful. It felt like it was very hard to get access to the criminal justice system. It was very hard to get key personnel at the prison to speak with us." The CDC/NIH-RWD partnership wanted to show the Site A DOC that youth-friendly clinics often address basic needs to attend clinics, specifically housing, transportation, and money issues, by providing YLWH with medical and social services to address their needs. Thus, the Site A DOC collaborating with youth-oriented clinics, specifically the CDC/NIH site and RWD site, would ensure providers coordinate with social services to organize the wrap-around services for YLWH in the criminal justice system before they're released.

Another important reason to ensure referral to youth-friendly clinics is the relationships youth build with providers trained in cultural competency. HIV diagnosis can often times lead to individuals having emotional turmoil or denial about being HIV positive. Youth-friendly clinics have specially trained providers to work with YLWH to be acutely aware of the struggles they may face daily, in addition to the complications of living with HIV. Once YLWH enter a youth-friendly clinic, they are linked with a highly skilled LTC Coordinator/Community Health Worker/Patient Navigator to address their needs. According to one staff member, their role is imperative:

I would make sure they have transportation to get here. Once they get here, I am the one making sure they have some type of beverage; they have some food, the doctor that they are going to see is there. Sometimes the client is really scared, so I will do some handholding. I was really serving as a client navigator with them while they were here.



The RWD site took a strategic approach to develop the CDC/NIH-RWD partnership with the Site A DOC. The CDC/NIH-RWD partnership cajoled the Site A DOC to meet with the CDC/NIH and RWD sites to explain the LTC program's primary goal. The meeting may have led to changes in opinion among the key opinion leaders within the Site A DOC to refer youth to youth-friendly clinics. One CDC/NIH staff member said, "It seemed like the Department of Corrections found the protocol necessary because after we met with their team like they seemed to understand why it was so important to refer to adolescent-specific services." The Site A DOC accepted the CDC/NIH-RWD partnership's invitation to tour both clinics to understand the youth services offered and the benefit of tailoring clinical care services for youth. The CDC/NIH-RWD partnership believed that if the Site A DOC learned more about the site's services, they would have better understood why it is appropriate to refer youth to youth-friendly clinics. An RWD staff member shared that after the Site A DOC toured the sites, they began referring clients to their clinic even though there was no formalized partnership:

We have attempted through the two and half years to three years through the collaboration to try to develop strong linkages that touch the lives of the incarcerated. And you know it has been successful, each month we get one or two referrals. It hasn't been to the extent that we would like, but we have been chipping away.

Thus, the analysis revealed that tours are beneficial because they allow potential partner organizations to fully understand a clinic's capabilities before referring clients to the clinic.

### **Aim 1 Conclusion**

Even though at the end of the federal sponsored LTC program, the CDC/NIH-RWD partnership could not establish a formalized LTC referral process with Site A DOC, the CDC/NIH-RWD partnership claimed that the endeavor to develop a partnership with Site A DOC had some positive outcomes. One positive outcome from the collaboration was uncovering just how many YLWH leave the criminal justice system and are not linked to appropriate care. The second positive outcome was that Site A DOC began to refer youth to youth-friendly clinics. Lastly, the results had shown a promising start for LTC referrals with the criminal justice system while illuminating areas for further improvement between the criminal justice and the health care system. We might conclude from this case study that health care organizations attempting to develop a partnership with the criminal justice system and to improve the LTC referral process will require an equal amount of patience and desire to implement the partnership. In this case study, the staff members mentioned that collaboration between different systems to

implement a LTC referral process was challenging. Thus, aim 2 of the case studies examine what the impediments between the CDC/NIH and the RWD sites in establishing the LTC referral process with the Site A DOC and with each other were.

## **Aim 2 Introduction**

Aim 1 investigated an inter-agency collaboration between the criminal justice system and two HIV clinics (RWD and CDC/NIH sites) to establish better LTC for YLWH released from the Site A DOC. Data analysis of aim 1 shed light on the need to support Black and Latinx HIV positive male youth removed from the criminal justice system. Moreover, the unsuccessful LTC referral process with the criminal justice system in aim 1 shows ample room for improvement, but impediments to forming partnerships. The providers' experiences implementing the LTC program clarified which barriers hindered their ability to do so and what strategies were employed or recommended for future partnerships.

A total of nine primary topics emerged showing that barriers to the formation of effective partnerships included: 1) Geographic location inhibits strategic planning between CDC/NIH site and RWD site, 2) Organizational culture, 3) Lack of youth-friendly clinic staff, 4) Poor communication, 5) Interpersonal conflict, 6) Lack of leadership buy-in, 7) Competition between Institutions, 8) Bureaucracy in government structures, 9) Lack of HIV surveillance data. These frequently-cited barriers to collaboration reduced the implementation of the LTC referral process with the Site A DOC. While the RWD site convinced the CDC/NIH site to partner with them to establish an LTC referral process with the Site A DOC, both the Site A DOC and the CDC/NIH site resisted the formation of a formal partnership. Due to the ultimate lack of formal collaboration with the Site A DOC, many YLWH released from the criminal justice system remained unlinked to youth-friendly medical services, a sub-optimal outcome.

### **Geographic Location Inhibits Strategic Planning Between the CDC/NIH Site and the RWD Site**

Throughout the lifetime of the LTC program the CDC/NIH site and the RWD site did not collaborate with agencies strategically. To partner strategically, agencies should identify and map stakeholders while developing their strategies, plans, and programs. Collaborators who understand which stakeholders are under-represented in the referral network can identify new potential collaborators and increase buy-in from related government agencies. This disjointed approach caused partner agencies to provide duplicate services.

The CDC/NIH site was not genuinely invested in the CDC/NIH-RWD partnership to expand the LTC referral network, but only cooperating to satisfy grant program requirements. The CDC/NIH site's inability to further invest is exemplified by the lack of effort to collaborate at the RWD site to partner with the Site A DOC. The CDC/NIH site was less interested in striking up a partnership than the RWD site because they had a strict regional focus on one of Site A's neighborhood.

The RWD site was open to seeing youth regardless of where they lived in Site A. In addition to that, they prefer to link youth to a clinic that best meets their needs; thus, the RWD site exemplifies what it means to be a youth-friendly clinic because they put youth's needs above the clinic's interest. Unlike the CDC/NIH site, the RWD site served in all five Site A's neighborhoods, yet both the RWD site and the CDC/NIH site gave the testing and medical care agencies an option to refer youth.

The CDC/NIH and RWD sites told the Health Department STD clinics in the Site A's locations to refer youth to either of their clinics because the main focus was getting youth linked to medical care. Clients were often happy to receive care in a different neighborhood than they reside, as long as that clinic was youth-friendly because their main concern was quality of care and working with a provider they can relate to. At the end of the program, the CDC/NIH staff member realized that establishing partnerships with agencies across Site A increased the quality of care provided by the CDC/NIH site and increased the likelihood that youth will be referred to a youth-friendly clinic.

### **Strategy to Overcome Barrier**

For a successful, anti-competitive collaboration, all partnership members must be on board with sharing resources. Unfortunately, the CDC/NIH site was not interested in sharing partner resources. Therefore, the RWD staff avoided pursuing partnerships with pre-established CDC/NIH partners out of sensitivity towards the CDC/NIH site's differing perspective and territorialism. The RWD staff member stated:

We have partnerships in the Site A that pre-dated the relationship with [the CDC/NIH site], and these were agencies that [the CDC/NIH site] was not engaged with. So, for example, certain alternative schools, or after school programs, or government programs. If we knew that there was a previous relationship with [the RWD site], then we would refer the agency back to them. But, if there was no standing relationship, then yes, we offered our services and built up a relationship.

If clinics shifted to a culture of putting youth's interest above all else, this would help mitigate competitive barriers to collaboration. The RWD site was less territorial, freely referred HIV-positive youth to other clinics, and encouraged all external partners to refer clients to clinics that best-suited their needs. Although it was not in the best interest of YLWH to have the RWD site not pursue relationships established by the CDC/NIH site, the RWD site made this decision by putting CDC/NIH sites preferences at the forefront of their decision-making process. The collaboration's whole goal was to provide YLWH with multiple options to access quality youth-friendly care, so the RWD site's inability to collaborate with CDC/NIH partners represents at least a partial failure.

### **The CDC/NIH Site's Organizational Culture**

Interviewees noted the CDC/NIH Site's organizational culture failed to embrace internal collaboration between departments, or interorganizational collaboration. A more in-depth analysis of the "divide and conquer" community engagement approach driven by the CDC/NIH site reveals that the CDC/NIH site developed an insular culture over the years. The CDC/NIH site functioned independently from the CDC/NIH hospital; this led the CDC/NIH site to be more insular and less likely to engage in the type of partnership the RWD site was proposing. Also, the CDC/NIH site provided a "one-stop-shop" for addressing all the clients' medical and non-medical needs; it wasn't in the CDC/NIH site's organizational culture to establish partnerships with other organizations that provided similar services. Lastly, the CDC/NIH PI insulated the CDC/NIH site from the hospital system to centralize clinic control under its authority alone. Under this leadership approach, the CDC/NIH site PI had complete autonomy to make high level decisions without any oversight.

The CDC/NIH PI did not make any attempts to integrate with any part of the hospital. When the CDC/NIH site was established in the 1980s, it was one of the first agencies to focus on HIV care and treatment services. The CDC/NIH site setting up best practice standards for providing medical care to HIV positive clients may have been the reason the CDC/NIH site was able to avoid oversight by the hospital administration. The CDC/NIH Supervisor noted, "So it was kind of like we were a CBO, which was fine, but we were like our own little CBO with like 30 people as opposed to like this pretty powerful institution in Site A, which is interesting." According to the CDC/NIH staff, better integration with their hospital would have given the CDC/NIH site a better ability to connect with the hospital system at large.

Moreover, the CDC/NIH site saw the RWD site staff as interested in expanding their partnerships with all agencies, including collaborating with agencies with similar services to their own. However, the CDC/NIH site was not known for doing that. A CDC/NIH staff member said, "My sense was that [the RWD site] just seemed that they wanted to partner more with similar agencies and sort of being more active around looking for potential partnerships." Thus, the CDC/NIH leadership's confidence in their ability to tackle big problems by themselves prevented them from immediately realizing the many benefits to a potential collaboration within the hospital system and external agencies/services such as the RWD site.

### **Strategy to Overcome Barrier**

A former staff member makes it clear in the below quote that the lack of collaboration between departments was not limited to the CDC/NIH site but rather permeated the entire CDC/NIH hospital as well as the goal to change the organizational culture towards openness to partnerships:

I feel as though even in the hospital, departments are often siloed from each other, so there isn't really much data sharing that goes on. I feel lucky where I am right now; we are trying to break down some of those silos. It is such a gigantic institution that has been around for such a long time, and pieces are added here. It is hard for people to know all that exists at the institution and hard for people to step out of their specific departments to cross-share with other departments.

Overarching organizations must encourage collaborations within the organization to establish a culture of partnership. In pursuit of this organizational culture shift, a former staff member joined the Office of Community Population Health for the hospital and has worked to eliminate any barriers to the partnership between the CDC/NIH site and other hospital departments.

### **Lack of Youth-Friendly Staff**

Towards the end of the LTC program, the CDC/NIH LTC Supervisor left the LTC program, and there was no one at the RWD site staff to fill the position to continue the CDC/NIH-RWD partnership with Site A DOC because the new RWD staff no longer had a youth-friendly culture. Towards the end of the LTC program the CDC/NIH site could not provide youth-friendly services that YLWH needed due to new staff hired at the CDC/NIH site that were not adequately trained as youth-friendly providers. The CDC/NIH Supervisor stated, "I will say that a lot of the challenges that we found within the clinic, within the LTC coordination in working with the clinic team, came about because of a change in staff." The CDC/NIH providers had a culture of expecting clients to initiate their care, did

not link youth to care quickly enough, and were too rigid in their expectations of disadvantaged YLWH. The CDC/NIH site's providers did not see shepherding youth through the LTC referral process as their responsibility. The CDC/NIH Supervisor stated, "The value of linkage-to-care was not necessarily, in the eyes of some of the clinic staff, it was not seen as valuable."

The CDC/NIH providers also did not link youth to care quickly enough. Youth-friendly clinics are known for following-up with newly diagnosed HIV youth the day of their diagnosis because they understand how quickly youth can fall through the cracks and not get linked to care. The CDC/NIH site's providers didn't understand its importance, even if the CDC/NIH leadership did. Thus, there was a misalignment between the CDC/NIH leadership directive and the follow-through by providers. The CDC/NIH providers did not follow-through on providing care within 48 hours. So, this internal mismatch between leadership and staff priorities led to a weak LTC referral process. The CDC/NIH PI wanted a youth-friendly clinic; however, this failed to inculcate staff with the same vision.

Lastly, the CDC/NIH providers set up unnecessary medical care barriers that were not responsive to YLWH's struggles. The CDC/NIH's providers did not accommodate tardiness to medical appointments because they wanted YLWH to understand that their time is just as valuable as youth's time. However, this outlook does not take into account the structural barriers that youth face. For example, non-disclosure of HIV status to the family due to its stigma can lead to challenges for youth leaving home without getting parent's approval and transportation to the clinic. The CDC/NIH site's providers didn't understand or believe that youth required intensive care to support YLWH and preferred traditional medical care models, including client initiation of services and penalties for delay. Moreover, the CDC/NIH staff were not determined to break down barriers to get clients the quickest care possible and provide them space where they were not judged. Though cultural mismatches between organizations can allow for growth and exchange, in this case, the cultural clash between the CDC/NIH and the RWD sites hindered effective collaboration. While the RWD site was experienced at providing youth-friendly services, it is clear that the CDC/NIH site no longer had staff that embraced youth-friendly services, which hindered RWD site staff ability to identify anyone at the CDC/NIH site to onboard to the LTC program to strengthen their CDC/NIH-RWD partnership with Site A DOC.

### **Strategy to Overcome Barrier**

For future LTC program awards, the CDC/NIH leadership could develop and enforce more youth-friendly services. The CDC/NIH Supervisor encouraged the CDC/NIH PI to require the staff to provide youth-friendly services and make this part of its explicit mission and hold providers accountable. One participant stated:

[The CDC/NIH PI] has this belief system, which supports the type of work the [the CDC/NIH site] is trying to do, my sense is that she had a hard time translating that to others and then holding people accountable to it. You know, as a leader. It is not like she wants to be a dictator, no one has to believe what they don't want to believe, but I think she has a responsibility to share her vision of how clients should be treated and make sure that is what is being communicated to partners, to clients, to whoever walks through our door, it is important for leadership to set that bar and hold people accountable when they don't meet it. And I think, I don't know if she felt she had the power to share that or didn't feel like it was her place, I don't know. But this is something I shared with her when I left.

Also, to ensure youth-friendly services, the CDC/NIH site should have field social workers who are culturally aware, keenly understand, and respond to cultural, psychological, and socioeconomic barriers that youth face. Youth-friendly provider's goal is to help youth understand the diagnosis, provide medical care, and ultimately get youth to grow into the person they want to survive with the disease. All youth-friendly clinics should make providers follow these guiding principles when caring for youth.

### **Poor Communication between The RWD and CDC/NIH Sites**

Communication between the RWD and the CDC/NIH sites was not consistent, which may have led to poor coordination of medical care. At the beginning of the program, the RWD PI and the CDC/NIH Supervisor had phone calls every other week, and the program staff had in-person meetings once a month. Unfortunately, at the beginning of the program, the CDC/NIH PI was not involved in the scheduled communication with the RWD site about the partnership. Also, once the CDC/NIH Supervisor left, the meetings became much less frequent. According to the RWD PI, "I don't know what happened, but we found it hard to schedule a time to talk with one another. We would try to schedule some time after the coalition meeting to talk, but a lot of times, it never happened." Unfortunately, the poor communication between the RWD and CDC/NIH sites were never resolved.

### **Strategy to Overcome Barrier**

The interviewees never used a strategy to improve the communication between two organizations. However, all program staff stated strong communication was the best way to surmount partnership barriers. Both

in-person meetings and phone calls worked well. The communication mode was less critical than leadership involvement, communication frequency, and willingness to tackle conflicts head-on. Due to a lack of consistent meetings, collaboration weakened, and; over time, it dwindled rather than grew. One strategy to ensure constant communication is to write this into the initial partnership Memorandum of Understanding (MOU). Thus, about meetings, the CDC/NIH Coordinator said, "Make sure that the MOU that is between both of your organizations are clear and that there are no shades of gray. Everything is black and white."

Both the RWD and the CDC/NIH staff stated that, in hindsight, they would have consistently scheduled meetings so that all staff views the partnership as a part of their job responsibilities. Staff must see a mandatory meeting on their Outlook calendars to appreciate its importance. At a minimum, the entire CDC/NIH-RWD partnership group should have had quarterly meetings.

Organizations must recognize at the outset that partnership development will need consistent effort for an extended period to establish an LTC referral process, especially with government institutions. For example, developing a formal referral process with the Site A DOC took two and a half years. Even then, the result was a few referrals a month but no formalized LTC referral network. So, while leaders have other important activities, they must prioritize attendance at regular meetings and negotiate the development process details. The RWD PI stated, "The consistent and competitive strike needed to achieve change is difficult." Moreover, a staff member noted the LTC referral process would have been executed if all staff from both organizations jointly worked on the program:

If we were working jointly with our partner, we would get it done faster. So, it dragged because it fell through the cracks, you know, when you don't follow-up because you are so busy with other things, things tend to drag. I honestly believe referral process with the Site A DOC is doable. I honestly believe that it can be done. It can be done if they work together and consistently push the [LTC referral process] together and develops a strategy together, then they can get it done.

Thus, open dialogue and continuous contact to keep the project goal's momentum are required to build a partnership between organizations.

### **Inter-personnel Conflict**

Personal barriers are just as essential to address as structural ones. In the examples below, Supervisors eschewed conflict resolution between staff and failed to replace integral team members (or reassign their work) to



promote a successful partnership. Ultimately, leaders of collaborating organizations must value those collaborations and be wary of personnel issues like these if they wish them to succeed. Poor inter-personnel relationships among the Coordinators hindered collaboration. Though both sites knew about the problem, neither Supervisor nor PI sought to resolve friction between the two Coordinators. A CDC/NIH staff member blamed their Coordinator, specifically stating, "It takes a lot of equanimities, maturity, investment, and commitment to work with a partner collaboratively, I think we could have used a little bit more of that from [the RWD Coordinator]."

Another personnel issue was that the CDC/NIH Supervisor was the glue that held the partnership together and built a strong relationship with the RWD site staff; however, the Supervisor left one year before the program ended, and the CDC/NIH site didn't hire anyone to replace the Supervisor. Furthermore, the CDC/NIH PI did not step in to fill this void. So, once the CDC/NIH Supervisor left, the HRSA-CDC/NIH partnership effectively dissolved.

### **Strategy to Overcome Barrier**

The RWD and the CDC/NIH staff highlighted communication strategies that could be used in the future to address conflicts. According to a staff member, one way to reduce friction is having regular meetings, and one consistent topic of discussion at meetings should always be ways to improve the relationship. The CDC/NIH Coordinator said:

My advice would be to conduct meetings to talk about what works and doesn't work in the partnership at least every quarter. Not only that, I think that it is okay to give compliments when compliments are due for it to be an easy working environment. The biggest advice I would give is to communicate. Communication is key to having a great partnership between these types of agencies that are in separate neighborhoods.

In summary, interviewees saw the importance of regular meetings to reduce inter-personnel conflict and improve communication. Interviewees professed that a great deal of relationship building and conflict resolution had to occur before establishing an effective partnership. Clinics can only set an effective LTC referral network if they communicate frequently.

### **Lack of Leadership Buy-In**

The staff noted that the CDC/NIH leadership's lack of involvement hindered the partnership. The CDC/NIH staff would talk with the RWD staff, but the administration did not engage. This led to delays in program momentum and implementation with the Site A DOC.

The CDC/NIH PI was essentially not involved in the joint effort with the Site A DOC. Both the RWD and the CDC/NIH staff agreed that the CDC/NIH PI should have been more involved and that the buy-in and inclusion would have helped implement the LTC referral with the criminal justice system. A staff member stated, "[The CDC/NIH Supervisor] was working hard, but it would have been better to get our PI involved, at least in the beginning." The CDC/NIH Supervisor stated that waiting for approval from the CDC/NIH PI created workflow delays, while the RWD PI could immediately initiate tasks without anyone else's approval.

The CDC/NIH leadership asked staff and the local coalition to prioritize HIV prevention interventions, specifically targeted efforts towards the scale-up of pre-exposure prophylaxis (PrEP) at the clinical level. At the time, federal agencies began to fund HIV prevention drugs and interventions; this meant less money for care and treatment interventions. Therefore, the CDC/NIH PI likely wanted to seek this new pot of funding and thus prioritized HIV prevention activities over care and treatment collaborations. Because the CDC/NIH PI did not invest in linkage-to-care activities, the CDC/NIH partnership missed an opportunity to build an LTC referral network with the criminal justice system.

### **Strategy to Overcome Barrier**

Staff recommended leadership must fully engage and invest in the program right from the beginning of the partnerships. CDC/NIH leadership's absence from the decision-making process hindered implementing the LTC referral with the Site A DOC. The RWD PI attended all joint meetings and finalized decisions on the call for their clinic. Meanwhile, the CDC/NIH Supervisor, who attended collaborative partnership meetings on the CDC/NIH PI's behalf, had to clear strategies with the CDC/NIH PI before implementing them. The CDC/NIH Supervisor was also unable to provide real-time feedback.

The CDC/NIH Supervisor proposed ensuring all staff members realize they must continuously push leadership to engage externally. The CDC/NIH Supervisor could have made the CDC/NIH PI or the hospital's vice president liaise with the Site A Commissioner of Health (Site A COH). The Site A COH leads the initiative to end AIDS in Site A. This could have helped increase external engagements. Both the CDC/NIH PI and the CDC/NIH Hospital VP had close relationships with COH. Despite this, no action was taken on this front. This missed

opportunity exemplifies how an insular culture and lack of staff or leadership buy-in can result in missed opportunities and ultimately less successful partnerships. The CDC/NIH Supervisor stated:

Well, there are ways to push the envelope and get peoples' ears by leveraging your connections. I'll be honest; I was hesitant to talk to [the CDC/NIH PI] to intervene with the Commissioner. Then again, even when I did ask her to get involved in meetings, it didn't happen; I didn't follow up on it to see if she could. I don't really know why now; it's not like I was intimidated by her; I guess I just felt like it wasn't my place since I wasn't in that leadership role. And where I sit now, I think it was my place. I think we could have pushed the envelope...That is what I think could have happened, but when you are in these kinds of programs, sometimes you have blinders on; I don't know why.

Thus, in hindsight, staff would have continuously advocated for leadership at the CDC/NIH site to help forge a partnership between the health care system and the criminal justice system. In the future, leader's attendance at partnership meetings could ensure formal implementation of new LTC referral processes. The CDC/NIH Supervisor stated that needing to report back to and wait for approval from the CDC/NIH PI made partnership decisions take too long and complicated the process. Thus, interviewees expressed the importance of making it mandatory that those with decision-making authority attend all interagency partnership meetings.

### **Competition Between CDC/NIH Site and RWD Site**

Multiple interviewees noted that the RWD staff were ready to collaborate, but the CDC/NIH and RWD staff were prepared to compete. Even though competition is part of Site A culture, the RWD PI spurred his team to adopt a collaboration culture because he felt it would help uncover previously untreated HIV-positive youth. A staff member stated:

As soon as I mentioned to my colleagues about this partnership, I pretty much received some negative feedback. They said, well, that is not going to work; that is just not going to work. Historically there has been a sense of competition between the two organizations, and so people right away went into competition mode. I actually heard from one of my colleagues say, 'Oh, we are going to kick their butts,' and I said to them, 'It is not about kicking butts; we are supposed to be working together'. Competition is sort of like an unspoken truth; nobody talks about it, but you know it is there. When you try to talk about it, all you hear is diplomacy from both sides.

### **Strategy to Overcome Barrier**

The RWD leadership immediately shut down any sense of competition and reinforced the LTC program's collaboration goal throughout its implementation. One strategy used to ensure collaboration over competition is to have a champion that continually reaffirms the partnership goal to employees. The data show that because the

RWD PI supported partnerships and instilled their importance upon the RWD Coordinator, this message was communicated to the RWD site staff. Staffs' willingness to collaborate spread through the whole clinic and facilitated the partnership with the RWD site due to the CDC/NIH-RWD partnership; in comparison, the CDC/NIH site staff did not have anyone in a leadership position advocating for the association. The data analysis revealed that in organizations collaboration champions can help overcome competition.

One staff member noted that funding accountability systems that ensure clinics collaborate and provide youth-friendly services would also promote partnerships. The RWD staff explained, "Sort of like a buddy system, if your partner is not doing well, they can hold you accountable and vice versa so that way each organization is forced to help the other one. And that will help create close relationships between partners." The LTC program was funded by the HRSA, the CDC, and NIH; however, none required clinics to collaborate to receive continued funding. The RWD site staff felt strongly that an accountability system would help: 1) Alleviate funding competition (which is intense in Site A where services overlap), and 2) Shift clinic focus from the number of clients they see to the quality of care they provide.

### **Bureaucracy in Government Structures**

The RWD and CDC/NIH sites had a hard time getting leaders at the Site A DOC to formalize the LTC referral network. The RWD and CDC/NIH sites were both at the mercy of large organizations (i.e., the Site A DOC) that are generally slow to change policies and protocols. One observation made by a CDC/NIH staff member was that the RWD site wanted the formal partnership with the Site A DOC to begin quickly. A CDC/NIH staff member stated, "Sometimes people look at structural change, and they get very frustrated that it is taking a long time, but the nature of structural changes is that they take a long time." Perhaps the CDC/NIH staff member was complacent and didn't try to accelerate the process because they had little hope of an effective partnership with the Site A DOC would ever form quickly under bureaucratic government oversight. In contrast, the RWD site was hopeful of a formal partnership with the Site A DOC.

### **Strategy to Overcome Barrier**

Referral partnerships flourish when the referring agency understands the benefit of collaboration with the referring agency. In the RWD-CDC/NIH partnership, referring agencies found it helpful to gain access to the

designated LTC Coordinator. The RWD Coordinator provided an example of this. The referring agency needed to liaise with a clinic that had relationships in different neighborhoods. The referring agency was very optimistic about the partnership results. In the past, referring agencies would call a clinic's general number but found it difficult to follow up with an actual human being who could definitively affirm the youth they referred to had to access care. The RWD PI stated:

Having that person designated to provide communication between the referral site and our program was helpful, particularly with our Department of Health. They have particular mandates to document referrals and linkages-to-care. And similarly, with the Department of Corrections make a lot of their initial referrals to a community-based organization to handle case management services. Then the community-based organization, in turn, is charged with getting people into care. So, we attended several meetings with this community-based agency that helped get their adult clients into care, which enhanced their comfort with our program in general, so we are hopeful that will translate into them sending us adolescents and young adult clients.

The CDC/NIH Supervisor agreed with the RWD PI's partnership strategies for trust-building partnership. These are: 1) Designating a specific point of contact (the RWD Coordinator) and 2) Assisting the referring agency with any client regardless of whether or not that client fell into their pre-determined target demographic. Thus, the key to building new relationships for potential collaborators is to be flexible and assist whenever possible and not just referring clients who may fall in their purported demographic target. The RWD Coordinator gained favor with the referral clinic and showcased their helpfulness when they went above and beyond their mission to help the Site A DOH and the Site A DOC refer clients to care outside their demographic target. This impacted future cooperation in a positive manner.

#### **Lack of HIV Surveillance Data-Sharing**

The risk of co-morbidities increases when novel pandemics threaten already-susceptible populations, such as YLWH. When hospitals redirect staff and resources towards directly combatting the novel pandemic, this leaves HIV client populations increasingly vulnerable. The RWD site was tasked with setting up a meeting with the local health department to obtain public health authority to access HIV surveillance data to identify newly diagnosed YLWH and quickly link them to medical care. The RWD site found it especially difficult setting up a meeting with the local health department representative to discuss a data-sharing agreement. When the LTC program was implemented, there was an Ebola and Zika outbreak. Clinics could have referred YLWH better if the Site A

Department of Health had allowed clinics to access HIV surveillance data in real-time. The lack of real-time data makes it more difficult for clinics to identify newly-diagnosed youth or when follow-up medical care is overdue. Despite replete experience with sensitive medical data, Site A clinics cannot access the Site A DOH HIV surveillance data.

Shared data would also allow for more effective new client incentive programs. In the past, client incentive programs would lead to PLWH lying about their HIV status or lying about seeking consistent care at another clinic to obtain an incentive (i.e., money, gift cards, etc.). The ability to share data with other health care agencies will allow staff to determine if they are duplicating efforts.

A lot of agencies use incentives to bring clients to care as well as to keep their clients in medical care. The downside to using this approach is that it can lead to clients lying about their HIV status to receive the clinic's incentives. Shared databases would allow clinics to differentiate newly-diagnosed HIV-positive clients from benefit-seekers and help them better invest in (bona fide) new clients.

### **Strategy to Overcome Barrier**

There is no satisfactory substitute for direct access to substantially complete HIV surveillance data. However, the RWD site successfully obtained the data to prove youth are not linked to medical care. The RWD site worked with the Site A DOC's designated case management society to circumvent their lack of access to the Site A DOH HIV surveillance data to assist with linking youth to medical care. Still, some clients remained lost in the system. Due to a carefully managed, trustful partnership spanning years, the Site A DOC's designated case management agency was willing to provide its case management data to the RWD site to determine how many YLWH were not linked to medical care. The RWD site used this data to show the Site A DOC that only a small percentage of YLWH were ultimately referred to Site A DOC'. The number of YLWH released each month by the Site A DOC was more significant than the number of clients the Site A DOC's designated case management agency saw. The referral is circuitous because it still relies on Site A's DOC's case management agency rather than directly involving the Site A DOC and Site A DOH.

One solution to the data-sharing challenge between local health departments and clinics could be the CDC vocalizing the promotion of data sharing. The CDC, along with the NIH, and the HRSA, funded the LTC program.

The RWD PI said it would have helped if CDC officials had conveyed the importance of sharing HIV surveillance and medical data to the partners. The CDC has a litany of success stories related to data sharing that occurred in other municipalities. The CDC's conclusions and recommendations are apt to be respected by any health care provider in the USA, including the Site A DOH and the Site A DOC.

## **Aim 2 Conclusion**

Based off LTC program staff's perspectives implementing the CDC/NIH-RWD partnership, the case study describes the key factors that hindered the partnership's attempt to implement a LTC referral network between the two HIV clinics and the Site A DOC. A total of nine primary topics emerged, showing that barriers exist to the formation of effective partnerships, which include the following: geographic location, organizational culture, lack of youth-friendly clinic staff, poor communication, interpersonal conflict, lack of leadership involvement, competition between institutions, bureaucracy in government structures and lack of HIV surveillance data.

This case study revealed that the RWD site thought their partnership with the CDC/NIH site would allow them to offer a more in-depth scope of services and tackle partnerships with big agencies (e.g., the Site A DOC). Unfortunately, the CDC/NIH site was not anxious to establish partnerships outside their neighborhood. Instead, the CDC/NIH site believed that they should maintain complete independence around core functions and prioritize other activities over their partnership with the RWD site. Personnel conflicts should be immediately addressed, and staff vacancies should be filled with youth-friendly staff to maintain program continuity. Leadership buy-in to promote collaboration and consistent involvement in the project is crucial for successful partnerships, and collaborative communication should happen at the leadership-level as well. Finally, health departments are consistently getting involved in new pandemics or epidemics. Therefore, health department staff should be ready and willing to adjust to changing circumstances, particularly the rapidly evolving needs of today's HIV-positive youth, to ensure clinics can access HIV surveillance data in real-time.

Investigations into strategies to overcome barriers in the RWD-CDC/NIH partnership showed that leadership buy-in, open communication, collaboration culture, mutual understanding, youth-friendliness, and data sharing would promote better youth HIV medical care. First, clinics must have leadership and working staff who believe in a partnership's importance to succeed. Leaders must buy into the partnership, communicate directly

with the leadership of partners, and enforce a culture of both inward and outward collaboration. A lack of institutional memory during staff turnover can be supplanted by strong leadership and communication. Strong communication appeared to be the best way to surmount partnership barriers and interagency conflict. Second, referral partnerships flourish when all partners understand the collaboration's benefits and their collaborators' capabilities. Clinic tours could help allow partners to understand one another's abilities. Third, YLWH significantly benefit from those clinics that provide youth-friendly services and can be geographically flexible in making referrals. Fourth and finally, real-time data sharing would make health care networks more efficient and strengthen the focus on capturing new or lost HIV clients.

These frequently-cited barriers to collaboration reduced the LTC referral process's implementation with the Site A DOC and the two HIV clinics. Though attempting to develop a LTC referral process with the Site A DOC took over two years, and the HIV referral process remains circuitous, the partnership is still a win because the system-level barrier to linkage-to-care was identified. This partnership shows clinics must always creatively overcome obstacles to formalize partnerships with large institutions (such as the criminal justice system). Moreover, although the CDC/NIH-RWD partnership was ultimately unsuccessful in establishing the LTC referral network with several targeted agencies, the findings should push organizations to think more strategically and stimulate thinking and conversation on utilizing health care partnerships to improve linkage to medical care referral systems.



## **CHAPTER 5: SITE B RESULTS**

### **Aim 1 Introduction**

This case study's overall aim is to provide a record of the CDC/NIH-RWD partnership for leaders to replicate in other HIV linkage-to-care (LTC) partnerships. From the perspective of LTC program staff involved in the partnership effort, it tells the story of how the CDC/NIH and the RWD sites endeavored to develop an LTC referral process in concert with each other, community-based organizations, and the city health department. It underlines their triumphs and challenges.

Aim 1 examines the HIV LTC landscape in Site B, description of the RWD and the CDC/NIH sites, staff's roles and responsibilities in the LTC program, and the CDC/NIH-RWD partnership approach to community engagement. The case study highlights four attempted partnerships: 1) the partnership between the CDC/NIH site and the RWD site, 2) the CDC/NIH-RWD partnership with the university, 3) the CDC/NIH-RWD partnership with the department of corrections, and 4) the CDC/NIH-RWD partnership with the health department.

In 2010, leadership at the CDC, the NIH, and a clinical research network came together to fund the CDC/NIH site's implementation of the SMILE program, here-in-after known as the former linkage-to care (LTC) program located in Site B. The former LTC program promoted the coordination of HIV focused agencies to ensure testing, identification of HIV status, and immediate LTC of YLWH within 42 days of diagnosis. According to informants interviewed from the CDC/NIH site, this program increased LTC within six months of diagnosis from 65.3% to 82.6% for youth ages 13-24 in Site B (Site B 2016 Community Impact Plan). This closely approached the National HIV/AIDS Strategy target of 85% (White House Office of National AIDS Policy, 2015).

In 2013, with momentum from the initial LTC referral network's success, the Secretary's Minority AIDS Initiative funded expansion of the LTC referral network. The Secretary's Minority AIDS Initiative provided full financial support for a federal partnership between the CDC, the NIH, the HRSA, and a clinical research network from 2013 to 2016. The federal agencies developed a cooperative agreement known as "the LTC program." This

was a partnership between a HRSA-selected HIV clinic and the CDC/NIH site. HRSA chose to fund the clinic through a mechanism known as the Ryan White Part D; here-in-after known as “the RWD site.” This CDC/NIH-RWD partnership lasted for three years (2013 to 2016). The LTC program's primary purpose was to support youth (age 13-24) timely linkage to an agency that best meets their medical and non-medical needs by expanding the LTC referral network developed in the aforementioned “former LTC program.”

### **Site B Characteristics**

At the beginning of the HIV epidemic in Site B, the populations with highest transmission rates were predominantly Black heterosexual women. In the early 2000s, however, the highest proportion of new HIV diagnoses were among Black men who have sex with men (MSM) under 35 years of age (61% of new HIV diagnoses). By 2014, youth aged 13-24 accounted for 27% of all new HIV diagnoses. In 2014, Site B ranked second in the United States for estimated HIV case rates. Site B is among the poorest and has one of the lowest educational attainment rates in the United States, which is a contributing factor to the severity of the HIV epidemic in Site B. In 2013, Site B held the rank of the country's most incarcerated major city, where one out of every seven Black men is or has been in criminal justice system.

In 2010, before the CDC/NIH site implemented the former (SMILE) LTC program, there was no formal LTC referral process to ensure YLWH were linked to medical care. One interviewee explained that the CDC/NIH site filled a much-needed gap in the community, “Youth have very different needs as compared to what adult needs are. I think what we provided was much different compared to adult care.” Three factors contributed to the collaboration of the CDC/NIH and RWD sites to develop a robust LTC referral network: natural disaster, the local coalition, and history of collaboration between the sites.

The HIV community's willingness to partner is in part a response to massive Hurricane in Site B, where the community facilitated these new partnerships between HIV clinics, community agencies, and government institutions. Although the natural disaster destabilized the local HIV health care system, it resulted in specialized health care physicians collaborating to ensure displaced PLWH had access to medication to support drug adherence and viral load suppression. The HIV-focused agencies realized that the community's limited resources needed to be strategically utilized, which could only occur if all the agencies pulled their resources together (i.e.,

financial resources, and staff expertise). Even though the massive Hurricane struck in 2005, the healthcare providers attributed the positive partnership building to the disaster, as it created an environment to foster partnerships during the implementation phase of the LTC program. One CDC/NIH staff member explained how massive hurricane directly influenced the CDC/NIH site's willingness to enter into a partnership with the RWD site:

Massive Hurricane showed us that we all need each other. No one man can stand-alone. I wasn't here, but [the federal agencies] didn't think this site could come back after massive Hurricane. We had to fight to come back to be a part of [the clinical research network]. You know, because [the clinical research network] didn't know if the agencies would be able to be up and running. We were there to tell [agencies] you can do this, and so we were resilient...That is why I keep saying that we couldn't let [the RWD site] fail because when they fail, we fail, and that wasn't going to happen... When massive Hurricane came, it was just a true testament of how we engaged the community to come to the table to learn about how we are going to address our issues for adolescents with HIV.

Coalitions proved to be another key vehicle for promoting the CDC/NIH-RWD partnership's initiative to expand the LTC referral network in Site B. Since 2002, the CDC/NIH site has supported the establishment and maintenance of a community-led coalition. The coalition brought diverse stakeholders together to address structural barriers to link and retain HIV-positive youth to medical care. The coalition members were groups of lawmakers, law enforcement agencies, public health officials, and health care workers coming together to develop or revise policies (defined as guidelines that regulate the environment and/or the individual within the environment), practices (described as standardized action or manner of doing something), laws, and systems to prevent barriers to linkage-to-care for youth living with HIV. One participant noted the coalition successfully showed agencies that there is strength in numbers to create positive change in the HIV community:

Before the coalition, each agency was doing their own thing; they did not trust each other. For them, there were no benefits to working together. However, now we have seen that as a part of the coalition being independent and not necessarily in competition with them that it brought all these individual key stakeholders together; it only enhanced their agencies.

The coalition also showed the benefits of agencies joining, which include opportunities to network and access much needed resources. The CDC/NIH-RWD partnership found the coalition to be an excellent platform to highlight the benefit of joining the LTC referral network. The CDC/NIH Supervisor provided an example of when the health department assisted a coalition member to get certified in HIV counseling and testing:

I would tell [the coalition member] that we would love for you to be a part of our discussions to come sit at the table to discuss whatever barriers or issues you are experiencing. I think it was an added benefit for the agencies to hear that if you are part of this, you get to network with other providers and find out what they are doing, you will get some capacity building training if you are not doing testing here, how about we hook you up with the Office of Public Health who is our partner and show your staff how to get training in becoming an HIV Tester and Counselor. We can show you how to get free HIV testing kits if you are paying for them currently. We showed here the benefit we can offer through [the coalition], and then we would sell the [the CDC/NIH-RWD partnership].

Both the RWD and the CDC/NIH sites were active members of the coalition before the start of the former LTC program. The RWD site's active participation and recruiting agencies to the coalition indirectly showcased the RWD site's value in partnerships. The RWD site leveraged its expertise in HIV testing to train coalition members on HIV outreach testing. The RWD site's willingness to share their HIV testing expertise with other coalition members exemplified their desire to collaborate in the community and the benefit of having the coalition platform to share best practices with other agencies in the HIV community.

The positive history of collaboration between the RWD and CDC/NIH site was the impetus for the CDC/NIH staff's swift willingness to share their resources with the RWD site freely. Before the LTC program, the CDC/NIH site established a strong relationship with the RWD site to outsource case management services. Thus, there was sharing of staff resources from HIV diagnosis through HIV care between the CDC/NIH and RWD sites. Moreover, a participant noted both sites found the previous sharing of resources to be a positive experience and facilitated the implementation of the "united front" approach to implement the LTC program: "Because of the prior relationship we had and knowing [the CDC/NIH LTC Supervisor] and [the CDC/NIH PI] from the community and having mutual patients for case management... we felt they would support us in the partnership."

In the former (SMILE) LTC program, the RWD site showed strong collaboration by referring youth diagnosed at the RWD site to the CDC/NIH site to receive medical care. Specifically, before the LTC program, the RWD site lacked the capacity to provide HIV test results to youth newly diagnosed with HIV and the capacity to provide medical care to youth under the age of 18. Thus, the RWD site understood youth needs and referred youth under 18 quickly to the CDC/NIH LTC Coordinator to coordinate youth services. The CDC/NIH Coordinator notified youth of their HIV status within 24 hours of taking the HIV test because the CDC/NIH site understood how quickly youth get lost from the HIV health care system.

## **CDC/NIH Site Overview**

The CDC/NIH hospital has several affiliated clinics throughout Site B, and each provides a variety of services. The CDC/NIH site was established in the 1980s to provide HIV prevention, care and treatment services, including: HIV testing, comprehensive medical care, laboratory services, health insurance, medication assistance, mental health services, legal support services, and referrals to specialists for additional medical care. According to one interviewer, “The CDC/NIH site is staffed by highly experienced, youth-friendly, and specially trained health care professionals who are passionate about delivering culturally sensitive and age-appropriate services to at-risk youth and YLWH”

In addition, the CDC/NIH site conducts clinical research to understand which interventions reduce viral transmission. The CDC/NIH site has also built rapport among its Black clients to implement quality HIV research and implement best practices in HIV prevention, care, and treatment services. As one staff member highlighted:

If people think you are only there to get something and not give anything in return, and in particular when it comes to African Americans, they are apprehensive, they always feel like they are the ginny pigs based on history, so our staff has to be skilled at dispelling even all that mistrust in the African-American community.

Lastly, as noted earlier, since 2002, the CDC/NIH site has ensured the implementation of a local coalition of the local health department, community-based organizations, and HIV clinics to develop strong partnerships.

## **RWD Site Overview**

The RWD site was established in the 1980s to provide HIV prevention, care, and treatment services but had never been involved in research. The RWD site has several affiliated clinics throughout Site B. All the sites offered wrap-around services to clients, which they referred to as a “one-stop-shop.” All sites provided HIV testing, primary medical care, laboratory services, health insurance assistance, medication assistance, behavioral and mental health care, dental services, housing, substance abuse treatment, legal support services, referrals to specialists for additional medical care, and case management services. Staff members at the CDC/NIH and the RWD site reported “In these two sites there is a youth-friendly clinic staffed by highly experienced and specially trained health care who are passionate about delivering culturally sensitive and age-appropriate services to youth”.

Before the LTC program, the RWD site had no designated staff to build community partnerships, ensure youth patient retention, or ensure youth were immediately linked to care. This changed with the implementation of the LTC program, and by the end of the LTC program, the RWD site successfully linked 100% of referred HIV positive youth to care within 42 days of being referred to the LTC Coordinator. Several RWD staff members attributed the LTC success rate to hiring a full-time LTC Coordinator whose demographics matched that of the majority of the youth served. In this case, the RWD LTC Coordinator was in his early 20s and identified as both Black and Queer. Thus, the LTC Coordinator mirrored the population they were targeting to get linked to care. A CDC/NIH staff member provided a perfect example of how a LTC Coordinator from the community can be an agent of change and help convince a patient lost to follow-up to recommence medication:

One particular client of mine went through all his appointments for the [former LTC program] before the [LTC program], but throughout that time, he had never started his medication because he was never ready. He was an MSM, and I felt that [the RWD LTC Coordinator] could be of better service to him because he was a black male, MSM, and I felt that [the RWD LTC Coordinator] could reach him, so what I did was call [the RWD LTC Coordinator] over... And since the time [the RWD LTC Coordinator] has been working with the client, the client has been taking his medication ever since... It's like, okay, this is another young black male, MSM, who is talking to me about medication, so maybe there are people who actually care. Because I think he saw me as a mother figure because I am older, but he saw himself in [the RWD LTC Coordinator]. So that actually worked. Sometimes you have to have people who look like them to relate to them.

This example shows providers and support staff can have a strong affinity with minority youth when they have a similar demographic as the clients they serve.

One year into the LTC program's implementation, the RWD site received federal funding to transition from an AIDS service organization to a Federally Qualified Health Center (FQHC), which provides services to everyone from birth to death. The RWD site and the CDC/NIH site both had very similar services, except that the RWD site had wrap-around services and case management services. Both sites had a positive reputation for collaboration with HIV-focused agencies as well as providing youth-friendly services. The two sites were also open to seeing youth regardless of where they lived because they believed that HIV positive youth need flexible geographic options for receiving care. Several staff members noted that this was a potentially significant reason for the success of the LTC program. One participant provided a great example of the importance of listening to youth's preference for medical care even if it means receiving care that is far away from where the client lives:

Because [a client] lived on the West Bank, [a referring clinic] thought [the client] should go to a clinic on the West Bank. Okay, you are going to Priority Clinic; well, guess what [the client] didn't show up to the appointment. [The client] already told [the referring clinic] he didn't want to go to a clinic that was nearby, so why did you make him go there... So [the CDC/NIH LTC Coordinator] got [the client] on the phone just by chance and asked the client where he would like to go. The client chose all the way across the river in Site B... Although [the receiving clinic] found funds for his transportation, [the client] was willing to catch the bus... so sometimes again, what seems easier in your mind for a clinic to be less than 15 minutes away from his housing, the client told you he didn't want to go there, so it's really about being youth-centered, meaning doing what is best for the client.

### **LTC Program Staff Roles and Responsibilities**

To enhance and strengthen the LTC referral network, the federal agencies expected the sites to hire an LTC Coordinator, an LTC Supervisor, and a Principal Investigator (PI). The LTC program's federal agencies expected the LTC Coordinator to build community partnerships to expand the LTC referral network and engage with HIV positive youth through in-person meetings, text messages, and phone calls. The LTC Coordinator provided HIV positive youth with appointment reminders and connected them to social service providers (i.e., housing, financial, and medical insurance assistance). Moreover, the LTC Coordinator offered intense case management services such as personally picking up clients from their homes. The federal agencies left it up to the sites to determine the roles and responsibilities the Supervisor and the PI held; in general, one or both should offer the LTC Coordinator support and provide strategies to consider when establishing new partnerships in the community and addressing barriers to a client's linkage-to-care.

For both sites, the PI had minimal involvement in the daily activities of the work. The PI allowed the Supervisors to have full control of the decision-making process for the LTC program. However, the Supervisors' execution of the LTC program was drastically different at each site. The CDC/NIH LTC Supervisor supported the LTC Coordinator in organized outreach events, identified new agencies, established new partnerships, and reviewed cases. However, the RWD LTC Supervisor was only able to provide support in reviewing cases assigned to the RWD LTC Coordinator.

Fortunately, the CDC/NIH LTC Supervisor and CDC/NIH LTC Coordinator provided additional support to the RWD LTC Coordinator to effectively implement all the responsibilities assigned to the RWD site and ensured the successful implementation of the LTC program. The CDC/NIH LTC Supervisor provided strategic direction for selecting agencies to establish partnerships, with input from the CDC/NIH and the RWD LTC Coordinators. The

CDC/NIH LTC Supervisor had the ideal background for identifying new partnerships and had 14 years of experience convening the local coalition, established several strong partnerships in the community, and was aware of the gaps in collaboration with local agencies. Thus, the CDC/NIH Supervisor joined the CDC/NIH LTC Coordinator and the RWD LTC Coordinator to conduct community outreach to recruit new agencies to join the LTC referral network.

Lastly, the CDC/NIH LTC Coordinator had a strong background in social work. And therefore, mentored the RWD LTC Coordinator on how to provide services to youth through a weekly one-on-one client case review with the RWD LTC Coordinator. Moreover, the RWD LTC Coordinator provided the CDC/NIH LTC Coordinator advice on collaborating with youth to get linked to care. The CDC/NIH LTC Coordinator noted these meetings were mutually beneficial, "It was very collaborative because again I am older, [the RWD LTC Coordinator] is younger so we both had different perspectives, and we were able to come to the middle. Sometimes he would say to me how to work with adolescents, and I would tell him something to do to work with them, so that worked for us."

#### **CDC/NIH-RWD Partnership's Strategic Approach to Community Engagement**

The CDC/NIH-RWD partnership approach with organizations in the community to expand the LTC referral network was a "united front" approach. One participant noted this approach was easy to enter for the two organizations due to both of them having a positive community reputation, "Site B is very small, to begin with, we are in close proximity, but that doesn't mean that because you are that close that you are friendly, that you are a partner, but for us knowing what our partner organization did in the community, being one of the first clinics that offered HIV testing made it easy to collaborate." Also, the two agencies understood clients are a delicate population that need to have multiple options to receive care. One staff member explained:

I think us working together in a collaborative fashion only benefits the whole community. What if there is one place and things aren't going right for them, or maybe it's a staff thing like the client feels like the staff looked at them funny, some people are that sensitive that they will turn around and leave. Still, if you have a partner that can work with them that the person feels supported there, that might turn them back around to keep seeking care. Sharing with anyone to keep our youth in care is the most important part; I just feel we did that with our partnership.

The CDC/NIH and RWD partnership implemented a multi-prong approach to engage with the community to promote the LTC referral network. The first approach was to jointly meet with community agencies to expand the LTC referral network. The second approach was to present the LTC program initiative at the coalition meetings. The third approach was through branding of the CDC/NIH-RWD partnership. The CDC/NIH and RWD sites were



strategic in their community engagement approach. The CDC/NIH-RWD staff would go out into the community to encourage agencies to join the coalition and then use that platform to discuss the LTC program's initiative to expand the community's LTC referral network. The CDC/NIH-RWD partnership knew that the community agencies felt more comfortable joining the LTC referral network when they saw the CDC/NIH and RWD sites, two well-respected health care institutions, coming together to form a partnership to strengthen the LTC referral network.

Moreover, the CDC/NIH site made sure the RWD LTC Coordinator had a prominent leadership role as co-chair of the coalition, which led to the implementation of the LTC program being a standing agenda item at the monthly coalition meetings. The CDC/NIH and the RWD Coordinators presented the tracking of the LTC program data to focus on the number of YLWH linked to care each month, which was a valuable way to show the impact that their effort was making towards youth in the community.

Lastly, building a partnership identity is another key step for community agencies to embrace the CDC/NIH-RWD site's initiative. Creating an identity was achieved through "branding," specifically giving the CDC/NIH-RWD partnership a distinct name from the organizational home name. This approach can help create loyalty, a sense of mutual interests, and align with the partnership's principles. In Site B, the branding of the partnership's different names was done by distributing coasters with the partnership name logo and the CDC/NIH and the RWD LTC Coordinators' names on it. The CDC/NIH site received funding from the CDC to implement different marketing tools to promote the LTC referral network. However, the RWD site did not receive any government funds to market the LTC program. The CDC/NIH site exemplified the true essence of partnership because the CDC/NIH site had no issue sharing its financial resources to market the CDC/NIH-RWD partnership. The success of the CDC/NIH-RWD partnership came from both sites' willingness to collaborate to increase the LTC referral network, utilize the coalition to expand partnerships, and to transparently cross-share available resources to support both sites' implementation of the LTC program.

#### **Key CDC/NIH-RWD Partnerships with Agencies in the Community**

The CDC/NIH-RWD partnership worked together to map out existing stakeholders and identify new organizations to partner with to expand the LTC referral network. The CDC/NIH-RWD partnership established several LTC referral processes with agencies in the community. The most noteworthy highlights were with

universities, the criminal justice system, and with the health department. The CDC/NIH-RWD partnership established the LTC referral process with universities, specifically Catholic Universities and Historically Black Colleges and Universities (HBCUs), to provide HIV testing services on the campuses and a formal LTC referral process for any student who tested positive for HIV.

Before the LTC program, Site B criminal justice system did not have a LTC referral process to the medical care system. Thus, the CDC/NIH-RWD partnership focused on the linkage of YLWH to youth-friendly clinics within the criminal justice system. As a result, the CDC/NIH-RWD partnership successfully established: HIV testing and counseling services, cultural sensitivity trainings, and a formal LTC referral partnership to ensure newly diagnosed incarcerated YLWH would be referred to the RWD and CDC/NIH sites. The CDC/NIH Supervisor noted that the success of the criminal justice system partnership with the RWD and the CDC/NIH sites was attributed to the long positive history that the RWD site had with the criminal justice system.

Both of us have enhanced our relationship with the system but in different ways and yet still a united front. There is this expectation that [the RWD site] will be doing a lot of direct services for juvenile corrections, and [the CDC/NIH Site] have come in and done training at a different angle around LGBTQ cultural sensitivity and working with populations of focus that might be identified as living with HIV. We used our different strengths in terms of previous relationships, but also in terms of other things we have to offer and then sharing with each other as we go through them, so that has been good. [The RWD site] certainly have a longer history with juvenile corrections than we do, so they certainly have been able to share contacts with us, so it has been helpful.

Lastly, The CDC/NIH-RWD partnership was sustainable in terms of collaborating with the health department to obtain public health authority of all the contact information for YLWH in the community. The RWD site and the CDC/NIH site did not push public health authority because both sites knew from past attempts that public health authority was not on the table due to health department's distrust of sharing client level data with non-government employees. Instead, they focused their efforts on a partnership with the health department to strengthen youth's linkage-to-care. Specifically, the CDC/NIH-RWD partnership concentrated its efforts on sharing information with the health department's disease intervention specialist (DIS). Over time, the CDC/NIH and the RWD sites were able to show their value to the health department's DIS by building their rapport with the health department staff. One participant noted:

I was also able to establish a relationship with two Disease Intervention Specialists at the local health department. If I was trying to locate a client, I could give the client information to the local health department and ask them to help me locate the client so that I could reach the client, and it got to the point where they were contacting me to locate a client. We got to a point where we were cross-sharing information...We had a process where we would rely on each other to find people that were lost to follow-up.

The health department DIS staff and LTC Coordinators need to collaborate because DIS staff are only assigned to locate PLWH who have been out of care for over a year; too long of a time period for YLWH to not receive care. The CDC/NIH-RWD partnership flourished when the health department frontline staff experienced the benefits of collaboration with the LTC Coordinators. In the course of the CDC/NIH-RWD partnership, the health department found it helpful to gain access to designated LTC Coordinators seeking to quickly link youth to medical care and non-medical care. At the end of the LTC program, staff noted that the DIS staff would call upon the LTC Coordinators to identify and link YLWH to care.

The CDC/NIH-RWD partnership developed a policy to improve the health department's system for allocating HIV medication to YLWH. In Site B, the health department's AIDS Drug Assistance Program is responsible for ensuring access to HIV medication and has a structure in place for distribution of medication statewide. The CDC/NIH-RWD partnership took the initiative to identify the barriers PLWH and health providers experienced when requesting access to HIV medication. The main obstacle determined was the health department's archaic system to fax a request for dispensing ART medication to YLWH. The CDC/NIH and RWD partnership tapped into the coalition buy-in to spearhead the initiative to streamline ART medication distribution. Specifically, the coalition members worked with the health department to develop an online application for medication distribution. This policy change was attributed to the health department's response to the collaboration among the coalition members to resolve these medication challenges.

#### **LTC Referral Process Between the CDC/NIH Site and the RWD Site**

The CDC/NIH site developed the "united front" approach around the LTC referral process to ensure clients were linked to the best Coordinator to meet their needs. There were many community members that were aware of the CDC/NIH LTC Coordinator from the past three years working on expanding the LTC referral network. To reduce confusion, the agencies would continue to reach out to the CDC/NIH LTC Coordinator. The CDC/NIH LTC Coordinator and RWD LTC Coordinator would discuss the case to determine which Coordinator would best meet

the clients' needs. Moreover, the CDC/NIH LTC Supervisor observed that the LTC Coordinators supported one another to ensure clients were linked to care, "Even when our community partners called [the CDC/NIH LTC Coordinator] to say I have a newly diagnosed person, and [the CDC/NIH LTC Coordinator] was already at an appointment then there was [the RWD LTC Coordinator] who would go out and meet the person. So, they were really there for one another."

The CDC/NIH LTC Coordinator initiated biweekly in-person meetings with the RWD LTC Coordinator to review youth barriers to medical care visits. Also, the Coordinators held weekly phone calls to discuss how to find the urgent resources youth needed. The Coordinators were very collaborative in prioritizing youth needs in the CDC/NIH-RWD partnership. The LTC Coordinators used the meetings to strategize the best communication styles and approach to engage youth newly diagnosed with HIV and re-engage youth that had fallen out of care. The CDC/NIH Coordinator's assistance to the RWD LTC Coordinator helped the RWD LTC Coordinator quickly understand how to provide intense case management services and tailor approaches to offer specialized services for each individual.

The RWD LTC Coordinator revealed that he found the meetings beneficial because the CDC/NIH LTC Coordinator shared years of experience working as a social worker to guide the RWD LTC Coordinator on how to address youth's barriers to care. Also, the RWD LTC Coordinator provided an example of the benefits of reviewing cases with the CDC/NIH Coordinator to identify the correct communication style to work with youth re-engaged in the medical care system:

There was a person that we got linked to care. This particular person had a very extreme mental disability. [The CDC/NIH LTC Coordinator] had worked with the [person] in the past, and was able to share information with me about the client, and [I] was able to tailor my linkage-to-care approach for the client based upon information [the CDC/NIH LTC Coordinator] shared with me, so if I didn't have that information on the client, as far as the client being bipolar and having angry outbursts attributed to the mental illness [the person have in the] profile, I would have walked into the situation where I was dealing with someone that was mentally ill, and I didn't know about it. Having that information in advance helped me provide the appropriate service to the person and prepared me to interact with the client.

The CDC/NIH Coordinator also benefited from the in-depth review of youth barriers with the RWD LTC Coordinator. The RWD LTC Coordinator had strong inter-personal skills working with the MSM population and shared with the CDC/NIH LTC Coordinator his perspective of how best to work with the adolescent MSM

population to link them with to medical care. Interviewees from both organizations noted that the Coordinators heightened level of collaboration contributed to improved linkages to care and treatment.

### **Aim 1 Conclusion**

In Site B, the CDC/NIH-RWD partnership's most common means of collaboration was client referrals between the two sites and the establishment of partnerships with agencies. At the end of the federal sponsored LTC program, the CDC/NIH-RWD partnership formalized the LTC referral process with the criminal justice system, HBCU universities, testing agencies, medical agencies, and an informal LTC referral process with the health department. The collaboration was perceived positively by every single interviewee. The partnership was successful because there was a champion at both organizations to ensure they worked together to serve YLWH multiple needs by expanding the LTC referral network. The collaboration was driven primarily by putting the clients' needs first and fostering positive interpersonal relationships. Five key factors allowed for a successful partnership. First was the community commitment through the history of a natural disaster to understand the importance of pulling resources together. Secondly, establishing a successful coalition to remove structural barriers and address agencies' needs to retain clients across the HIV care continuum. Thirdly, the positive history of collaboration between the RWD site and the CDC/NIH site helped facilitate a quick partnership to implement the LTC program. Fourthly, the "united front" approach to jointly go out into the community to meet potential partner agencies and collaborate to address individual clients' needs led to successful linkage-to-care rates. Lastly, the support of the CDC/NIH LTC Supervisor in all aspects of the LTC program implementation and the desire to see the program implement successfully at both sites is needed to expand the LTC referral network.

### **Aim 2 Introduction**

Aim 1 investigated an inter-agency collaboration between the RWD and the CDC/NIH sites to establish better LTC for YLWH to youth-friendly clinics. Data analysis of aim 1 shed light on the positive factors to implement a successful LTC program. Although aim 1 showed the successful implementation of the LTC program by the CDC/NIH-RWD partnership, there were impediments to forming the collaboration at the early stage of implementation. The providers' experiences implementing the LTC program clarified which barriers hindered their ability to implement the LTC program and what strategies were employed to ensure a successful partnership.

A total of three primary topics emerged showing barriers to the formation of effective partnerships: 1) Federally Qualified Health Center (FQHC) status impacted staff investment levels in the LTC program, 2) history of interpersonal conflict between leadership at the CDC/NIH site and the RWD site impeded pre-implementation phase of the partnership, and 3) the federal agencies pushed the health department to give the CDC/NIH-RWD partnership access to the HIV surveillance data, which impacted the working relationship between health department leadership and frontline staff implementing the LTC program activities. These frequently-cited barriers to collaboration were identified at the beginning of the project, and appropriate actions were put in place to mitigate these barriers.

#### **FQHC Status Led to Staff's Lack of Investment in the LTC Program**

During the first year of the LTC program implementation, the RWD site obtained the FQHC status, which impacted staff investment levels. There were three reasons the organization sought the FQHC status: 1) Following Massive Hurricane, many PLWH left Site B, decreasing the RWD site's patient base and jeopardizing its solvency; 2) HIV became a more manageable and chronic disease, which led to fear that Congress would decrease funding to the HRSA Ryan White Part D program, their main source of funding for running interventions; and 3) The launch of the Affordable Care Act and the Insurance Marketplace there would lead to more people seeking primary care services, with a greater opportunity to increase the number of clients seen at their clinic. Thus, the RWD board decided that it was the right time to apply for FQHC status. Additionally, there was a sentiment that the name of the organization should be changed to encourage all age groups to receive medical care. The start-up phase of the FQHC led to the hiring of new providers and facilitated the enrollment of YLWH of all ages, similar to the CDC/NIH site.

Multiple participants noted that the new RWD providers hired to support the roll-out of the FQHC were focused on increasing client enrollment of YLWH. One participant noted, "There is more competition with start-up agencies trying to get their patient base established, that sort of thing...I see the competition more with doctors, especially those that are adolescent or pediatrician doctors." Thus, the RWD site's providers saw collaboration with the CDC/NIH site as a vehicle for only referring YLWH to the RWD site resulting in an internal mismatch between the previous AIDS service organization's LTC priorities and the FQHC LTC priorities.

Also, the staff noted that the RWD LTC Supervisor's lack of involvement hindered the partnership. The RWD LTC Supervisor's inability to support the CDC/NIH-RWD partnership was due to day-to-day responsibilities and supporting the start-up of the FQHC and implementation of the LTC program. It was noted that the RWD LTC Coordinator had limited assistance in the CDC/NIH-RWD partnership to expand the LTC referral network:

When it actually came down to produce results for the program and to establish the MOU, to establish and maintain the partnership, that is where the roles and responsibilities for leadership failed to become apparent. There were certain responsibilities of the [the RWD LTC Supervisor], [the RWD Executive Director], of the Data Manager that they refused to do because they basically just didn't want to. They agreed to the program because they wanted to help the youth, it sounded like a great idea at the time, but when it actually came time to show up and show out, they didn't. All the responsibilities just fell on one person, me, or on our partner and not necessarily on in-house staff. So, I just don't think they saw the value in it, and they didn't want to do the work.

Both the RWD and the CDC/NIH staff noted that RWD leadership was aware of the RWD LTC Supervisor's workload but did not reduce their day-to-day responsibilities to protect time for the LTC program. Therefore, on the surface, the RWD site was the ideal partner to match with the CDC/NIH site, but a more in-depth examination would have revealed to federal agencies a staffing gap to appropriately manage and restructure the organization in Site B.

### **Strategies to Overcome Barrier**

The CDC/NIH site staff and the RWD LTC Coordinator developed strategies to ensure RWD providers did not dismantle the LTC referral process established between the two sites. Staff at the RWD site quickly adhered to the CDC/NIH-RWD partnership's goal due to the following: 1) Utilization of the memorandum of understanding (MOU) with frontline staff to adhere to the process put in place to ensure youth-friendly services are provided, 2) The federal agencies mandated a joint client quota enrollment number to reduce competition between the CDC/NIH and RWD site, and 3) The RWD LTC Coordinator having full autonomy to make executive decisions on behalf of the RWD leadership.

### **Utilization of the MOU**

The RWD providers agreed to the LTC referral process procedures set up between the CDC/NIH site and RWD site in the MOU. However, the RWD providers were experiencing workplace burnout which led them to not cooperate at the bare minimum to satisfy MOU program requirements. The RWD provider's lack of investment is

exemplified by the lack of effort to always follow the MOU to refer clients at the RWD site to the CDC/NIH LTC Coordinator. The RWD LTC Coordinator immediately shut down RWD providers' attempt to not provide medical care locations to newly diagnosed YLWH at the RWD site in order to secure enrollment for medical care at the RWD site. One strategy used to ensure collaboration was the RWD LTC Coordinator taking on the champion role to reaffirm the partnership goal continually. The data show that the LTC program was successful at the RWD site because the RWD LTC Coordinator supported partnerships and instilled their importance upon the RWD providers. The RWD LTC Coordinator spurred colleagues to adopt a collaboration culture because he felt it would help uncover previously untreated YLWH.

### **Joint Client Quota Enrollment Number**

The second strategy employed was to remind RWD staff of the federal agencies to establish a joint client referral quota for the CDC/NIH-RWD Partnership. The federal agencies developed a joint client enrollment number, which helped the CDC/NIH and the RWD sites limit the competition for clients and to collaborate and link youth to medical care. In the LTC program, the RWD funding systems and the CDC/NIH sites were different. The CDC/NIH site received guaranteed funding from the CDC for the program's length. However, the RWD site received a grant from the HRSA fund but did not guarantee to fund the LTC program's duration. The RWD site used the federal agency's non-commitment to financing as a tool to get staff to adhere to program requirements.

The RWD LTC Coordinator said:

It was up to me as LTC Coordinator to kind of push them and bring them into the light and say, hey, we are getting paid to do this, so we have to do what we were paid to do because once the next fiscal year comes around and the opportunity for this grant comes again, we probably won't be considered for it because when we got the money the first time, we didn't do what we were supposed to do.

Moreover, the new health providers at the FQHC were aware of the HRSA's continued funding contingency on client quota status. The CDC-NIH-HRSA agency agreed that the client quota status would be shared by the CDC/NIH-RWD sites each month to prevent competition between the CDC/NIH site and the RWD site. The RWD LTC Coordinator made sure all the health providers are aware that the CDC/NIH and the RWD sites had a joint client referral number per month. The RWD LTC Coordinator said:



I think [the RWD health providers] had a clear understanding of what we were supposed to be doing, but I don't think we had a shared understanding of our expectations in the partnership... It had everything to do with not recognizing that this program requires us to work together; it is not optional. I had to remind leadership that we are in a partnership, so you can't get mad if I refer a client to my partner's clinic for care; that is where the client wants to go.

The CDC/NIH LTC Supervisor echoed the importance of making the joint referral number a component for future federal funding that encourages partnerships to improve the LTC referral network. The CDC/NIH LTC Supervisor said:

[The CDC/NIH LTC Coordinator] was able to get the goal number of four clients per month by herself, so for us, we were thinking we should be able to increase that number if we have one more person on board to do LTC. We had to get [the RWD LTC Coordinator] to understand it is okay if [the CDC/NIH LTC Coordinator] got five and you only got two clients because the bottom line is that collectively we got above four clients. So, our goal was to continue to meet our goal that we had in [the former LTC program] and now bring over that expectation in [current program]. So, in our nature, we are competitive beings; you can't get that out. It looks good to say that you aren't. So, in that competitive nature, that can be a problem, so I think in future partnerships, it's good to continue to make the referrals jointly, and when presenting referral numbers, don't say this site had these many referrals and the other site had these many referrals, just give a total for the paired site.

### **The RWD LTC Coordinator Making Executive Decisions**

The third strategy employed was driven by the RWD LTC Coordinator taking full autonomy of the LTC program to make executive decisions on behalf of the RWD leadership in order to make the LTC referral network successful in the community. Because the RWD LTC Supervisor did not provide support to implement the LTC program activities, the RWD LTC Coordinator was largely the only one involved in the CDC/NIH-RWD partnership from the RWD site. Thus, the RWD LTC Coordinator took on the leadership role without asking the RWD leadership for approval. In future LTC programs, staff recommended officially designated leadership be fully engaged and invested in the program right from the beginning of the partnership. The RWD leadership's absence from the decision-making process was not detrimental due to the RWD LTC Coordinator stepping into the role and support from the CDC/NIH Supervisor. Moreover, the RWD LTC Coordinator felt that it would not be possible to vet everything with the RWD Leadership, given they were not invested in the LTC program. The RWD LTC Coordinator experienced backlash from RWD leadership for taking executive action without RWD leadership approval. The CDC/NIH LTC Supervisor provided some insight into the RWD LTC Coordinator challenge working at the RWD site:

There is always a chain of command of how you are supposed to do things, and [the RWD LTC Coordinator] could have felt that he wasn't getting support. But my thing was, how could he get help when [RWD leadership] are clueless? They don't know what to do in terms of LTC, you know, they just started it, and so a lot of times, [RWD LTC Coordinator] was on his own.

When the RWD Coordinator was questioned if leadership was receptive to the request of getting them more involved, the RWD Coordinator shared that leadership did not want to participate or take advice from a less experienced staff member. The RWD leadership believed seasoned staff had a better understanding of youth's needs than newly employed staff. The RWD Coordinator explained:

No, they were not receptive to it at all. And the reason they weren't receptive to it at all had a lot to do with the fact that they were leadership and I was considered to be an employee who was on a much lower level than they were, who had less education, and who had less work experience than them, but I felt like I knew the protocol, I understood the program, I understood the partnership, I understood what we agreed to do as individuals and as a collective agency to further the mission and the goals of the program, being a lower-level employee led to it not being received well. And I went to leadership to say we are not following this protocol, that we need to revise our approach, just fell on deaf ears.

Moreover, the RWD LTC Coordinator expressed that the RWD LTC Supervisor could not assist with the program and the Coordinator took back full control of the program as the RWD LTC Supervisor believed the RWD LTC Coordinator was fit to make leadership decisions. The RWD LTC Supervisor wanted to make sure youth were given the best possible care from the RWD site, which meant giving the RWD LTC Coordinator full autonomy to implement the LTC program. The RWD LTC Coordinator said:

[The RWD LTC Supervisor] was too busy. [The RWD LTC Supervisor] would always say that this is my program that this is what I am responsible for. I knew that there were some things that I did that were just completely above my pay grade that I wasn't supposed to be handling or be in charge of. Still, I took on the responsibility because that is just who I am. I wanted the young people that I was working with to be given the things they needed, so I had to make executive decisions about things because I just wanted to do what was right for youth, and I made a commitment to work on this program and to help people who are YLWH, so I was willing to go the extra mile.

While this approach was successful for the program, it was not successful in the long run and led to the RWD LTC Coordinator leaving the program once the timeline for capturing new referrals was completed. Ultimately the RWD LTC Coordinator got in trouble with RWD leadership for following the instruction of the LTC referral process between the CDC/NIH site and the RWD site. Therefore, the program outcome was successful, but the RWD LTC Coordinator resigned from employment at the RWD site.

In the future, one participant recommended federal agencies inform potential sites of what is expected of them regarding the level of time commitment, resources, and partnership level. The CDC/NIH LTC Supervisor could not provide time towards the program because the RWD site was not prepared to allocate the CDC/NIH LTC Supervisor level of effort towards the program. Several staff members stated that it is common for agencies to accept government funds without having a clear understanding of program expectations. Therefore, the federal sponsor's responsibility is to conduct its due diligence to ensure the selected organization has full capacity to implement the program. One participant explained:

I would advise the CDC, the NIH, and the RWD site that when they are thinking of pairing, there are many other things that they need to think about, like letting all stakeholders know what they are getting involved in when they agree to take on the money. Not how the HRSA did it. Where they were like, we have money, and we want you to apply. And if your agency requires money, I can see how they didn't ask questions. They are just like, oh, just give me the money. I can figure it out, so I would really advise agencies to really be careful because you can really not be at the capacity to carry out the activities...I just think that if they had known what they were fully getting themselves into, they would have been fully prepared for the time commitment and the type of staffing to get... Just let everyone involved know what is going to be happening and give them all the expected deliverables. When you pair sites, are you looking for commonalities, or are you looking for differences? Be strategic about that when you design the partnership.

### **Leadership's History of Interpersonal Conflict Impede CDC/NIH-RWD Partnership**

Inter-personal barriers are just as detrimental to a partnership as structural ones. A staff member reported a history of dislike between leadership at the RWD site and the CDC/NIH site, "I think a barrier was the decades of dislike between [the CDC/NIH PI] and [the RWD Executive Director]. It could have been a big problem that people in leadership don't get along too well." The frontline staff feared leadership's interpersonal issues could lead to poor implementation of the LTC program.

### **Strategies to Overcome Barrier**

The RWD and the CDC/NIH staff highlighted communication strategies used to address the conflict between the two PIs. Both sites knew about the problem, and the CDC/NIH Supervisor sought to resolve friction between the two PIs at the early stage of implementation. Specifically, conflict resolution occurred when the CDC/NIH site was upfront with leadership's personal dislike for one another. The CDC/NIH site took the lead to set up a meeting to address the issue proactively. According to the CDC/NIH LTC Supervisor, the way to improve the communication strategy was to focus on the partnerships that are beneficial for meeting the youth's needs. The

CDC/NIH LTC Supervisor asked the CDC/NIH leadership to put aside the interpersonal issues with the RWD leadership to allow for the potential positive outcomes of the LTC program to the community. The CDC/NIH LTC Supervisor and PI were true leaders because of the mutual respect for transparency about what must be done to have a successful program. The CDC/NIH LTC Supervisor organized a meeting with leadership from both organizations at the beginning of the program to openly acknowledge the strained relationship between the two organizations and reassure the RWD site that the CDC/NIH staff were team-oriented. Therefore, the CDC/NIH LTC Supervisor immediately shut down the interpersonal conflict and asked for a meeting to stress the value, benefit, and advantage to the partnership to achieve the LTC program's objectives. After the meeting to ensure conflict resolution, the CDC/NIH LTC Supervisor worked to help the RWD site make the start-up implementation process easy for the RWD site. This led the RWD leader to feel comfortable having the RWD staff engage in a partnership with the CDC/NIH site. The CDC/NIH LTC Supervisor explained:

I just made them feel that we could do this together. And look, if they failed, we failed, and that wasn't going to happen, not on my watch. So, for me, I saw this as a collective effort...I didn't want [the RWD site] to have to reinvent the wheel. Here is what an MOU with a community partner looks like, and so I made sure that they had everything they needed to meet those deliverables. I can understand it would be daunting for someone coming into this program.

Thus, the CDC/NIH staff's open level of communication and reassurance of collaboration allowed the RWD to perform well at the job facilitated a positive working relationship between the CDC/NIH and the RWD staff.

The CDC/NIH Supervisor played a pivotal role in the partnership and built a strong relationship with the RWD site staff. Ultimately, both organizations' leaders must value collaborations and address interpersonal issues as soon as possible if partnerships are to succeed. Thus, poor interpersonal relationships between the PIs were addressed right away.

#### **Federal Agencies Push Health Department to Grant Clinics Access to HIV Surveillance Data**

The CDC/NIH site staff understood their limitations to get public health authority. However, the ATN staff pushed the CDC/NIH site to move quickly to advance the health department's acceptance to provide a data-sharing agreement that allowed clinics' access to HIV surveillance data for YLWH. When the CDC/NIH site implemented the former LTC program, they sought out public health authority from the health department in order to access HIV surveillance data to identify newly diagnosed YLWH and quickly link them to medical care. As

one participant noted, “Our local health department here doesn’t trust anybody, [the RWD site] doesn’t work with them, so I knew they weren’t going to get public health authority.” When the CDC/NIH site asked for a data-sharing agreement with the health department they were met with a quick no to grant access to HIV surveillance data. Instead, the health department offered to share de-identified data on the number of YLWH in the community on a quarterly basis, which was at odds with the need to link youth to care within 42 days of HIV diagnosis. Thus, the lack of real-time HIV surveillance data proved quite difficult to access for the RWD site and the CDC/NIH site. The health department did not want to grant the CDC/NIH, and the RWD sites access to HIV surveillance data because there were concerns of the needed protection of identifiable data points, including names and contact information.

Once the LTC program started, the federal agencies tasked the RWD site to seek public health authority to access the HIV surveillance data. The RWD site staff were unable to change the health department leadership’s decision to not allow the CDC/NIH site nor the RWD site access to the HIV surveillance data. One staff member noted the CDC/NIH-RWD partnership was okay with not receiving public health authority, “We didn’t want to push for public health authority because it was hurting the existing relationship, we are having with the local health department.” However, leadership at the clinical research network, ATN, and the CDC leadership continued to press for access to HIV surveillance data, which led to tension between the health department leadership and the CDC/NIH and the RWD site staff. One staff member stated:

I just got so frustrated from the National Coordinating Center stressing the importance of getting public health authority. I understood that it's ideal, but it's working; we don't need it, so why keep pushing this. And the National Coordinating Center felt that we are going to the CDC or whomever to make [the health department leadership] change her mind, and that was not going to happen. So that is why I wanted to tell [the Program Director of the National Coordinating Center] please don't have us go down that road, please don't ruin our relationship with [the health department representative], you are going to ruin what we already have.

The only outcome from CDC’s involvement was the health department increased the frequency of providing de-identified reports from on a quarterly to a monthly basis.

## **Strategy to Overcome Barrier**

The staff members at both clinics said it would have helped if CDC officials had conveyed the importance of sharing HIV surveillance and medical data to the partners before implementing the LTC program, as one staff member explained:

With this LTC collaboration, even before LTC, with this public health authority issue, if the CDC and [the CDC/NIH site] sent out a joint letter to [the health department] to get public health authority and had meetings to come to a decision, it would have been better. Why is it that we now have to go individually and fight for it? It should have been discussed in that whole collaboration that came out between the CDC, the NIH, and the HRSA. You know, a letter from the federal agencies should have been sent to the local health departments saying we are going to need your health departments to grant public health authority to these 14 sites. So, it should have been CDC brokering what kind of data we could get. So that could have been done differently. But that wasn't the case. Some sites have earned it, and others didn't, but there were bridges burnt along the way for sites to have some type of relationship with the health department, which really impacted their data.

Moreover, the CDC has numerous success stories related to data sharing agreements that occurred in other municipalities. The CDC's conclusions and recommendations are apt to be respected by health care provider in the USA and the health department. However, the timing to request the data sharing agreement is vital to ensure health care providers are not blamed for the request.

The CDC/NIH-RWD partnership staff explained to the health department staff that the push for public health authority was not coming from either clinic. The CDC/NIH-RWD partnership found a satisfactory substitute for direct access to HIV surveillance data. The sites built a strong relationship with the health department by assisting the DIS staff to identify lost to follow-up clients. This led to the LTC Coordinators' ability to call up the DIS staff to obtain client sensitive data to locate youth in the community and get them linked to medical care. Thus, the key to building new relationships for potential collaborators is to be flexible and assist whenever possible.

## **Aim 2 Conclusion**

Capturing providers' perspectives implementing the LTC program, the case study describes the key factors that hindered the partnership attempt to implement an LTC referral network between the two HIV clinics and the local health department. A total of three primary barriers emerged: 1) The FQHC status led to lack of staff investment in the LTC program, 2) Interpersonal conflict between leadership at the CDC/NIH site and RWD site, and 3) The federal agencies push to access HIV surveillance data led to tension between health department

leadership and staff implementing the LTC program. Thankfully, the cited barriers to collaboration did not impact the LTC program because the sites could implement strategies to overcome the obstacles. While most RWD site staff were unable to support the implementation of the LTC program activities, the CDC/NIH-RWD partnership successfully implemented all of the required activities mainly due to the RWD LTC Coordinator stepping into the champion role. Personal conflicts were immediately addressed. Leadership at the CDC/NIH site filled the vacancy to maintain program continuity. Lastly, the CDC/NIH-RWD partnership did not push for public health authority and instead showed the DIS the benefits of collaborating with the sites, which led to an informal data-sharing.

## **CHAPTER 6: SITE C RESULTS**

### **Aim 1 Introduction**

This case study seeks to provide officials in the health department (HD) and HIV clinics clear examples of how the CDC/NIH and RWD sites made efforts to give more backbone to the existing linkage-to-care (LTC) program for youth living with HIV (YLWH) by expanding government and community partnerships and understand the challenges they encountered.

Aim 1 examines the HIV LTC landscape in Site C, description of the RWD site and the CDC/NIH site, the LTC program staff's roles and responsibilities, and the CDC/NIH-RWD partnership approach to community engagement. The case study highlights four attempted partnerships: 1) The joint CDC/NIH-RWD partnership with the health department, 2) The RWD site's partnership with the emergency department, 3) The RWD site's partnership with the juvenile hall, and 4) The partnership between the CDC/NIH site and the RWD site.

In 2010, before the CDC/NIH site implemented the LTC program in Site C, there was no formal LTC referral process to ensure people living with HIV (PLWH) were linked to medical care. Moreover, the HD had no specific LTC standards for connecting YLWH to medical care nor dedicated LTC staff to ensure YLWH were LTC. Instead, the HD recommended the community HIV testing agencies provide PLWH with a minimum of three clinics to receive medical care but did not require the HIV testing agencies to actively assist the YLWH to connect with medical care. Thus, the LTC program's goal to promote the coordination of HIV focused agencies to ensure testing, identification of HIV status, and immediate LTC of YLWH within 42 days of diagnosis was needed in Site C.

From 2010 to 2013, the CDC/NIH site implemented the former LTC program. The former LTC program was innovative and the first of its kind in Site C. The CDC/NIH site hired a dedicated LTC Coordinator to: link youth, within 42 days of their HIV positive diagnoses or lost to follow-up status, to medical agencies with expertise in providing youth or young adult services, provide intense case management to address barriers to receiving continuous HIV care, and to build community partnerships to expand the LTC referral network. The CDC/NIH site



was granted public health authority to access the HD's HIV surveillance data in order to quickly identify newly diagnosed YLWH and youth lost to follow-up and link them to care. Lastly, the CDC/NIH site created a local coalition focused on addressing structural barriers (i.e., policies) to improve LTC referral outcomes (i.e., reduced community viral load) and support the expansion of the LTC referral network.

In 2013, the HD attempted to increase LTC rates by mandating that all the CDC and the HD funded agencies meet a client LTC quota to receive continued government funding. The oversaturation of LTC programs and LTC quota caused organizational overlap and impeded the CDC/NIH site's ability to get agencies to join the LTC referral network due to agencies' competition for clients. The same year, the Secretary's Minority AIDS Initiative provided full financial support for a federal partnership between the CDC, the NIH, the HRSA, and ATN, a clinical research network. The partnership's goal was to strengthen the former LTC program through a mandated collaboration between the CDC/NIH site with a HRSA Ryan White Part D (RWD)-funded clinic, referred hereafter the RWD site. This CDC/NIH-RWD partnership lasted from 2013 to 2016. The CDC/NIH-RWD partnership decided to target their efforts to establish partnerships with the emergency department, the health department and the juvenile hall to strengthen the LTC referral process to youth-friendly clinics. The CDC/NIH site also took on a capacity-building role to support the RWD site to become a youth-friendly clinic.

### **Site C Characteristics**

Site C has a total population over 10 million and is a mix of urban, suburban, and rural areas. In its fourth decade, agencies in Site C continue to deal with a high HIV prevalence despite their efforts to reduce the HIV epidemic. The CDC/NIH site and the RWD site are located in the same suburb of Site C that has a much higher HIV incidence than any other suburb in Site C. Specifically, in 2016, the HD reported 1,820 new HIV infections, 83% in Black MSM ages 18-29.

During the implementation of the LTC program, the HD defined prompt LTC of PLWH by a viral load test appearing in the HIV surveillance database as a proxy for a medical care visit occurring within 90 days of HIV diagnosis. The HD LTC goal was aligned with the 2015 NHAS goal to LTC PLWH within 90 days of HIV diagnosis. The federal agencies of the LTC program required an even shorter timeline to link YLWH to medical care; the

CDC/NIH and RWD sites were required to link YLWH to care within 42 days of youth's referral to the LTC Coordinator.

### **CDC/NIH Site Overview**

The CDC/NIH site provides coordinated care to LGBTQ youth ages 12–24. The CDC/NIH site takes a holistic approach to medical care for YLWH by addressing the physical, emotional, and social needs. The site has an interdisciplinary team of psychologists, social workers, health educators, and a LTC Coordinator who collaborate with adolescent physicians to guide youth through the HIV care of continuum cascade. The CDC/NIH site built a reputation in the community to train and provide capacity-building support to the HIV focused agencies on youth development, youth empowerment, and cultural competency working with LGBTQ YLWH. Therefore, the CDC/NIH site experienced no hesitation entering into a partnership with the RWD site centered around building the RWD site's capacity to provide youth-friendly services to LGBTQ at-risk youth and YLWH.

### **RWD Site Overview**

Before the LTC program, the RWD site provided services to anyone with HIV, but the RWD site was respected in the HIV community for their coordinated medical care from preconception counseling to prenatal, delivery, and postpartum care for females living with HIV. The RWD site identified itself as a youth-friendly clinic due to its long history of treating pregnant women living with HIV and their children perinatally infected with HIV. The RWD site saw the LTC program as a mechanism to expand its work with YLWH by targeting its efforts to provide medical care services to the LBGTQ youth.

### **LTC Program Staff Roles and Responsibilities**

The CDC/NIH and RWD sites assigned three employees to the LTC program: the LTC Principal Investigator (PI), the LTC Supervisor, and the LTC Coordinator. At both locations the PIs designated decision-making authority to the LTC Supervisors. The CDC/NIH LTC Supervisor took the lead to determine which agencies to target to join the LTC referral network, initiated meetings with the RWD site, and was the convener of the local coalition's monthly meetings.

The CDC/NIH site had hired two LTC Coordinators during the implementation of the LTC program. Before the CDC/NIH-RWD partnership, the former CDC/NIH LTC Coordinator (2010-2013) primarily served as a central

resource across Site C for newly diagnosed YLWH or YLWH lost to follow-up care. In early 2014, the former CDC/NIH LTC Coordinator resigned from the position, which was also around the same time the CDC/NIH site lost access to HIV surveillance data. These significant changes led the CDC/NIH site to focus its effort on maintaining existing partnerships and develop new partnerships with community testing agencies.

Because the CDC/NIH site received complex cases, the CDC/NIH leadership considered it crucial to hire a new CDC/NIH LTC Coordinator with a strong background in social work, mental health training, trauma-informed care, positive youth development, and mirrored demographically the target population it was seeking to recruit into medical care. The new CDC/NIH LTC Coordinator had a masters in social work, was a male in his 20s, Latinx, and Queer. The CDC/NIH LTC Supervisor noted the new CDC/NIH LTC Coordinator excelled at the maintenance of old partnerships, establishment of new partnerships, linked to care YLWH, coordinated social services, provided intense case management services, and obtained a leadership role in the local coalition in order to advocate the importance of expanding the LTC referral network.

The RWD PI's goal was to incorporate the LTC program's roles and responsibilities within the existing clinic staff structure. Thus, RWD PI selected an adolescent HIV physician to be the RWD LTC Supervisor. The RWD LTC Supervisor took the lead to build partnerships with the CDC/NIH site and large institutions, specifically the juvenile hall and the emergency department. The RWD PI selected a clinical research nurse to serve as the RWD LTC Coordinator. The RWD LTC Coordinator was a Latinx female in her late 40s. The RWD LTC Coordinator had experience implementing HIV research projects, however, the RWD LTC Coordinator did not have experience building community partnerships nor providing case management services. The RWD LTC Coordinator's role with YLWH was confined to reminding clients of their medical appointment, set up transportation for medical visits, and address barriers to filling ART prescriptions. The YLWH were assigned to a case manager to receive case management services.

#### **CDC/NIH-RWD Partnership's Strategic Approach to Community Engagement**

Both the CDC/NIH and the RWD sites wanted to address the HIV epidemic by identifying more undiagnosed youth and referring newly diagnosed YLWH to a youth friendly clinic. For the CDC/NIH-RWD partnership to increase the number of YLWH linked to care, it was imperative for the CDC/NIH-RWD partnership to

build new relationships with testing agencies, re-establish old partnership with the juvenile hall, and conduct community outreach events to connect with at-risk youth in the community. The CDC/NIH-RWD partnership's approach to community engagement started off as a "divide and conquer" approach and over a two-year period transitioned into a "united front" approach.

At the beginning of the LTC program the CDC/NIH site took a "divide and conquer" approach meaning the CDC/NIH site did not join the RWD site to establish partnerships in the community. The CDC/NIH site took the lead to guide the RWD site's strategic partnerships, specifically for the RWD site to independently build partnerships with the emergency department and the criminal justice system. Moreover, the CDC/NIH LTC Supervisor preferred the RWD site staff not communicate with the CDC/NIH site's existing network of agencies. The CDC/NIH site preferred the "divide and conquer" approach because the CDC/NIH site staff did not want to associate its organizational mission of providing youth-friendly services with a non-youth friendly clinic, which was the reputation the RWD site had in the HIV community. However, over time the CDC/NIH-RWD partnership's "divide and conquer" approach transitioned to a "united front" approach due to the RWD site's acceptance of the CDC/NIH site's capacity-building support to transform the RWD site to a youth-friendly clinic, acceptance of CDC/NIH leadership's strategic approach to community engagement and fostering the relationship between all frontline staff. Key activities that exhibited a "united front" approach can be seen in the CDC/NIH site's leadership to strategically orchestrate testing agencies to an open house clinic tour to showcase the CDC/NIH and RWD sites' youth-friendly services. Also, towards the end of the LTC program, the CDC/NIH site invited the RWD site to attend community outreach events to jointly build new partnerships with testing agencies.

#### **CDC/NIH-RWD Partnership with the Health Department**

The CDC/NIH-RWD partnership established a "united front" approach with the local health department. From 2010 through early 2014, the CDC/NIH site had access to the HIV surveillance data. Before 2010, the health department didn't have personnel assigned to review HIV surveillance data to track whether PLWH had consistently accessed medical care. Therefore, in 2010, the CDC/NIH site convinced the HD leadership that they could fill a gap at the HD through a data-sharing plan. The data-sharing plan deputized the CDC/NIH LTC

Coordinator as a county employee in order to give the CDC/NIH site full public health authority to access the health department's HIV surveillance data.

For four years, the CDC/NIH LTC Coordinator was given office space at the local health department to access HIV surveillance data. The LTC Coordinator used the surveillance data to identify client information on newly reported HIV diagnoses and lost to follow up medical care and used the information to link clients to medical care in real-time successfully. The former CDC/NIH LTC Coordinator generated weekly monitoring reports, helped ensure that YLWH were linked to medical care within 42 days of initial diagnosis, and provided updates to testing agencies on the successful linkage to medical care. This innovative approach to grant public health authority to HIV clinics in order to access HIV surveillance data significantly increased client referrals to youth-friendly clinics to ensure quick uptake of ART medication.

In 2014, the CDC/NIH site and the RWD site jointly met with the HD representative to request the RWD site be granted full public health authority by the HD. Through this authority, the RWD site would help the CDC/NIH site identify more YLWH and link them to medical care. Unfortunately, just as the LTC program launched, the local health department permanently halted the CDC/NIH site's access to HIV surveillance data. The CDC/NIH LTC Supervisor explained, "It all turned out that we opened up a can of worms by having [the RWD site] come to the table and want similar access to the data." The local health department was willing to provide monthly aggregated de-identified data of the number of individuals diagnosed with HIV conducted at each testing agency. However, this new data-sharing agreement hindered the CDC/NIH site's ability to improve linkage to medical care and shorten the time from diagnosis to access to medication. Specifically, because the CDC/NIH site depended on the data to discuss collaboration with the HIV focused agencies that were territorial over their federal agencies' client LTC quota. The RWD LTC Supervisor explained, "There are some bigger organizations like AIDS Healthcare Foundation that do a high volume of testing, but have poor linkage rates, like 48% unlinked, and are unwilling to collaborate." Thus, the start of the CDC/NIH-RWD partnership led to the unraveling of the former LTC program.

#### **RWD Site's Partnership with the Emergency Department**

One successful partnership to highlight was the RWD site's partnership with the emergency department. The RWD site successfully got the emergency department to see the need to tailor medical care for young adults,

ages 18- 24 years old, through a formalized LTC referral process between the RWD site and the emergency department. The RWD site noted that the RWD site's close proximity to the emergency department, both located in the same hospital, and the RWD LTC Supervisor's explanation of the RWD site's youth-friendly services to medical personnel with decision-making authority were the key facilitators towards developing a formal LTC referral process.

### **RWD Site's Partnership with the Juvenile Hall**

One of the RWD PI's goal was to re-establish an LTC referral process with the juvenile hall to ensure YLWH received care at the RWD site. The juvenile hall is an institutional setting that temporarily house youth before their court dates or after judgment. During the intake process, youth are screened for HIV and receive medical care if they test positive for HIV, but there is no formal LTC referral to medical care once they leave. Twenty years ago, the RWD PI recalled it took the RWD site two years to develop a LTC referral process between the RWD site and the juvenile hall and lasted for ten years. The RWD PI didn't push past a verbal agreement with the juvenile hall leadership to develop a formalized LTC referral policy for YLWH. Without a standard LTC procedure in the juvenile hall, the LTC referral process broke down over time. The RWD PI explained that the demise of the LTC referral process could be attributed to juvenile health staff turnover: "They have all new staff, so no one remembers the old system we created with them." Despite the RWD site's ambitions, the LTC referral process ended because institutional memory failed to maintain the informal verbal agreement between the RWD site and the juvenile hall.

During implementation of the LTC program The RWD LTC Supervisor with support from the CDC/NIH site produced a document to guide the LTC referral process and distributed it to the local juvenile hall's medical facilities for consideration. The LTC referral protocol document made the juvenile hall's medical staff aware that they need to discharge YLWH with extra ART medication and during regular clinic hours to facilitate a smooth transition to medical care. Unfortunately, the RWD site was not able to develop a LTC referral process with the juvenile hall.

The RWD site attempted a formal LTC referral partnership with the juvenile hall for three years but was unsuccessful. The RWD site held multiple meetings with juvenile hall leadership but could not get a formal LTC

referral process due to staff turnover. The RWD LTC Supervisor explained, “So you could make a really good relationship with one person like I had a really good relationship with the Medical Director of Juvenile Hall, he was very like-minded, and we shared similar goals in terms of how to provide services to youth, but then he left the position.” Thus, the long process of developing a relationship with personnel to establish the LTC referral can be destabilized with leadership leaving the organization. The RWD LTC Supervisor explained:

In hindsight, it may have helped to get the [LTC referral process] further along in the beginning if we had done joint outreach or joint meetings with stakeholders at the Juvenile Hall. Thinking about it, we could have used the united front approach, like we are both youth centered clinics, we both accept youth. It would have shown that this is important. Here are two youth clinics that want to work with each other to create a referral process...I just felt like bringing in [the CDC/NIH PI] and leadership from my hospital to work jointly with [the juvenile hall leadership] could have helped force those large systems to make a decision. Instead, these large institutions, we're like yeah, we want to do this, but they didn't take steps to make it happen.

Thus, the CDC/NIH site had an established LTC referral process with the department of probation and could have leveraged that relationship to present a “united front” with the RWD site in order to gain buy-in from the juvenile hall leadership to expediate the formal LTC referral process with the CDC/NIH and RWD sites

#### **LTC Referral Process at the CDC/NIH Site and the RWD Site**

The CDC/NIH sites designed a LTC referral model based on the mode of HIV transmission and age of HIV diagnosis. The CDC/NIH-RWD partnership sheds light on the importance of recognizing the diversity in services in the subpopulation of YLWH. The CDC/NIH leadership recommended applying a client-centered approach that simplifies and adapts HIV services across the HIV continuum of care to reflect the preferences and expectations of various groups of YLWH while reducing burdens on the health system. The CDC/NIH leadership and RWD LTC Supervisor agreed that a one-size-fits-all LTC referral process limits both quality and efficiency. Thus, all youth perinatally infected with HIV referred to the CDC/NIH site or the RWD site would be managed by the RWD site due to RWD’s long history of working with youth perinatally infected with HIV. All LGBTQ YLWH would be managed by the CDC/NIH site based on their non-HIV medical services for LGBTQ youth. Moreover, the complex HIV cases referred to either the CDC/NIH site or RWD site would be discussed on a case-by-case basis to determine the best location for YLWH to receive medical care.

Once the CDC/NIH site or the RWD site received notice of a newly diagnosed YLWH or lost-to-follow-up, each site had a different style for providing care to YLWH. At the CDC/NIH site the CDC/NIH LTC Coordinator took a hands-on approach when caring for YLWH to understand youth's non-medical care needs evidenced by the CDC/NIH LTC Coordinator's intake assessment process in the field.

At the RWD site, the LTC referral process did not change with the LTC program's implementation, except for the increased frequency of tracking the client through the HIV continuum of care went from every six months to the RWD site to ensuring youth attended a medical visit within 42 days of referral to the RWD site, and that youth would attend three medical care visits spaced out over 365 days. When YLWH came to the RWD site for medical care, they assigned YLWH a case manager, a nurse, and a physician for direct medical care. The main difference at the RWD site in comparison to the CDC/NIH site was the hands-off approach by the RWD LTC Coordinator due to the RWD case manager providing direct client care to link and retain youth to care. And the expediency to get YLWH linked to care varied between the CDC/NIH site and the RWD site. Frequently, the RWD site took a long time to connect youth to appropriate medical care. The RWD staff thought that the LTC program's requirement to link youth to medical care within 42 days of diagnosis was too stringent, even though the time frame was longer than the current HD's LTC target of fewer than 30 days (DHSP, 2018).

The RWD site noted the importance of HIV providers recognizing that young people born with HIV will have a different set of needs for LTC and a different ART uptake approach. Therefore, the RWD LTC Supervisor highlighted the unique challenges youth perinatally infected with HIV experience:

This group of young people feels forgotten and marginalized; they cannot relate as well to other youth infected through behavioral transmission. It is often difficult to find a support network. Many of these patients have lost their parents to AIDS and have been raised by relatives or in the foster care system. Furthermore, they have different relationships with medication and medical visits since they have been on treatment for their whole lives. Therefore, they present a more difficult population to engage.

Thus, all of the different social factors experienced by perinatally infected youth impeded their quick link to medical care within the LTC program's requirement of getting youth LTC within 42 days of getting referred to the LTC Coordinator.



## **Aim 1 Conclusion**

In Site C, the CDC/NIH-RWD partnership's most common means of collaboration was the CDC/NIH site providing capacity building support to the RWD site to become a youth-friendly clinic, client referrals between the two sites and the attempted partnerships with the health department. Also, towards the end of the LTC program the CDC/NIH and RWD sites were able to establish a “united front” approach to community engagement. The CDC/NIH staff attributed the CDC/NIH-RWD partnership’s transition to a “united front” approach to the RWD site’s active transformation to a youth-friendly clinic.

Even though this case study revealed the CDC/NIH-RWD partnership’s challenge reestablishing a partnership with the health department and with the juvenile hall, this case study identified key ingredients to a successful partnership. Specifically, the frontline staff at both organizations were given decision-making authority which allowed them the opportunity to build a true collaboration. The other key ingredients were staff who have open communication skills and a common vision to link YLWH to care that best meets their medical and non-medical care needs.

## **Aim 2 Introduction**

Aim 2 examines barriers to the CDC/NIH-RWD partnership’s attempt to expand the LTC program and strategies to overcome the obstacles. The eight barriers that emerged from the case study are the following 1) The federal funding requirement led to competition for clients, 2) The siloed funding streams impacted CDC/NIH-RWD partnership implementation of the LTC program, 3) The RWD site’s community reputation impeded collaboration with the HIV community, 4) The RWD leadership’s vision for the LTC program is different from CDC/NIH leadership’s vision for how the CDC/NIH-RWD partnership should execute implementation of LTC program, 5) The RWD staff selection impeded partnership development to expand the LTC program, 6) The RWD site lacked youth-friendly services, 7) The CDC/NIH site and the RWD site were unable to access HIV surveillance data, and 8) The RWD’s unsuccessful LTC referral process with the juvenile hall. These frequently cited barriers hindered the expansion of the LTC program. The sites either proposed strategies to overcome barriers or implemented strategies to overcome the barriers.

### **Federal Funding Requirement Led to Competition for Clients**

In 2013, HIV focused agencies began scaling the LTC referral processes to ensure newly diagnosed HIV positive people were linked to care in response to the new CDC funding requirement. The HD rapidly scaled up LTC programs at HIV testing agencies and medical care agencies. The HD also changed their within-county funding requirements to include a monthly client linkage-to-care enrollment quota that agencies had to adhere to in order to maintain yearly funding allocations. This approach unintentionally created competition among HIV-focused agencies receiving CDC or HD funding. Specifically, testing agencies that provided medical care were more inclined to retain newly diagnosed YLWH than refer them to other, more youth-friendly clinics because they were afraid, they would lose sponsored funding. There is limited funding to conduct HIV prevention, care, and treatment interventions. Therefore, any money allocated towards this initiative is highly sought after by HIV focused agencies. Thus, the CDC did not implement a way to ensure that all these agencies collaborated and coordinated efforts towards linking youth to medical care that meets their individual needs. The short oversaturation of LTC initiatives funded by the CDC and the HD was not strategic and led to duplication of efforts or even agencies competing with one another for clients.

This competition means agencies lost focus of seeking the best care possible for YLWH. Agencies in Site C vocalized the importance of collaboration to the HD and one another, but they exhibited organizational self-preservation in practice. Moreover, the federal agency that sponsored the RWD site reinforced competition when it began to defund agencies that did not meet the client quotas. Some agencies that were providing quality care even had to close their clinics as a result. The push by federal agencies to integrate LTC programs into organizational processes was a barrier to establishing LTC referral network for agencies that had a built in HIV testing clinic and HIV medical care clinic due to organization's unwillingness to refer clients outside of their own organization. The CDC/NIH-RWD partnership was frustrated that they could not overcome the competition barrier, which led to the duplication of LTC efforts and fractured the collaboration among Site C agencies.

### **Strategy to Overcome Barrier**

The LTC program's federal agencies were acutely aware of the competitiveness among similar agencies; therefore, they introduced a monthly joint client linkage-to-care quota between the RWD site and the CDC/NIH

site. Moreover, there were monthly inter-agency meetings to continually follow-up on the site's collaborative partnership. If the client referral target was not met, then both sites were considered underperformers. This would be a good strategy to adopt for future LTC programs because it advanced the LTC partnership between the CDC/NIH and RWD sites. The CDC/NIH LTC Coordinator explained:

The partnership was needed because if we worked independently, the competition would have been super salient. The fact that the numbers were shared, we were expected to meet. On our monthly calls, we had [the National LTC Coordinator] checking in to see how we were working with our partner to ensure a shared vision and genuinely collaborative partnership ... The way that I collaborate with [the RWD site] is how I wish I could collaborate with other clinics, especially between the providers at each clinic. Some community providers are territorial or protective of their client numbers, so in a larger picture, the LTC field for youth in our area definitely could be improved, like the process can be enhanced and modeled after how we work with [the RWD site].

It can be inferred from this approach's effectiveness that future federal agencies change grant requirements to better support collaboration. Specifically, relaxing the client enrollment quota requirements (metrics) and instead require clinics to prioritize health outcomes. For example, these outcomes could include viral load suppression. In this way, donors could better leverage funding to contribute to the public health goal of providing quality care to YLWH. Instead, donors currently make a budget dependent upon the number of clients seen monthly at the clinic, which begets interagency competition.

### **CDC/NIH-RWD Partnership Impacted by Different Funding Streams**

Federal funding given to the RWD site did not meet the needs of the LTC program. The CDC/NIH site received its grant from the CDC and the NIH; the RWD site received funding through the HRSA Ryan White Part D program. The federal agencies worked separately to determine the budget to implement the LTC program. The CDC/NIH-RWD partnership ended up taking much more RWD staff time than initially anticipated, and the HRSA funding was entirely insufficient for remunerating the time. The CDC/NIH and RWD sites' staff never revealed how much money each site received to implement the LTC program. This siloed funding stream to implement the LTC program at the federal government level in combination with limited funding allocated to the RWD site negatively impacted how the CDC/NIH and RWD sites collaborated.

The RWD PI revealed that HRSA awarded the RWD site a tiny budget to implement the LTC program, which was woefully small to support a full-time LTC Coordinator. Instead, the RWD LTC Coordinator was funded at

a 40% level of effort. This explains why the RWD site could not adopt the grant requirement to hire a full time dedicated RWD LTC Coordinator to build community partnerships and support youth through the HIV care continuum. Moreover, HRSA doesn't allow funding recipients to request increased funding once the HRSA funds are awarded to the site. The RWD PI explained:

Well, we had to carve out the funding because the amount was not adequate, and we complained to HRSA that the salary they gave us was not enough for a full-time person. I had to carve out the money out of other funds to make this program work. They only gave us \$100,000 with indirect costs per year. The one thing about HRSA that is a challenge is that the money never goes up from the first year, so we may have realized that we need more funds to do the activities, but we won't ever get the funds... it's just challenging with HRSA funding.

Therefore, for the program's duration, the RWD LTC Coordinator was unable to fully invest in the LTC program. The Site C funding to fully support 100% level of effort at the RWD site impacted the length of time the RWD site invested in the LTC program policy change in the LTC referral process at agencies, providing intense case management to youth, attending coalition meetings consistently, and frequently reaching out to HIV focused agencies on developing partnerships to strengthen the LTC program. Moreover, the RWD staff initially reported that the Site C of progress to get an LTC referral process with the juvenile hall and universal testing for 13-year-olds and older was due to leadership turnover at the two institutions. However, more in-depth analysis concludes that the RWD staff didn't have time to continuously pursue the relationship-building needed to establish system change with critical agencies in the HIV community.

### **Strategy to Overcome Barrier**

Because the RWD site received very little money from the HRSA to implement the LTC program, the CDC/NIH site used the CDC and the NIH funding to develop joint promotional materials for itself and the RWD site to increase LTC referrals. This "swag" included items such as business cards, flyers, pens, and bags. Moreover, the RWD LTC Supervisor assumed more responsibility seeking partnerships to strengthen the LTC program. For future programs, the CDC/NIH Supervisor stated, "I think if we were funded the same way since we are expected to have a joint effort and be able to contribute equally, that would have helped." Thus, the federal agencies need to be more coordinated in allocating funds to agencies to foster true collaboration.

## **RWD Site's Community Reputation Impedes Collaboration**

The RWD site did not have a positive reputation for entering partnerships to improve the community nor serving YLWH. The RWD site was known to work in siloes and not open to partnerships to improve the HIV community. The CDC/NIH site noted that RWD leadership's reputation for not being interested in partnerships hindered the possibility of a smooth start-up between the RWD site and CDC/NIH site. The CDC/NIH LTC Supervisor explained:

I think [the RWD PI] is symbolic of my perception of [the RWD site] before this relationship. Disconnected from what was really happening and their reputation as a community collaborator ... I don't think as an organization they have been known to sit in partnerships, create partnerships, and work in collaboration with agencies to do community work hasn't been their strength or hallmark.

At the beginning of the LTC program, the CDC/NIH site stated that the RWD site was catering to a niche population and that their Site C of integration into the larger HIV community impeded community partnership development, especially with youth-focused agencies. The RWD site was a referral agency for HIV positive pregnant women and perinatally HIV infected children. In Site C, once an agency is seen as serving a specific population, it is challenging to change community members' opinions about whom the site serves.

## **Strategies to Overcome Barrier**

The CDC/NIH site strategized to help the RWD site obtain a youth-friendly reputation in the HIV community by 1) the RWD site becoming a member of the coalition, 2) the CDC/NIH site orchestrated a tour of the RWD site, which increased the visibility of RWD site's services, and 3) the CDC/NIH site welcoming the RWD site to jointly attend community HIV testing events. These three strategies helped the RWD site gain a positive reputation in the HIV community.

## **Engage Coalitions to Build Partnerships**

The RWD site overcame its image as a non-community collaborator and a non-youth-friendly clinic through its continual presence at the coalition to learn new ways to provide youth-friendly services and adopt those new ways at the RWD site. Because the RWD site is part of a broader, well-known coalition, it had access to a network of youth-focused agencies to expand its partnerships. The coalition's strength in collaboration stems from intentionally and continually diversifying the agencies that are in the coalition.

The coalition was an ideal environment for the RWD site staff to learn things from other youth-focused agencies, such as which services they should offer. The RWD LTC Coordinator explained, “The coalition helped me gain a big picture of all the activities going on to help youth in the community, which I never knew about all the resources available to youth when I was just working in the clinic.” Moreover, the RWD site learned new ways agencies were tailoring youth-friendly services and worked hard to implement those changes at the RWD site. The RWD LTC Supervisor explained:

You do feel like, well, we do a really good job, we take care of clients, and we do it the best, so we did have a little bit of that bias, so to be a little bit humble and sort of open your mind to some other ideas or suggestions, or practices that maybe you’re not doing that you actually should consider doing, so I was open to that. Still, I did feel myself feeling like okay I have to be a little humble and be open ... To improve our relationship, such that we were communicating on a more regular basis and also learning from each other how to implement youth services and thinking of novel ideas because though we sort of think of ourselves as being experts and being good at working with youth, I think we can always learn new best practices, so that is how I saw it.

The CDC/NIH site used the coalition to help the RWD site obtain a youth-friendly reputation in the HIV community. The coalition overcame the RWD site’s reputation for only serving perinatally infected youth by updating coalition members at the coalition meetings on the RWD site’s progress in transforming to a youth-friendly clinic through the learned techniques taught at the coalition meetings. This increased the RWD site’s credibility as a youth-serving agency among the HIV community. Ultimately, this helped the RWD site build new partnerships in the HIV community.

#### **HIV Community Tour of RWD Site Increased Visibility**

The collaboration between the CDC/NIH and RWD sites to set up the “progressive clinic tours” helped the RWD site achieve credibility as a youth-friendly clinic among HIV community agencies. The CDC/NIH site worked with the RWD site for one year to set up “progressive clinic tours” so that testing agencies and youth-friendly agencies would visit the RWD and CDC/NIH sites. The RWD site incorporated the CDC/NIH site’s recommendations to make the clinic youth-friendly; afterward, the CDC/NIH site orchestrated the tours for the HIV community to visit the RWD site in order to redefine the RWD site’s image as a youth-friendly clinic, not just a clinic for HIV-positive pregnant women. When the CDC/NIH LTC Supervisor was asked if the RWD site’s public image changed through the tours, the participant explained, “probably, just because I don’t think people are aware of them to the

extent that the services that they have to offer. I think it was helpful for people to see that.” Ultimately, this collaboration was so successful that the CDC/NIH site and RWD site staff mutually expressed their interest in holding annual joint tours.

### **United Front Approach at Community Outreach Events**

As noted in aim 1, over time, the CDC/NIH site was more comfortable publicly announcing the CDC/NIH-RWD partnership to expand the LTC referral network. Thus, the two sites took a “united front” approach by jointly attending community outreach HIV testing events to build partnerships with testing agencies in order to identify more YLWH who need to be linked to care. The CDC/NIH LTC Coordinator explained:

We ultimately decided to do the united front approach, we thought that would be easier for our community partners to understand...we just presented it like oh now there is like an additional person, as an additional support, same project, just one new face, so that is how it was approached with existing partners from the SMILE program. For new partners, we decided our approach would be doing outreach events together. We created a lot of outreach material, that was collaborative, it did not have our institution names on it, just had the PEACOC logo as one project, with our names and numbers, so it looked like a joint effort.

In conclusion, coalition involvement, community tours and community outreach events helped the RWD site gain a positive reputation in the HIV community.

### **RWD Leadership’s Competing Vision for the LTC Program**

The CDC/NIH and RWD sites’ leadership did not see the LTC program's goal the same way. The RWD PI collaborated with the CDC/NIH site to increase client enrollment of YLWH seen at the RWD site and increase the RWD site’s government funding in HIV care services. In contrast, the CDC/NIH site prided itself in establishing partnerships to link YLWH to care that best meets their need. At the beginning of the LTC program, the RWD PI met with the CDC/NIH PI and the LTC Supervisor to discuss the strategic expansion of the LTC referral network set up by the CDC/NIH site in the former LTC program. The discussion was unproductive because the RWD PI did not see the value in the partnership with the CDC/NIH site, which was evident in the first meeting with the CDC/NIH site. One participant explained:

When [the RWD PI] was at the meeting, honestly, it didn't go well because it is sort of became this discussion about contracts each of us has with the Department of Health, as well as Part D funds that were flowing into the county, and sort of questioning how was this different than the contracts that they already had and that we had, so it became a bit clustered, to be honest. Partially because [the RWD PI] brought up things that probably shouldn't be brought up, so it detracted from our ability to have a conversation that is very clear, and honestly, I went back to [the CDC/NIH PI] and said I don't think this is going to work out.

The CDC/NIH LTC Supervisor's gauge on RWD PI's unwillingness to truly enter a partnership was accurate.

This was evidenced by the RWD site staff not directly involved with the LTC program. The CDC/NIH site used community outreach events to promote the LTC program; after establishing a "united front" with the RWD site, the RWD site was invited to the events to jointly promote the LTC program. The RWD non-LTC program staff utilized this opportunity to bring RWD staff not directly involved in the CDC/NIH-RWD partnership to use the event as a way to self-promote the RWD site's services. Moreover, the RWD site staff who were not part of the LTC program borrowed credibility from the CDC/NIH site's youth-friendly brand to spotlight only the RWD services. These conflicting messages impeded the LTC program's promotion, which was for the RWD site and CDC/NIH site to collaborate to spread the message of the importance of quickly linking youth to medical care, either RWD site or CDC/NIH site, that best meets youth's needs.

The CDC/NIH site staff confronted the RWD site staff about the mixed messages: team versus silos. Although the RWD LTC Coordinator communicated that she understood the partnership's purpose, the RWD staff not directly involved with the LTC program continued to disseminate information about the RWD site at future community outreach events. Most likely, the RWD PI had instructed the RWD staff to advertise only the RWD site out of a sense of continued siloed approach.

The RWD LTC Supervisor explained the RWD staff's promotional behavior. Before the Affordable Care Act, the local health department referred clients to the RWD site because it was part of Site C. With the expansion of the Affordable Care Act, the RWD site lost clientele. The RWD LTC Supervisor explained:

Now with the Affordable Care Act, more people having access to health care. It's been a big discussion with our administrative people that we actually do need to advertise now because a lot of clients are going elsewhere for their care and for us to stay competitive, we need to be present. People don't have to rely on going to the county anymore because now they have insurance and can go somewhere else to get their health care, so if we want to stay as a competitive health care provider, we need to advertise.



Thus, the RWD site's leadership sought to remain competitive by advertising and making more agencies aware of their services, even if advertising meant at the expense of promoting the collaborative partnership with the CDC/NIH site to expand the LTC referral network.

### **Strategies to Overcome Barrier**

The RWD PI purported that the RWD site was youth-friendly at the beginning of the collaboration and was ready to seek new partnerships separately from the CDC/NIH site. However, the RWD LTC Supervisor and Coordinator respected the CDC/NIH LTC Supervisor's approach to community engagement and followed the CDC/NIH site's lead instead of following RWD PI's preferences. RWD LTC Supervisor's goal was to establish trust with the CDC/NIH site and didn't want the CDC/NIH site's territorialism of partnerships to hinder the RWD staffs' desire to develop a beneficial collaboration with the CDC/NIH site.

The RWD LTC Supervisor strategized to help the RWD site develop a truly collaborative partnership with the CDC/NIH site by: 1) Engaging in frequent in-person meeting and 2) Taking the lead in implementing the project without informing the RWD PI of the progress made strengthening the partnership with the CDC/NIH site. These two strategies helped the RWD site build a close relationship with the CDC/NIH site, which led to the strengthening the partnership from a "divide and conquer" approach to a "united front" approach when engaging HIV community partners.

### **Meetings Built True Collaboration**

The RWD and CDC/NIH LTC Supervisors and Coordinators developed a strong working relationship through in-person meetings. Having open communication between the CDC/NIH and RWD site staff helped improve client care and improved partnership development. Early in the LTC program, the two sites explained their services to one another and came to realize that the staff on the ground had a similar mission to ensure youth have the best services possible to stay in care. Due to endless meetings, the CDC/NIH site also witnessed the RWD site's action to provide the best possible services to care for youth by evolving to a youth-friendly clinic.

Moreover, the RWD LTC Supervisor utilized the meetings to share a collaborative vision with the CDC/NIH LTC Supervisor. The two Supervisors had a similar idea for the partnership, leading to the eventual establishment of a strong collaboration between the RWD site and CDC/NIH site. The RWD LTC Supervisor was an integral

member in ensuring frequent meetings and a quorum in attendance. The RWD LTC Supervisor's goal was to overcome RWD PI's overt siloed approach through the CDC/NIH and RWD staff attendance at monthly in-person meetings to discuss strategies to expand partnerships in the community. The CDC/NIH LTC Supervisor noted that the in-person meetings helped the two agencies build a positive relationship by sharing personal stories to build trust between the site staff. The RWD LTC Supervisor kept up the communication with CDC/NIH site because the Supervisor believed maintaining a relationship through consistent meetings was an essential element of a successful partnership. Moreover, the CDC/NIH LTC Coordinator noted that the CDC/NIH and RWD sites worked well to ensure that scheduled meetings were kept and that the partnership approach was intact:

I definitely think [the RWD site] was the glue in terms of the meetings and calls. I think we balanced each other out nicely and [the CDC/NIH site] was open to being held accountable and [the RWD site] definitely keep us on track with that. I definitely feel like we both brought our strengths to the table for sure...We really complemented each other.

After two years into the partnership, rapport and trust grew between the CDC/NIH and RWD LTC Coordinators. Thus, the continuous in-person meeting was a strategic approach the RWD LTC Supervisor used to get the RWD-CDC/NIH partnership to evolve from a "divide and conquer" approach to a "united front" approach.

### **Program Leadership Critical to Strong Partnerships**

The partnerships established through the LTC program revealed that having the right people leading the expansion of the LTC referral network enables a strong collaboration between youth-friendly clinics in charge of expanding the LTC referral network. Initially, the CDC/NIH site was not hopeful that a partnership with the RWD site would be successful because of the RWD PI; however, once the RWD LTC Supervisor took charge of the LTC program, the CDC/NIH site became more invested in partnering with the RWD site.

The RWD LTC Supervisor was aware of the territorial nature of the HIV community and didn't want that to affect relationship-building with the CDC/NIH site. Therefore, the RWD site did not seek conflicting partnerships with agencies already partnered with the CDC/NIH site. The RWD PI's interview responses suggest that the RWD LTC Supervisor deliberately did not inform the RWD PI of the changing relationship between the two sites which evolved from the "divide and conquer" approach to the "united front" approach; the RWD LTC Supervisor knew the relationship went against the RWD PI's expectation for the partnership. Because the RWD LTC Supervisor didn't provide the RWD PI any updates and did not attempt to change the PI's view on collaboration, the

partnership's continuation was not possible once funding for the LTC program ended. The RWD site's PI explained the decision against working with the CDC/NIH site after the end of funding, "You know we kind of did our separate thing because we are a relatively different kind of program, you know... [the CDC/NIH site] are right there in Hollywood. We are focusing on the county, so we set out to divide up our work. I think we will continue that way." Thus, at the end of the LTC program, the strategy of not helping the RWD PI have a clear understanding of the CDC/NIH and RWD sites' collaborative effort was a short-term strategy for the implementation of the LTC program. The sites did not provide any long-term strategies.

### **RWD Staff Selection Impedes Partnership Development**

The CDC/NIH LTC Supervisor strongly believed that staff selection is vital to building partnerships and direct service delivery. The CDC/NIH site had a previous collaborative experience with the RWD site that left the CDC/NIH staff less than hopeful that the new collaboration would meaningfully improve the LTC referral network—mainly because, in the former collaborative partnership, the RWD site picked inappropriate staff members to work on the program.

At the beginning of the LTC program, the CDC/NIH LTC Supervisor did not support the RWD PI's decision to select a clinical research nurse to serve as the RWD LTC Coordinator. Instead, the CDC/NIH LTC Supervisor wanted the RWD site to select a person with a background in social work or community health because they are trained to build relationships with people. The CDC/NIH LTC Supervisor explained:

We didn't have a sense of [the RWD LTC Coordinator] being someone who would be able to support someone's hand as they sort of walked through this difficulty in their life...I know this might be bad to say, but if you send out a nurse and a social worker out there separately, you will probably see that the social worker is able to create stronger relationships than the nurse, so it will be easier for the social worker to create a linkage-to-care referral process because it is just not a nurse's strength.

The RWD site created an unnecessary impediment to youth-centric care by not hiring staff that mirrored demographically the population it served. The CDC/NIH site noted that the lack of appropriate staff selection hindered both medical care and community outreach event efforts. The RWD site leadership mistakenly believed that experience (majority of the RWD staff had worked at the clinic for over 25 years) trumped the importance of having at least some staff with a shared cultural understanding of the clients they served. By hiring only older

staff, the RWD site lacked ethnic and cultural diversity to make the clinic inviting for Black and Latinx YLWH. The CDC/NIH staff member explained the importance of having staff that mirror demographically the community:

A lot of the people doing the work it's like very community-based, and it's very community-driven, you know, so there is a lot of distrust when it's like not young gay men of color doing the work to work with young gay men of color. The kind of trend is like inter-community. I think when you go to a clinic that says they work with the community, but no one works there, that looks like the community you're like this isn't a community organization, this is a hospital-driven organization, and that's not part of the community, but they want to serve our community, I think it takes longer to build that trust and rapport.

Thus, the RWD LTC Coordinator's hiring at the beginning of the CDC/NIH-RWD partnership compelled the CDC/NIH Supervisor to take a “divide and conquer” approach to build partnerships to strengthen the LTC referral network. The CDC/NIH site's staff never raised the issue of inappropriate staff selection with the RWD site's staff or RWD leadership because the CDC/NIH site wanted to maintain a positive working relationship with the RWD site and believed that if they advised the RWD site of staff selection that it would come off as disrespectful and strain the direct service delivery relationship between the RWD site and the CDC/NIH site.

### **Strategy to Overcome Barrier**

The CDC/NIH site realized that they weren't going to identify another person for the RWD LTC Coordinator position. Thus, the CDC/NIH site worked to cultivate a relationship with the RWD site to have open communication, which helped the LTC Coordinators improve client referral quality. The two LTC Coordinators' open communication led to the Coordinators clearly understanding of one another services, which helped them determine which clinic might provide the best care for a given client. Also, the relationship helped remove structural barriers to linkage-to-care.

The CDC/NIH LTC Coordinator advanced the strong partnership between the CDC/NIH and RWD sites. The CDC/NIH LTC Coordinator utilized their social work background to establish trust with the RWD LTC Coordinator. The CDC/NIH LTC Coordinator initiated calls with the RWD LTC Coordinator to occur every two weeks to discuss client barriers to LTC and helped the RWD LTC Coordinator understand the type of services needed for each client to support them through the HIV continuum of care. The CDC/NIH LTC Coordinator wanted to build RWD LTC Coordinator's skillset for working with youth. The CDC/NIH LTC Coordinator explained, “Our goal was establishing that there is another alternative.”

The CDC/NIH LTC Coordinator successfully built the RWD LTC Coordinator's skillset in addressing YLWH structural barriers to care. For instance, the LTC Coordinators spurred HD to develop a consent policy for minors. Before the CDC/NIH-RWD partnership, if the client was covered under their parents' insurance, HIV testing labs notified parents about their child's HIV test results. However, parents are not notified of the client's HIV status with the new consent policy for minors. The CDC/NIH and RWD LTC Coordinators cultivated a close professional relationship that strengthened the LTC referral process between the CDC/NIH and RWD sites. Strong relationships like these facilitate referrals and ultimately long-term care for YLWH. When relationships are healthy, two organizations can quickly and effectively exchange information on client needs and medical history to facilitate effective care. Collaboration like this did not exist before the CDC/NIH-RWD partnership.

The RWD LTC Supervisor provided an example of the positive bi-directional LTC referral process between the CDC/NIH and RWD sites. The CDC/NIH and RWD sites agreed that data-sharing client information was needed to facilitate a smooth transition to medical care and access essential services. The successful linkage-to-care between the CDC/NIH-RWD partnership stems from both staff understanding to put youth's needs first to cross-share information about the client to ensure they received the services needed to link and retain the client in medical care successfully. The RWD LTC Supervisor explained:

We had a young man who had been in juvenile hall and tested positive for HIV there, and then he was released from juvenile hall, and went to [the CDC/NIH site] and was seen there once, started on medication but then ended up back in juvenile hall and then seen by us. That was where the two LTC Coordinators were talking about the management of the client. They were able to provide timely medical care for the client successfully...The fact that the two LTC Coordinators have such good communication that it was easy to communicate about the client with one another and information was shared immediately, there was no difficulty trying to find out what had happened in the past or anything like that. So, they were both openly talking about the client's challenges, and then I think it was also one of those situations where the idea of putting aside your personal feelings about where this person belongs, to allow the client to decide where they felt comfortable and where they would be followed and not having any hard feelings about it, and just being open-minded and saying we think either institution is a right place for you to be followed. We are open to whatever your decision is, and we want to support you in your decision and just let us know how we can help you.

In the above example, the CDC/NIH-RWD partnership found it helpful to share the client's medical records and past challenges staying engaged in care in order for the LTC Coordinator to understand a better way to serve the client to attempt to get the client to link and remain in care. This approach helped the LTC Coordinators brainstorm ways to re-engage with such clients. In conclusion, when the CDC/NIH site realized the RWD LTC

Coordinator could not be replaced, the CDC/NIH LTC Coordinator successfully built up the capacity of the RWD LTC Coordinator to address youth's barriers to care.

### **RWD Site Lacked Youth-Friendly Services**

HIV focused agencies in Site C, and the CDC/NIH site did not see the RWD site capable of caring for YLWH due to lack of youth-friendly services. At the beginning of the program, the RWD site staff identified itself as a youth-friendly clinic to HRSA and to the CDC/NIH site. The RWD site thought "youth-friendly" meant any clinic that serves YLWH. However, many more factors go into making a clinic youth-friendly. The CDC/NIH Supervisor explained his clinics' reservation for joining the CDC/NIH-RWD partnership:

[The RWD Site] felt like they were already experts in working with youth but just didn't have the community's visibility. So really, that is why our clinic strategized the type of clients they saw because we just didn't think they were ready to work with youth. It was pretty much this is what you are good at, and this is what I am good at. Let's not rock the boat too much; we can still work together but let's also play into each other's strengths.

Thus, at the beginning of the CDC/NIH-RWD partnership, the CDC/NIH site and agencies in Site C did not introduce the RWD site to community agencies because the RWD site led the reputation to enter into partnerships and serve YLWH.

The CDC/NIH site's experience working with non-youth friendly clinics led to their expertise in supporting the RWD site become a youth-friendly clinic. The CDC/NIH site provided the RWD site with WHO's adolescent-friendly health services self-assessment to help the RWD site objectively determine whether it was youth-friendly.

The RWD LTC Supervisor explained:

[The CDC/NIH Site] had suggested that we do the self-assessment questionnaire and look internally at our clinic and figure out how youth-friendly are we. I feel like that was really helpful and eye opening and gave us ways to kind of work towards improvement, because we do like to think of ourselves as youth-friendly but maybe that wasn't always translating beyond the patient-provider relationship.

The RWD LTC Supervisor's willingness to be critiqued and the CDC/NIH site's use of a standardized metric to measure performance were equally helpful in collaborating to design a youth-friendly clinic.

### **Strategy to Overcome Barrier**

The site was able to overcome the barrier. The CDC/NIH site visited the RWD site and, provided the RWD site with a standardized tool developed by World Health Organization self-asses the clinic's youth-friendly services.

This strategy helped the RWD site learn it was not youth-friendly and which benefits it needed to implement to become so. Over time the RWD site successfully became youth-friendly: It remodeled its clinic space, provided accessible services through appointments every Tuesday evenings, trained providers to be youth-friendly, and prepared outreach materials that included LGBTQ-friendly language. The CDC/NIH site's main goal was to use the multi-year grant to establish partnerships in the community and transform the RWD site into a youth-friendly clinic. Once the transformation was complete, the CDC/NIH site engaged in a "united front" approach, with the RWD site expanding the LTC program in the community.

### **Inability to Access HIV Surveillance Data**

The most substantial relationship the CDC/NIH site had in the former LTC program was with the local health department, which lasted four years before starting the LTC program. For the duration of the former LTC program, the CDC/NIH site worked very closely with the local health department to link YLWH to care. The former CDC/NIH LTC Coordinator became "deputized" as a county employee and given office space at the local health department. As a deputized official, the former CDC/NIH LTC Coordinator was granted access to HIV surveillance data, which enabled her to receive contact information for newly reported cases of HIV in real-time. This allowed a high number of clients to be referred to medical care.

Unfortunately, the CDC/NIH site's partnership with the local health department dissolved as soon as the CDC/NIH site entered into a partnership with the RWD site. Specifically, the local health department rescinded the CDC/NIH site's public health authority to access HIV surveillance data. The CDC/NIH site's loss of accurate and timely HIV surveillance data meant it could not make real-time strategic decisions to quickly and easily provide support to newly diagnosed YLWH to link them to medical care. The CDC/NIH LTC Supervisor expressed the site's challenges in losing public health authority, "[HD] are sharing with us aggregate data, but it just isn't the same. When we had public health authority, we were able to call up a clinic and say, hey, it looks like you need help with someone to get them medical care." Those with full public health authority can access client names and contact information. Those without full public health authority may only access de-identified health information.

The HD is allowed, under HIPAA (Health Insurance Portability & Accountability Act), to share HIV surveillance data with local clinics tasked with containing the infectious disease. Under HIPAA, the HD had the

authority to designate clinics as having full public health authority. Unfortunately, HD was only willing to share de-identified data with the CDC/NIH and RWD sites during the implementation of the LTC program. The CDC/NIH site staff stated the most significant barrier experienced was no longer having public health authority. The RWD LTC Supervisor explained, “The main challenges we faced as we established the local program included not having public health authority to receive client-level data.”

Unfortunately, the RWD PI’s misunderstanding of HIPAA damaged the LTC referral partnership between the CDC/NIH site and the local health department. At the beginning of the LTC program, the RWD PI convinced HD that it put itself at legal risk by sharing client names with the CDC/NIH site. Meanwhile, from the CDC/NIH site’s perspective, the CDC/NIH site mysteriously lost access to this data once they lobbied the HD to expand public health authority to the RWD site. If the RWD PI had engaged in more open dialogue with the CDC/NIH site, the CDC/NIH site staff would have likely cleared up the misunderstanding and reassured the RWD PI that if the data were responsibly used to control infectious disease, sharing it with trained clinic staff who could reach out to treat clients lost-to-care was in the overriding (and legal) best interest of public health. The CDC has advocated explicitly for local health departments to share HIV surveillance data with community agencies to strengthen the LTC referral network. As it were, this did not happen.

The RWD leadership severed the CDC/NIH site’s partnership with the local health department; the RWD leadership had a meeting with health department officials to ask the local health department to deny them and the CDC/NIH site access to HIV surveillance data. The RWD leadership explained:

I even went to meetings with [the RWD LTC Supervisor] and [the RWD LTC Coordinator] to talk with local health department staff, and there are a lot of issues with confidentiality, which is what I raised with them at the beginning, it is kind of a problem to get a list of names of people recently diagnosed with HIV, I did not want it. I did not think it was our role to get the list of people tested in the community that were not linked to care. I thought that was a health department’s job. And I didn’t think it was legal for them to release names to us, and [health department official] talked to their council, and the council agreed... I wouldn’t let my clinic take [public health authority] because again, we met with Office of AIDS and said we did not feel that it was ethical.

The CDC/NIH staff did not know about RWD PI’s successful request to deny public health authority to the sites.

The local health department stopped responding to emails or calls from the CDC/NIH and the RWD staff.

Essentially, the local health department’s relationship with the CDC/NIH site dissolved.



## **Strategy to Overcome Barrier**

The site was unable to overcome the barrier. However, the site provided a recommendation for future programs, the CDC needs to explain to health departments the benefit of strengthening the coordination between health departments and youth-friendly clinics. One participant noted:

I think the biggest example is when LTC started. If the CDC could have gotten the buy-in from the Local Health Department, it would have been easier. It would have helped a lot to build a partnership between the health department and us...We were like most sites where no information was actually sent to the county health department by CDC or HRSA. We basically brought it up as soon as it was on the radar. We told them that we were thinking of being an LTC site, so we had forewarned them. Because we were having regular meetings with the health department at that time, we kept asking them if they had received information from the CDC about the program, and they would be like no. So, I think that was hard for us, and I don't think it is necessarily about getting noticed by the CDC/NIH, CDC, or HRSA. In this case, I think it was more about how our partner should reach out in a way that made sense, they just didn't have that relationship, but we had brought it up.

Such coordination would ensure that the two entities function as strategic partners in the national response, harness their potential to identify recently diagnosed youth, support treatment initiation, address poor adherence to treatment, and suppression of viral loads. The CDC involvement would have leveraged the reach, trust, and commitment the CDC has with health departments. Specifically, the CDC should have recommended health departments modify current policies to allow data sharing with youth-focused agencies. This would have eliminated barriers that prevent robust information exchange. Data sharing would promote quick LTC referrals and enable youth lost to follow-up to re-engage in the HIV continuum of care. Unfortunately, the CDC, the NIH, and the HRSA representatives failed to inform the local health department that their funding requirement necessitated the HD grant the CDC/NIH site and the RWD site full public health authority. Lastly, another critical government agency to build an LTC referral partnership with is the criminal justice system.

## **Aim 2 Conclusion**

This case study demonstrated that the CDC/NIH and RWD sites experienced eight barriers implementing the LTC program to improve Site C's LTC referral network. First, federal funding requirements have the potential to lead to competition between HIV focused agencies targeting the same age group to get linked to care. Second, siloed funding streams impacted the CDC/NIH-RWD partnership implementation because the RWD site did not receive enough funding to hire a full-time LTC Coordinator to implement the program, which impacted direct client

services and community outreach efforts to build partnerships. Third, the RWD site's community reputation for not sitting in partnerships and only having the expertise to care for pregnant women living with HIV impeded collaboration with the HIV community. Fourth, the RWD leadership sought HRSA funding to increase client enrollment at the RWD site instead of seeking the funding to strengthen the Site C LTC referral network. Therefore, the RWD vision for the LTC program is different from CDC/NIH site's vision. Fifth, the RWD staff selection demographic did not mirror the HIV community's demographic. Therefore, the RWD site didn't look like an agency that is part of the community but rather part of the status quo of agencies not interested in cultivating a relationship with the population it serves. Sixth, the RWD site lacked youth-friendly services, which hindered its ability to collaborate with youth-focused community partners to link to care YLWH. Seventh, the denial of access to HIV surveillance data reduced the quality of strategic LTC decisions at the CDC/NIH site. The loss of access was at the hands of the RWD leadership, which is known for not having a culture of collaboration. The RWD leadership decision to not meet with the CDC/NIH site to air their concerns and instead go directly to the health department to remove public health authority is consistent with the RWD site's history of poor leadership and non-collaborator in the HIV community. The eighth and last barrier was the RWD site's inability to obtain a LTC referral process with the criminal justice system due to high staff turnover at the criminal justice system.

Although the CDC/NIH-RWD partnership experienced numerous barriers, the partnership also implemented a successful approach to strengthen the LTC referral process for YLWH. The CDC/NIH site leveraged its positive reputation to promote the RWD site and help the site build partnerships with youth-focused agencies. Also, the CDC/NIH-RWD partnership evolved over time from a "divide and conquer" approach to a "united front" community engagement approach can be attributed to the selection of leadership. The RWD and CDC/NIH LTC Supervisors both served in a leadership role, had decision-making authority, and were invested and willing to put in the consistent effort until system-level changes bear fruit. The RWD LTC Supervisor was the strategic mastermind behind building trust and confidence with the CDC/NIH staff to provide the RWD site with capacity building support to become recognized in the community as a youth-friendly clinic. Also, RWD LTC Supervisor respected the CDC/NIH site's strategic partnership engagement approach. The "united-front" community engagement approach led to more community agencies willing to refer YLWH to the RWD site. The CDC/NIH-RWD partnership leaned into each organization's strength working with a specific demographic within YLWH, which led

to the implementation of differentiated service delivery models-based on youth's specific needs. Thus, building effective LTC referral networks takes consistent effort that was only possible with the right leadership, patience to develop a partnership that is a "united front" community engagement approach, and differentiated service delivery model.

In conclusion, Site C had eight barriers. The CDC/NIH-RWD partnership recommended two proposed strategies to overcome the barriers. Also, the CDC/NIH-RWD partnership implemented six strategies and, and out of those implemented five were successful. Both the CDC/NIH site and the RWD site were actively involved in strategizing how to overcome the barriers. The CDC/NIH-RWD partnership's effort to overcome the barriers most likely facilitated the CDC/NIH-RWD partnership's community engagement transition to a "united front" approach.

## **CHAPTER 7: CROSS-CASE ANALYSIS RESULTS**

### **Introduction**

This dissertation sought to illuminate how health facilities can establish partnerships in the community to streamline the linkage-to-care (LTC) process for YLWH in three US cities: Site A, Site B, and Site C. In this section, the results of the analysis from the partnership efforts across the three cases are presented. A total of six themes were revealed in all three case studies and examined in the cross-case analysis.

### **Description of Each Partnership**

Based on data analysis, Site A case study experienced eight barriers implementing the LTC program, and the CDC/NIH-RWD partnership implemented only three strategies to overcome these barriers. Of these strategies only two strategies were successful in overcoming the barriers. The inability to develop strategies to overcome majority of the barriers coupled with a weak collaboration between the CDC/NIH and RWD sites throughout the implementation of the project most likely is the cause for an unsuccessful community to facility partnership with the criminal justice system. Site B CDC/NIH-RWD partnership only experienced three main barriers, and all three barriers were addressed and resolved. The CDC/NIH-RWD partnership successfully expanded several communities to facility LTC partnerships that the other two locations were unable to establish. Lastly, Site C CDC/NIH-RWD partnership is centered around the CDC/NIH site providing capacity-building and scaling up youth-friendly services to the RWD site in order to garner more interest from the community to develop a LTC referral process. Although the Site C CDC/NIH-RWD partnership experienced eight barriers, similar to the Site A CDC/NIH-RWD partnership, the Site C CDC/NIH-RWD partnership implemented six strategies to overcome these barriers, and were successful, which led to a stronger collaboration between the CDC/NIH site and the RWD site.

Across the three case studies the following six themes affected the implementation of the partnerships between the CDC/NIH site and the RWD site as well as between the CDC/NIH-RWD partnership with community:

1) History of collaboration; 2) Culture of collaboration inside the organization as well as in the community; 3)

Government influence; 4) Lack of HIV surveillance data-sharing; 5) Staffing; and 6) Community engagement approach.

### **Previous History and Culture of Collaboration**

The previous history of collaboration influenced the CDC/NIH-RWD partnership's LTC referral network expansion approach. The purpose of the CDC/NIH-RWD partnership was to refer YLWH to care that best suits their medical and non-medical care needs. The Site A CDC/NIH site historically was an insular institution that did not seek partnerships with other departments in the CDC/NIH hospital nor seek to obtain best practices from organizations outside the organization. Thus, the Site A CDC/NIH site had a culture incompatible with the LTC program's goal of collaboration to expand the LTC referral network. This unique history helps explain why the Site A CDC/NIH-RWD partnership did not successfully expand the LTC referral network with large government institutions.

In Site B, the CDC/NIH site and the RWD site were well-respected agencies and known for entering into collaborations in their community, which gave the CDC/NIH-RWD partnership momentum to expand the LTC referral network with large government institutions. Moreover, in Site B, the CDC/NIH and the RWD sites had a previous history of working together; thus, even though the RWD front line staff noted they were overworked from other job-related responsibilities, they entered the partnership with enthusiasm that they were partnered with the CDC/NIH site. Lastly, in the community, the HIV-focused agencies' experiences of sharing resources after a natural disaster had a lasting impact on how the HIV community band together to support each other. All of these factors positively influenced the CDC/NIH-RWD partnership's "united front" approach to jointly go into the community to encourage agencies to join the LTC referral network.

In contrast, in Site C, the CDC/NIH site and the RWD site had a less-than-positive history of collaboration. The RWD leadership was known for not collaborating with the community. These two factors drove the CDC/NIH site to doubt the partnership's prospects in jointly identifying new agencies to join the LTC referral network. Therefore, the CDC/NIH site strove for a "divide and conquer" approach, meaning the two organizations independently went out into the community to encourage more organizations to join the LTC referral network. Another critical contributor to the "divide and conquer" approach, the approach similarly taken in Site A, was the

HIV community has a history of competition. In Site C, as in Site A, funding depended on the number of clients linked to care. In Site C, the CDC/NIH site was the first organization to implement the LTC referral network; however, partners in the network felt the network was unnecessary once government funding required each organization have their own linkage-to-care program. Staff cited over-saturation of LTC referral programs in the city ultimately made it difficult to expand the LTC referral network. Therefore, government funding requirements caused a somewhat unhealthy competition culture and lack of trust amongst agencies when it came time to implement a collaborative LTC program.

Moreover, the LTC program staff across the three case studies made observations of implementation success in other cities which were similar to the observations I made during my analysis of the partnership barriers across the three case studies. Both Site C's and Site A's LTC program staff commented that Site B had a culture for collaboration due to not having an oversaturation of LTC programs in one geographic area. Specifically, when the Site A RWD PI was asked to provide detail on why there was competition between the CDC/NIH site and the RWD site, the Site A RWD PI replied:

I think there is always competition among programs, and I think what is different about Site A as compared to Site B or someplace where you got one program for a geographic area, in Site A, you have multiple programs, so it's not just our partner organization that we are experiencing competition with, it's other adolescent and young adult programs.

The Site B RWD LTC Supervisor confirmed the lack of barriers implementing the CDC/NIH-RWD partnership in comparison to other sites' CDC/NIH-RWD partnerships by stating, "I know other sites struggled with their paired sites like in Site C. We didn't have those issues." Moreover, the Site B RWD PI echoed the Site A RWD PI observation by stating, "It was just a sense that I got from the other partner sites that they had more competition than collaboration." Thus, the perceived lack of competition in Site B's CDC/NIH-RWD partnership was seen among the Site B staff and by LTC program staff in other cities. The one common factor noted was the influence the community's culture of collaboration had on the CDC/NIH-RWD partnership's initiative. While each of these situations are different, the common element is that a history of collaboration (or perceived collaboration) tends to breed further collaboration, and a history of competition caused by external entities or insular culture can rule out the possibility of effective partnerships.

## **Government Influence on Program Implementation**

Government influence in the health care system threatened the sustainability of HIV services in the agencies, which directly impacted how sites approached the implementation of the LTC program, specifically, how the sites collaborated to determine where youth should receive medical care. In Site A, before the initiation of the CDC/NIH-RWD partnership, Site A was saturated with CDC-funded LTC referral programs. The CDC inadvertently incentivized competition because it based funding on the number of clients LTC and ignored the appropriate coordination of services amongst organizations to link clients to care. Moreover, in Site A, the CDC/NIH leadership instructed the local coalition and the CDC/NIH site to divert attention towards implementing HIV preventative interventions due to the scale-up of government funding towards PrEP interventions. Thus, the CDC/NIH leadership could not invest effort into the LTC referral process with large government institutions due to diverted attention into other projects. In Site C, the affordable care act reduced the number of PLWH seen at the RWD site due to the PLWH having more options to receive medical care at different locations. Thus, the RWD leadership saw the HRSA funding to implement the LTC program as an opportunity to increase the number of YLWH to be seen at the RWD site. The RWD site's organizational change led to a significant effort to retain any client seen at the RWD site.

Lastly, in Site B, the RWD site feared the loss of government funding, which drove leadership to obtain Federally Qualified Health Center (FQHC) status in order to expand the type of services offered in the community and increase the number of clients served. Thus, the co-locating of services, specifically, the ability for the RWD site to provide HIV testing and medical care at the same location, led to the smooth transfer of newly diagnosed youth to RWD medical providers. However, this approach impeded the agreed-upon collaboration with the CDC/NIH site to allow the LTC Coordinators to discuss each client's background with one another in order to strategically determine where youth should receive medical care. Also, the LTC program coincided with a major restricting of the organization to a FHQC. With the change in providers, the LTC program expansion lost priority to other more pressing concerns centered on the transition to FQHC.

## **Lack of HIV Surveillance Data-Sharing**

All three case studies worked to address the persistent lack of coordination between the health department and the HIV-focused agencies by requesting health departments grant the sites public health authority to have full access to the client-level health information found in the HIV surveillance data. Unfortunately, the confidentiality of health information was a formidable barrier to coordinating care for YLWH. Health departments across the country have a one-way centralized HIV surveillance system to get HIV-focused agencies to provide health department staff with better data visibility of testing and viral load (VL) suppression data for people living with HIV. Currently, most state and local health departments receive the person's name, contact information, HIV test results, the location where people were diagnosed with HIV, and CD4 and VL lab results. Because data is one of the most powerful drivers for decision-making among the CDC/NIH-RWD partnerships, all three locations attempted to use HIV surveillance data to impact youth's service delivery directly. All three case studies justified access to real-time HIV surveillance data to make it quicker for clinics to identify newly-diagnosed youth or when follow-up medical care is overdue to locate youth and get them into care. The other benefit shared by Site A and Site C sites was that the shared HIV surveillance data would allow for more effective new client incentive programs. A lot of agencies use incentives to bring clients to care as well as to keep their clients in medical care. The downside of using this approach is that it can lead to clients lying about their HIV status to receive the clinic's incentives. Shared databases would allow clinics to differentiate newly-diagnosed HIV-positive clients from benefit-seekers and ensure LTC program staff are not duplicating effort with another health care agency.

Unfortunately, all three CDC/NIH-RWD partnerships were unsuccessful in developing a formal data sharing agreement to access client-level data found in the HIV surveillance data. Instead, the Site C and Site B established health department data sharing agreements to receive routine de-identified data. However, the staff at both organizations noted that the data was of no use because it was not in real-time. Also, the Site A never had a chance to discuss a data-sharing agreement with the Site A Department of Health because Site A DOH leadership had many issues to address in the city and was unable to meet with LTC program staff to discuss the issue. Staff noted the main problem for not granting full public health authority or, in some cases, sites not wanting public health authority had to do with believing access to surveillance data breached long-held traditional boundaries



between the medical community and government community. Thus, some members of the HIV community thought the government should only use the HIV surveillance system to monitor HIV case rates in the community.

LTC programs' work in developing a data-sharing agreement between clinics and health departments revealed that existing public health laws are not clear and challenged the conventional wisdom of how the HIV surveillance system should be used and impacted the LTC program's mission to get medical care agencies in a community role to immediately linking HIV positive youth to medical care. YLWH need to be seen as a priority to get linked to care, which is why in this case, the CDC/NIH-RWD partnerships believed access to clients' privacy was a benefit not just for the community but, more importantly, for the client. Moreover, the case study revealed that health departments are woefully under-resourced to meet youth's needs. At the Site A site, the health department had to control the Zika outbreak and was so overwhelmed with that outbreak that staff didn't have the time to meet with HIV clinic leadership to address youth's needs.

A recommended strategy for future LTC programs among all three case studies was that the CDC should provide a letter of support for HIV clinic's access to HIV surveillance data before the LTC program begins. The Site B CDC/NIH-RWD partnership was successful in an informal collaboration to link youth to care through a partnership with the health department. The CDC/NIH-RWD partnership forged a middle ground by ensuring the health department had the sole power to review client-level information to protect individuals' privacy. HIV clinics would also be readily available when called upon by the health department disease intervention specialists to assist in locating YLWH. It is important to note that health department staff and clinic staff discussed confidentiality concerns between the health department and clinics. However, all the CDC/NIH and RWD partnerships requested all YLWH sign a client release form to facilitate information sharing between LTC Coordinators. Every case study cited success in sharing client-level information between the clinics to identify the best clinic to meet youth's needs and brainstorm with Coordinators on how to address non-medical barriers youth experienced.

## **Staffing**

Staffing was cited as thwarting or contributing to the implementation of the LTC referral networks. The specific staffing thematic barriers identified were the following: staff selection, staff resources and leadership buy-in.

### **Staff Selection**

Interviewees noted in all three case studies that staff selection was vital to building or hindering partnerships and direct service delivery for YLWH. Specifically, staff selection of adolescent physicians and LTC Coordinators impacted the implementation of the CDC/NIH-RWD partnership. All the sites hired an LTC Coordinator to implement day-to-day activities. Therefore, there was a great deal of discussion about the qualities needed for a LTC Coordinator. First, Coordinators who were familiar and respected in the HIV community developed relationships with other organizations without experiencing as much difficulty as Coordinators who had no partnership building experience. This trait was deemed essential across all the case studies. Secondly, several interviewees cited clinics strived to hire LTC Coordinators who mirrored the community they served as it would lead to more credibility with youth and youth-focused agencies. Thirdly, data showed that it was beneficial for sites to hire a LTC Coordinator with a background in social work or community health because they are trained to build relationships with people as oppose to sites who hired a nurse with no experience in community outreach or case management.

In Site C, the RWD LTC Coordinator lacked expertise in community outreach and working with youth. However, this barrier was reduced with the help of the CDC/NIH site. Specifically, the CDC/NIH LTC Coordinator initiated calls with the RWD LTC Coordinator to occur every two weeks to discuss client barriers to LTC and helped the RWD LTC Coordinator understand the type of services needed to support youth through the HIV continuum of care. The CDC/NIH LTC Coordinator wanted to build RWD LTC Coordinator's skillset for working with youth.

The Site C and the Site B site staff noted that the medical providers hired to support the LTC program's implementation focused on increasing client enrollment of YLWH. One participant noted, "I see the competition more with doctors, especially those that are adolescent or pediatrician doctors." Thus, the medical providers saw collaboration with the partner site as a vehicle for only referring YLWH to their medical site. In Site B, the

CDC/NIH-RWD partnership staff utilized the memorandum of understanding (MOU) that explained in detail the agreed upon LTC referral process between the two sites as a resource to gain buy-in from RWD providers. The MOU was a successful tool to explain to RWD providers the importance of adhering to the collaboration with the CDC/NIH site. Additionally, in Site A, the newly hired medical providers were not accustomed to the depth of specialized medical care required for YLWH. Thus, the Site A medical providers treated youth as adults, which was the opposite of the youth-friendly care model the CDC/NIH site leadership instilled in the past. Although it is ideal to hire a person with the qualities identified above, it can still be hard to employ appropriate staff for the position if there is limited funding to hire full-time staff.

### **Staff Resources**

According to the interviewees, the primary staffing challenge was insufficient HRSA funding to support a full-time RWD LTC Coordinator to support all activities to implement the LTC program in all three RWD sites. The strategy to overcome the funding constraints was to distribute responsibilities assigned to the LTC Coordinator to other staff members. In Site A, Site B, and Site C, this approach constrained the time and/or quality of work the other staff were able to commit to the LTC program. In Site B, the CDC/NIH site understood the lack of staffing resources given to the RWD site. Thus, the CDC/NIH site overcame this barrier by providing additional time and effort to support the RWD site in its activities to ensure the expansion of the LTC referral network.

### **Leadership Support**

The data revealed that when leadership was reluctant to support the CDC/NIH-RWD partnership, the sites experienced difficulty establishing partnerships with large institutions. In all three case studies, leadership was cited as contributing or hindering the development of partnerships. Leadership support is defined by the extent of committed leadership to facilitate or directly administer all tasks needed to develop an LTC referral pathway with another organization. In Site C, several staff members noted the RWD leadership's inability to sit in partnerships was an initial barrier towards establishing a partnership with the CDC/NIH site.

Educating staff on the importance of placing youth in care that best meets their needs was cited as the most common strategy to overcome the tension with medical staff. Fortunately, the RWD PI designated the RWD LTC Supervisor as the leader of the LTC program at the RWD site. The change in the LTC program's day-to-day

leadership led to an improved working relationship with the CDC/NIH site. Also, in Site C, the RWD leadership operated from a medical model and not a youth-centric care model, which caused friction with the CDC/NIH leadership's preferred approach for caring for youth. The Site C CDC/NIH site reported greater success linking youth to care when staff went out into the community to meet with newly diagnosed youth in a neutral location, provide transportation to medical care visits and accompany youth to appointments. At Site C, the CDC/NIH site noted initial friction with the RWD site because the RWD site did not provide those services to youth at the RWD site. However, over time the CDC/NIH leadership and frontline staff site and the RWD frontline site agreed that youth who needed intense case management services were referred to the CDC/NIH LTC Coordinator to provide intense case management services.

In Site B, leadership from both organizations were in opposition to the partnership in the pre-implementation phase. However, frontline staff at the CDC/NIH site was direct with leaders of the importance of setting aside personal feelings about the organization's leadership and focusing on the program's vision. The CDC/NIH staff member had credibility in the community and was well respected by leaders at both organizations. Thus, the CDC/NIH staff member was able to disarm both leaders by setting up a meeting to neutralize both leaders and help leadership find common ground and compromise on establishing an LTC program that benefited both agencies. The fundamental strategy used in this example is the CDC/NIH PI transferred decision-making power to frontline staff for the benefit of the program to succeed.

In Site A, the CDC/NIH PI and RWD PI had different level of engagement in the CDC/NIH-RWD partnership, which influenced the implementation of LTC referral pathways with government institutions. In Site A, RWD leadership emphasized the importance of partnership to staff members inside the organization and in the community. However, the CDC/NIH PI was not actively engaged in the CDC/NIH-RWD partnership and did not delegate authority to any staff member, which hindered the partnership's effort to establish partnerships with large government institutions in the community. Both the RWD and the CDC/NIH staff agreed that the CDC/NIH PI should have been more involved and that the buy-in and inclusion would have helped implement the LTC referral with large government institutions. Staff recommended leadership must fully engage and invest in the program right from the beginning of the partnership. If leadership is unable to attend the meeting, then it is imperative in leadership's absence to designate another person with respect in the community to assume leadership's decision-

making power to ensure a smooth progression of the CDC/NIH-RWD partnership. All these factors influenced how the CDC/NIH-RWD partnership went out into the community to promote the partnership's initiative and to streamline the coordination of linkage-to-care efforts for YLWH.

### **Community Engagement Approach to Establish Referral Pathways**

Collaboration with community agencies to implement an LTC referral pathway with health facilities that were youth-friendly clinics was the main focus of the LTC program across all three case studies, however, the community engagement approach to establish the referral pathway differed across all three cities. As noted earlier, both the Site A and Site C sites cited challenges forging LTC referral pathways, whereas the Site B sites did not. All three cities noted a great deal of relationship building took place to attempt collaboration with community agencies. The critical difference noted amongst all three cities was the CDC/NIH-RWD partnership's community engagement approach. The distinct factor that stood out was the "united front" approach used in the early phase of the CDC/NIH-RWD partnership to engage with community agencies. As noted earlier, the Site B CDC/NIH site and the RWD site had a long history of providing services in the community for YLWH, which led to a positive reputation for collaborating in the HIV community. Thus, the CDC/NIH-RWD frontline staff leveraged their positive reputation in the HIV community and long history in the community to go together to meet with community agencies.

Specific "united front" approach strategies used to build partnerships in the community included the following: the CDC/NIH-RWD frontline staff with decision-making authority delivering presentations to the leadership in community agencies, facilitating tours to give leadership at community agencies an in-depth view of services provided to youth referred to the clinic, and the two LTC Coordinators agreeing to linkage-to-care requests made by community agencies for all ages living with HIV in order to show community agencies the health facilities cooperation and flexibility to meet the community agencies' goals. All of these "united front" strategies showed the true spirit of collaboration.

Lastly, even though there were challenges coordinating LTC referral partnerships within cities, the program had success in linking youth to care in other cities involved in the LTC program. The participants noted that the LTC referral network occurred beyond city boundaries. During program implementation, it was revealed

that youth are a transient population. The LTC Coordinators made sure to smoothly transfer youth enrolled in the LTC program to an LTC Coordinator in another city. The Site C LTC Supervisor shared, “Our relationship with other LTC Coordinators through the initial training and subsequent [national meetings] has even allowed for cross country referral of clients.” Moreover, the relationships built across the cities allowed for seamless linkage to medical care for youth seeking to relocate to other metropolitan cities. For instance, the Site A RWD LTC Coordinator stated:

I actually had like two cases in the project where I reached out to LTC Coordinators in California to inform them of a client that was moving to their city and to set up medical care for them. There was one that I transferred to Site B before we got IRB approval for the project, and heard that the LTC Coordinator was able to successfully link the client there. I also had transfers from other states to my state, and I helped the client look for better services in my state.

Thus, this multi-case study shows the potential impact LTC referral networks can have not only in one city but across the country if there is a coordinated effort in place and dedicated LTC Coordinators ensuring continual retention in care. Although there was success in referring clients across city boundaries, the collaboration within cities to provide timely linkage-to-care was different depending on the city youth lived in.

## **Conclusion**

Capturing providers' perspectives implementing the LTC program, and the cross-case results revealed recurring themes that hindered the partnerships' attempt to implement a LTC referral network between the two HIV LTC programs and the community. A total of six primary themes were identified as barriers to the formation of effective partnerships: a history of collaboration between the CDC/NIH site and the RWD site, the culture of collaboration, government influence in program implementation strategy, utilization of HIV surveillance data for decision making, staff, and the community engagement approach to recruit partners to join the LTC referral network. Investigations into strategies to overcome barriers in the RWD-CDC/NIH partnership showed that selecting the right staff, identifying key leaders, having a collaborative culture in the community and the organization, strong coalition consisting of diverse stakeholders and having a data-sharing agreement provides agencies with the opportunity to swiftly coordinate services with agencies in the community in order to link youth to care within 42 days of referral to a youth-friendly clinic.

## **CHAPTER 8: DISCUSSION**

### **Overview of Dissertation**

Well into the fourth decade of the human immunodeficiency/acquired immune deficiency epidemic, the health care system in the United States continues to face challenges improving linkage-to-care referral rates for YLWH. According to the latest CDC data, 2019 National HIV Surveillance System Report, HIV diagnoses increased among persons aged 13-24 years (CDC, 2019). Research showed that LTC is not a straightforward process, with only 66% of identified YLWH LTC (Philbin et al., 2014).

There are several identified factors to the low LTC rates. First, the growth in the number of HIV service providers and agencies has led to a lack of or inadequate coordination in the provision of care, thereby resulting in low LTC rates (Rosenberg, 2010). Second, navigating care in the current disjointed system is often even more challenging for YLWH who have less experience with the health care system (J. D. Fortenberry et al., 2017). To address this fragmented delivery of care and improve the LTC referral process, new initiatives are needed to help create these linkages among agencies and providers to ensure YLWH are linked-to-care (Mugavero et al., 2011).

This dissertation examines how two HIV programs came together to address the fragmented LTC referral process and attempted to establish a formal HIV LTC referral network among health departments, testing agencies, criminal justice system, community agencies, medical agencies, and other youth serving agencies, in both traditional and non-traditional health care systems. Because the attempt to build LTC referral networks is relatively new, it is important to better understand organizations attempt to lay the foundation for partnerships with different entities, the barriers experienced entering those partnerships and strategies used to overcome the barriers.

The end goal of the project examined in this dissertation were to integrate cities' systems of care to ensure organizations actively linked YLWH to care, preferably to youth-friendly clinics. This aim was created because past research showed youth are more likely to get linked-to-care if they are referred to a youth-friendly

clinic (Tanner et al., 2014; Philbin et al., 2016). Ultimately, having coordinated services through an LTC referral network can help identify YLWH in the community, get these youth linked to appropriate medical and nonmedical care, and ensure that they're retained in medical care (J. D. Fortenberry et al., 2017).

This dissertation used a multiple case study design in which each LTC referral network constitutes a case. I conducted a secondary data analysis of 15 pre-identified interview and partnership-related document data (Community Impact Plan) from all three cases. I collected qualitative Interview data from PEACOC's Principal Investigators, LTC Coordinators, and LTC Supervisors from February 2016 through March 2016 as part of the PEACOC study.

My data analysis utilized qualitative content analysis to create new knowledge from raw unordered interview data, examined individual cases in a systematic manner, and compared barrier data across all three cases. Review of partnership-related documents provided valuable foundational information on LTC referral network development, as well as validate and supplement findings from the analysis of secondary data found in the interview data.

## **Aim I Results**

Aim 1 helps the HIV community understand the complexity of the barriers across three case studies as it relates to establishing an LTC referral network. Understanding this level of detail can provide unique information about what to expect when creating linkages between agencies. My descriptive analysis provides useful information on each case studies' HIV linkage-to-care landscape, description of the CDC/NIH and RWD sites' services, staff's roles and responsibilities, the CDC/NIH-RWD partnership's approach to community engagement to expand the LTC referral network, and key partnerships targeted to join the LTC referral network.

All three case studies were placed in urban cities ranked the highest in HIV incidence. Also, all three case studies took place in urban areas where Black and Latinx LGBTQ populations are greatly impacted by HIV. My dissertation findings demonstrate that CDC/NIH and RWD sites with similar services for MSM population had a stronger collaboration in their community engagement approach to expand the LTC referral network.



## **Youth-friendly Clinic**

The most salient factor across the three case studies was the need for youth-friendly clinics to assist with the coordination of the LTC referral network. Site B case study was the only case where the HIV community considered the CDC/NIH site and the RWD site as both youth-friendly clinics. The CDC/NIH-RWD partnership's community reputation as a youth friendly clinic fostered the ability to persuade large government agencies to join the LTC referral network. Dissertation results at the Site C reveal that the CDC/NIH-RWD partnership had trouble expanding the LTC referral network due to RWD site's reputation as not having youth-friendly services and past history of poor participation in partnerships. Lastly, the Site A case study had youth-friendly leaders at both the RWD site and CDC/NIH site; however, the CDC/NIH site's staff unwillingness to provide youth-friendly services outweighed leadership support for youth-friendly services. Thus, findings show that youth-friendly clinics are necessary for agencies to join the LTC referral networks tailored for YLWH.

## **Identification of Main Partners**

Cross-case analysis of the case studies revealed the importance of targeting key partners to strengthen the LTC referral network and facilitators to establish those partnerships. The salient partnerships to develop in the future include collaborations among: nearby HIV programs that provide similar services, the criminal justice system, HIV testing agencies, and the local health departments.

First, the partnership between the CDC/NIH site and the RWD site allowed for the two HIV medical care sites to smoothly link clients to each other's clinics. Specifically, the relationship between the LTC Coordinators facilitated the two sites to easily call each other to ensure clients could be seen by a provider as soon as possible.

Second, all three case studies demonstrated the importance of including the criminal justice system in the LTC referral network. The inability of health facilities to establish partnerships with the criminal justice system created a persistent gap in service provision. Also, case studies show engaging the criminal justice system leadership required an excessive amount of time to obtain leadership buy-in to join the LTC referral network. Therefore, most sites were unable to achieve their goal due to frequent criminal justice staff turnover and/or PEACOC leadership's competing priorities. Although a partnership with the criminal justice system requires a lot of work, this is a necessary partnership to establish, given the large Black and Latinx populations in the system.

Third, across the three cases, partnerships between HIV testing agencies strengthened the LTC referral network. A few of the case studies revealed challenges establishing referral pathways with HIV testing agencies. Specifically, HIV testing agencies that had co-location of HIV testing and medical care services known as “one stop shop” were not as willing to cooperate with other agencies to get youth linked to medical care services that were outside their clinic.

Fourth, across the three case studies, the CDC/NIH-RWD partnership attempted a partnership with the health departments. Unfortunately, all the cases were not able to develop the strongest collaboration to expand the LTC referral network. The Site A case study revealed health department staff prioritized Ebola and Zika outbreaks over meeting with the RWD site to discuss the need for strengthening the LTC referral network. The Site C health department had the strongest collaboration with the CDC/NIH site prior to the PEACOC project; however, due to community physician’s misunderstanding of PHA and HIPAA, the partnership diminished. In addition, the health department staff had no designated LTC staff member to ensure youth got linked to medical care; thus, once the Site C CDC/NIH site was cut off from HIV surveillance data the Site C CDC/NIH site experienced greater challenges getting youth linked-to-care.

#### **Coalition Support for Expanding the LTC Referral Network**

Coalition utilization proved to be another key vehicle for promoting the LTC referral network. Across the cases the coalition was the perfect platform for agencies to learn of the benefits for joining the LTC referral network. Unfortunately, the Site A CDC/NIH-RWD partnership did not utilize the coalition to create a partnership with the criminal justice system. On the other hand, the Site B CDC/NIH-RWD partnership developed a formal referral pathway with the criminal justice system and relied heavily on the coalition to expand the LTC referral network. Site B also utilized the coalition to persuade the health department to develop an online ART distribution system to create an easy system to get medication refills.

Dissertation findings are consistent with the literature presented by Boyer et al. (2016) that coalitions support system-level changes are needed to improve LTC rates for YLWH. Also, dissertation findings are consistent with results presented by Damschroder et al. (2009), which demonstrated strong networks and relationships as

critical components of social capital that facilitate the successful implementation of interventions (Damschroder et al., 2009).

### **United Front Community Engagement Approach**

Case study results demonstrate that having two well-respected agencies present together in the community to recruit more agencies to join the LTC referral network, can be key to helping expand that network. This is known as the “united front” approach. Site B and Site C used the “united front” approach and implemented the following strategies when attempting to get new agencies to join the network. Strategies included: joint development and delivery of PPT presentations to community agencies, leadership joining frontline staff in the partner engagement meetings; conducting clinic tours to potential agencies to showcase the benefits of linking youth to youth-friendly services; assisting potential agencies with linkage-to-care services for PLWH outside the 12-24 years old age group in order to build agency trust, and jointly distributing outreach material to the community.

### **Aim 2 Results**

Through a qualitative study of three LTC referral networks targeting YLWH, this dissertation advances an understanding of the challenges to implement these networks and types of strategies employed to overcome such challenges. I drew from the ecological framework to explore the multi-level barriers affecting linkage-to-care referral networks across the three cases. The ecological framework is a common model to explain HIV interventions using the proposed three levels: (1) Systems, (2) Organization, and (3) Individual.

Aim 2 dissertation results show systematic, organizational, and individual level barriers towards the expansion of the LTC referral network. I found the ecological framework useful, as it assumes linkage-to-care is influenced on multiple levels, and clearly identifies barriers at each level. Individual level barriers include selection of staff and leadership involvement. Organizational level barriers include financial resources and a culture of collaboration. System level barriers include government influence on program implementation and the health department’s refusal to share HIV surveillance data. This refusal was due to a misunderstanding of HIPAA guidance on granting community agencies public health authority (PHA); PHA allows agencies to serve in a government capacity to control an epidemic. Even though the CDC/NIH-RWD partnership experienced barriers to

expand the LTC referral network, each CDC/NIH-RWD partnership demonstrated unique strategies to overcome the barriers to expand the LTC referral network.

### **Individual Level Barriers**

Staff themselves can thwart the successful formation of referral networks. One individual barrier identified in both this dissertation and existing literature is leadership (Gilman et al., 2012; Kinsky et al., 2015). In contrast, this dissertation identifies a new barrier not mentioned across previous case studies in the context of referral networks: selection of staff.

### **Selection of Staff**

Several interviewees noted staff selection is vital. They noted staff hired for the project needed to possess the following traits: knowledge regarding youth-specific issues, experience forming positive partnerships, community outreach experience, age/race/and gender similar to YLWH, the ability to address conflict and knowledge of how to implement a youth centric model.

### **Strategies to Overcome Barrier**

Staff provided a few strategies to overcome staff lack of youth-friendly traits: cross-share best practices to serve youth, cross-share best practices to engage agencies in the community, conduct joint outreach events, and train staff on the youth centric model.

### **Leadership Involvement**

Lack of leadership involvement was a barrier to implementation. Interviewees at Site A noted that they would have been able to gain partnership with the criminal justice system if the Site A RWD leader was involved in daily decisions and was an advocate of the partnership with criminal justice system leadership. An interviewee explained, "Change is often glacial, and demands chipping away on a regular basis. Lack of a dedicated person will hinder this process." Moreover, dissertation reveals that leaders who do not have a reputation for entering into partnerships and have interpersonal conflict with staff external to their agency led to challenges expanding the network.

### **Strategies to Overcome Barrier**

The following strategies were used to overcome lack of leadership involvement: transfer decision-making power to frontline staff, educate staff on how to provide youth-friendly services, and creating partnership agreements to refer youth to agencies that address their needs. Other strategies not implemented, but proposed for the future include: agencies' need to be very selective of the leader hired and frontline staff's need to vocalize the need for leadership involvement on day-to-day decision making. Also, willingness by leaders to surmount partnership barriers through face-to-face meetings, tackle conflicts head-on, and come to a resolution with partners, can allow expansion of LTC referral networks—even in competitive environments.

### **Organizational Level Barriers**

Organization-level barriers that have been identified in the dissertation and are similar to the narrative literature include resource availability and organizational culture (Simonsen et al., 2015).

### **Financial Resources**

Financial resources were a barrier during project implementation. First, the funding stream for the RWD site was a different than the stream for the CDC/NIH site. Second, the funding amounts were smaller for the RWD site, which meant the RWD site hired fewer workers for the same project. Third, the RWD site had HRSA funding, which does not allow grants to request additional money after the grant is awarded.

### **Strategies to Overcome Barrier**

The lack of adequate funds to the RWD site left the RWD site reliant on the CDC/NIH site for financial support of joint outreach, and reliant on the CDC/NIH site staff to provide additional time to support the RWD site implementation of the LTC program.

### **Culture of Collaboration**

The dissertation results across the case studies revealed when one or both of the PEACOC partner sites lacked a culture of collaboration, that impacted the community engagement's approach to engage agencies to join the LTC referral network. Specifically, an organization's lack of cultural collaboration led to the Site A CDC/NIH site and Site A RWD site independently reaching new agencies. This approach is known as the "divide and conquer"

approach. Site C was the only case study that used the “divide and conquer” approach and transitioned to the “united front” approach towards the end of two years of collaboration.

### **Strategy to Overcome Barrier**

Dissertation results show a culture of collaboration between two agencies can occur overtime. The Site C CDC/NIH-RWD partnership transitioned to a closer collaboration towards the end of the project. The two agencies accomplished a stronger collaboration through frequent meetings held in person to build staff trust, reduce staff’s fear of losing clients, and strengthen interpersonal relationships.

### **Systems Level Barriers**

My dissertation findings confirm government influence on program implementation, and a misunderstanding of HIPAA policies, are system-level barriers (Kinsky et al., 2015; Philbin et al., 2014; Tanner et al., 2013).

### **Government Influence on Program Implementation**

My dissertation shows that federal agencies' funding mechanism caused five barriers to partnerships. First, the oversaturation of LTC programs in a community, coupled with federal agencies' monthly client referral enrollment quota, led to competition between agencies serving the same age group. This oversaturation of LTC programs stems from fragmented federal agencies funding similar work in the same geographic catchment area. Also, the client enrollment quota tied to the continuation of funding leads to a lot of organizational pressure to sustain funding. Lastly, Site A and C case studies reveal agencies with HIV testing services and medical care services located inside an agency also known as co-location of services or “one stop shop” will more likely retain their clients in their own clinic instead of giving YWLH options to receive care at other agencies that are better suited for the youth’s individual needs.

Second, the Ryan White Part D (RWD) site and the Centers for Disease Control and Prevention (CDC)/National Institute of Health (NIH) site siloed funding streams coupled with different funding amounts for each agency, causing implementation challenges within the CDC/NIH-RWD partnership. Interviewees noted that,

due to lack of similar funding, the agencies did not have the staff levels and financial resources to put 100% level of effort into the project.

Third, the HRSA does not have a mechanism to provide additional funds to an existing award.

Dissertation findings show this is an issue when agencies under-budgeted the number of resources needed to support partnership efforts towards expanding the LTC referral network (e.g., funds for advertising the partnership). The HRSA, the CDC and the NIH should come together to determine how much it would cost to implement a similar LTC referral network.

Fourth, federal agencies currently award agencies a three-to-five-year grant, however, most system-level programs need more than five years to get fully implemented, which is why the PEACOC project was not able to develop a very diverse LTC referral network. Dissertation results show that as soon as agencies start working well together and begin to trust one another, funding end. This precludes true system-level changes and reduces cooperation.

Fifth and finally, the decline of HIV care and treatment funding leads agencies to continuously scan the environment for funding sources, leading agencies to take a business model of organizational self-preservation over the continued high level of effort towards the existing award. Site C analysis shows that, at the beginning of the project the CDC/NIH-RWD partnership confronted challenges getting agencies to join LTC referral due to agencies fear of losing clients to competing agencies, which initially discouraged agencies to join the LTC referral network.

### **Strategy to Overcome Barrier**

The most frequently used strategy to overcome competition was the CDC/NIH-RWD partnership's willingness to serve as a resource to assist youth to care that were outside the target age group (12-24 years old) in order to show the potential agency that the network was useful in helping clients get linked-to-care.

### **Misunderstanding of Health Policies Impedes Data-Sharing**

The misunderstanding of external policies led to different levels of data-sharing between health departments and health facilities. The CDC/NIH-RWD partnership wanted the health departments to grant them

full public health authority to access HIV surveillance data. The public health authority would allow health facilities to act on behalf of the health department to quickly link YLWH to care. Unfortunately, the dissertation results show a misunderstanding of the Health Insurance Portability and Accountability Act (HIPAA) led to Site C CDC/NIH site's loss of public health authority or the CDC/NIH-RWD partnership's inability to receive public health authority and inability for Site A and B to have full public health authority.

### **Strategy to Overcome Barrier**

One strategy to overcome health departments' unwillingness to share identified client level health data: CDC held several meetings with health departments to increase the frequency of sharing de-identified client data from quarterly reports to monthly reports. CDC provides health departments with a letter of support to share data, and then sites get the agencies in the referral network to agree to include in the client release form that the client's information will be shared with other agencies to support LTC efforts.

### **Existing Literature/Gaps in Literature**

Research in hospice, nursing, and other settings suggest interagency collaboration can improve LTC across the health care system (Wittenberg-Lyles et al., 2010). HIV prevention research is further along in coordinating services between agencies; however, this is possibly due to the large population of undiagnosed individuals, versus a relative scarcity of diagnosed PLWH that need to be linked-to-care (Pinto et al., 2017) in a given geographic area. In 2019, Dave et al. systematically reviewed 152 interventions along the HIV care continuum in high-, middle-, and low-income countries (Dave et al., 2019). Dave et al. (2019) reported that only five percent of interventions addressed LTC barriers, and called for more research into the subject (Dave et al., 2019).

Even though the low LTC rates for YLWH is a long-standing problem (CDC, 2019), attempting to implement a structured referral process to connect several agencies to strengthen their communities' LTC referral networks is still a relatively new concept. Studies of collaboration are prevalent outside of HIV care and treatment programs, but scarce within HIV care and treatment programs; nevertheless, federal initiatives are beginning to address it in research and practice. The HRSA funded project known as *The Systems Linkage and Access to Care for Populations at High Risk of HIV Infection Initiative (SPNS)*, was implemented from 2011 through 2015 (Myers & Xavier, 2019). The HRSA funded the SPNS program across six states: Louisiana, Massachusetts, New York, North Carolina,



Virginia, and Wisconsin (Myers & Xavier, 2019). This project is aligned with my dissertation as it examines how to improve coordination of care with traditional and non-traditional agencies in the community in three different states. The SPNS study is in contrast to the dissertation because the key agency spearheading the expansion of the LTC referral network is the health department. The SPNS study results were able to get community agencies access to HIV surveillance data, develop a referral pathway with the criminal justice system and establish collaboration with several agencies in the community. The minimal barriers to expanding the LTC referral network could be correlated to the health departments are charged with developing an LTC referral network.

This dissertation and the literature reveal the importance of addressing physicians' concern with sharing client level data between agencies. Buchbinder et al. (2020) demonstrated physicians were in support of utilizing HIV surveillance data to link PLWH to care, however, they did qualify their support with making sure health departments addressed the following concerns with clinics: government assistance vs. overreach, privacy and confidentiality, HIV stigma, HIV exceptionalism, HIV criminalization, and data integrity and sharing (Buchbinder et al., 2020). In another article, Sweetney et al. (2019) noted that a health privacy attorney supported health facilities' access to HIV surveillance data because this does not violate HIPAA. Literature affirms the dissertation findings that HIPAA is complex and challenging for public health practitioners and legal counsel to understand, which leads to conflicting interpretations. The dissertation findings show that RWD site C leader misunderstood how the HIV surveillance data would be used by clinic staff. Moreover, the RWD site C leader believed the clinic's access to the HIV surveillance database was a breach of HIPAA regulations. Thus, RWD site C leadership misunderstanding of HIPAA regulations led to Site C health department's decision to revoke the CDC/NIH site's public health authority to access the HIV surveillance.

The CDC's Data to Care Project is aligned with the dissertation's interviewees recommendation for CDC involvement in brokering partnership between health facilities and health departments. In 2018, the CDC's HIV Prevention Branch funded 61 local health departments through a cooperative agreement PS18-1802 titled *Integrated HIV Surveillance and Prevention Programs for Health Departments*, commonly known as the Data to Care project. The CDC funded health departments to establish a data-sharing agreement with community agencies to utilize HIV surveillance data to link PLWH to care (Sweetney et al., 2019). The Sweetney et al (2019) article revealed that health departments are open to sharing data with community agencies when CDC is spearheading

the cross-sharing of data. The federal agencies' involvement effectively meets the National HIV/AIDS Strategy call-to-action to improve care coordination between agencies to improve LTC rates (NHAS, 2010). Thus, the dissertation results align with new federal initiatives to expand and share data to improve LTC rates for PLWH.

This dissertation aims to fill a gap in the literature on creating LTC referral networks for YLWH, barriers to coordination of care, and to provide a guide to key stakeholders with suggested steps for advancing the LTC referral network. Between a lack of minimal historical examples and a clear government mandate for enhanced collaboration, the HIV community needs to concentrate on identifying, learning from, replicating, and understanding LTC networks, which are critical to advancing this field.

### **Dissertation Strengths**

The dissertation results are based on scholarly analysis and testimonies. The dissertation's strengths include:

- 1) I obtained enough information to provide an in-depth understanding of the individual cases and across three cases. Hopefully, this approach will increase the generalizability of barriers for future agencies to consider when they try to implement a similar LTC referral network.
- 2) Threats to trustworthiness of study participants' recounting of events was not an issue because I developed a strong rapport and trust with the participants during program implementation. My strong relationship with participants allowed them to be candid and not filter their answers for social desirability; rather, they were open to revealing "unpleasant truths," with the understanding that I would uphold their privacy.
- 3) I adhered to Yin (2009) recommendation to design a multiple case study that used the logic of replication, in which the inquirer replicates the procedures for each case.
- 4) According to Creswell (2016) researchers should choose no more than four or five cases. In quantitative studies researchers are motivated by large number of cases to generalize findings. However, in qualitative research generalizability is a term that holds less meaning. The dissertation had a total of three case studies which falls in line with Creswell's recommendation.

The dissertation findings should benefit agencies and federal government sponsors to improve the LTC referral processes and coordination among all the key stakeholders.

## Dissertation Limitations

My dissertation has eight limitations, which are primarily due to my methodology:

- 1) My sample consisted of accessible cases instead of purposeful maximal sampling (Creswell, 2016). The PEACOC study implemented the LTC referral network across 15 states. However, I only had direct access to interview in three states. If I had included more states, then I could examine the difference between two HIV program sites coming together to expand the LTC referral network, versus cases where one HIV program site worked alone to expand the LTC referral network (as is the case in 12 other states). According to Palinkas et al. (2016) implementation research to explore barriers and facilitators of evidence based best practices require purposeful sampling to fully capture all of the factors that influence implementation. Future studies like this should use purposeful maximal sampling.
- 2) I did not interview YLWH to understand their perspective on sharing client-level data with multiple members of the LTC network.
- 3) I interviewed staff implementing the study, but could have obtained a richer understanding if I had interviewed prospective community agencies that were asked to join the LTC referral network. It is important to understand prospective agencies' perspectives on joining (or refusing to join) an LTC referral network. Also, interviews with agencies could have provided a deeper understanding of how the CDC/NIH site and RWD site engaged community members to join the LTC referral network.
- 4) I conducted my analysis two years after the projects concluded. Recall bias is strong years after an event, and this also precludes me from re-questioning past interviewees. Faulty memories (on the part of interviewees) may have tainted my portrait of the evolution of the network over time. Follow-up interviews would have allowed me to ask additional questions for clarification and further explore emerging themes.
- 5) I asked structured questions, which made each interview last an average of 93 minutes. To prevent interview fatigue and respect interviewees' generous time, I did not probe the interviewees much, which led to less data obtained on some of the emerging barriers revealed during the interview.
- 6) I collected data at the end of the study only; conducting the study at multiple points in time might have yielded additional insights. HIV LTC referral networks are not static. Data gathered at one point in time (cross-sectional data) represented a snapshot of perspectives at the one-time point. The lack of multiple interviewees overtime

introduces recall bias and limits the inferences that can be made about changes in the partnership over time. In hindsight, ideally, I would have interviewed participants at the beginning of implementation, mid-way into implementation and at the end of the partnership to have a full understanding of the evolution of the partnership.

7) While I aimed to interview all leadership staff at each organization directly involved in the LTC program, I could not interview the Site A CDC/NIH PI due to scheduling conflicts. This interviewee was vital to understanding the leadership decision-making process for level-of-involvement in the CDC/NIH-RWD partnership.

8) I paid a second coder to code a subset of the interview data due to limited funding availability. The second coder analyzed 27% of all key informant interview transcripts, which is aligned with the standard qualitative data analysis standard of 25% of transcripts coded for validity (MacPhail et al., 2016). In the future, if researchers have the funds to hire a second coder to review all the data then I would recommend that they do so in order to ensure reliability of the data analysis. My data analysis was nonetheless reliable; a coding comparison query comparing data from the two coders (myself and one other) resulted in a reliability (ICR) of .53. This is considered satisfactory since an average .4-.6 ICR is considered acceptable (MacPhail et al., 2016). Moreover, an .53 ICR is impressive given there were more than 30 codes used to code the entire text (MacPhail et al., 2016).

Although the limitations mentioned are typical for a real-world study conducted retrospectively (Browne & Braun, 2001) I would make several changes to this study, given the opportunity and resources; these changes include modifying the sampling and returning to the sites to measure the effects of implemented changes. First, I would increase the sample size by purposefully interviewing sites with key differences, and also by interviewing more sites to form a good standard for comparison. Second, I would conduct multiple interviews over time, recommend changes to sites and agencies, and have them implemented in real life. Third, I would revisit these sites at later points in time, and measure how both these, and other changes in the organizations, led to differences in LTC for PLWH. Such a project would dramatically improve the quality of this work, but could take many years and is thus beyond the scope of a doctoral dissertation.

### **Implications for Research, Federal Policy and Practice**

My dissertation has implications for research, federal policy, and practice. HIV LTC referral networks are a necessity for YLWH in need of services that often cannot be met by one agency. Moreover, those involved in the

HIV arena recognize that successful LTC is an ongoing and challenging process. My examination of the aim 1 and aim 2 results allows for implications for researchers, federal agencies attempting to research, fund, promote or create LTC referral networks targeting YLWH, and practitioners.

### **Research Implications**

Based on the dissertation results and current literature, I recommend researchers examine the following research topics: Firstly, the LTC outcomes when clinics have access to HIV surveillance data; secondly, the connection between environment and culture of collaboration; thirdly, researchers should examine the LTC rates based on mode of HIV transmission.

1) The health departments implementation of data-sharing agreements: Many of the Adolescent Medical Trial Unit (AMTU) sites of the Adolescent Medicine Trials Network (ATN) 128 protocol successfully obtained full public health authority from the local health departments to utilize the HIV surveillance data to actively link-to-care YLWH. Therefore, the ATN principal investigators or CDC should conduct a retrospective study to interview health department (HD) staff to capture HD staff reasoning for agreeing to share HIV surveillance data with HIV clinics. Also, the study should collect quantitative data on the number of YLWH linked-to-care before the AMTU-HD partnership and then collect the LTC rates after the AMTU-HD partnership. Also, collect data on the percentage of YLWH that fell out-of-care and relinked-to-care before the AMTU-HD partnership and the relinked-to-care rates after the AMTU-HD partnership.

2) LTC rates based on mode of transmission: Currently researchers do not distinguish LTC rates based on youth's mode of transmission (i.e. perinatally infected, blood transfusion, or sexually). Researchers should consider the correlation between mode of HIV transmission and LTC rates. My dissertation results highlight that youth perinatally infected with HIV can face more complex challenges with LTC, unlike their behaviorally infected counterparts. The literature affirms youth perinatally infected with HIV are often angry they have a communicable disease through no fault of their own and fear that they will never be able to enter into a successful intimate relationship (Le Roux et al., 2017). Although the literature affirms the challenge providers experience when giving care to youth perinatally infected with HIV, I could not find references to system-level interventions tailored for

youth perinatally infected with HIV. Research should also examine all the facilitators to get youth perinatally infected with HIV to get linked-to-care.

3) Culture of collaboration linked to environmental events: Researchers should conduct a deeper examination of a community's culture of collaboration and environmental events. The dissertation results show that agencies are open to interdependence within the community they are serving when there has been a natural disaster, as exhibited by the Site B LTC referral network. Rier & Indyk (2006) opine that forming partnerships to strengthen the LTC referral network will only occur once providers recognize their interdependence with each other to meet the needs of PLWH (Rier & Indyk, 2006). Thus, researchers should examine whether HIV LTC referral networks are more successful in communities that experienced a devastating event that brought agencies temporarily together to address the situation.

### **Federal Agency Policy Implications**

Dissertation results reveal that federal agencies have a lot of influence on the success of LTC referral networks. Federal agencies must identify a new funding mechanism that rallies staff around a new, less competitive, more collaborative way of doing business in the HIV service delivery system, especially for agencies providing services to YLWH. My recommendation for federal agencies is to restructure funding to be less competitive among agencies in the HIV community. Below are my five recommendations to federal agencies to improve funding structure to reduce competition and improve program implementation:

- 1) HRSA, CDC, and health departments collaborate to decide which agencies should receive funding to expand the LTC referral network.
- 2) Federal agencies consider a policy change to adjust the award period from three-to-five years to a five-to-seven-years for agencies implementing system-level interventions. The additional amount of time will allow implementing agencies approximately two years in the pre-implementing phase to build consensus in the community around which agencies to target for inclusion into the LTC referral network. With a more generous schedule, implementing agencies can thoughtfully create LTC referral processes to link-to-care YLWH and collect enough data to examine the LTC referral network's impact on long-term health outcomes (e.g., Viral load).

- 3) All LTC programmatic implementations are administered from the same federal agency to ensure partners have the administrative requirements and programmatic oversight of partnership implementation.
- 4) HSRA leadership considers provisions to obligate grantees additional funding within an award period.
- 5) Federal agencies consider HIV quality improvement indicators (e.g., viral load suppression rates) to measure continued funding and remove the client enrollment quota. Federal agencies should begin a paradigm shift to hold providers accountable for providing quality HIV care, especially to YLWH.

### **Practice Implications**

This dissertation responds to the call for improving LTC rates for YLWH at the system level. By identifying the existing practice gaps and developing recommendations to address those gaps, we can create a robust system that supports and retains YLWH. To this end, I recommend the HIV community ensure YLWH are referred to youth-friendly clinics and HIV surveillance data is shared with community agencies to get YLWH linked-to-care.

In the future, LTC referral networks need to ensure there is a referral process to youth-friendly clinics. Youth-friendly clinics have staff on hand that can set up appointments, recommends where to go for specific services, accompany youth to medical and non-medical care, follow-up with YLWH, such as calling youth to ensure their non-medical care needs are met. Also, youth-friendly clinics are skilled at providing support services, such as housing and transportation, to ensure youth get LTC. Thus, youth-friendly clinics are the ideal clinic to refer YLWH. Although examples of youth-friendly services for YLWH were presented in this dissertation, documentation on how to implement youth-friendly clinics remains poor. Because clinics do not have an ideal model to base their services, the clinics often do not provide youth-friendly services to YLWH. Future researchers should expand documentation on the process for linking a client to a youth-friendly clinic and the youth-friendly clinic coordinating services. The goal is to get a youth-friendly clinic to also coordinate where youth receive care because they will have a deep understanding of respecting youth's requests.

Protective measures through the utilization of HIV surveillance data need to be put in place to ensure continuity of care. Health surveillance systems are currently passive, but there needs to be a change to make them active. Active HIV surveillance data is where health facilities view the data to identify YLWH not LTC and get youth linked-to-care. My dissertation results highlight in the wake of the recent Ebola and Zika crises, health department

leadership could not hold meetings with HIV clinics due to the risk of outbreaks. Without the meetings, the health department deprioritized the HIV issue. It is also likely the health department staff felt overstretched and only performed essential functions, leaving little time to devote towards improving LTC rates.

Clinics access to identifiable client data would help project YLWH, who may be in imminent danger from an outbreak detrimental to vulnerable populations. The risk of co-morbidities increases when novel pandemics threaten already-susceptible populations, such as YLWH. When hospitals redirect staff and resources towards directly combatting the novel pandemic, this leaves HIV client populations increasingly vulnerable. Recently, the New York Times published a World Health Organization article that showed PLWH sent to a hospital for being COVID-19 positive are 30% more at risk to die of COVID than individuals not living with HIV (New York Times, 2021). Moreover, the ineffective adoption of COVID vaccine utilization among the Black and Hispanic population makes the situation even more urgent to share data with clinics to quickly locate youth out-of-care and provide them medical services in their home.

Implementers should take the following steps to establish a partnership between the community agencies and between the health department and community agencies to share client level data. First, the health department staff who want to share client-level data can mitigate risk by implementing data-sharing agreements. The health department staff or legal counsel need to be informed how the partner agency will address the following: client permission and consent, government assistance vs. outreach, privacy and confidentiality, HIV stigma, HIV criminalization, data integrity, and data sharing. The lack of real-time data makes it more difficult for clinics to identify newly-diagnosed youth or when follow-up medical care is overdue. Implementers can use my dissertation findings to make the case to their health departments that in the face of insufficient human resources and the rise in frequency of different outbreaks, the health departments should be open to data visibility with community agencies providing services to at-risk and youth living with HIV. Data-sharing will enable community agencies to accelerate youth's access to HIV test results, locate YLWH, quickly get them into medical care, connect them with support services, and improve the quality of care by linking them to youth-friendly sites.



## **CHAPTER 9: PLAN FOR CHANGE**

### **My Dissertation's Potential for Effecting Change**

Although I can no longer apply my plan for change to YLWH focused interventions in the United States, I can utilize the plan for change chapter to influence linkage-to-care efforts in an African setting. Non-profit organizations and federal agencies can build on my dissertation findings in the following ways: first, by developing stronger connections between HIV health centers and the criminal justice system; secondly by getting federal agencies to improve collaboration around how funding is awarded and which agencies are funded. To this end, I had the opportunity to use the dissertation findings towards a CDC funded project in Uganda.

### **HIV LTC Landscape in Africa**

Ensuring prompt linkage-to-care for all people diagnosed with HIV is a key component in the effort to meet the UNAIDS targets to have 95% of people with HIV diagnosed, 95% on ART and 95% virally suppressed to end the AIDS epidemic by 2030 (Abuelelam et al., 2019). ART initiation and linkage-to-care is a challenge in South Africa. A recent modelling study, in South Africa, demonstrated that it takes on average 4.9 years for 50% of HIV seroconverters to get LTC (95% CI 4.2–5.7) (Maheu-Giroux et al., 2017). Furthermore, they identified that men and participants aged less than 30 years were found to have the lowest rates of linkage-to-care (Maheu-Giroux et al., 2017). Similarly, my literature review in the U.S. setting identified that young Black male clients were independently at higher risk of not being on ARTs and not being virally suppressed (Zanoni et al., 2014). A potential solution to this, within a healthcare context, is to strengthen LTC networks in Africa.

### **LTC Referral Pathway with the Criminal Justice System**

Until recently, the criminal justice system is often missed during implementation of WHO test and treat policies in Africa. One study in South Africa showed a high percentage of undiagnosed PLWH in the prison system and those that are identified and put on ART medication stay on their regimen consistently (Herce et al., 2020). For this reason, the criminal justice system is a prime location to identify undiagnosed PLWH and out-of-care PLWH

to reach UNAIDS 95-95-95 targets. The criminal justice system provides a clinical venue where vulnerable populations, who would otherwise be missed, can be engaged for counselling, testing, ART medication and linkage to medical care.

Recently, there are a few published articles on HIV care and treatment programs in the African criminal justice system. For instance, in South Africa in 2020, Mabuto et al. (2020) conducted an observational study of continuity of HIV care following release from correctional facilities in South Africa. This article is groundbreaking as it is the first description of LTC efforts following release from the criminal justice system in South Africa. The article calls for innovative approaches to improve system-level communication between correctional health services and community clinics. Herce et al. (2020) conducted a feasibility study to distribute ART medication to inmates in prison. Results revealed 95% of inmates living with HIV remained in care in the correctional facilities. Herce et al. (2020) call on further research to develop, deliver, and evaluate new strategies to promote linkage-to-care interventions for PLWH released from South Africa's criminal justice system. Although the articles focus on South Africa correctional settings, there is currently a lack of HIV care and treatment services in correctional settings across the African continent. Delivery of HIV care and treatment programs in Africa's criminal justice system is very minimal, which raises the need to provide HIV services to this vulnerable population and ensure there is smooth linkage-to-care once released from the criminal justice system.

Africa is similar to the United States when it comes to the lack of HIV services available to inmates in the criminal justice system. Dissertation results revealed how complicated it is for the community agencies to forge a collaboration with the criminal justice system. Thus, there needs to be more advocacy work to integrate the criminal justice system with the HIV service delivery system. Currently, many YLWH goes through the criminal justice system, yet criminal justice system settings rarely address youth's linkage-to-care upon release from the system. Most youth released from the criminal justice system have no medical insurance, extreme economic insecurity, and unstable housing (Bailey et al., 2019). Thus, implementers should bring HIV care to the forefront of criminal justice staff consciousness upon youth's release from the criminal justice system.

Implementers can advocate change by implementing the following steps: educating the criminal justice staff on the importance of their organization's role in combating the epidemic; share data on the number of YLWH released from the criminal justice system, and rates of youth not LTC due to lack of LTC referral process in place;

and organize a clinic tour for the criminal justice staff to view services at the referral site. The criminal justice staff visual of the site is critical to get their buy-in on referring youth to the site. Taken together, these steps will ideally build a relationship between the criminal justice system and the HIV service delivery system.

### **Federal Funding Influencing Implementation**

Many of the barriers to collaboration in the United States and Africa are influenced by decreased amount of federal funding available to agencies. Loss of federal funding coupled with multiple agencies implementing similar projects led to competition between the agencies to get awarded the federal funds. For instance, dissertation findings show in Site B and Site C that integration of HIV testing and HIV care services, also known as the co-location of services, made several agencies unwilling to collaborate to expand the HIV service delivery system. In the United States, the “one stop shop” approach is a barrier since agencies that provide the “one stop shop” approach are in close proximity to one another and compete for the same clients. However, at the moment, a “one stop shop” approach to support LTC is beneficial in Africa due to the shortage of HIV care sites. Nonetheless, United States federal agencies must be aware that problems associated with competition could occur in Africa, if there is an oversaturation of HIV clinics that implement LTC services in close proximity.

This historical context for competition in the USA is similar to the President’s Emergency Plan for AIDS Relief (PEPFAR). Overtime, Congress has decreased PEPFAR funding, which has increased unspoken competition between international non-profit organizations. Moreover, prior to PEPFAR funding, the United States Agency for International Development (USAID) was the only federal agency implementing HIV prevention, care and treatment programs in Africa. However, with the PEPFAR initiative the Centers of Disease Control and Prevention (CDC) came in to expand HIV prevention, care and treatment programs. Unfortunately, the in-country relationship between USAID and CDC representatives is strained, which has led to weak collaboration and duplicative efforts in some countries. This dissertation suggests that better collaboration between USAID and CDC would improve the lack of collaboration between implementing partners in Africa. Thus, the CDC and the USAID leadership staff must seek to address conflicts as soon as possible, respect one another, and maintain open dialogue about what must be done next, in order to collaborate successfully.

### **Recent Utilization of Dissertation Findings to Create Change**

In my current position with the Catholic Relief Services (CRS), I manage a CDC funded program to improve HIV care and treatment services for children living with HIV in South Africa, Uganda, Tanzania, Nigeria, Zambia and Zimbabwe. In November 2020, I provided a technical review of Uganda's Ministry of Health tool kit to strengthen community-to-facility referrals, linkages, and coordination for HIV and TB care. I offered the following recommendations based on my dissertation findings: health workers should have a youth-centric perspective when working with youth; inclusion of youth-friendly clinics as a referral to care site; provided characteristics of what makes a clinic youth-friendly; provided differentiated service delivery models based on the mode of transmission; and inclusion of agencies that provide psychological support to youth perinatally infected with HIV.

As for next steps, I will reach out to the Office of Global AIDS Coordinator to share my findings and discuss whether there would be an opportunity to allocate funds towards strengthening the LTC referral pathway between the criminal justice system and the health care system. I am hopeful that OGAC will utilize my findings to provide federal funding towards linking-to-care youth released from the criminal justice system.

## **APPENDIX A: INTERVIEW GUIDE**

### **Section I. General Introduction:**

In this interview, I would like to learn about your experiences and involvement with ATN 128/PEACOC. Specifically, I'd like to better understand the process of partnering with your site in terms of improving linkage-to-care, engagement-in-care and retention-in-care for youth with HIV infection. This will include your impressions about the process of HIV care at your site, your thoughts about how things have changed for the better or for the worse, and your ideas about how the process could be strengthened.

Your responses are confidential, and you will not be individually identified in any reports or publications associated with this project. In addition, sites themselves will not be individually identified, and we will remove/de-identify information that would identify specific sites and thus potentially link information to you. Information from this interview will help us to understand the experience of an intervention requiring partnering of two different HIV youth-serving organizations working in the same city or region.

### **Section II. Specifics & Permission:**

I will not be asking you any personal information other than your own insights and experiences. In sharing your perspectives, you'll be reflecting on what is going on in your site. It is important that you remember during this interview not to share any personal identifiers for yourself or any of the patients in whose care you have been involved. This interview may take up to 120 minutes.

Everything you say will be completely confidential. I'll make some notes as we talk and digitally record the interview, but I will not ask for your name or any other personal identifiers on the digital recording. After the interviews are transcribed within the next 90 days, the digital recordings will be destroyed. In addition, any information in the transcripts that could reveal your personal identity will be completely removed and each interview will be assigned a code number. Furthermore, when reporting information from the interview, no identifying information will be included.

As I've stated some of the questions will ask about your personal perceptions of the linkage-to-care process at your site, thus you may feel uncomfortable giving your real opinions. You may choose not to answer any questions you wish, or you may decide to terminate the interview at any time without any negative consequences. Remember, participating in this interview is entirely up to you, and no one will be upset if you do not want to

participate. Although there are no direct benefits associated with your participation in this interview, we hope that the information we obtain will assist us in improving the HIV care process for all youth.

Do you have any questions about what I've just told you? If at any time during this interview you have any questions or if something, I say is not clear, please let me know, and I will clarify. Remember that you are free to refuse to answer any questions or to end the interview at any time. Also remember that after the digital recording has been transcribed, it will be destroyed.

Do I have your permission to conduct the interview with you?

Do I have your permission to digitally record this interview?

Interviewer's Signature: \_\_\_\_\_ Date: \_\_\_\_\_

*Note: Probes are intended as flexible guides to interviews in obtaining additional information or elaborations of responses to initial questions. They are not scripts and should not be viewed as rigid components of each question.*

### **Section III. Interview Questions**

#### **BACKGROUND:**

How long have you been with your organization?

What is your current position in your organization?

How long have you been in your current position?

Please provide former positions/roles within your organization \_\_\_\_\_

In what capacity (e.g., LTC Coordinator, LTC Supervisor, Principal Investigator) do/did you serve on the PEACOC Project?

Prior to PEACOC, how long have you implemented or overseen HIV related projects? Would you consider a range (e.g., <6 months, 6-12 months, 1-3 years, 3-5 years, 5-10 years, 10 plus years).

Prior to PEACOC, how long have you implemented or overseen HIV youth focused related projects? Would you consider a range (e.g., <6 months, 6-12 months, 1-3 years, 3-5 years, 5-10 years, 10 plus years).

Prior to PEACOC, how long have you implemented research projects? Would you consider a range (e.g., <6 months, 6-12 months, 1-3 years, 3-5 years, 5-10 years, 10 plus years).

Has your organization been involved in other collaborative projects with your PARTNER organization prior to the PEACOC Initiative?

[Follow up]

- If yes, please describe in what capacity.
- Was the past experience a positive or negative experience with your PARTNER organization?

### **Interviewees General Thoughts about Partnerships**

In your opinion, what are the top three most essential elements of a successful partnership intended to strengthen linkage-to-care processes in the community?

[Follow up]

- Do you think these are unique to your community? If so, why? If not, why?

In general, what are three potential barriers to establishing and maintaining a partnership with another HIV focused health service organization to improve linkage-to-care in the community?

[Follow up]

- Do you think these are unique to your community?
- Do you think these barriers can be addressed? If so, how? If not, why?

What advice would you give an organization that is planning to establish a partnership like the SMILE/PEACOC within their community?

### **Planning**

I'd like for you to think back to the time when people first began thinking and talking about applying to implement the PEACOC project.

What prompted your organization to apply for continued funding for the SMILE program?

[Follow up]

- Who participated in the decision at your organization? How much agreement was there?
- Thinking about your PARTNER organization, who approached whom about the partnership requirement?
- How did your organization feel about the requirement to establish a partnership with your PARTNER organization to transfer best practices?

- What issues did your organization consider in deciding to collaborate with your PARTNER organization?  
What were the “pros” and “cons” so to speak?
- During the formation phase of the partnership how confident was your organization that the partnership activities would meet the needs of HIV infected youth in your community? What gave them that level of confidence or lack of confidence?
- What were the key factors in your decision to move forward in a partnership?

**Formation stage: I’d like for you to think back to the time when you received the PEACOC protocol.**

- Please describe your organization’s understanding of the goal for the PEACOC partnership for the ATN128/PEACOC Project.
- How did you go about gaining a clear understanding of the goal of the partnership?
- Was the partnership plan overly complex? Understandable? Realistic and feasible?
- To what extent were the needs and preferences of HIV infected youth in your community considered when deciding to implement the partnership? Can you describe specific examples of how this was done?
- Were there revisions or refinements to the partnership plan?
- Who was involved in the planning process? What are their roles?
- In your opinion were the appropriate people involved in the planning process? How engaged were they?
- Did you discuss a plan to track the progress of the partnership based on your plan? If yes, what did the plan look like?

Can you briefly describe the plan for implementing the partnership, Specifically:

**Community Engagement**

How would you describe your partnership’s approach for community engagement (i.e., engaging new or existing partners about the PEACOC Project)?

[Probes: Was it a Divide and Conquer approach or a United Front approach]

[Follow-up]



- What were the key factors that influenced your decision toward this approach? In your opinion was this the best approach? If yes/no, please explain.

- Did your original approach change during the course of implementation? If yes, what factors influenced the change?

Before starting the ATN 128/PEACOC project, how involved were personnel from your organization in interactions with other youth-serving agencies in your community?

[Probes]

- Were these mostly HIV-related agencies?
- Were any of these youth-serving agencies?

### **Referrals for Linkage-to-Care**

How did your partnership decide to handle new referrals of youth with HIV diagnosis in your community?

[Probes]

- How did you handle overlap in your geographic catchment area?
- How did you handle referrals from:
  - 1.New agencies shared between partners?
  - 2.Existing relationship would be maintained with respective partner?
  - 3.Overlapping partners would be shared?

Please describe your institution's local youth linkage-to-care process before the Partnership with your PARTNER organization

[Follow-up]

- In your opinion, what aspects of your institution's local youth linkage-to-care process seemed to work best before the partnership?
- In your opinion, what aspects of your local youth linkage-to-care process seemed to work less effectively before the partnership?

- What if any lessons have you learned from your PEACOC partner to improve linkage-to-care process at your institution? How about lessons learned to improved LTC process in your community?
- Has your partnership with your PEACOC partner impacted your institution's youth linkage-to-care process? If yes, how so?
- Has your partnership impacted youth linkage-to-care in your community? If yes, how?

Overall has your partnerships LTC referral process worked well?

[Follow-up]

- If yes, without using any identifiers, can you describe a recent case that reflects successful LTC with your partnership? What aspects of this particular instance made it successful?
- If no, without using any identifiers can you describe a recent case that reflect an unsuccessful LTC encounter due to unsolved problems with your PARTNER organization? What about this particular instance was it that made it unsuccessful?

### **Structural Change Objectives**

How did you discuss the joint development and implementation of SCOs in the community?

Can you please give me an example of a joint Structural Change Objective that you agreed seemed necessary to support youth linkage-to-care referral process?

[Follow-up]

- Which sector did the partnership decide to focus on?
- Why did the partnership decide to focus on this sector?
- What led to the partnerships decision to focus on this sector jointly?
- What have been the pros and cons of the partnership's decision to target this sector jointly?
- How satisfied are you with type of SCOS developed through this partnership?
- Was the SCO completed? If so, what key factors allowed it to be completed? If not, where there external factors that caused the SCO to be incomplete?

### **Local Health Department**

Before starting the ATN 128/PEACOC project, how involved were personnel from your organization in interactions with the local health department? Did your site have formal interaction with your local health department to discuss specifically youth's linkage-to-care process?

How did you and your PARTNER organization agree to work with your local health department for Public Health Authority/data sharing plan

### **Geographic Catchment Area**

What issues did you all consider in deciding how you wanted to partner in your geographic area?

What were the "pros" and "cons" so to speak?

Outside of your LTC staff who else knew about the partnership plan? Can you briefly describe their reaction to the partnership plan?

### **Formation Process**

In your opinion did any of the partnership process NOT work well?

[Follow-up]

- If NO, without using any identifiers, can you describe a successful LTC with your partnership?
- If YES, without using any identifiers can you describe an unsuccessful LTC encounter?

Were there any unintended consequences of the partnership that impacted your institution's implementation of the youth linkage-to-care referral process in your community?

[Probes: regulations, policies, staff turnover]

### **Barriers/Facilitators Towards Implementation of the PEACOC Project**

What were the facilitators to project implementation of the multi-component HIV service delivery intervention at your organization? Did that impact the partnership in anyway? If yes, provide an example of how.

What were barriers to project implementation of the multi-component HIV service delivery intervention at your organization? Did that impact the partnership in anyway? If yes, provide an example of how.

**Roles and Responsibilities**

Once the partnership plan was complete, in your opinion, did all PEACOC Team members at your organization have a clear understanding of their roles/responsibilities in relation to the partnership?

If not, why do you think this is the case?

**Trust**

During the formation stage of the partnership did your organization feel comfortable contacting your PARTNER organization with questions or concerns about the initiative? If no, why?

Did the trust level change at any time during implementation? If yes, why? Please provide an example of how you had done so in the past.

**Communication**

What was your communication strategy for getting the word out about the partnership?

[Follow up]

- How did the community react to this partnership?

What is the process for addressing areas for improvement in the partnership?

Can you please describe the method (email, phone, in-person) and frequency (weekly, biweekly, monthly) of communication between you and your PEACOC partner?

[Follow-up]

- What factors played into your method and frequency of communication?
- Do you feel that the frequency and method of communication was regular enough for this type of partnership? If not, why?
- How helpful were these meetings?

**GENERAL ORGANIZATIONAL CAPACITY**

Now, I'd like for you to move forward in time to when you received notice that your PARTNER organization received Westat and IRB approval to begin implementation of the study. Think back to that time...right when you are ready to begin to enroll clients into the project.

**Staff Capacity**

At that time what were the HIV/AIDs knowledge, skills and abilities that your organization brought to the community?

What were the organizational gaps in HIV knowledge, skills and abilities for HIV infected population in your community?

**Climate**

How satisfied are LTC staff at your organization with the partnership-working environment?

**Culture**

How would you describe the culture of your LTC team at your organization? (e.g., general beliefs, values, assumptions that people embrace. PROBES: does your culture embrace open-source sharing? Is there a culture to partner with organizations with similar or same services to improve the linkage and retention of clients into medical care?

Do you feel like the culture of your own LTC team is different from your overall organization? In what ways?

How do you think your organization's culture (general beliefs, values, assumptions that people embrace) affected the implementation of the partnership? Can you describe an example that highlights this?

To what extent are new ideas embraced and used to improve patient care in your LTC team at your organization?

**Leadership**

During the pre-implementation phase who were the key influential people at your organization to get on board with this partnership? What were the influential individuals saying about the intervention? During the implementation phase did their view change? If so, how? To what extent do you think they influenced the formation of the partnership activities?

During the pre-implementation phase are there leaders in your LTC team or any organizational leaders who seemed unsure or perhaps reluctant of the partnership activities? If yes, why?

In your opinion, how would you describe leadership across the partnered sites to implement partnership activities? (probes: was leadership equally distributed i.e., scheduling meetings, strategizing around linkage-to-care issues and barriers in the community)?

How would you describe the effectiveness of leadership across the partner organizations?

**Structure**

In your opinion, at the formation stage was there any resources that your organization lacked to implement the partnership with PARTNER organization?

[Probes]

- Skilled personnel and expertise working with youth?
- Connection to people, organizations and groups to conduct community outreach?
- Sufficient budget to partake in all the objectives
- Space, equipment, goods
- Technology

During the implementation phase what were some changes that needed to occur at your organization to ensure that the partnership was successful?

[Probes]

- Were there Staff time/schedule changes?
- Did you utilize technology to communicate with PARTNER organization?

**Resource Utilization**

Did you use any discretionary and uncommitted resources towards implementing the project? If yes, in what way?

**INNOVATIVE SPECIFIC CAPACITY**

Partnership AMTU and RWD sites: Now I would like to ask you more specific questions about efforts that you and your PEACOC partner site are involved in jointly, specifically to improve linkage-to-care services to HIV-positive you in your community.

**Inter-organizational Relationships**

Can you provide an example of how you reached out to your PARTNER organization as resource for the Initiative?

Since starting the ATN 128/PEACOC project, how has your organization's involvement with other youth-serving agencies changed?

[Probes]

- Were these changes positive, negative, or both positive and negative?

- Could you give a specific example of how interactions with other agencies have changed?

How has your PEACOC partnership facilitated or enhanced:

- your network of partner agencies in the community?
- Your network of HIV-related agencies?
- Your network of youth-serving agencies?
- Expanded interactions/facilitated relationships with diverse systems/sectors?
- A relationship with the health department?
- How significant were these relationships for providing optimal care for clients?
- In your opinion what factors are needed for these positive effects to be duplicated in another partnership?

The ATN128/PEACOC Project required partners to work collaboratively to obtain referrals to eliminate competition among partners. How confident was your organization that it would not experience competition with your PARTNER's organization to implement this initiative? What gave them that level of confidence or lack of confidence?

[Follow-up]

- How significant were these effects for providing optimal care for clients?
- Has your PEACOC partnership negatively impacted your relationship with other agencies?
- What if anything was done to prevent competition or address competition?
- In your opinion What advice would you give for reducing the impact on client care or expansion of your network?

### **Innovation-Specific Knowledge, Skills and Abilities**

To what extent is Leadership and staff at your organization aware of the needs and preferences of HIV infected youth in your community? How have they shown this to you?

These are individual level questions, but responses should be aggregated to characterize more generally the extent to which the organization encourages individuals to take the initiative to bring ideas in from outside.

- To what extent do you network with colleagues or people in similar professions/positions outside your setting? What are the venues?
- What kind of information exchange do you have with others outside your setting about HIV infected youth interventions?
- What professional networking do you engage in? Listservs? Local or national conferences? Trainings?
- To what extent does your organization encourage you to network with colleagues outside your own setting to strengthen your skillset in working with HIV infected youth?
- Are you able to attend local/national conferences? Other venues?

### **Program Champion**

Are there particular individuals within your organization who really stood out as a champion of the partnership? By champion, I mean someone who went above and beyond the call of duty, someone who is personally invested in making the partnership succeed. If yes, can you please describe how that individual demonstrated their support the partnership within your organization and in the community?

### **Support Staff for Maintaining Partnership During Implementation**

What steps have been taken to encourage staff at your organization to commit to the partnership and partnership's planned interventions?

[Follow-up]

- How efficient does the PEACOC partnership activities and documentation seem to staff?
- What organizational processes or systems are currently in place that support partnership activities?
- What can make PEACOC partnership more manageable?
- What could make PEACOC partnership more efficient?
- How has the PEACOC partnership been integrated into daily operations?
- How were LTC staff held accountable for implementing PEACOC partnership activities?



## **MOTIVATION**

### **Compatibility**

Was your PARTNER organization approach to community engagement and client recruitment efforts compatible with your organization's approach to work in the community?

How do partnership activities fit with other policies and practices used within the organization?

Which partnership activities do staff seem to understand the most? The least?

Was the PEACOC Project discussed with other staff (outside of the PEACOC team) at your organization? If yes,

[Follow-up]

- To whom was it presented/discussed?
- How did they perceive the partnership?

### **Priority**

To what extent was the partnership initiative seen as equally or more important than other linkage-to-care initiatives implemented within your organization?

What are the competing priorities i.e., ways of planning, implementing and evaluating) that have a higher priority than the partnership activities?

How have competing priorities been addressed?

### **Observability**

What were the outcomes achieved by this partnership?

Have partnership outcomes been communicated to staff, leadership, and other key stakeholders? What was their perception for maintaining the partnership?

### **Relative Advantage**

To what extent did your organization view partnership with your PARTNER organization to improve the linkage-to-care process in your community as better than working independently to implement the program?

In your opinion did your team members receive a return on investment of time by collaborating on the partnership activities? If yes, briefly describe how. If not, briefly describe why.

Has your organization benefited from participating in a partnership with your PARTNER organization?

[Wait for response to first question; then ask all the following questions]

How has your partnership had an impact on:

[Follow-up]

- Patient care?
- Patient recruitment efforts? Before you were paired with your PARTNER organization, how confident were you that your site could meet the PEACOC goal referral number of 4 clients per month? What prompted you to feel this confident? Who shared your level of confidence in your organization? Who did not? After you partnered with PEACOC partner site did you feel confident that you would meet your referral goal number?
- Patient retention efforts?
- Community outreach efforts? Before you were paired with your PEACOC partner site, how confident were you that your site could meet the PEACOC goal of expanding partnerships with youth serving agencies? What prompted you to feel this confident? Who shared your level of confidence in your organization? Who did not? After you partnered with PEACOC partner site did you feel confident that you would continue to expand your partnerships?
- Structural Change Objectives?
- Intra-organizational changes?
- Organization's public image?

To what extent did implementing the partnership provide an advantage for your organization compared to other organizations in your area? Is there a competitive advantage?

Is there something about the partnership that would bring more HIV infected youth into your organization, instead of another one in your area? How about initiate or strengthen more partnerships with your organization due to the partnership?

### **Complexity**

How complicated was it to transfer best practices working to improve HIV infected youth's linkage and retention in medical care your PARTNER organization?

During the implementation phase was the partnership activities perceived as relatively difficult to implement by your team members?

[Follow up]

- If yes, please explain why.
- If no, please explain why.

**Community Context & Incentives** (incentives may include clinical performance measures and pay for performance)

What kind of local, state, or national performance measures, policies, regulations, or guidelines influenced the decision on how you would partner with your PEACOC Partner to implement PEACOC activities?

What community contextual factors have inhibited the implementation of this partnership? (community trust, LTC saturation, transportation).

[Follow-up]

- How have you overcome those challenges?

### **Evaluation, Future plans and Ongoing Support**

How can leaders better communicate expectations and/or support for the PEACOC partnership?

Have you met with your PARTNER organization to assess the progress made towards the PEACOC intervention goals based on partnership?

[Probes]

- In what ways did the partnership meet the needs of HIV infected youth in your community (e.g., improved access to services? Reduced wait times)? Can you please provide an example?
- How well do you think the partnership met the needs of HIV infected youth in your community?

How will outcomes attributed to the partnership be distributed to stakeholders?

Have you elicited information from joint partners regarding their experiences with the partnership and/or partnership SCOs? If yes, what are their experiences?

Regarding the implementation of the PEACOC partnership within your community, over all what do you feel is most essential partnership activity to support HIV+ youth linkage and retention in care?

[Probes]

- (area of discussion may include Community Partner identification and engagement, youth recruitment and venues, accessibility to testing /prevention services).

What elements of the PEACOC partnership would you personally like to see sustained after funding for the project ends?

Who else in the community shares your desire to keep the partnership and partnership activities going?

What steps are being integrated into daily tasks and operations to ensure that partnership activities are institutionalized after the project funding ends?

Do you foresee partnership continuing at the organizational level after funding for the project ends?

[Follow up]

- If not, why?
- If so, what partnership activities would you like to see continue/sustained in your community
- What steps will your partnership need for this to happen? What resources are needed to make that a reality?

What are the general attitudes and expectations in your organization toward maintaining SCOs or system changes implemented through the project?

What are the leadership's expectations for sustaining the Partnership and partnership activities post-ATN funding?

•Was there anyone who should have been included in planning for partnership sustainability that was left out? Do you know why they were left out of the discussion?

What type of support (TA, trainings) does your organization need to continue the partnership activities and the partnership?

•For partnerships that will no longer continue post-ATN funding, how will staff be trained on how to work with the same target population to implement the intervention without a duplication of services?

**Wrap-up**

Do you have any general thoughts about your PEACOC partnership that we have not covered or might help me understand the partnership better? This can include suggestions, frustrations or interesting experiences.

May I contact you again with follow up questions or for clarification?

## APPENDIX B: FINAL CODEBOOK

Code Name	A priori Themes	Parent node (P)/Child node (C)	Definition	Example Quote
Availability of resources	X	P	A lack of resources (e.g., human, financial, physical space, time) has hindered several LTC partnership attempts. The level of resources dedicated for implementation and ongoing operations, including, human, money, physical space, and time.	We also lacked the time. [RWD LTC Coordinator] and I had no time for one another.
Bureaucracy		P	Time consuming process to get approvals for key stakeholders to implement project.	They now know what they need to do, but they are also trying to figure out how to operate within their limitations, which is hard.
Delegation of authority		C	Division of authority and powers downwards to the subordinate.	As a Supervisor I feel like I had authority over the Coordinator in terms of things like their time and things like that, but I didn't have decision-making authority necessarily about things like committing to specific events or other kinds of activities, whereas [RWD PI], she was the decision maker.
Lack of a signed MOU		C	Memorandum of Understanding (MOU), a document formally establishing a partnership with another agency and defining how the partnership will carry out activities. Without the MOU partnership is not able to formed or maintained.	I think by not having things like MOUs (memorandum of understandings) and agreements its kinds of impairs or doesn't make clear the responsibilities of the partnership.
Misunderstanding of external policies	X	C	The misunderstanding in how to properly share personal health information or protected health information (PHI) with other health care	I do think that our county's understanding of HIPAA regulations impacted the number of referrals we saw per month.

			agencies to facilitate better linkage-to-care.	
PEACOC Protocol requirements		C	Project demands are overwhelming to implement.	The demand of the project for each organization is one barrier. And it is not only the demands of the project itself, it is also looking at the demands that they have for other projects that they are also required to invest a lot of time in.
Type of health care setting		C	The type of organization impacts how organizations can interact with HIV positive youth to link them to medical care.	I mean I think we were really at the mercy of some of these like larger organizations that have very slow-moving processes for changing policies and protocols.
Community Reputation		P	Partners perceive the group as having/ will have a negative impact on the community's perception of their organization for collaborating with the other agency.	How are we going to start getting people to refer their youth to this clinic when they are not known for this in the community.
Competing Priorities		P	Factor that hindered staff's decision to participate in the LTC referral network is the priority of that partnership among responsibilities that already exist.	My PI is invested in youth services, and I think that because he is so invested in it, that he can't invest the amount of time needed in one particular project because he is invested in so many projects.
Competition	X	P	Contesting for revenue or other resources. Also, competition for patients and, thus, an unwillingness to share patient information or refer patients to other agencies for care.	Historically there has been a sense of competition between the two organizations, and so people right away went into competition mode.
Territorial		C	Relating to the ownership of an area or patients.	Everyone is territorial over their clients, it now seems to be a money maker. You know the more clients that come to you, the more money you can make.

Differing Expectations		P	Partners have different agendas/vision for the partnership. Struggles emerge because not all members expect the same structure, procedures, and/or outcomes.	I think everybody had different ideas of what we both should do.
Distrust		P	Mistrust in the environment can create a culture of mistrust that impacts establishing trust in the partnership.	Our local health department here doesn't trust anybody.
Federal agency involvement		P	Federal agency involvement or lack of federal agency involvement leads to partnership not being able to adhere to project's expected outcomes	You can't demand or make someone do something, you need to respect the agency, and whatever they tell you. You don't go above their head and say well CDC said we should have public health authority.
Government Mandate for Partnership		P	Federal agency requiring organizations partner with one another to implement the project.	It was like they were forced to do something. I think it's awesome that they were just called up and said you don't need to do anything just apply and you are guaranteed to get the money.
Implementation Climate	X	P	Implementation climate is a stakeholder's capacity for change, shared receptivity of involved individuals to participate in the intervention, and the extent to which the use of that intervention will be expected, supported, and rewarded within the stakeholder's organization.	When I would bring it up and it was always met with, I understand, I get it, I just don't do that or like I don't have time to do that or like that is not the way our program is structured.
Interpersonal tension		P	Conflicts are not discussed and resolved openly by partners. The partnership dissolves as it deals with problems and frustrations.	I think if we had a stronger partnership, we could have implemented these SCOs and what lacked the strength was some petty interpersonal relationship issues that we had.
Key Personnel		P	Staff can hinder formation or	None



			maintenance of partnership.	
Apathy		C	Lack of enthusiasm, interest or concern or staff burnout	She just didn't want to, or she was too busy.
Bad selection of personnel		C	The “wrong” people are selected to be a part of the partnership.	I think that it takes a lot of equanimity, maturity, investment and commitment to work with a partner collaboratively, I think we could have used a little bit more of that from [RWD LTC Coordinator].
Intra-organizational staff overlap		C	Duplication of responsibility between PEACOC program’s delineation of roles and organization’s structure of personnel roles.	I feel like my job overlaps with other people’s jobs here, particularly social workers here.
Non-youth friendly personnel		C	Personnel disconnected from understanding HIV needs in the community. The extent to which patient needs, as well as barriers and facilitators to meet those needs, are accurately known and prioritized by the organization.	If a client lived in [neighborhood A] why would they go all the way up to [neighborhood B] for services, it doesn’t make sense. The reason clients would be referred to us is because we specialize in adolescents and the client lives closer to our location.
Staff turnover		C	Staff turnover can lead to additional time to redevelop relationship with agencies to continue partnership.	. So, you could make a really good relationship with one person, like I had a really good relationship with the Medical Director of Juvenile Hall, he was very like- minded and we shared similar goals in terms how to provide services to youth, but then he left the position.
Lack of awareness of partner's LTC referral process or services		P	Not knowing agencies services can lead to agencies not cross sharing best practices to work with clients and not referring clients to agencies.	Being completely out of the loop of what the organization is doing is a barrier to nobody knowing what anybody is doing, so this can lead to a duplication of services.
Lack of Transparency		P	Lack of transparency between organizations and lack of transparency around funding.	I don't know anything about my partner's budget so I don't know how it was compared to ours, but it seemed like they were given a lot less than our clinic was given.

Lack of Youth-Friendly Clinic		P	Clinic does not cater to youth's needs which can be shown in the clinic space design, clinic hours, staff hired to work with youth and targeted services provided to youth.	I think our PI was somebody who from day one of her work has always been like within 48 hours, she has always been like as soon as possible and the clinic team who was there when I left had an issue with that directive. And so that, of course, impacted LTC but also generally speaking all of the workflow as it relates to the clinic.
Linkage-to-Care Program Saturation		P	Too many clinics that are attempting to strengthen linkage-to-care systems can lead to competition.	Maybe a little bit of oversaturation of similar efforts in the community, so living in this urban area there are many agencies, maybe some overlap so maybe a little bit of confusion on the part of outside organizations to try to figure out where is the best place to send people and who are the true experts in managing youth with this disease.
Organizational Leadership	X	P	An agency's leadership has a lot of influence on how staff view the priority of the initiative compared to their other responsibilities. Lack of leadership support for a LTC referral network can effectively prevent its formation and maintenance.	So I would say it is sort of buy-in and engagement of leadership from the beginning because I think that sometimes the barriers at least what we faced and I can imagine other sites faced it, there were different layers of people that were involved in sort of the different layers involved meaning different level of authority were involved in sort of the day-to-day of the project and that could be a little bit confusing at times because decisions had to be made, but then you were sort of waiting on leadership to kind of make decisions.
Organization's Culture	X	P	In order to form a strong referral network, all agencies involved in a LTC partnership must be willing to form interagency partnerships.	Because she is somebody who has worked independently and her program has been fairly insulated in a lot of ways, I don't know if she feels like oh this is absolutely a thing we need to keep doing. I think if it happens naturally then maybe, but my sense is that she won't push for it.
Poor Communication		P	Partnership has limited or unclear methods of communication.	Not communicating can be a barrier, cause like I said you could have the same agenda and just not even know because you didn't communicate.

Project Timeline		P	The length of project funding is not enough to accomplish a strengthened linkage-to-care network.	The idea is realistic but the timeline they gave us to do it was not feasible.
Siloed Funding Streams		P	Separate financing and administrative silos made efforts to coordinate and expand HIV testing and linkage services challenging.	I will say I was a little unhappy when my partner site got money to have Quality Assurance personnel when our money was taken away to do the same thing, but we still did the job.

## APPENDIX C: KEY TERMS

**HIV Continuum of Care:** The HIV care continuum is a public health model that outlines the steps or stages that people living with HIV go through from diagnosis to achieving and maintaining viral suppression. The steps are diagnosis of HIV infection, linkage-to-care, receipt of medical care, retention in medical care, achievement and maintenance of viral suppression.

**HIV Community:** A group of organizations working in the same geographical area striving to end the HIV epidemic in their community.

**Linkage-to-Care:** Connecting two or more services in addressing the needs of youth living with HIV.

**PEACOC Linkage-to-Care:** Linked to Care is defined as having attended a 1st medical appointment within 42 days after referral.

**Linkage-to-Care Referral Network:** A group of organizations in a geographic area that collaborate to refer youth to agencies to address their medical and non-medical needs.

**Referral:** Directing youth to another person or place for help, information or services.

**Viral Suppression:** A very low or undetectable amount of HIV in the body. Clinically defined as having less than 200 copies of HIV per milliliter of blood.

**Youth-Friendly Clinic:** How and where a clinic provides nonrestrictive services based on age (and potentially gender, disability, religion), access to care, providers and support staff oriented to youth-centric approach, appealing facilities with convenient hours, youth involvement, and comprehensive services.

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