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#### LOYOLA UNIVERSITY CHICAGO

## "POSITIVE PEERS": EXPLORING HOW AND WHY TO INCORPORATE PEERS INTO HIV PREVENTION SERVICES

# A DISSERTATION SUBMITTED TO THE FACULTY OF THE GRADUATE SCHOOL IN CANDIDACY FOR THE DEGREE OF DOCTOR OF PHILOSOPHY

PROGRAM IN SOCIAL WORK

BY

**ALLISON TAN** 

CHICAGO, IL

DECEMBER 2011

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#### **ACKNOWLEDGMENTS**

I can honestly say that it "takes a village" to write a dissertation. While the work reflected in this study is all my own, I am humbled and grateful beyond words to the "village" in my life...

First, I must thank the Graduate School at Loyola University for their investment in my research through both the Community Stewards Fellowship and the Summer Research Mentoring Program, as well as several travel reimbursements which made it possible for me to attend a variety of conferences to present my work along the way. Through their funding, I was blessed to be able to enlist the invaluable assistance of two students: Victoria Rice and Michael Heisler. Victoria's assistance with timely transcription and Michael's assistance with program description collection and quantitative analysis cannot be underscored. I am impressed with the young scholars both of them are already becoming.

I must also mention a special "thank you, thank you, thank you" to Deanna D'Amico Guthrie for her friendship and willingness to share her own dissertation experience with me. Deanna "blazed the way" ahead of me, offering me an inspiring model to follow. She assisted specifically in this study by serving as a secondary coder on the qualitative data.

To my best friend, Suzanne Satterlee – the most thorough editor I know – I thank you for your thoughtful feedback, grammatical guidance, and fresh eyes. Along the way,

you undoubtedly learned more about HIV prevention than any Communications/Spanish major needs to know.

To my family, I want to express my love and appreciation for your support. To my mom and dad, I always smile when I hear how proud you are of me. To my husband, Alex, I simply could not and would not have been brave enough to return to school and earn by PhD without your support. Thank you for sharing your life with me and giving me a partnership that makes my hard work possible.

To the many service providers who I interviewed for this study, I am grateful for your willingness to participate, encouraged by your stories of success, and challenged to think differently about research and evaluation because of the practice wisdom you shared with me.

And finally, I eternally grateful to my committee members – Dr. Christine George and Dr. Janet Myers – for their mentorship, accessibility, and support of my research. I am especially humbled by the guidance of my Dissertation Chair – Dr. Susan Grossman. The challenging and rich experience I have had at Loyola I owe entirely to Susan. My greatest piece of advice to any new doctoral student is simple: find a faculty member *half* as supportive and wise as Susan Grossman, and your experience will be everything you want it to be and more.

To all those living with HIV... and to those who provide them with hope along the way.

Our only access to knowledge may be through the experience of the experiencers themselves. If we are going to advance social work knowledge to make it more accountable and responsive in changing and uncertain contexts...it is our responsibility to the profession that we enable and create cultures and environments in which this can happen.

~ Jan Fook, Theorizing from Practice

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#### **ABSTRACT**

In 2002, the Human Resource Service Administration (HRSA) began encouraging and funding a new strategy in HIV prevention. Referred to as Prevention with Positives (PwP), this approach to HIV prevention focused efforts on intervention with individuals who were already HIV-infected. This study examines one particular model for the delivery of these important prevention messages to men and women living with HIV – the utilization of a peer-based model. "Peer-based" refers to any program which utilizes HIV-positive individuals as service providers for other HIV-positive individuals. A nationwide sample of such programs was used to provide an exploratory look into the possibilities peer-based programming may hold for PwP interventions.

Through a set of semi-structured interviews with various levels of program staff (administrators, supervisors, and peers) using a mixed methods approach, this study seeks answers to two research questions: 1) To what extent do peer-based models of HIV service delivery adhere to an established set of program characteristics of Prevention with Positives interventions? and 2) What are the experiences of peer-based PwP program staff in terms of implementation and provision of peer-based services? A set of 19 key PwP program characteristics identified in the literature served as a foundation for understanding how peer-based programs fit and/or expanded upon existing traditional PwP strategies.

Findings are discussed in an applied manner, with service providers and funders in mind. Programs participating in the study demonstrate a strong level of fit between the established PwP key program characteristics and the peer-based model, including several program characteristics which may be *better* accomplished through the incorporation of peers (e.g. rapport). Advice for other service providers and agencies considering incorporating a peer-based program into their HIV services includes much discussion of additional considerations and commitment to be required (especially related to supervision, recruitment of peers, and management and training needs). However, the overall value peers add to HIV service delivery is found to far exceed the challenges.

#### CHAPTER ONE

#### INTRODUCTION TO THE STUDY

#### **Overview of the Problem**

It has been almost 30 years since the beginning of the HIV/AIDS epidemic in America, and we continue today to invent and reinvent the highest quality of HIV services p ossible. In 2003, the Centers for Disease Control (CDC) introduced a nationwide campaign called "Advancing HIV Prevention" which outlined four main strategies:

- 1) Make HIV testing a routine part of medical care;
- 2) Use new models for diagnosing HIV infection outside of traditional medical settings;
- Prevent new infections by working with people diagnosed with HIV and their partners; and
- 4) Continue to decrease perinatal mother-to-child transmission.

In response to the third of these strategies specifically, much attention has been paid to primary prevention, commonly referred to as Prevention with Positives. Prevention with Positives (PwP) is the term used by the Health Resources and Service Administration (HRSA) HIV/AIDS Bureau to describe fundable prevention programs aimed at individuals already HIV-infected. According to the joint guidelines for prevention

programs from the CDC, HRSA, and National Institutes of Health, effective PwP interventions are those which lead to: a) reduced risk of transmission of HIV to non-infected individuals (measured by marked behavior change in individuals' safer sex practices and increased efforts toward partner notification of HIV-positive status), and b) reduced rates of opportunistic infections among HIV-positive individuals (HRSA, 2003). Malitz & Eldred (2007) provide a history of PwP as well as an introduction to some of the early research. Recognizing the need for a "multi-focused approach to the challenge of preventing HIV transmission" (Malitz & Eldred, 2007, p. 1), initiatives have emerged from a variety of federal agencies since the year 2000 aimed at HIV primary prevention (what has come to be known as Prevention with Positives). After an alarming Institute of Medicine report suggested increasing numbers of HIV-positive individuals engaging in activities risking transmission to others (IOM, 2001), HRSA began exploring ways to fund and support quality primary prevention programs nationwide.

In an early study funded by HRSA, Morin and colleagues (2004) conducted exit interviews with 618 HIV-positive patients nationwide to inquire about what type of safer sex information they received from their medical providers. They found and documented many missed opportunities; only 25% of patients reported having any type of safer sex talk with their physician, and only 6% said they spoke of specific sexual activities. These findings were also supported by a separate study conducted at 6 large California clinics in the late 1990's which found that one in three (34%) HIV-positive patients reported never having safer sex conversations with their medical providers (Marks et al., 2002).

These studies and others like them led to HRSA's development of a Special Projects of National Significance (SPNS) initiative in 2003, which funded 15 clinical settings to implement PwP programs. Program administrators and evaluators from these 15 agencies provide some of the earliest documented literature on PwP program development and outcomes; their projects are heavily utilized and discussed throughout the review of the literature in Chapter Two. Using data from all individuals participating in the SPNS demonstration project sites (n=4,016), risk of HIV transmission has been extrapolated to suggest 68 new infections can be prevented annually through these 15 programs alone, and if PwP was implemented routinely in all clinical settings nationwide, more than 17,000 new infections might be prevented each year (Morin et al., 2007). Responding to this documented need for PwP interventions, the present study examines one particular model for the delivery of these important prevention messages to men and women living with HIV—the utilization of a peer-based model. In short, the peerbased model deals with the ways in which HIV-positive men and women can be used to provide services and powerful prevention messaging to other HIV-positive men and women. I am not suggesting that peer-based services are the only way to provide PwP interventions; yet, I present this study as a compelling evidence for why the peer-based model is a valid option.

#### **Research Questions and Assumptions**

This study is as an exploratory look into current Prevention with Positives programs, with a specific emphasis on the potential fit of peer-based models. For the purposes of this study, "peers" are defined as individuals who are HIV-positive with

demographics and socioeconomic status reflective of the clientele served by the agency. Using a set of characteristics of established PwP programs nationwide, I investigate the depth and breadth of current peer-based programming from a national sample, asking how a peer-based model of PwP services fits with key program characteristics from non-peer-based PwP models and then what the experiences of staff have been during the process of implementing and providing those services. The methodology employed in this study reflects a collaborative approach to research; I place tremendous weight upon the practice wisdom service providers share throughout this study.

The research questions to be addressed are:

- 1) To what extent do peer-based models of HIV service delivery adhere to an established set of program characteristics of Prevention with Positives interventions?
- 2) What are the experiences of peer-based PwP program staff in terms of implementation and provision of peer-based services?

Although the design of this study and its exploratory nature describes the peer-based model as it occurs and identifies thematic content from interviews with staff in their own words, I must acknowledge my own assumptions about what the study might find. While the present study does not take a hypothesis-testing approach, per se, these assumptions are still worth noting. I hold two main assumptions, which are correlated directly into the two research questions above. The first assumption is: There will be a good fit established between traditional/non-peer-based PwP interventions and peer-based PwP models of service delivery. The second assumption is: There are key aspects of peer-based services which are entirely unique, and these characteristics are associated with

both strengths and challenges inherent in the peer-based model. These assumptions are based on my firsthand experience in the field (consisting of nearly ten years of HIV direct practice and consultation) as well as my knowledge of the existing literature on the subject.

#### **Rationale and Purpose of the Study**

While the early findings from evaluation of PwP programs may make a powerful and compelling case for the potential of such programs, it is still not a HRSA requirement for all HIV medical providers to include such prevention and risk reduction messaging. I point out that the literature continues to suggest that HIV-positive men and women would welcome risk reduction and safer sex conversations with their medical providers (Rutledge, 2009). However, it is clear that such research must continue to build the evidence base needed to garner support from HRSA and other large, governmental funding sources with power over the type of services provided to people living with HIV/AIDS.

One specific consideration in the design of PwP interventions for which there is considerable debate within the literature is the question of *who* should be providing the prevention messaging; that is, what type of service provider best delivers the HIV prevention message to persons living with HIV? "Even when there was agreement about the appropriateness of HIV prevention services, there was no consensus among providers...about who should be responsible for it" (Morin et al., 2004, p. 964). Among the 2003 SPNS grantees, the model of service provision varied; some used provider/physician-delivered interventions, others employed specialists (most often social

workers), and still others implemented peer-based interventions. Three of the fifteen programs in the SPNS project utilized a peer-based model.

The literature includes few attempts to compare the effectiveness of PwP models based on who delivers the intervention (see Myers et al., 2010 for the first such attempt based on the most recent SPNS data). One of the few comparison studies concluded there to be no significant, reportable difference between nurse-administered messages and peer-delivered messages, which may suggest the *who* doesn't matter (Nyamathi, Flaskerud, Leake, Dixon, & Lu, 2001). However, considering the powerful history of peer/consumer involvement in the HIV/AIDS movement (Roy & Cain, 2001), a case might be made for a natural fit between PwP programs and the utilization of peers. Rationale for the peer-based model are carefully considered in the literature review provided in Chapter Two. Some of the most compelling arguments for utilizing the peer-based model are its cost-effectiveness, the reduction of burden on other professional staff, and the added value of peer-based messages for both the recipient and the provider of the services in terms of hope and empowerment.

The primary impetus for this study is to contribute to the literature and scholarship regarding peer-based interventions. There is currently a gap in the literature with regard to systematic, empirical understanding of these interventions and the mechanisms that guide their functioning. I am committed to bridging the difficult divide between the academic research community and those providing direct practice in the field; toward that end, this study utilizes both qualitative and quantitative elements to systematically understand peer-based programming in collaboration with programs'

service providers in order to inform evidence-based practice and the future direction for HIV funders.

#### Significance for HRSA and Other Stakeholders

The 2006 Congressional reauthorization of the Ryan White CARE Act, the largest source of funding for the care and treatment of individuals living with HIV, reflected several competing trends in HIV service delivery. The new name for the Act became the Ryan White Treatment Modernization Act; the "modernization" included a shift toward a medical model of service delivery and a reduction in funding for non-medically necessary services including housing, alternative therapies, and some forms of psychosocial prevention services. When HIV prevention services *are* funded, HRSA (in collaboration with the Centers for Disease Control) maintains a set of evidence-based interventions (known in the field as DEBIs – Diffusion of Evidence-Based Interventions) which are strongly encouraged for use by grantees.

In times of limited and uncertain financial resources, this study investigates whether the utilization of a peer-based model of HIV prevention programming may be a viable option for service delivery. The roles peers can play in the provision of HIV prevention services may be instructive to community agencies providing HIV services as well as to HRSA in considering an additional DEBI of peer-based HIV prevention programs. Assuming a good fit between the PwP program structure and the peer-based model, incorporating peers into HIV prevention more broadly may be a particularly cost-effective method of providing effective PwP services. Therefore, the direct implications of this study are aimed at HIV agencies and funders, specifically HRSA and its partners.

It is my belief that the present study can serve as a first step in the development of a peer-based DEBI to add to the rich collection of resources for HIV service providers nationwide.

While the implications of this study are focused on programs and funders, it is important to note that an increase in the scholarship and literature regarding the viability of peer-based programming also has potential implications for persons living with HIV. As more agencies seek to implement this type of peer-based service provision, a shift may occur among professionals toward a more optimistic and empowering view of individuals with HIV. This in turn may result in a more hopeful outlook among individuals living with HIV about their own future and their potential to affect change in their own communities.

#### Philosophy of Research

The social work researcher often fails to explicitly acknowledge the ontology that guides his or her research design, hypotheses, methodology, and ultimately the conclusions those researchers disseminate into the literature. One's ontology, especially as trends in the field move toward a more diverse range of possibilities from positivist and post-positivist perspectives, can be vital to understanding the research being generated. In an effort to ensure transparency in this present study, I wish to include a few words about my own philosophy of research, as this ontology has directly led to the distinct methodology decisions I have made. Guided by my personal commitment to conducting research which informs evidence-based practice and program evaluation in the area of HIV treatment and care, my ontology is rooted in the conviction that what is

'real' must be determined in active, engaged *practice*. Such an ontology aligns with that of a contemporary pragmatist approach to the understanding of knowledge acquisition and the determination of truth. This philosophy stems from an appreciation for the need to be flexible in one's thinking in order to "work in changing circumstances" (Fook, 2002, p. 80). Thus, we must begin by recognizing that in social work research, there is no "one-size-fits-all" solution and then allow "real world" practitioners to inform our research.

While the incorporation of practitioner knowledge into social research and evaluation might seem common sense, much of recent empirical research remains devoid of practitioner input. This is likely the influence of positivist thinking, especially prominent among many social work researchers and academicians. Such thinking is responsible for creating the current "invisible status" (Tyson & Bulanda, 2010, p. 348) of practitioner knowledge while also moving the process of program evaluation and effectiveness research *away* from direct practitioners. With this shift, "the function of research has been seen from the perspective of tertiary institutions as the post hoc evaluation of intervention effectiveness" (Poulter, 2006, p. 328). Looking back over the past several decades of positivist social work research, the detrimental consequences of such post hoc evaluations are evident. This type of external top-down research and evaluation has oftentimes led to "prescriptions for evaluation research that were incompatible with the treatment that practitioners wanted to conduct" (Tyson, 1995, p. 444), and, perhaps even more significantly, debilitated the capacity of practitioner

involvement in research by claiming that their proximity to the problem issue impaired their judgment about treatment efficacy.

Another perspective within the field of social work does exist—one that looks far more positively upon the value practice wisdom can provide to effectiveness research and the roles practitioners can hold at the research table. Even the term "practice wisdom" has come to carry a connotation that is weak and slightly demeaning to those in direct practice. Therefore, establishing the centrality of practice wisdom in the research and evaluation process requires that researchers reframe practice wisdom not as "unarticulated, non-codified and undocumented" but as "the ability to base sound judgments on deep understandings in conditions of uncertainty" (O'Sullivan, 2005, p. 222). Researchers truly committed to emphasizing the centrality of practice wisdom will need to become advocates for a new understanding of practice wisdom, which is far from haphazard and unarticulated:

The clinician's informed judgment is a helpful resource in an evaluation of practice, because the worker knows the entire context of the treatment, knows the client, can interpret the client's feedback about the accuracy of the practitioner's communications, and can distinguish what changes are occurring (Tyson, 1995, p. 432).

The new view of practice wisdom must be established within the research agenda as capable of yielding explicit, objective, and distinct knowledge that is perhaps more credible and valuable than researcher-generated "truth" alone.

Given this commitment to research rooted heavily in the voice of practitioners, a collaborative approach is taken in this present study based on my belief in the power and potential of practice wisdom and the genuine desire to inform the replication of peer-

based PwP programs in "real world" settings. This ontology also finds strong support in the literature on HIV prevention research (Dworkin, Pinto, Hunter, Rapkin, & Remein, 2008; Evans & Lambert, 2008; Heckathorn, Broadhead, Anthony, & Weakliem, 1999; Nakibinge, 2009). Involving the community (in this case "community" may include consumers of services, peers providing the services, and direct practitioners and program administrators) in the process of program design, description, implementation, and evaluation can be a powerful and insightful research methodology.

In their critique of the CDC's Diffusion of Evidence-Based Interventions (DEBI) model, one set of authors stressed the dangers of top-down dissemination and the consequences of eliminating local interventions. Instead, they argue: "The mode of implementation and dissemination can and should honor the years of cumulative local knowledge creation, production, and maintenance on the ground that has existed in communities all along...researchers must first honor local knowledge" (Dworkin et al., 2008, p. 54-55). The current study, therefore, demonstrates a rigorous research methodology, which still maintains community collaboration and an emphasis on practice wisdom.

#### **CHAPTER TWO**

#### REVIEW OF THE LITERATURE

This chapter presents an overview of the literature relevant to one's understanding of Prevention with Positives (PwP) programming generally as well as the specific nuances of the peer-based model of HIV service provision. Those two segments of research serve as the structure of the chapter. As with any good literature review, the main aims of this chapter are to: "put the researcher's current efforts into perspective," "create a foundation based on existing knowledge," and "suggest the most appropriate" way to further expand on what is already known" (Grinell & Unrau, 2005, p. 47). While the Prevention with Positives terminology and HRSA-funded service category are relatively recent advances in the field of HIV, there is some literature available regarding effective HIV primary prevention programs in general. While these studies cannot necessarily be associated with PwP programs specifically, the similarity in desired program outcomes and modalities of treatment make this literature worth noting. Effective primary prevention interventions have been associated with a number of different subgroups within the HIV community. These groups include: intravenous drug users (Broadhead et al., 2002; Nyamathi et al., 2001; Weeks, 2009), high-risk youth (Bettencourt, Hodgins, Huba, & Pickett, 1998; Luna & Rotheram-Borus, 1999), and heterosexual women (Anderson, 1996; Doull, 2004; Downing et al., 1999; Gillman, 1996). Intravenous drug users demonstrate a need for structure and accountability, yet

with access to programs that provide these characteristics, they are often successful because of the presence of social support (Nyamathi et al., 2001). Youth are particularly adherent to prevention messaging because of their inherent desire to be independent and empowered (Bettencourt et al., 1998). Women have been documented as adherent to culturally-appropriate prevention messaging because of their innate caregiving tendencies, the need to be healthy in order to provide for others, and the desire to be empowered (Downing et al., 1999).

HIV prevention research and evaluation literature has also identified several specific settings in which primary prevention messaging has displayed some level of effectiveness with HIV-positive individuals. These settings include: homeless shelters and housing projects (Downing et al., 1999; Nyamathi et al., 2001), jails and prisons (Collica, 2006; Sifunda, 2006), and primary medical care sites (Mamary, 2004; Marino, Simoni, & Silverstein, 2007; Nyamathi et. al., 2001).

The review of Prevention with Positives research includes key concepts like partner notification and disclosure, safer sex practices, and messaging; this section includes important summaries of the key researchers and program administrators involved in early PwP research and key characteristics of PwP programs. It is important to bear in mind the limited available literature on outcomes measurement and efficacy studies of PwP programs given their relatively short history; the earliest PwP programs only began in 2003. Table 1, later in this chapter, refers specifically to those 15 pioneering Special Projects of National Significance (SPNS) project sites on which much of the limited available research is based. Some additional literature is reviewed in this

chapter which is not focused on PwP, per se, but which includes elements of primary HIV prevention that emerged in the literature prior to the HRSA language around PwP programming. Additionally, it is incumbent upon the reader to recognize the influence of one article in particular on my work; Patricia Gilliam and Diane Straub's (2009) review of the first decade of Prevention with Positives research served to enrich the methodology of this larger literature review process as well to guide the identification of many of the program characteristics outlined in Tables 2 through 5.

The literature review then narrows in focus to address research related to the peer-based model more specifically. First, literature on the theoretical support for peer-based programming is discussed. Then, a review of the peer-based HIV prevention literature focuses on several areas: evidence of peer-based effectiveness, a summary of unique characteristics of peer-based programs, and documented benefits and challenges inherent in implementing a peer-based program. Just as the PwP outcomes and effectiveness research is only beginning to emerge, so too is the research measuring peer-based programming's empirical impact. The literature reviewed in this chapter represents the breadth of research available as of early 2011. I have recently learned of one set of nationwide peer-based programs targeting women of color which have just begun (HRSA, 2011). However, the Albert Einstein College of Medicine, which serves as the evaluation center for these new programs, estimates that the earliest outcomes data will not be ready for dissemination until 2014.

The literature review process serves as much more than simply an overview of the topic. My actual methodology, conceptualization of variables, and instrumentation were

derived from this literature; most notably, Tables 2 through 5 show a collection of key program characteristics identified in the literature which served as the starting point for the questions asked of service providers participating in this present study. I intend for this literature review to clearly delineate what is currently known about Prevention with Positives programming and the peer-based model. Additionally, and perhaps more importantly, this literature review explicitly links my methodology with the existing knowledge outlined within.

#### **Prevention with Positives Research**

The overwhelming majority of the literature available to date regarding PwP implementation and outcomes originates from the aforementioned HRSA-funded Special Projects of National Significance (SPNS) initiative, which focused on PwP programs within medical clinic settings. These interventions were provided with quality improvement, technical assistance, and evaluation guidance through the Enhancing Prevention with Positives Evaluation Center (EPPEC) at the University of California at San Francisco. The 15 intervention sites included in the 2003 SPNS grant cycle are outlined in Table 1. The mode of service delivery varied by site and included four (4) provider/physician-delivered models, three (3) specialist-delivered models, five (5) models delivering services through a combination of provider and specialist, and three (3) peer-based models. While this present study of peer-based PwP programs is not focused exclusively on programs in clinical settings, the research generated from these clinical interventions forms the strongest segment of initial literature on PwP programs.

The subsequent section of this literature review describes common PwP program characteristics gleaned from this literature, largely published in a 2007 supplement to the journal *AIDS and Behavior* which included 13 separate articles written by the grantees and evaluators themselves. Only one out of the 15 interventions concluded with a recommendation *against* the replication of their model (Nollen, Drainoni, & Sharp, 2007), citing too many challenges in implementation and securing agency support.

Table 1: SPNS Prevention with Positives Grantees (adapted from Koester et al., 2007)

Site of Intervention	Mode of Delivery	Behavioral Theory?
Johns Hopkins University	Provider-delivered	Yes – TTM
– Baltimore		
University of Alabama –	Provider-delivered	Yes – TTM
Birmingham		
University of California –	Provider-delivered	Yes – TTM
Davis		
County of Los Angeles	Provider-delivered	No
St. Luke's Roosevelt	Specialist-delivered	Yes – TTM and MI
Hospital - New York		
University of Washington	Specialist-delivered	Yes – TTM and MI
- Seattle		
El Rio Health Center –	Specialist-delivered	No
Tucson		
DeKalb County, Georgia	Provider and Specialist	Yes – TTM
	(Mixed)	
Whitman Walker Clinic -	Provider and Specialist	Yes – TTM
Washington, DC	(Mixed)	
Drexel University –	Provider and Specialist	No
Philadelphia	(Mixed)	
University of North	Provider and Specialist	Yes – MI
Carolina – Chapel Hill	(Mixed)	
Owen Clinic, University	Provider and Specialist	Yes – TTM and MI
of California - San Diego	(Mixed)	
Fenway Community	Peer-delivered	Yes – IMB, TTM, and MI
Health – Boston		
Mt. Sinai Hospital –	Peer-delivered	No
Chicago		
University of Miami	Peer-delivered	Yes – IMB

Table 1 also indicates a major commonality in the theoretical framework chosen for the PwP interventions. The overwhelming majority (11 out of 15, or 73%) of these intervention sites chose a theoretical foundation rooted in one of three behavioral theories and approaches: the Transtheoretical Model (TTM), Motivational Interviewing (MI), and/or the Information, Motivation, and Behavior Theory (IMB). The Transtheoretical Model of behavior change (Prochaska & DiClemente, 1982; Prochaska, DiClemente, & Norcross, 1992) stresses individual readiness to change using the Stages of Change framework; this model has been demonstrated to be extremely effective in addictions treatment and aligns naturally with a harm reduction approach to counseling. The theory and practice of Motivational Interviewing (Miller & Rollnick, 1991) is a technique of client-centered, client-directed, non-confrontational counseling, which has also been strongly supported in the addictions treatment literature. Citing its client-centeredness as key to HIV primary prevention, Motivational Interviewing is already being described as "a promising approach to safer sex counseling for HIV-infected clients" (Golin et al., 2007, p. 73). The Information, Motivation, and Behavior Theory similarly emphasizes behavior change that is rooted in the client's personal motivation to change. The unique component of the IMB model is its added emphasis on education, through the provision of health information. The logic, then, is that educated clients are motivated to engage in long-term behavior change. The popularity of these particular theoretical frameworks within the early PwP programs suggests a likely fit between PwP and behaviorallyoriented, non-judgmental approaches to service provision.

Aside from the documented success of primary prevention with certain subpopulations and practice settings and an understanding of common theoretical
frameworks of early PwP interventions, little is available in the literature to allow for
empirically-supported statements of program effectiveness. Yet, some glimpses of
potential are on the horizon. One CDC-funded study involving seven clinics providing
PwP physician-delivered safer sex messaging recently reported a 42% reduction in highrisk sexual behavior after 6 months of the intervention (Gardner et al., 2008). The
preliminary outcomes associated with the SPNS projects have just recently begun to
emerge in the literature. The three earliest published outcomes-focused articles all
showed increased condom use, decreased risk-taking behaviors, and increased likelihood
of status disclosure (Illa et al., 2010; Myers et al., 2010; Teti et al., 2010).

As PwP interventions continue to mature, additional outcomes-oriented research should be forthcoming from the SPNS grantees in the next few years. Until that time, much literature already exists relating what has been learned thus far by service providers involved in PwP program implementation and evaluation. From their documented successes, lessons learned, and challenges (much of which was published in the aforementioned supplement to *AIDS and Behavior*), the literature is already rich with considerations for replication and potential innovation utilizing additional modalities for PwP interventions.

Key Characteristics of Established Prevention with Positives Programs

Prior to the SPNS initiative, relatively little research had been conducted to

describe the components of primary prevention programs; thus, replication of

standardized models of primary prevention did not occur during that time. Before the SPNS initiative, the few components identified as integral to successful HIV primary prevention programs included social support, mutual understanding, and educational content. A number of programs articulated the need for social support (Koopman, Gore-Felton, & Marouf, 2000; Lesserman, Perkins, & Evans, 1992; Serovich, Brucker, & Kimberly, 2000). Social support was most often operationalized in these studies in the context of psychosocial support groups, mentoring/buddy programs, and the building of family and friends networks. Additionally, a sense of mutual understanding and solidarity was identified as a particularly significant protective factor in several effectively implemented primary prevention programs (Harris & Alderson, 2007). Mutual understanding and solidarity is most commonly associated in the literature with discussion of peer-led components to programming and/or opportunities for individuals living with HIV/AIDS to interact with each other. Lastly, the early research on effective models of primary HIV prevention showed the critical importance of the inclusion of educational components; these educational efforts were most beneficial when focused on dispelling the myths and misinformation associated with HIV and improving hope and quality of life for newly-diagnosed individuals (Bastardo & Kimberlin, 2000; Harris & Larsen, 2007; Madray & Van Hulst, 2000; Molassiotis et al., 2002). This early research aligns with more recent literature on PwP interventions, as will be discussed at length below and illustrated in Tables 2 through 5.

Since the inception of PwP, especially through the dissemination of research from SPNS grantees and evaluators, PwP interventions have become more clearly described in

the literature. Articles have been written with titles like *Reframing Prevention with Positives* (Gerbert et al., 2006), which have attempted to shed light on the lessons learned thus far in PwP work and the characteristics associated with the most successful attempts at implementation of new and innovative PwP interventions. Tables 2 through 5, when taken together, provide a comprehensive review of the available literature from the early SPNS publications, specifically identifying key program characteristics organized into four categories: content, messaging, organizational support, and relationship. While these programs are not yet empirically-supported as effective, the commonalities across the literature suggest that understanding these characteristics and ensuring their inclusion in future PwP interventions may greatly enhance the likelihood of effectiveness of PwP programs. Therefore, the program characteristics in these four tables are combined and utilized in the present study as the basis for the quantitative approach to examining the level of fit between known PwP program models and the peer-based service model.

The *content characteristics* (Table 2) of established PwP programs begin with the inclusion of behaviorally-based theory (i.e. Transtheoretical Theory and/or Motivational Interviewing). As previously discussed, these theories and models align closely with harm reduction approaches to HIV prevention. Harm reduction refers to an approach toward behavior change that allows for a tapering off of risk behaviors over time rather than a requirement for immediate abstinence and/or sobriety. Such a harm reduction approach is critically important for a successful HIV prevention intervention since risk reduction behaviors are often exercised over time and require such latitude. From a public health standpoint, harm reduction makes sense because less risk taken is better

than no behavior change at all. Additionally, the literature on key program characteristics for PwP interventions suggests the importance of a balance between scripted

Table 2: Prevention with Positives: Key Program Characteristics – Content

Characteristic	Study or Studies
Based on a behavior change theory (i.e.	Callahan, Flynn, Kuenneth, & Enders,
Stages of Change and/or Motivational	(2007); Estrada, Trujillo, & Estrada
Interviewing)	(2007); Gardner et al. (2008); Gerbert et
	al. (2006); Golin et al., (2007);
	Kalichman (2008); Morin et al. (2004);
	Nollen, Drainoni, & Sharp (2007); Teti et
	al. (2007); Zuniga et al. (2007)
Harm reduction approach	Callahan, Flynn, Kuenneth, & Enders,
	(2007); Kirshenbaum et al. (2007);
	Mitchell et al. (2005)
Balance of scripted content and	Koester et al. (2007); Raja, McKirnan &
individualized flexibility	Glick (2007); Zuniga et al. (2007)
Tailored to specific targeted subgroup	Gilliam & Straub (2009); Raja,
	McKirnan, & Glick (2007)
Emphasis on personal goals and skills	Kirshenbaum et al. (2007); Mitchell et al.
building	(2005)

conversations and/or curriculum and the flexibility to adapt to the individual's unique situation. In most instances, the balance has been achieved either through a standardized assessment and scripted conversation (often done via computerized surveys known as Audio Computer Assisted Self Interview, ACASI) followed by a personalized conversation with the physician or specialist, or through the use of structured group curriculum coupled with individualized discussion.

The literature on characteristics of effective HIV prevention *messaging* (Table 3) is particularly rich and insightful. While the idea that a non-judgmental approach is critical to discussions of individuals' sexual and risk-taking behaviors may seem fairly

self-explanatory, the delineation of additional messaging strategies proves less intuitive.

Two approaches to prevention messaging that have been shown to be effective in

Table 3: Prevention with Positives: Key Program Characteristics – Messaging

Characteristic	Study or Studies
Non-moralistic, non-confrontational	Morin et al. (2004)
messages	
Consultation and/or collaboration	Gerbert et al. (2006)
messages	
Loss-framed messages	Richardson et al. (2004)
Wellness messages	Gerbert et al. (2006); Kirshenbaum et al.
	(2007); Mitchell et al. (2005)
Altruistic messages	Offer et al. (2007); Relf et al. (2009);
	Rutledge (2009)

reaching individuals living with HIV with safer sex information and prevention planning are consultation and collaboration.

Physicians with a collaborator style regularly assess and counsel patients about transmission prevention, keeping in mind that there's deep psychological motivations why people do things and aim to teach patients the tricks on how to reduce risky behaviors; physicians with a consultant style remain scientific about it and do not aim to change, but to tell them what risky behaviors are and what the alternative is so patients can make their own decisions (Gerbert et al., 1999, p. 317).

These findings suggest that striking a balance between the collaborator and consultant styles is the best way to approach safer sex conversations with patients.

Additional literature suggests other messaging strategies which seem to be effective. These include loss-framed messages (Richardson et al., 2004), wellness messages (Gerbert et al., 2006; Kirshenbaum et. al, 2007; Mitchell et al., 2005), and altruistic messages (Offer et al., 2007; Relf et al., 2009; Rutledge, 2009). A loss-framed message is something like, "If you don't use clean syringes, you could get hepatitis," whereas a wellness message proposes something like, "If you use condoms you will

protect your sexual partners." The research on altruistic messaging hinges on the findings from qualitative interviews with newly-diagnosed individuals in which messages routinely exhibit themes of personal responsibility to protect others (Offer et al., 2007). An altruistic prevention message might be, "Consider the responsibility you now have for protecting your current and future sexual partners." Individuals have been found more likely to disclose their status to others, especially to sex partners, if they receive HIV prevention messages aimed at their altruistic motivation. What these types of messages have in common is the necessary avoidance of judgment and scare tactics in conveying the importance of HIV protection and disclosure.

The literature on PwP program implementation also includes many references to organizational support characteristics, emphasizing that the implementation of a quality PwP intervention requires support at the organizational level. As summarized in Table 4,

Table 4: Prevention with Positives: Key Program Characteristics – Organizational Support

Characteristic	Study or Studies
Institutional/agency support and belief in	Koester et al. (2007); Mitchell et al.
importance of HIV primary prevention	(2005); Morin et al. (2004); Myers et al.
	(2007); Teti et al. (2007)
Ongoing opportunities for training of	Koester et al. (2007); Marks et al. (2002);
program staff	Morin et al. (2004); Myers et al. (2007);
	Raja, McKirnan, & Glick (2007); Teti et
	al. (2007)
Established written procedures and clear	Mitchell et al. (2005); Morin et al.
sense of staff roles and responsibilities	(2007); Myers et al. (2007)
Integration with other agency services	Kalichman (2008); Mitchell et al. (2005)
Involvement and collaboration with the	Dworkin, Pinto, Hunter, Rapkin, &
community during the planning and	Remien, (2008); Evans & Lambert
evaluation stages	(2008); Heckathorn, Broadhead,
	Anthony, & Weakliem, (1999); HRSA
	(2011); Nakibinge (2009)

PwP interventions should include ongoing training of staff (including communication skills, HIV education, and theoretical orientation), be well-integrated with other agency services, and have clearly-delineated roles and responsibilities for staff as well as established written procedures. One study reports the detrimental impact on a program when there is not institutional support for and belief in the importance of HIV prevention; "prevention fatalism" is a term given in reference to some physicians who exhibit a deeply-held belief that no matter what the intervention, people are still going to infect others (Myers et al., 2007; Steward, Koester, Myers & Morin, 2006). Research makes the case that new PwP programs should be implemented only after careful involvement of and collaboration with the community (including persons living with HIV) and key staff members in order to avoid the detriment of negative attitudes upon the program's success. Emphasizing the importance of community involvement, one of the most recent SPNS sites reports, "We realized that we had developed this program based on what we thought the women's needs were. But we hadn't surveyed the women to find out what they perceived to be the most pressing needs" (HRSA, 2011, p. 2).

Table 5: Prevention with Positives: Key Program Characteristics – Relationship

Characteristic	Study or Studies
Longer duration of provider/client	Kalichman (2008); Wilson & Kaplan
relationship	(2000)
Strong provider/client rapport	Kirshenbaum et al. (2007); Mitchell et al.
	(2005); Morin et al. (2004)
Type of relationship:	See Table 1 for variety of intervention
Physician	modalities
Specialist	
Peer	

The last set of key program characteristics identified in the literature describes the relationship (Table 5) between the client/patient and the physician/service provider. Several PwP programs refer to the importance of the client/patient having ongoing access to the provider of HIV prevention services; they suggest that the individual having an ongoing relationship with the provider (as opposed to a one-time encounter) is likely associated with successful HIV prevention outcomes. It naturally follows, then, that these programs also emphasize the importance of developing and maintaining a level of rapport (i.e. caring, trust, and camaraderie) between the provider and the client/patient. Both duration of the relationship and depth of rapport resonate with the aforementioned findings of early primary prevention research suggesting the importance of social support and mutual understanding in the HIV helping relationship. The research and publications on the SPNS PwP interventions reference multiple successful models (i.e. physiciandelivered, specialist-delivered, and peer-based); however, it is the purpose of this present study to investigate the peer-based model in particular. The relationship characteristics of duration and rapport are seen as particularly strong rationale for the consideration of peer-based programming. The remainder of this literature review focuses on the unique components of the peer-based model.

# **Theoretical Support for Peer-Based Programs**

Turning attention to the specific model of peer-based PwP interventions, a number of additional theories discussed in the literature provide strong support for the effectiveness of peer-based programming. This present study is guided by a belief in the potential of the peer-based model of HIV primary prevention services to be a viable way

to engage individuals in services and achieve improved outcomes of health and well-being. This belief originates from my firsthand experience in the field of HIV service delivery; moreover, an examination of the literature finds evidence supporting peer-based models that is rooted in widely-accepted theory.

First and foremost, peer-based models find strong support in *empowerment* theory, which is widely applied to the field of HIV in the literature. Empowerment theory essentially stresses the fundamental importance of instilling and building in clients a sense of hope, self-efficacy, and pride. It is often applied particularly to work among oppressed, vulnerable client populations. Therefore, the theory is particularly applicable in the field of HIV, which is still highly stigmatized. Empowerment principles are cited as relevant and efficacious in explaining the success of peer-based prevention services (Gutierrez, 2000; Marino et al., 2007; Gutierrez, 2000; Williams, 1995). Empowerment theory's emphasis on group cohesion, solidarity, mutual understanding and support, and pride in personhood and community make it a natural fit with peer-based models of primary prevention. The concept and results of empowerment are clearly seen throughout this present study's findings.

Additional theoretical support and consideration for peer-based programming can be drawn from several *theories of hope* originally linked to peer-based PwP program effectiveness by Harris and Larsen (2007). These theories of hope (Dufault & Martocchio, 1985; Farran, Herth, & Popovich, 1995) focus on how hope can be fostered within the context of meaningful relationships. They place emphasis on hope as being future-oriented and essential to a purpose-filled, healthy life. Having hope in one's future

is, therefore, linked to improved health outcomes. All theories of hope suggest the origins of hope exist in the context of relationship with others. Harris and Larsen (2007) have successfully utilized these hope theory frameworks to suggest the benefit of peer-based models in increasing the hope and quality of life in both the individuals receiving the peer-based service and the peer providing the service. Themes of hope are also evident in the content of this present study's interview guidelines.

Finally, in a study of HIV-positive intravenous drug users, application of Heckathorn's (1990) Group-Mediated Social Control Theory led to favorable peer-based primary prevention outcomes (Broadhead et al., 2002). Heckathorn's theory focuses on the harnessing of "peer pressure" in a positive manner to achieve desired outcomes. One of the recent SPNS grantee programs, Supporting Healthy Alternatives through Patient Education (SHAPE), also identified this theoretical framework as uniquely relevant to the employment of HIV-positive peers in the provision of PwP services. Authors reporting on the efficacy of the SHAPE program saw first-hand the benefits of peer-based groups: "Just as peers influence risk-taking behaviors, peers also influence preventative actions" (Estrada, Trujillo, & Estrada, 2007, p. 96). This type of theoretical support for the positive harnessing of peer pressure has also been identified in Kelly's (2004) use of "popular opinion leaders" to deliver messages of safer sex and harm reduction to their peers. This theory, in particular, provides rationale for peer-based services because peers provide a type of persuasion through social control other modalities of service delivery cannot mimic.

#### **Peer-Based HIV Prevention Research**

In discussing the positive findings from a peer-based PwP program, one SPNS grantee said, "Knowing that peers influence desired program outcomes such as safer sex or safer injection practices is important. However, this information alone is insufficient to help other programs replicate proven prevention interventions" (Raja et al., 2008, p. 10). The aim of the present study is to collect thematic content from peer-based PwP program service providers and utilize it to accurately describe peer-based interventions in order to aid in future replication. It is important to note that while peer-based models are not yet proven "evidence-based" practices, they have gained some acclaim within the HIV field. HRSA has acknowledged that peers have been "integrated into every aspect of HIV/AIDS service delivery and...peers often can accomplish things that non-peers cannot" (HRSA, 2005, p. 1). Likewise, a survey of Ryan White CARE Act Title I (now termed "Part A") grantees lists the use of peer advocates in substance abuse outreach as "innovative" (Tobias, Wood, & Drainoni, 2006). Within the literature, peer-based counseling has emerged as an "increasingly viable option" in the provision of PwP services (Harris & Larsen, 2007, p. 843). One systematic review of the global research on the efficacy of peer-based interventions has recently been published (Simoni, Nelson, Franks, Yard, & Lehavot, 2011). These authors' assessment of the current literature base on peer-based HIV prevention interventions points to encouraging results when looking at self-reported outcomes measures of behavioral and cognitive nature, but they also stress the lack of empirical evidence to support for biological and health-related outcomes for such interventions.

While the research regarding the effectiveness of peer-based PwP interventions is still forthcoming, the literature does present evidence of successful peer-based models in *secondary* HIV prevention (i.e. prevention messaging aimed at HIV-negative individuals) both domestically (Dickson-Gomez, Weeks, Martinez, & Convey, 2006) and with highly marginalized populations internationally (Gao & Wang, 2007). Much has also been written about the effective employment of peers in reaching HIV-negative heterosexual women with prevention messages and safer sex strategies aimed at increasing condom and contraceptive use (Fogarty et al., 2001), with female intravenous drug users in interventions aimed at harm reduction approaches (Cabral et al., 1996), and more recently with HIV at-risk individuals living in rural communities (Hilfinger-Messias, Moneyham, Murdaugh, & Phillips, 2006). As peer-based programs continue to gain momentum and garner praise, there is now new evidence in the literature of attempts to adopt peer-based PwP messaging more routinely internationally, especially in sub-Saharan Africa (Lifshay et al., 2009; Simoni et al., 2011).

Unique Characteristics of Peer-Based Prevention with Positives Programs
In comparison with the provider- and specialist-delivered models of PwP
programs implemented through the SPNS initiative, peer-based interventions were found
to be the most patient-driven (i.e. client-centered) and comprehensive (Koester et al.,
2007). The literature on peer-based programming suggests a number of characteristics
completely unique to the peer-based model. These characteristics could, therefore, be
added to the key program characteristics in Tables 2 through 5 to more fully describe a
peer-based PwP program. Based on the rationale provided by Raja, McKirnan & Glick

(2007) these characteristics include the ability of peers to better understand obstacles, stigma, and isolation; to better evaluate the feasibility of a suggested behavior change strategy; to have fewer time constraints; and to be a source of credibility and motivation to the program.

Looking at all of the literature reviewed on peer-based interventions, two program characteristics stand out as perhaps the most significant contributions to quality programming. One of the main arguments in favor of peer-based services is the benefit of fewer time constraints, which one study referred to as peer-based services' unique capacity to be a "consistent presence" (Downing et al., 1999). In keeping with the importance of depth of rapport and duration of relationship as discussed earlier in this review of the literature, utilizing peers increases the likelihood that the prevention provider will be available and accessible to the client in his/her time of need. The reduction of time constraints was also noted by several other similar feasibility studies (Grimley, Backmann, Jenckes, & Erbelding, 2007; Morin et al., 2004). This characteristic is especially significant in comparison with provider-delivered PwP interventions. "HIV prevention efforts are often difficult for clinicians to emphasize in settings delivering comprehensive HIV care due to time constraints and competing clinical priorities" (Grimley et al., 2007, p. 38).

A second unique characteristic of peer-based programs is the incorporation of an empowerment message. Participants in peer-based programs often report feelings of hope and empowerment as a result of interacting with a peer (Downing et al., 1999). One of the current HRSA project sites chose a peer-based model because they have observed

that meeting with a peer "can be very reassuring...and present a real sense of hope" to their clients (HRSA, 2011, p. 4). Literature is also widely available regarding the mutual benefit of peer-based programs; that is, the characteristic of empowerment (as well as other related characteristics including understanding, friendship-building, and life purpose) is mutually beneficial for both the client and the peer provider (Sandstrom, 1996).

## Documented Benefits of Peer-Based Model

The first outcomes studies from the Special Projects of National Significance (SPNS) clinical sites have emerged in the literature only very recently. These studies do show support for the effectiveness of peer-based models of PwP interventions (Illa et al., 2010; Myers et al., 2010; Teti et al., 2010). In the first published article presenting the SPNS-wide outcomes data, Myers and colleagues (2010) state that the early outcomes show peer-delivered interventions to be essentially the same as health educator/social worker-delivered interventions. This same article also reports data indicating that peerbased models show strong positive outcomes after six months (although the effectiveness seems to decrease by 12 months). In Philadelphia's SPNS program, a multi-dimensional model was used to reach patients with PwP messages from medical providers, health educators, and peers. The outcomes data from that program at 6 and 18 months (Teti et al., 2010) shows strong positive results overall and particularly powerful qualitative data in support of the value of the peer-based component in particular. Likewise, one Chicago site of the SPNS project recently published the results of a randomized controlled trial which showed moderate positive effects for their peer-based program, especially looking

at outcomes related to transmission risk behaviors (McKirnan, Tolou-Shams, & Courtenay-Quirk, 2010). More outcomes data from these recent SPNS studies will continue to be published in the coming months.

Outside of the clinical settings reflected in the SPNS outcomes data, several additional small feasibility studies report findings that suggest peer-based interventions may be equally as effective as more traditional non-peer-based models (Broadhead et al., 2002; Nyamathi et al., 2001). Other studies and programs report findings that indicate the peer-based component of prevention services may actually lead to better health outcomes (Bettenourt et al., 1998; Harris & Larsen, 2007). One study concludes: "Interventions that employ peer leaders to endorse change may produce or accelerate population behavior changes to lessen risk of HIV infection" (Kelly et al., 1991, p. 168). The literature suggests several specific benefits of the peer-based model, especially for PwP programs. First and foremost, peers are uniquely equipped for the task. Perhaps the most profound statement to this effect in the literature is this one: "It is far easier to train most people living with HIV/AIDS for a particular skill than it is to help someone not living with HIV to understand the experience of those infected" (Roy & Cain, 2001, p. 430). Peers are uniquely equipped to be powerful conduits for HIV prevention planning and behavior change because "peer counselors can be receptive listeners who understand the struggles and lived experience of fellow consumers in a way that non-consumer professionals cannot" (Brown, Shepherd, Merkle, Wituk, & Meissen, 2008, p. 176). In addition to being uniquely equipped, peers are also able to intercede in people's lives in ways that have been documented to alleviate or overcome life's complexities. One

peer-based youth HIV organization "has found that when young people are brought together to help one another and to mentor their peers, living with HIV becomes more manageable" and their peer-based services have been evidenced as an essential "entry point into the HIV/AIDS service system" (Bettencourt, et al.,1998, p. 28). Another peer-based HIV prevention program targeting African American heterosexual women in an urban area also identifies "the complexity of interpersonal, cultural, gender, and socioeconomic factors contributing to African American women's self-efficacy and practical ability to manage HIV/AIDS" as meriting "the inclusion of peer educators" (Downing et al., 1999, p. 244). Peers have more time and more familiarity with the complexity of life with HIV/AIDS, making them effective catalysts for behavior change and attitudinal improvement.

Peer-based programs also enhance the quality of life and social support of people living with HIV/AIDS. A study of 118 HIV-positive patients in Venezuela showed a significant relationship between health-related quality of life (HRQL) and social support. (Bastardo & Kimberlin, 2000). Three additional studies also support this claim (Friedland, Rewick, & McColl, 1996; Nunes, Raymong, Micholas, D'Meza-Leuner, & Webster, 1995; Sowell et al., 1997). The importance of peer-based services and relationships with peers for HIV-positive individuals has been described by one researcher this way:

For most of the rest of their lives after becoming infected, HIV-seropositive individuals are clinically asymptomatic or have mild, non-specific and easily manageable signs and symptoms. However, the social framework in which they live is continuous and is perhaps the major determinant of quality of life, and ultimately serves as either a facilitator or barrier to good clinical care. Peer

counseling is an effective strategy for helping patients overcome some of these barriers (Anderson, 1996, p. 2).

Peers as a source of social support have been associated with the ability to manage uncertainty and provide HIV prevention information as well as "ventilation" (Brashers, Neidig, & Goldsmith, 2004), also referred to as acting as a "sounding board" (Adelman & Frey, 1997; Albrecht & Adelman, 1987). Social support is also critical because research shows a strong link between quality social relationships and improved physical and mental health (Beckman, Glass, Brisette, & Seeman, 2000).

Interestingly, peer-based programs have been found to be mutually beneficial for both the provider and receiver of services in terms of social acceptance, support, and empowerment and personal growth (Marino et al., 2007). While the present study is most concerned with program outcomes for the receivers of services, this additional benefit to those providing the services remains noteworthy.

# Documented Challenges of Peer-Based Model

The literature also includes references to several challenges and obstacles inherent in implementing a peer-based model of PwP services. Future researchers' attempts to provide applied research toward the replication of peer-based PwP programs must consider these challenges in order to anticipate and prepare accordingly. Perhaps the most significant challenge documented in the literature is the intensive supervision, training, and support that such programs require for peer-based staff (Bettencourt et al., 1998; Downing et. al, 1999; HRSA, 2005; Koester et al., 2007; Marino et al., 2007; Raja et al., 2007; Raja et al., 2008). Training and supervision specifically addressing issues of

professionalism, grief and loss issues, and time management are the most commonly documented needs. Peer staff also often exhibit difficulty in maintaining appropriate boundaries in the helper/helped relationship (HRSA, 2005; Raja et al., 2008). Additional obstacles documented in the literature include the recruitment of competent peer staff (Raja et al., 2008; Roy & Cain, 2001) and the rate of peer staff turnover (Bettencourt et al., 1998).

Another potential challenge of a peer-based model of service delivery is that such a model adds an "extra stop" for patients (Grimley et al., 2007) who would have to speak with multiple service providers during a single clinic visit, versus a "one-stop-shop" model of physician-delivered prevention messaging. HRSA (2005) also points out the challenges associated with hiring HIV-positive individuals, given their sometimes unpredictable health status and the potential loss of public benefits due to increased income.

In conclusion, regardless of the challenges associated with the peer-based model, the aforementioned benefits and the early research on PwP program implementation suggest peer-based PwP interventions are a viable option worthy of additional research, dissemination, and replication.

#### CHAPTER THREE

#### METHODOLOGY

This chapter presents a detailed description of and rationale for the current study's methodology. Beginning with a review of the study's two main research questions, this chapter first presents an initial justification for this study's methodology based on the literature. This is followed by a description of the sampling strategy utilized. I then provide specific definitions for key concepts in the study as well as the conceptualization of its primary dimensions/variables. The Data Collection section provides an overview of the Interview Tool as well as an outline of the interview procedure. Finally, the methods employed for the analyses of the data (both quantitative and qualitative) are presented as well as a rationale for the inclusion of Chapter Four, which sets up the study through a contextual, holistic approach to understanding the sample.

## **Research Design**

Currently, there is a push in the field of HIV toward evidence-based interventions, which often take the form of "boxed" interventions dictated by funders. My personal experience with this trend and my resulting belief that more than quantitative approaches are necessary served as the impetus for this study. Carter and Little (2007) write of the need for rigorous qualitative research components to counterbalance the evidence-based movement:

The urgency around quality and synthesis results in part from the rise of the evidence-based medicine movement, which promotes the use of standardized

assessment criteria and checklists, and the resulting concern of qualitative researchers that inappropriate measures will be used to evaluate their work (p. 1316).

Toward that end, a mixed-methods methodology was chosen for this study in order to offer an innovative balance between evidence-based practice and qualitative, process-oriented research. The experiences and perceptions service providers shared in interviews regarding the implementation and delivery of peer-based services were systematically analyzed using an inductive approach (see Data Analysis section) in order to paint an accurate picture of staff experiences, which could then be used to form a foundation for suggesting peer-based best practices for future service delivery.

As stated in Chapter One, the research questions guiding this study are:

- 1) To what extent do peer-based models of HIV service delivery adhere to an established set of program characteristics of Prevention with Positives (PwP) interventions?
- 2) What are the experiences of peer-based PwP program staff in terms of implementation and provision of peer-based services?

It is important to note that these research questions do not aim to establish causality or engage in program evaluation. Instead, the methodology derived from these questions is a mixed methods approach aimed at systematically understanding how well the peer-based model may fit the provision of PwP services, culminating in a presentation of well-established and legitimate implications for funders and agencies interested in replication.

The methodology utilized in this study hinges upon a set of semi-structured phone interviews with service providers in peer-based PwP programs nationwide. There are

both quantitative and qualitative aspects of the Interview Tool. The quantitative components of this study primarily address the first research question: *To what extent do peer-based models of HIV service delivery adhere to an established set of program characteristics of Prevention with Positives interventions?* As described in the following section on the Conceptualization of Variables, the quantitative variables included in the interviews are derived from answers to questions about key program characteristics as described in the literature on PwP services (see Tables 2 through 5 in the Literature Review). Interviewees were asked to consider if, how, and why their peer-based PwP programs do or do not incorporate each of the established key program characteristics. Interviewees were also asked to share their own "practice wisdom" regarding how important they have found each of these key characteristics to be in their work.

Responses in this section of the interview were quantified in this section of the interview via Yes/No responses as well as a 10-point scale assessing perceived level of importance for each program characteristic.

Qualitative data in this study address the second research question: What are the experiences of peer-based Prevention with Positives program staff in terms of implementation and provision of peer-based services? The use of semi-structured interviewing to address this aspect of the study reflects my commitment to the aforementioned ontology emphasizing the value of "practice wisdom" as well as the literature's emphasis on the subjective nature of PwP program outcomes. (See the Philosophy of Research section in Chapter One.) The qualitative approach to this study allows for a better understanding of programs as they actually occur, rather than as they

relate to a prescribed model (Carter & Little, 2007; Schwandt, 2001). The interview process was intentionally organic, approaching each interview as a "guided conversation" (Grinell & Unrau, 2005, p. 248).

# Support for Methodology in the Literature

Within the field of program evaluation, especially at a community-based level, the need for strong methods of rigorously assessing and describing programs at the point of implementation is well-documented. One meta-analysis of this literature base (Durlak, 1998) summarizes two overarching themes: 1) implementation varies greatly from one program to another, and 2) the process of program implementation has major implications for outcomes and evaluation. The primary suggestion to implementation researchers is to begin with clear operational definitions for as many program characteristics or components as possible, which enhances the likelihood of program fidelity (Mowbray, Holter, Teague, & Bybee, 2003). The use of established key program characteristics throughout this present study does exactly that. The method of engaging service providers in a process of describing their own programs has also been suggested in the literature as a means of avoiding Type III and IV errors in understanding programs' processes and outcomes (Scanlon, 1997). Type III errors generally refer to instances where program evaluation research incorrectly attributes a programs' outcomes to an intervention, thus fitting a solution to a problem. Type IV errors are also common in program evaluation research and are best described as instances where researchers and service providers believe a solution works when it does not.

Outside of the Special Projects of National Significance (SPNS) process evaluation research, most HIV primary prevention research to date has focused on individuals as the research subjects (either receivers or providers of peer services); most often, this research and its findings are reported out of a methodology weighted heavily upon qualitative interviews with program participants (Downing et al., 1999; Harris & Larson, 2007; Marino et al., 2007). While research of that nature has certainly furthered the depth of knowledge on PwP programs and peer-based services specifically, the methodology of this present study takes a different approach by focusing on PwP programs as the unit of analysis.

Mitchell et al. (2005) utilized a program evaluation model which included heavy reliance on logic models to distinguish between program outcomes and outputs. Their study pointed to the importance of qualitative *and* quantitative measures of PwP program effectiveness, especially given the unique nature of PwP desired outcomes. They stressed the challenges of program evaluation since most PwP program outcomes are subjective and self-reported (e.g. behavior change, reduction of sexual risk, etc.). The decision to include a chapter on Contextual/Holistic Analysis (see Chapter Four) comes as a direct result of the caveats Mitchell and colleagues provide.

Semi-structured interviews have been utilized by other HIV researchers throughout the early process of PwP implementation and evaluation research.

Kirshenbaum and colleagues (2007) conducted qualitative focus groups with 12 facilitators of one HIV prevention intervention in order to identify implementation challenges and discuss key components of the program. In their mixed-methods study,

Morin and colleagues (2004) utilized qualitative in-depth interviews of program staff in order to place the quantitative data from more than 618 exit interviews of clients into context. And, in a study perhaps most similar to the one being proposed here, Koester et al. (2007) published findings from 61 in-depth interviews (primarily qualitative in nature) which addressed challenges and lessons learned in the implementation of some of the earliest SPNS grantees' PwP interventions. The wording of several of the present study's questions regarding program characteristics are modeled after the interview tool used by Koester and colleagues.

The PwP literature also captures considerations regarding measurement and evaluation accounted for in the present study's design. Researchers have documented the need to gain insight into the actual program intervention in order to be able to truly assess its merit and outcomes. One such study suggested that a formal process evaluation methodology of "successful HIV prevention interventions [is] necessary to understand how and why such interventions work" (Dickson-Gomez, et al., 2006, p. 669). Similarly, other researchers have utilized a "project ethnography" approach to see what *really* occurs in interventions; they have found that "observation of actual intervention practices can reveal divergence and convergence from intervention theory or planning documents" (Evans & Lambert, 2007, p. 467). The semi-structured interviews in this present study aim to allow service providers a forum to present their programs clearly and accurately in their own words.

# **Population and Sampling Strategy**

The present study utilized a combination of purposeful and snowball sampling. While such an approach to sampling was necessary because no sampling frame (i.e. a comprehensive list of peer-based PwP programs) exists, this technique was also used to select expert informants based on their unique ability to speak about the issue at hand. Sampling began with evaluators from the Enhancing Prevention with Positive Evaluation Center (EPPEC) at the University of California at San Francisco. EPPEC houses the researchers responsible for the initial SPNS findings from the PwP programs in clinical settings. EPPEC provided contact information for the four peer-based programs which were a part of the 2003 SPNS initiative. These four programs are geographically unique – Chicago, Miami, Boston, and Philadelphia. When contacted, three of the four SPNS programs agreed to participate, and each agency also provided me with information about any other peer-based PwP programs they were aware of. Those agencies were contacted, and so on. I also contacted with peer-based PwP programs I was personally aware of, and several of those programs also furthered the "snowball."

Table 6: Identified Peer-Based Prevention with Positives Programs

Programs	Refused	No Response	Participated	Rate of
Identified				Participation
17	2	8	7	42%

A set of Eligibility Screening Questions (see Appendix A) was used to ensure a program met the study's definition of peer-based PwP programming. Table 6 shows the number of programs identified as eligible for inclusion in the present study, as well as the rate of recruitment for participation. It should be noted that the "universe" of peer-based PwP programs is dynamic; since the time of this study's recruitment phase, several new

programs have been implemented (under the most recent SPNS cycle) and others have ended due to reduction in funding. All 17 identified peer-based PwP programs were contacted for participation in the study. Forty-two percent of those programs completed participation in the present study. Taking into consideration aspects of study feasibility as well as desired rigor, I aimed to gain cooperation from as many peer-based PwP programs as possible; however, a 100% rate of participation was never expected, especially given the busy schedules of service providers and the lack of incentive for study participation. The goal of the sampling process was to ensure enough diverse and experienced program staff were included to allow the study's findings to be illustrative of the wider universe of peer-based PwP programs; such an illustrative sample does not afford a level of statistical generalizability, but does present opportunity to describe what this type of service provision can be (Mason, 2002). This theoretical generalizability is discussed further at the conclusion of Chapter Six. In a later discussion of the study's limitations, I acknowledge the possibility of selection bias in terms of what programs were included in what programs may be absent from the sample.

Consent for participation in the study was requested first from the program administrator. The consent process required program administrators to grant me access to multiple levels of staff as informants for the interviews; only programs willing to provide a minimum of one administrator, one program supervisor, and one direct service provider/peer were chosen for study participation. Therefore, the sample of seven programs resulted in a total of 21 individual interviews conducted as a part of this study. Table 7 provides an overview of the demographic breakdown of the 21 informants.

Reasons for multiple levels of staff interviews included: increasing the sample size through multiple interviews per site, ensuring accurate representation of the program,

Table 7: Description of Informants

Characteristic	Number (N = 21 informants)	
Gender		
Male	12	
Female	9	
Race/Ethnicity		
Caucasian	8	
Hispanic	5	
Asian	1	
African American	7	
Education Level		
High School	2	
Some College	6	
Bachelors	4	
Masters	6	
Doctorate	3	
Average Length of Time Employed at		
Agency:	7.2 years	

strengthening findings through the triangulation of data, and allowing for exploration of differences in perceptions and experiences based on staff type.

This sampling strategy and the resulting sample size of seven programs with informant interviews from multiple levels of staff are well-supported and justified within the literature. Janice Morse (2000) succinctly summarizes four factors a researcher should consider when determining sample size in studies like this one. Those factors are:

(a) scope and design of the study, (b) nature of the topic, (c) quality of the data, and (d) use of shadowed data. Regarding the *scope of the study*, Morse suggests that the more focused a research question is the fewer cases one needs for sample size. The first of this study's research questions—rooted in established literature and asking about an already

determined set of 19 program characteristics—was specifically focused to account for the small sample size by triangulating the study's findings with existing information. Regarding the *nature of the topic*, Morse discusses the need for sample size to be larger in instances where the topic is less obvious or hidden. If this present study had aimed at understanding PwP program outcomes, I would most certainly have needed to derive a larger sample; the focus of this study, however, is on implementation and practice, which can be seen as much more accessible and tangible elements. The exploratory, rather than hypothesis testing, nature of my approach to this study also allows for a smaller sample size (Small, 2009). Regarding the *quality of data*, Morse urges the researcher to anticipate the likelihood that some interviews will go poorly and result in unreliable data; this is one of the reasons I chose to interview multiple levels of staff at one agency. Finally, Morse describes the value of *shadowed data*, which she defines as interviewees reporting on "the experience of others, how their own experience resembles or differs from others, and why" (2000, p. 4). She suggests that the use of shadowed data can make the case for a smaller sample size. The present study includes an aspect of shadowed data given the framework of pre-established program characteristics used to understand informants' experiences.

# **Conceptualization of Variables**

As opposed to a traditional approach to variable conceptualization (which would identify and objectively operationalize and set up measurements for the dependent variable, independent variables, and perhaps even intervening variables), I instead define and describe the study's "key concept" (Grinell & Unrau, 2005) and the "dimensions"

through which to measure that concept. This conceptualization fits more appropriately with the exploratory and qualitative nature of the study's aims.

# Key Concept

The key concept in this study is the understanding of staff perceptions and experiences in providing peer-based Prevention with Positives services. As such, several terms had to be defined for this study.

# Prevention with Positives

As noted in Chapter One, HRSA (2005) defines PwP programs as those HIV prevention programs targeting HIV-infected individuals which lead to: a) reduced risk of transmission of HIV to non-infected individuals (measured by marked behavior change in individuals' safer sex practices and in increased efforts toward partner notification of HIV-positive status), and b) reduced rates of opportunistic infections among HIV-positive individuals. Therefore, for the purposes of determining programs eligible for participation in this study, any program with the above aims was considered regardless of their funding streams. This meant that eligible programs may or may not use PwP language to define themselves. The Eligibility Screening Questions (Appendix A) were developed to aid in determining the fit of the program with this study's inclusion criteria. *Peer-Based* 

# This study also requires a clear articulation of what it means to be a "peer-based" program. A "peer" is defined as an individual living with HIV who is demographically similar to those clients being served and is utilized by the agency (either paid or volunteer) to provide services to other individuals living with HIV. As one researcher on

the benefits of peer-based services points out, "peer-based" can mean different things in different agencies, which can lead to vague program integrity (Kelly, 2004). It is important to distinguish between an *intentionally* peer-based program and a program in which one or more of the case managers simply happen to be HIV-positive. Given the differences among peer-based programs, Chapter Four has been included to acknowledge and capture the diverse ways in which the peer-based model can be applied.

## Dimensions/Independent Variables

While the terminology of independent variables aligns well with the quantitative section of the interview (which addresses the level of "fit" between established PwP program models and the peer-based model), I find that the primarily qualitative nature of the interview (focusing on the perceptions and experiences of service providers) is better conceptualized by referring to the dimensions under investigation. The complete Interview Tool can be found in Appendix C.

Fit with Established Key Program Characteristics

The previously presented thorough review of the literature yielded an extensive set of program characteristics associated with established PwP interventions. These key program characteristics are clearly listed in Tables 2 through 5 in the Literature Review in Chapter Two. These characteristics were used as the basis for evaluating the fit of peer-based program models. Interviews began with a quantitative section, in which the informant was asked whether or not their program includes each of these characteristics (a Yes/No response) and then how important he or she perceived each of these

characteristics to be for a successful peer-based PwP program (a 1-10 rating). See Appendix C for the full Interview Tool.

Staff Experiences

The qualitative component of the interviews aimed to engage interviewees in a process whereby they could articulate in their own words how their peer-based programs were implemented and how they function. As Kelly (2004) states, qualitative interviewing holds value because researchers "must examine peer-based programs' functioning much more closely to determine whether it is likely to have an impact on members of the target population" (p. 141).

Open-ended interview questions asked informants about the nature of their program and their perceptions of the uniqueness of the peer-based model. Informants were also asked to share both positive and negative experiences of clients through stories from their practice. Appendix B is an Interview Preparation Document, which was sent to informants prior to the scheduled interview. Selections from these open-ended questions were provided ahead of time so that the informant might begin to think and formulate their responses ahead of time. Many of the interview questions were developed and modeled after existing interview tools utilized by SPNS evaluators (Koester, et al., 2007; Morin, et al., 2004).

#### **Data Collection**

The Interview Tool (Appendix C) consists of both open- and close-ended questions covering the following areas:

• Fit with PwP program characteristics – measured by Yes/No and 1-10 ratings

- History and current status of the program
- Experiences garnering agency buy-in for the peer-based model
- Expansion upon any program characteristics ranked exceptionally high or low on the
   1-10 scale
- Positive experiences and perceptions of the peer-based model
- Challenges associated with the peer-based model
- Advice for other agencies considering implementing a peer-based program
- Definitions and ways of measuring program success
- Demographic data on informants—limited to position title, length of employment,
   gender, race/ethnicity, and education level

Interviews were conducted via telephone and lasted an average of 30 minutes. Interviews were audio recorded and transcribed by a graduate research assistant. Completed transcriptions were shared with the informant via email; while not a requirement of study participation, I welcomed feedback and clarification from the informant regarding what was said during the interview. This process of "stakeholder checks" in qualitative research enhances the credibility of the findings (Thomas, 2006) by allowing participants to clarify comments and even add to their initial interview as they feel so inclined. This step, while a bit time-consuming, reflects my commitment to collaborative research and the importance of accurately representing the practice wisdom of service providers. Upon completion of the transcripts, quantitative data was managed in Excel while qualitative data was managed using Atlas-ti.

# **Data Analysis**

#### Quantitative Data

In response to the first research question (*To what extent do peer-based models of HIV service delivery adhere to an established set of program characteristics of Prevention with Positives interventions?*), the quantitative data were analyzed in two ways. First, informants' Yes/No responses to each of the program characteristics were analyzed to determine level of fit based on percentages for each program characteristic and an overall percentage of fit. Second, descriptive statistics were utilized to analyze the level of perceived importance for each program characteristic. The level of analysis for the quantitative data is the program, thus there is an *N* of seven programs. The data presented was analyzed by taking the average of informant responses for each of the programs in the sample. Given the small sample size, very little can be concluded with regard to variation in program characteristic responses by level of staff (i.e. do peers rate certain characteristics as more important that administrators?). However, the research does cautiously present some such data because implications may exist for future research.

# Qualitative Data

There are numerous ways in which to conduct qualitative data analysis; the strategy chosen for this study is one similar to what Thomas (2006) called the General Inductive Approach. The inductive approach was selected for its fit with this study because this study *is* guided by specific objectives, hypotheses, and research questions (as opposed to traditional qualitative grounded theory studies). Thomas states that a General

Inductive Approach is most appropriate when the goals of a study are to: (a) condense textual data into summary format, (b) establish clear links to the study's objectives and the summary of textual findings,; and (c) develop a framework of the experiences or processes the data indicate. I conducted this study with exactly those ends in mind. Therefore, the General Inductive Approach provided me with the best means by which to analyze informants' responses in a way that valued each person's perspective and accounted for the nuances of the practice wisdom and program characteristics they described.

Qualitative data analysis centers around the interpretation of raw textual data into categorical coding. Utilizing the coding features in the Atlas-ti software, qualitative data are analyzed through cross-sectional indexing. That is, the text of interviews is read as a whole and thematic content is categorized in order to provide "analytic handles" (Mason, 2002, p. 153) upon which to base the study's finding. The coding method is holistic, rather than structural or question-based (Saldana, 2009) since themes emerge in the course of organic conversation rather than in response to one specific question at a time.

Recognizing the tendency toward interpretive bias which is common in categorical coding of qualitative data, I took several protective measures. First, the incorporation of the stakeholder checks (described previously as a means of soliciting feedback and quality checking of the interview content by providing the interviewees with transcripts of their interviews to be reviewed and approved) provided some element of protection against such bias, especially related to what was said in the interview. This method of reflecting preliminary data back to informants is well-supported in the fields of

community-based, collaborative, and participatory action research (Nyden, Figert, Shibley, & Burrows, 1997; Patton; 2002). Secondly, I enlisted feedback and assistance during the qualitative coding process from a colleague with experience in qualitative research coding and the Atlas-ti software. Adding an additional person to review transcripts and brainstorm categories greatly enhanced the validity of the study's findings by reducing the chance of interpretive bias. A second coder reviewed and independently coded 20% of the total interviews using my existing codebook. Upon comparison, the rate of intercoder reliability was initially 83% and increased to 92% after discussion and a few minor adjustments to the codebook. These achieved reliability rates are consistent with the benchmarks for quality generally recommended in the field of qualitative research (Miles & Huberman, 1994).

## Mixed-Methods Approach to Data Analysis

The approach I have taken to integrate the quantitative and qualitative aspects of this study aligns with what Mason (2006) writes about as "mixing methods in a qualitatively driven way" (p. 9). As such, the quantitative and qualitative analyses occur independently, more of a model of multi-nodal analysis than true "integrated mixed method analysis." I find that the multi-dimensional nature of explaining peer-based PwP programs requires quantitative elements in order to measure program fidelity via a set of established program characteristics and qualitative elements to account for the variation in the practice wisdom of individual informants.

Caracelli and Greene (1993) suggest that the use of mixed methods approaches to research can serve several key purposes, including: triangulation (corroboration of data

across different methods), complementarity (the measurement of overlapping facets of a phenomena), and expansion (increasing the breadth and range of inquiry). The process of "typology development" fits best with the strategy of analysis utilized in this study. In Typology Development, "the analysis of one data type yields a typology (or set of substantive categories) that is then used as a framework applied in analyzing the contrasting data type" (Caracelli & Greene, 1993, p. 197). Such integration of data types ensures a level of *complementarity*.

This Typology Development approach is seen most clearly in this study's data analysis in the way the qualitative thematic content was coded to reflect the categories of the program characteristics the quantitative analysis relied upon. For example, the informant's ratings (1-10) to the question "How important is...to the peer-based model?" were often expanded upon in the context of the "guided conversation" which followed. This *triangulation* of the data enhances the validity and quality of both the qualitative and quantitative contributions of the study, as combined they yielded even more powerful insights than could have been achieved if each were used separately from the other. This type of data analysis integration also accounts for the ways the qualitative and quantitative elements can enhance each other and enrich the study through the *expansion* of its reportable findings.

# Contextual/Holistic Analysis

Prior to presenting the quantitative and qualitative findings (Chapter Five), a chapter has been included which provides a more contextual, holistic approach to the analysis of the programs included in this study. Mason (2002) presents the value of

coupling traditional cross-sectional data analysis with contextual analysis to address "the limited explanatory potential of cross-sectional data organization for many of the questions about social process, and interpretive and qualitative complexity with which qualitative researchers frequently wish to grapple" (p. 168). As I listened to informants describe the nature of their peer-based programs, it became evident that much variation exists with regard to how peers are utilized in each agency's program. Chapter Four presents aggregate program data by way of describing the overall sample and also includes "snapshot" descriptions of each program. These snapshots and the contextual discussion serve to paint a broad picture of what a peer-based program can look like in practice, using a "qualitative logic of comparison" (Mason, 2006, p. 16). By describing the breadth of options for incorporating peers in this way, I aim to account for the "wider universe," capturing the idiosyncratic nature of each program. This chapter will be especially valuable to anyone considering implementation of a new peer-based PwP program, as it allows for a "sense of distinctiveness" (Mason, 2002, p. 165) not necessarily reflected in the cross-sectional analyses which follow.

#### **Ethical Considerations**

# Confidentiality

This study was given "exempt" status by the Institutional Review Board at Loyola University – Chicago after they deemed the nature of the study to be more in line with program evaluation than human subjects research. This determination was made because no identifying information about clients/patients was requested. The informants who participated in interviews were asked only for demographic information which does not

identify them (i.e. race/ethnicity, education level, gender, and employment status). At the beginning of each interview, a Consent Script was used to obtain a verbal assent of the informant's informed consent to participate in the study. The Consent Script may be found in Appendix D.

Throughout the presentation of findings and discussion, I have maintained the anonymity of both the informants and the programs themselves to the best of my ability. No program or service provider names are reported in the study findings. Additionally, it is important to note that the various levels of service providers interviewed were also ensured that the confidentiality of their comments would be maintained when speaking with co-workers. Each informant was interviewed individually, and their comments were not shared with other informants from the same program. This was particularly important to ensure that direct service providing peers felt free to share their honest opinions without concern that their supervisors would be aware of their responses.

## Diversity and Vulnerable Populations

I specifically designed this study with a focus on programmatic-level data, in part to protect the confidentiality of persons living with HIV, an often vulnerable and stigmatized population. Participating programs represent a diverse selection of agencies especially with regard to target population (e.g. women with HIV, African American, Latino, and men having sex with men (MSM).

#### Risks and Benefits

This study did not provide incentives to informants or survey respondents or participating agencies. It is my experience that the HIV service provider community has

a history of openness and curiosity toward research, especially if they believe the research will benefit the community at large. Problems with recruitment did not necessitate incentivizing. Because the nature of interview content focuses primarily on programmatic-level data, there were no significant risks associated with participation in this study.

#### CHAPTER FOUR

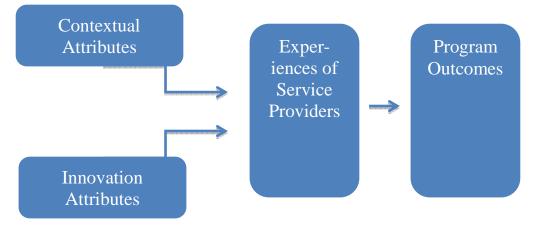
# HOLISTIC, CONTEXTUAL ANALYSIS: DESCRIPTION OF PROGRAMS

As study informants began to describe their peer-based Prevention with Positives (PwP) programs, it became clear that every peer-based PwP program is unique. In the sample of programs included in this study, much diversity exists in terms of program design. Kelly (2004) makes a similar observation, stating that peer-based programs each take slightly (or sometimes entirely) different approaches to their chosen program design; he stresses the critical need, therefore, for researchers to carefully examine how each peer-based program actually functions in order to: (a) ensure common understanding as to what "peer-based" means, (b) capture the range of options available for incorporating peers, and (c) account for program fidelity. It is important to note that the issue of ensuring program fidelity among HIV PwP programs in general has been thoroughly addressed by the Centers for Disease Control (CDC) in their procedural guidance to agencies (CDC, 2009). That guidance offers a set of core program components of PwP evidence-based interventions as well as a discussion of how agencies can go about adapting the interventions for their unique agency contexts and populations.

This chapter is dedicated to holistic, contextual analysis of the programs in the study's sample in order to account for the versatility and diversity among the sample's participants. As explained toward the end of the previous chapter, employing contextual analysis as a method of social services research allows for a thorough description of the

programs in this study's sample as a means of understanding the context in which each of the programs each operate. Contextual analysis is often coupled with more traditional cross-sectional qualitative data analysis (see Chapter Five) when small samples of programs are being used to draw "theoretical generalizations" regarding the larger "universe" of similar programs (Mason, 2002, p. 122). Especially given the wide range of program design and setting variation among peer-based PwP programs, the contextual analysis in this chapter is crucial to understanding the peer-based model and establishing implications for future peer-based programming based on the practice wisdom of the 21 informants who took part in this study. Figure 1, below, illustrates this rationale for contextual analysis. Contextual attributes and attributes of the innovation

Figure 1: Rationale for Contextual Analysis (Adapted from Meyer & Goes, 1988)



combine to impact the experiences of service providers and, ultimately, the outcomes of the program. Chapter Five provides thorough data analysis which accounts for the "innovation attributes." This chapter aims to put those program characteristics *into context* by providing a detailed description of each of the seven programs in the sample. As such, the contextual analysis in this chapter is not intended to read as an outcomes-

focused discussion. The ultimate aim of this chapter is to illustrate the diversity in this study's sample with regard to program context, which may be particularly informative for current and future peer-based service providers considering replication of similar program models.

This chapter begins with program "snapshots"; these are descriptions of each program's setting and design. To preserve the anonymity of the programs, no actual agency or program names are included in these descriptions, and I have included as much information about the model of the program as possible without identifying them. These data were collected both through the actual interviews with service providers as well as through additional direct communication with the program supervisors via phone and/or email to collect some programmatic information. Following the seven snapshots, Table 8 provides a concise summary and comparison of the seven programs side-by-side. Table 9 displays some additional data analyzed in aggregate as a way to understand the "average" program as well as the variation in terms of program size, budget, and history. The chapter concludes with a discussion of themes and important observations gleaned from the contextual analysis of the seven programs included in this study.

## **Program Snapshots**

## Program A

Program A operates out of a large hospital system in a major metropolitan area.

The hospital system offers a comprehensive range of medical and support services, and has a twenty-year history of providing HIV primary care services. As such, the hospital as a whole—and the HIV department specifically—has a history of participating in

federally-funded health services research. The peer-based PwP program began as a funded program under the 2003 SPNS grant cycle, which focused on PwP programs within clinical settings. As one of fifteen sites in the SPNS research initiative, the hospital utilized a program design combining provider-driven messaging and peer-based messaging. Upon the conclusion of the SPNS funding cycle in 2007, the peer-based branch of the PwP program was continued with some slight adjustments to program design.

As of 2011, Program A targets HIV-infected women. One peer facilitates weekly group sessions open to all HIV-infected women seen in that clinic. Originally designed as a five-part series, the number of group sessions constituting the program has been reduced to three since the original funding ended. The first session covers basic HIV education, the unique impact of HIV on women, and an initial discussion about behavior changes that would reduce the likelihood of transmitting HIV to their partners. The second meeting is specific to male and female condom use and negotiation, with additional discussion of female biology and the unique considerations for HIV transmission to women. The final session is a discussion of partner disclosure, as well as risk reduction goal setting, maintaining optimal physical health, and healthy relationships. While the group session content for Program A was originally outlined in a fairly scripted manner (including weekly session information, video clips, group discussion questions, etc.), the peer facilitator of the group currently allows for the inclusion of participant-driven topics, as needed. The peer who currently facilitates the women's support group has been doing so since 2003, which gives her the perspective to

know what will work best during a given session depending on what the women need to cover. She also frequently maintains contact with women after they have attended the three sessions, and many women choose to continue attending the group, regardless of the planned three-session format.

Program A strives to integrate the group within the comprehensive model of HIV services the hospital offers. The peer facilitator has the ability to aid women participants in scheduling their medical appointments as well, and she often schedules primary care appointments either immediately before or after the group session for their convenience. The medical providers are familiar with Program A and often ask the peer facilitator to follow up with women on specific issues they are facing. The ultimate aim of Program A is to empower women living with HIV by providing them with educational material and promoting behavior change through empowerment that can positively impact their lives.

## Program B

Program B operates out of a large hospital system in a major metropolitan area, a setting very similar to that of Program A. Their peer-based PwP program also began as a funded program under the 2003 SPNS grant cycle, which focused on PwP programs within clinical settings. Also similar to Program A, as a SPNS research program, the hospital utilized a program design which combined provider-driven messaging and peer-based messaging. Upon the conclusion of the SPNS funding cycle in 2007, Program B was closed due to lack of funding. The snapshot of the program below describes Program B as it was in 2007.

The PwP intervention designed under the SPNS demonstration project included two arms of service: one peer-facilitated and one specialist-facilitated. Upon entry into the program, patients completed a computerized HIV transmission risk assessment survey, which assigned them to one of two categories based on their responses: low-risk or high-risk. Patients categorized as low-risk were assigned to the peer-based arm of the study. Peers were well-integrated into the multi-disciplinary team, attending regular meetings alongside case managers, social workers, and medical providers. The three peers employed by Program B focused on the provision of sexual health information and patient support through individual meetings with patients.

Peers met with patients in one-on-one sessions over the course of a year. Four sessions took place within the first three months, and then follow-up sessions occurred quarterly for the remainder of the year. The content of these sessions with was based on eight scripted modules from a manual, which covered a range of topics including HIV information, risk reduction, sexual behavior and health, and partner disclosure as well as special topics like substance abuse and domestic violence. Patients were given the choice of which modules to cover, based on how relevant they felt the content to be; only the module on sexual behavior and health was mandatory. The module on partner disclosure was the most frequently selected module. Quarterly follow up sessions also included the collection of blood work specific to STI co-infections, a measure of program success because it was a proxy for not having engaged in unprotected sex.

Messaging was delivered from a self-care, non-judgmental perspective, focusing on information that shaped healthy behaviors among patients and could result in the

patients being more likely to engage in behaviors that did not risk HIV transmission with their partners. The spectrum of assistance offered ranged from helping participants navigate risky encounters to serving in a general supportive role, which Program B saw as a unique benefit of the peer-based model. Those who observed Program B saw the peer providers as the key component of the program. According to clinic administration, the peers were well-respected, and many patients told program staff that it was the peer who kept them engaged in the program.

### Program C

Program C also originated out of the 2003 SPNS demonstration projects. The setting for Program C was a medium-sized hospital located in a high-risk neighborhood in a large urban environment. This peer-based PwP program was also closed at the conclusion of the SPNS funding cycle due to the inability to sustain the model through other funding sources. The snapshot of the program below describes Program C as it was in 2007.

The design of the SPNS intervention included a comparison group and an intervention group. All enrolled patients completed a computerized assessment of their HIV knowledge, including HIV prevention-related topics; this assessment also included educational modules on a range of HIV prevention topics. The control group received only the computerized content. The experimental group, however, also met with a peer provider multiple times on an individual basis. Peer providers were thoroughly trained in the computerized modules and were able to utilize the patient's responses to the survey to tailor the content of their conversations.

Program C employed two peer providers who were hired specifically to reflect the high-risk demographic of the hospital's patient base. As much as possible, program staff matched patients with the peer most similar to the patient's demographics. The peers, who were trained in motivational interviewing and HIV prevention counseling, used the scripted content from the written curriculum modules as a starting point to continue a personal dialogue with the patients. The rapport that developed between the patients and peers often resulted in conversations that continued outside of the formal sessions. The peer's sessions with the client bridged the gap between information covered in the modules and questions patients may not have felt comfortable raising with their health care providers with. Program C was seen by the peer providers and the program's supervisors as an extension of the care patients received from the hospital as a whole.

## Program D

Program D functions within the context of one of the nation's largest HIV clinics, a stand-alone clinic affiliated with two major hospital systems in a large metropolitan city. The clinic has been providing HIV and infectious disease care to more than 1,200 patients annually for nearly 15 years. The clinic's services are viewed in the city—and the nation—as exemplary. The clinic strives to remain on the cutting edge of HIV service provision and has a history of participating in HIV research funded by all of the major federal agencies.

While the clinic offers a full range of HIV services, including several programs which utilize peers in some capacity, Program D incorporates peers specifically through the Patient Navigators model. This model originated in the field of breast cancer support

services and recently has been adapted and incorporated into a number of other medical settings including HIV (Bradford, Coleman, & Cunningham, 2007). The aim of patient navigation is increasing the comfort level of the patient by providing him or her with a fellow patient who can help orient him or her to the clinic and services provided. Peers employed by Program D serve as patient navigators who are matched with new HIV patients at the clinic in order to provide them with orientation to the clinic's services as well as support and encouragement to engage in care.

Often, the patient navigators are brought in at the time of new diagnosis to augment the conversation between the medical provider and patient. Patient navigators are encouraged to disclose their own HIV status to the patient at their own discretion, when they deem it to be most appropriate to the patient's well-being. Administrators of Program D cite the critical importance of peers as patient navigators at their clinic due to the overwhelming nature of the large clinic's services as well as the value peers add to the helping relationship in terms of hope and empowerment for newly-diagnosed patients. Program D has a long history of sustainability, largely attributed to the clinic's ability to obtain several major federal grant opportunities to fund the patient navigators program.

# Program E

Program E is run by a moderate-sized AIDS service organization located in an urban neighborhood of a major metropolitan area. The agency is well-known locally and nationally as a peer-based agency with its beginning in grassroots HIV advocacy. As of 2011, about 95% of the agency's staff is living with HIV. Program E utilizes two to three peers to teach an interactive, sixteen-hour HIV education training program. While

Program E occurs in a group format, the intervention is designed to be more of a formalized training than a support group. Case managers, medical clinics, past program participants, and support groups, as well as advertisements, refer participants to the program. Program E is open to anyone living with HIV (and some HIV-affected individuals) interested in increasing their knowledge of HIV.

About 12 to 15 participants are scheduled per group, and the sixteen hours are generally spread across three to five days. Group scheduling is flexible and tailored around participants' availability. Training commences with an HIV risk and antiretroviral regimen adherence assessment, along with a pretest to determine the participant's baseline HIV knowledge and risk-taking behavior issues. After an overview of the training's expectations and goals, the peer facilitator engages in a discussion of HIV history, pathogenesis, treatment, and medications. Speakers from other departments within the agency attend the sessions in order to present information about specific topics such as substance abuse, mental health, and nutrition. After completion of the sixteen hours, participants are given a post-test and asked to return for three follow-up sessions in the following year. Basic lab markers (CD4 count, viral load, etc.) are recorded at the three month and six month points for outcome assessment.

Program E has a long-standing reputation throughout the city, and many training participants use the program as a launching point for their own entry into the field of HIV service delivery. Program E is actually a required training for a number of agencies' case managers and peer providers. Participants often report that this training, facilitated by

someone living with HIV, provides a perspective that is not included in other similar trainings offered through city departments and agencies.

## Program F

Program F operates as a part of the range of services offered at an urban community health center serving a primarily gay and lesbian population. The health center has a long-standing reputation in the community and was founded on the premise of health care consumer advocacy and empowerment, making the peer-based model a popular one for many of the programs offered throughout the health center.

Program F was designed in the 1990's by one of the nation's leading experts at peer-based programming within the HIV field. From its inception, Program F has been a module-based curriculum, which allows for a balance of evidence-based scripted HIV information and prevention messaging strategies and flexibility for the peer provider to make the intervention compatible with his or her own personal style. Topics addressed in the curriculum include: quality of life issues, mental health, medication adherence, prevention planning, conflict management, medical visit compliance, and general encouragement and support.

Program F is currently run by one peer provider who makes himself available for both one-on-one sessions and group forums. Scheduling is informal, based on the needs of the clients as assessed by the peer. The scheduling format found to be most efficient and acceptable for both the health care provider and the client is one in which the client first meets with the peer, then the physician, followed by a debrief with the peer. Given the limited amount of time one peer provider has to offer, Program F generally targets

newly-diagnosed patients and patients who have exhibited challenges with medication adherence.

## Program G

The agency which operates Program G is a small, grassroots, community-based organization located in an urban neighborhood, which is split between an African American and Hispanic demographic. The agency operates with a relatively small staff who are largely representative of the populations served. Services provided agency-wide include case management, HIV prevention counseling, and alternative therapies for HIV-infected patients. Largely dependent on available funding, which has been sparse and inconsistent, some version of the peer-based prevention program has been included intermittently throughout the agency's history.

Program G is a group-level intervention, currently led by one peer facilitator.

Due to lack of Hispanic peer leadership at the present time, no Spanish-speaking group exists; thus Program G currently targets only African American clients. The group meets twice per month, though the frequency of meetings is reduced to once a month during the winter. The peer facilitator is primarily responsible for the organization and content of the group. Sessions range from those organized around an activity to education workshops on topics including medication adherence, safer sex practices, and nutrition.

The peer provider delivers the information on some topics, while other sessions are led by pharmaceutical representatives.

The peer facilitator does some outside recruitment for the group, and additional recruiting is done via referrals from other internal programs at the agency. The current

success of Program G has been attributed by clinic leadership to a highly-engaged and charismatic peer facilitator who is respected by the rest of agency staff. The peer is given a high degree of autonomy and is seen as an integral part of the agency's service team. The peer participates in staff meetings, updates the team on his groups, and asks for assistance when necessary.

## **Program Similarities and Differences**

The program snapshots are intended to reflect the range of program options available within the peer-based model of service delivery. Because each of the seven programs in this study was so unique, I felt it important to describe each one individually. As the snapshots demonstrate, while the programs share some basic similarities (each of the programs had to meet the eligibility guidelines for a Prevention with Positives program in order to be included in the sample: see Appendix A), each organization makes

Table 8: Summary of Program Description Information

Program	Modality	Target	DEBI	Funding	Peer
		Population		Source	<b>Payment</b>
Α	Group	Women	No	CDC and City	Hourly
	_			Dept. of Health	
В	Individual	Low-risk	No	HRSA	Hourly
		Patients			
С	Individual	All HIV +	No	HRSA	Salary
D	Individual	New patients	Yes- Healthy	HRSA	Stipend
			Relationships		
Е	Group	All HIV +	No	State Dept. of	Salary
				Public Health	
F	Individual	Newly	No	City Dept. of	Salary
	and Group	diagnosed and		Public Health	
	_	non-adherent			
		patients			
G	Group	African	No	City Dept. of	Hourly
		Americans		Public Health	

their own decisions that determine how they utilize peers and how their peer-based program operates on a day-to-day basis. Table 8, above, provides an overview of the seven programs side-by-side in order to further illustrate these differences.

Of the seven programs in the sample, the model of service delivery is evenly split; about half of the programs utilize peers to provide services to clients on an individual basis, while the other half of the programs utilize peers as group facilitators.

Organizations are also split in the way the peers are compensated. About half of peers in the sample are paid an hourly wage for their time, while another half are paid as salaried employees. A third option for the payment of peers also exists, as one organization pays their peers on a stipend basis, meaning they are paid a flat rate per week or month for their time; stipend payment is typically a much lower rate of pay than the hourly wage of a "regular" employee. Table 8 also indicates another 50/50 split among programs in terms of the source of program funding. About half of programs in the sample received the majority of their funding from federal sources (most commonly HRSA or the CDC), while the other half received the majority of their funding from more local sources (either state or city Departments of Public Health).

Perhaps the most notable area of variation among programs in the sample can be seen in terms of the target population. While a few of the programs did not specifically tailor their program to any particular subgroup (that is, they simply provide the services to all HIV-positive clientele), most of the programs indicated that their peer-based PwP program was specifically targeted to a smaller segment of the HIV community. The choice to tailor their programs was sometimes made based on a demographic

characteristic. Examples of demographically-targeted programs in the sample include Program A, which focuses on women, and Program G, which serves the African American client base only. The CDC offers a collection of evidence-based interventions (DEBIs) with proven success in HIV prevention, many of which are specifically designed to target certain demographic groups and/or risk factor groups. However, only one of the seven programs in the sample chose to utilize and adapt a DEBI. (For more on this topic, see the latter section of this chapter.)

While some programs targeted a subgroup based on demographics, other programs in the sample chose to target their peer-based PwP program to certain clients/patients based on health status. For example, Programs D and F target new and/or newly-diagnosed patients. An interesting contradiction in strategy seems to exist between Program B and Program F; Program B utilizes peers to work with low-risk clients/patients, while Program F does just the opposite by asking peers to work specifically with clients/patients who are non-adherent and non-adherent to medical care. These variations suggest the range of options available to organizations who utilize peers, which will be discussed in more detail in the latter section of this chapter.

In addition to the similarities and differences evident among peer-based PwP programs in terms of their model of service delivery, an even greater range of diversity exists among these programs in terms of their administrative elements. While all of the programs included in this study are located in large urban environments, there is a wide range in terms of the size and scope of both the program and overall organizational settings of these peer-based programs. Table 9 displays a combined summary of the size

of the organization, program, years in existence and annual budget for the sample as a whole.

Table 9: Aggregate Program Description Data

	Mean	Median	Range
Size of Agency			
# of Clients Served	46,236	9,000	1,300 – 265,772
# of Agency Staff	607	165	9 – 3,000
Size of Program			
# of Clients Served	169	163	80 - 300
# of Program Staff	3	2	1 - 6
# of Peer Providers	3	2	1 - 10
History of Program			
Years Active	7.56	7.09	4.00 - 11.50
Budget (Annually)			
Agency Overall	\$36,246,996	\$15,000,000	\$484,972 - 185,051,000
Program Only	\$237,271	\$225,000	\$13,624 - 600,000

With regard to the larger organizations under which the peer-based programs operate, Table 9 shows that the "average" organization serves more than 46,000 clients/patients annually (median = 9,000), employs more than 600 staff (median = 165), and has an operating budget of just over \$36 million (median = \$15 million). However, the ranges provided in Table 9 illustrate the wide variation from one organization to the next. While the average number of clients served may be 46,000+, in the cases of the large hospital settings, the number of clients served often includes both HIV-positive clientele as well as the general medical population, including the largest, which served more than 265,000 annually. The smallest of the organizations in the sample serves only 1,300 clients in a given year. Likewise, the largest organization in the sample employs approximately 3,000 staff members, while the smallest operates with only 9 total staff.

The characteristics of the peer-based programs themselves reveal similar variation. The "average" peer-based PwP program in the sample serves 169 clients/patients each year, employs 3 clinical staff and 3 peer providers, and has an annual operating budget of just over \$237,000. However, there is wide variation across programs. The smallest of the peer-based programs in the sample serves about 80 clients each year, while the largest serves 300. Several of the programs employ only one peer provider while the largest peer-based program in the sample employs an average of 10 peers at any given time. The program budgets ranged from \$13,000 to \$600,000.

### **Contextual Themes**

At the beginning of this chapter, Figure 1 illustrated the rationale for including contextual analysis in this study. The Innovation Attributes of the peer-based PwP programs in the sample have been measured and will be described extensively in Chapter 5. However, it is important to recognize the ways in which the Contextual Attributes of the programs in the sample also impact one's understanding of the peer-based service model. The program snapshots, coupled with the aggregate administrative program data in Table 9, provide a more complete picture of the peer-based model than the Innovation Attributes alone. As Figure 1 shows, contextual analysis is needed in order to account more completely for the variation in the experiences of service providers as well as the ultimate outcomes of these programs. As will be discussed later with regard to the selection bias limitation of this study, it is important to acknowledge and understand that the programs in the sample do not necessarily reflect the entire "universe" of peer-based PwP programs; as such, the contextual themes discussed in this section are intended to

provide information to the reader regarding what peer-based PwP programs *can* look like rather than offering a comprehensive picture of what such programs *must* look like in practice.

It is my hope that the program snapshots, this descriptive data, and the discussion that follows may serve as a resource for potential program funders as well as individual agencies and service providers currently considering how to best incorporate peer providers into their HIV prevention programs. Toward those ends, the remainder of this chapter discusses a few key observations drawn from these rich program descriptions which may be particularly enlightening for those service providers considering future replication of peer-based PwP programming.

Observation #1: Peer programs "fit" best when they are tailored to the unique setting in which they are implemented.

If the programs included in this study are any indication of the nature of peer-based PwP programming nationwide, then one overarching conclusion must be made: every peer-based PwP program will be unique. As the descriptive data show, peer-based PwP programs currently function within some of the largest HIV service-providing medical settings as well as in small, grassroots community-based organizations. In large institutions, the peer-based program may be a relatively small component of the overall service delivery system, but it may also be a well-integrated mechanism for enriching HIV services and adding to the multi-disciplinary team of providers involved in the patients' care. In small agencies, the peer-based program may shoulder the majority of

direct client contact; small agencies in particular may rely on peers as integral members of the staff in an effort to stretch small budgets in big ways.

The snapshots of these seven peer-based PwP programs describe seven different models for how peers can be incorporated into services. By definition, all PwP programs have the same ultimate aims—reduced transmission of HIV and improved health outcomes for those already infected. However, the design of each peer-based PwP program is entirely unique. The options for future peer-based programs can be, therefore, numerous. A program could certainly choose to structure its services similar to one of these existing models; the snapshots provide a wide range of options including individual and group modalities, training and educational approaches as well as counseling and empowerment approaches, and patient navigation assistance. The programs in this study have already demonstrated a level of innovation, which could certainly be replicated. However, taking cues from the diversity of models included in this study, designers of a new peer-based program should also innovate because no two peer-based PwP programs should look exactly the same.

## Observation #2: Peers are versatile.

The contextual analysis of the programs in this study illustrates the flexibility that peer providers bring to the table. Because of the nature of their paraprofessional status, many peer providers provide an agency with a broader range of options in terms of how to utilize them. In the seven programs included in this study, for example, peers are utilized to interact with clients/patients on a one-on-one basis just as often as they are utilized to engage in group-level interventions. One program in the sample actually

utilizes their peers in *both* an individual and group setting. Peers can be trained to provide impactful individual services to clients/patients, in which they share their stories one-on-one in a way that forges lasting connections and models hope for the future.

Peers can just as readily be trained to function as group facilitators, both of educational groups and psychosocial support groups.

In addition to the wide range of options for utilizing peers in individual and group settings, the programs in this study also suggest that peer services can—and do—work effectively to target any number of subgroups within the HIV-positive population. Some of the programs in this study choose to target their peer-based programs to a certain demographic group (e.g. women, African Americans, etc.). There is certainly reason to believe that similar peer-based programs could be designed which utilize peers to target other demographics, such as youth, intravenous drug users, transgendered individuals, and many others. Other programs in this study target their peer-based services to certain individuals within their larger clientele based on HIV health status. As outlined earlier, some programs target newly-diagnosed individuals or individuals new to medical care, while other programs focus peer attention on individuals known to struggle with adherence to medication and/or medical visit compliance. Once again, this range of options suggests that peers can be utilized in many different ways, at the discretion of the agency designing the intervention.

Observation #3: Peer models can be supported through a variety of funding types.

Whether a prospective peer-based program would be operated out of a large medical institution or a small grassroots agency, the first concern of many administrators

will inevitably be how readily funding can be found to support and sustain the program. While the nature of human services funding is almost always precarious at best, the contextual analysis indicates several options for securing and using funding. There are a number of options available to agencies and institutions alike with regard to how peers are compensated. First, some programs compensate peer providers in the same way other staff are paid, which includes salary and full benefits. Other programs choose to pay peers on an hourly basis for the work they do. Hourly compensation may be the best option for programs which utilize peer providers on more of a part-time basis, and it may also allow agencies to save money. A third option is to pay peers a stipend, which is an even more cost-effective option utilized by programs with paraprofessional models. Because the way in which peers are compensated can reflect an agency's commitment to the peers and affect the way in which the peers are viewed by colleagues, agencies are encouraged to make these compensation decisions thoughtfully.

Regarding sources of potential funding, the programs in this study indicate that funding for peer-based PwP programs can be found at all levels of government: local, state, and federal. Funding secured from state and city Departments of Public Health is most commonly filtered through Ryan White Treatment Modernization Act funding streams. While none of the programs in this study indicated receiving private foundation funding, it seems likely that such opportunities also exist. The CDC and HRSA certainly have a documented track record of support for peer-based PwP programs, which began with the Special Projects of National Significance in 2003, although these grant opportunities are typically tied to research protocols which are one-time funding

opportunities. The CDC in particular has frequent grant opportunities for HIV prevention programs that are willing to utilize and/or adapt existing evidence-based interventions (DEBIs). It is interesting to note that only one of the peer-based PwP programs in this study utilized a DEBI in its program design. This is likely because, to date, there is no CDC-approved DEBI which specifically functions as a peer-based intervention. It seems probable that peer-based PwP programs could receive additional federal funding if more effort were given to adapting existing DEBIs to work within a peer-based environment. In the findings and discussion of this study's interviews with peer-based service providers (Chapters 5 and 6), much more is said about the challenges of sustainable funding for these programs.

#### CHAPTER FIVE

### RESULTS

# **Research Question #1: Quantitative Results**

The first research question driving this study is: To what extent do peer-based models of HIV service delivery adhere to an established set of program characteristics of Prevention with Positives (PwP) interventions? To answer this question, the quantitative elements of this study measured the level of "fit" between the peer-based programs in this sample and the set of program characteristics that emerged from the literature to describe PwP programs in general. For each of the established program characteristics, informants were asked two questions. First, "Does your program include this program characteristic?" and second, "How important do you believe that characteristic is for a successful peer-based PwP program?" Answers to the first question were coded as Yes/No responses. The second question sought responses on a ranking scale from 1-10, in which 1 was "Not Important" and 10 was "Essentially Important." Table 10 shows the responses to these questions. The data in Table 10 is based on an N of seven programs. The percentages and ratings were derived from an average of the responses given by the three service providers interviewed from each program.

## Overall Level of Fit

The column of percentages in Table 10 refers to the level of fit between the key program characteristics of PwP programs generally and the seven peer-based PwP

programs included in the sample. Percentages for each characteristic indicate the inclusion of that characteristic in the peer-based programs (e.g. 100% means that all programs in the sample included that particular characteristic in their program design.).

Table 10: Quantitative Results: Full Sample (N = 7 programs)

		Importance of Characteristic for a			
		Peer-Based Program			
Program Characteristic	% Yes	Min	Max	Mean	Standard
8					Deviation
CO	NTENT CH	ARACTE	RISTICS		
Behavior Change or MI	100%	6	10	8.76	.77
Harm Reduction	90.47%	1	10	8.81	1.29
Scripted Content	85.71%	5	10	8.12	2.06
Tailored to Subgroup	47.62%	1	10	7.67	1.11
Personal Goals	85.71%	6	10	8.40	1.22
CONTENT OVERALL	81.9%			8.35	
ORGANIZATIONAL SUPPORT CHARACTERISTICS					
Ongoing Training	95.24%	8	10	9.71	.29
Written Policies and	90.47%	6	10	9.52	.71
Procedures					
Service Integration	80.95%	7	10	9.29	.57
Agency Support	95.24%	6	10	9.62	.58
Community Involvement	85.71%	3	10	8.95	1.54
ORGANIZATIONAL	89.52%			9.42	
SUPPORT OVERALL					
RELA	TIONSHIP	CHARAC	CTERISTIC	CS	
Duration of Relationship	100.00%	5	10	9.14	1.15
Rapport	100.00%	7	10	9.62	.55
RELATIONSHIP	100%			9.38	
OVERALL					
MESSAGING CHARACTERISTICS					
Non-Moralistic Messages	76.19%	1	10	9.14	1.48
Loss-Framed Messages	21.43%	5	10	8.60	1.49
Personal Health Messages	95.24%	5	10	8.60	1.2
Altruistic Messages	95.24%	5	10	8.02	1.57
MESSAGING	72.03%			8.59	
OVERALL					
OVERALL "FIT"	84.08%				

As the final row of Table 10 indicates, the overall degree of fit across the program characteristics was 84.08%. This suggests a high level of fit between known characteristics of PwP programs and the peer-based model, which supports the first assumption of the study. However, it should be noted that this overall level of fit is slightly low because of a weakness in the instrument related to the question about Loss-Framed Messages. As the interviews unfolded, I became aware of a weakness in the way the question was worded. The Loss-Framed question asked, "Is a peer provider of your program more likely to say: 'If you use condoms, you will protect your sex partners' or 'If you don't use clean syringes, you could get hepatitis'?" The intended distinction between these two choices focused on the difference between a wellness message (the first option, which stated positively what to do) as opposed to a loss-framed message (the second option, which stated what not to do). However, service providers often chose their response based on the content of the statement (focused on condoms versus syringes) instead. Therefore, I have strong reason to believe the data related to this characteristic specifically (21.43%) is not reliable. Taking the Loss-Framed Messages variable out of the calculation of "Overall Fit," the previous rate of 84.08% would increase to 88.25%.

In order to better interpret the level of fit data, Table 10 also shows the breakdown in level of fit based on the four categories of program characteristics: Content,

Organizational Support, Relationship, and Messaging. These overall fit statistics were calculated by taking an average of all service provider responses in the category. The categories of Organizational Support and Relationship show higher level of fit, with

levels of 89.52% and 100% respectively. The characteristics in the Relationship category (duration of the relationship and established rapport) were found to have the strongest level of fit with the peer-based model (100%). This finding is of critical importance to the study overall and is discussed at length elsewhere in this chapter and in Chapter Six. The weakness in the messaging data can be seen more clearly seen when comparing the percentages across the four categories; the Messaging category has a lesser degree of fit (72.03%), which I attribute to the limitation of the data as described above.

Another point of clarification in the data which might have resulted in a slightly lower level of fit than actually exists, relates to the service integration characteristic, under the category of Organizational Support. The relatively low percentage of "Yes" responses to this characteristic may be explained by the research-oriented nature of two of the programs in the sample. The question related to service integration asked, "Is your peer-based program well-integrated with other services at your agency?" Two of the programs in the sample were originally designed and implemented through a strict research protocol of a time-limited nature. Several service providers from those programs answered "No" to this question of service integration, stating the research nature of their program made integration less feasible and less of a priority. These same service providers did, however, acknowledge the importance of service integration for others implementing peer services that will become part of regular programming. (See Mean of 9.29 and Standard Deviation of .57 for the same characteristic, which is one of the strongest variables regarding perception of importance.)

# Applicability of Characteristics for Peer-Based Model

After service providers were asked whether or not their peer-based program included each of the program characteristics, they were then asked to share their perceptions regarding how important each of those program characteristics is for an effective peer-based program. The mean responses (1-10) are included in Table 10, along with the range and standard deviation for each. Responses indicated overall that each of the program characteristics were applicable to the peer-based model of service delivery; the lowest individual mean score was 7.67 out of 10. Aside from the Messaging characteristics, service providers rated the characteristics related to content lowest in terms of their importance for peer-based programs (Mean = 8.35). The lowest rated characteristic overall was "Tailored to Subgroup" (Mean = 7.67). The question asked for this program characteristic was, "How important do you believe it is for a peer-based PwP program to be specifically tailored and/or targeted to a subgroup within the HIVpositive population?" While nearly half (47.62%) of the programs in the sample were tailored in this way (to women, African Americans, etc., see Table 8), service providers indicated that this type of tailoring may not be as important to a successful peer-based program as some of the other characteristics considered. Second, service providers were not in agreement with regard to the importance of scripted content for a peer-based program. The average rating of importance was relatively low (8.12) and the Standard Deviation (2.06) for those responses shows the largest amount of variation among all of the program characteristics in question. The inclusion of scripted content is further

discussed in the next section of this chapter, which addresses discordant responses based on level of staff.

By contrast, service providers' perceptions of the applicability and level of importance for other program characteristics were particularly strong. As with the level of fit data mentioned above, service providers deemed Organizational Support characteristics and Relationship characteristics to be of highest importance and applicability to the peer-based model of service provision with average overall category scores of 9.42 and 9.38 respectively. Not only did service providers rate these characteristics highest on the 1-10 scale, but ratings were uniformly high, with little variation across respondents. For example, when asked, "How important to a successful peer-based program is the provision of ongoing opportunities for training of staff?" the average rating was 9.71 (the highest of all program characteristics); the Standard Deviation was .29, thus indicating that nearly all service providers see ongoing training as "Essentially Important" for a peer-based program.

## Discordant Responses by Level of Staff

Service providers were not unanimous in their ratings about the importance of program characteristics. In particular, the responses of different types of providers—peers, supervisors, and administrators—were different across some characteristics. With so few programs in the sample, my ability to draw statistical conclusions is limited. However, variations in the responses of different types of staff regarding certain program characteristics are noteworthy. Table 11 displays the responses for five of the program characteristics stratified by staff type. Across program characteristics, these five were the

only characteristics for which different types of staff responded differently. For all other program characteristics, all three levels of staff generally rated their importance for a successful peer-based PwP program similarly.

The first three program characteristics in Table 11 (scripted content, tailored to subgroup, and personal goals) all fall under the category of Content characteristics. As the ratings indicate, the closer the staff member is to direct service provision, the more

Table 11: Respondent Perspectives of Program Characteristics Stratified by Type of Staff: Select Characteristics

Characteristic Level of Staff	Perceived Importance Mean (scale 1-10)		
Scripted Content	Witchi (Scale 1 10)		
Administrator	7.33		
Supervisor	7.83		
Peer	8.88		
Tailored to Subgroup			
Administrator	7.25		
Supervisor	8.50		
Peer	8.75		
Personal Goals			
Administrator	7.67		
Supervisor	8.50		
Peer	9.00		
Agency Support			
Administrator	9.33		
Supervisor	10.00		
Peer	9.50		
Community Involvement			
Administrator	9.50		
Supervisor	8.57		
Peer	8.88		

importance they said they placed on the inclusion of scripted content, the value of a tailored/targeted program, and the significance of talking with clients/patients about their personal goals for the future. Overall, this finding may suggest that those directly

delivering services are more keenly aware of the content needs of a program. Peers in particular rated the importance of scripted content higher (8.88) than did administrators and supervisors (7.33 and 7.83, respectively). While peers spoke often of their desire for the flexibility to make the program their own (see Qualitative section), these data suggest that peers also placed value on the scripted content they were given to structure their interaction with clients/patients.

In contrast to the peers' perception, supervisors in particular placed value on the importance of agency support for their peer-based PwP program (Table 11). The question asked to measure this program characteristic said, "How important is it for an agency as a whole to support the concept of HIV prevention?" Every supervisor interviewed rated this program characteristic as a 10 – "Essentially Important." While this characteristic was rated fairly high by all levels of staff, it was highest among supervisors. This may be an indication of the pressure many supervisors feel in their roles as middle managers. Second, an interesting pattern emerged among responses of service providers when asked, "How important is it for a peer-based program to include the community (including persons living with HIV) in the design and evaluation of the program?" Administrators ranked community involvement higher (9.5) in terms of importance than other types of staff (8.57 and 8.88). Despite the time it may take the ensure community involvement, the administrators in this sample appear to value the perspective of clients/patients.

# Unique Peer-Based Components

One of the assumptions of this study was that the peer-based model of service provision may include certain elements that uniquely equip peer-based programs for success in HIV prevention. The data in Table 10 not only indicate a strong level of fit between the peer-based model and more traditional models of HIV prevention services (based on the literature from which these key program characteristics were derived), but it also begins to identify a few uniquely applicable program characteristics achieved when peers are incorporated. The peer-based model appears to be especially well suited to fit the Relationship characteristics of PwP programming. The strength of perceived importance for establishing rapport (Mean = 9.62) as cited by the service providers in this study perhaps reflects the priority that peer-based programs place on relationship. Of all four categories of program characteristics, the Relationship category yielded a degree of fit at 100%. The remainder of this chapter will demonstrate how the qualitative data corroborates the importance of these unique peer-based characteristics.

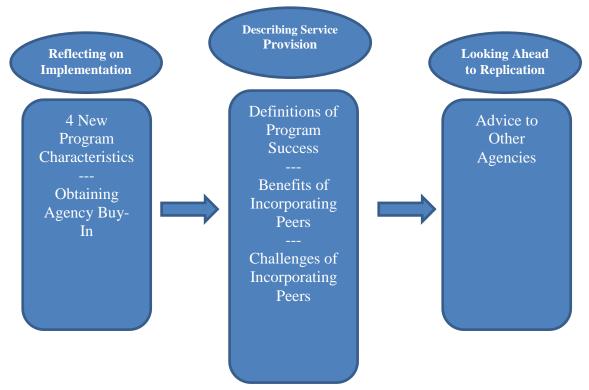
## **Research Question #2: Qualitative Results**

The second research question driving this study is: What are the experiences of peer-based PwP program staff in terms of implementation and provision of peer-based services? Through an conversational approach to semi-structured interviewing, the 21 informants in the study shared with me their experiences and the "practice wisdom" they have developed over many years of service delivery. I originally developed 28 codes across the 21 interviews based on the established program characteristics (18 codes) and the overarching topics emerging from the interviews (e.g. obtaining buy-in, defining

success, benefits, challenges, advice, etc.). Following this pre-coding stage, analysts engaged in a process of "coding as analysis" (Miles & Huberman, 1994; Saldana, 2009), wherein the process of coding interview transcripts led to the splitting of existing codes into more detailed subcategories (e.g. benefits to clients, benefits to agencies, and benefits to peers) and in some cases further subcategories beyond those. The final codebook included 67 individual codes which, when applied, resulted in 390 quotations/passages of interview text.

In order to make sense of the 67 different codes, I developed a conceptual framework (see Figure 2) at the conclusion of the data analysis phase to illustrate a structure for interpreting and discussing the qualitative findings in this study. Looking at

Figure 2: Conceptual Framework for Qualitative Data Analysis: Understanding the Experiences of Peer-Based Service Providers



each of the codes individually and then collectively, I divided the service providers' coded responses into three categories. The first category, "Reflecting on Implementation," includes the codes related to service providers' identification of unique peer-based program characteristics, as well as their stories regarding the process of obtaining initial buy-in/support for their peer-based programs. The second category, "Describing Service Provision," includes all codes and themes related to the ways in which service providers define and measure their programs' success as well as the rich data related to benefits and challenges of the peer-based model. The final category, "Looking Ahead to Replication," captures the themes that service providers stressed as most important in terms of advice for other agencies considering incorporating peers into their future HIV prevention programming. For the remainder of this chapter, findings will be organized in terms of these three overarching categories. In each of these three areas, a set of tables will present the frequency of each theme coded to represent the experiences of informants. Unless otherwise noted, all frequencies are based on an N of 21 informants – three from each of the seven programs in the study's sample.

## Reflecting on Implementation

## New Program Characteristics

In addition to the key PwP program characteristics drawn from the literature, for which the peer-based programs in the sample demonstrated a strong level of fit, service providers also reflected upon additional program characteristics and considerations which were perhaps unique to the implementation of a peer-based PwP program. Table 12 shows the four most commonly described additional characteristics; service providers

stressed the importance of each of these considerations based on their firsthand experiences implementing their peer-based programs.

Table 12: Program Characteristics Unique to Peer-Based Model

Additional Program Characteristic	# (%) of informants
Initial Training	10 (48%)
Supervision	7 (33%)
Peer Recruitment	4 (19%)
Flexibility	4 (19%)

The peer-based program characteristic identified by nearly half of all interviewed service providers is the intensive amount of *initial training* that programs have to invest in upfront when hiring paraprofessional peers. One supervisor spoke candidly:

There is lots of training prior to starting, and I don't know if that would be prohibitive to other agencies. You know, if we knew people were going to need so much training, we'd never have started the program.

It should be noted that "ongoing training" is one of the key program characteristics identified in the literature for PwP interventions in general. However, peer-based service providers made an important distinction between ongoing training and initial, upfront training.

Those who discussed the need for initial training of peers spoke of three distinct areas of needed training: a) program structure, b) HIV knowledge, and c) professional skills development. Program structure referred to the need to train peers in the specific model of the program, in order to ensure program fidelity. This included training in motivational interviewing, computerized assessments, program manuals, and curriculum modules. One administrator shared,

We had a pretty extensive up front training where we had them go through intervention modules. And they had to demonstrate a certain amount of

competence and mastery of that material before they could move on and administer it. And we actually did have someone who we didn't think was actually mastering the material that we did have to let go from the project.

Service providers cited this type of initial training in the program itself as essential, especially when dealing with paraprofessional staff.

In addition to training peers in the program structure, several service providers – especially supervisors – also stressed the need to train peers with regard to basic HIV knowledge. Service providers discussed the danger of assuming that, just because the peer is HIV-positive, he or she has a solid understanding of HIV. One supervisor said,

I think as a peer you have to be very well trained because there is a lot of bias going into it as a peer and sometimes misunderstandings. I think that with peers—it depends on the population—but the peers that we were working with didn't necessarily have a lot of knowledge before they started.

To accomplish this aspect of initial training, several programs utilized a pre- and post-test during the orientation process. In addition to recognizing that a lot of misinformation exists within the HIV community, supervisors also cited initial training in HIV knowledge as important because of the ever-changing nature of the HIV epidemic.

Lastly, service providers also discussed the need for initial training in aspects of professionalism and skills development.

Because we use paraprofessionals for the most part, many of the professional skills other staff members have are lacking. The peers needed to receive initial training on things like boundaries, documentation, etc.

One peer described this aspect of his initial training this way:

You know, they taught us how to run a group, what things you shouldn't do. You know, how to maintain a group, how to keep them coming back, and kind of how to speak to people, like what to say and what not to say.

A number of service providers cited training in professional skills, including basic communication, as an important component of initial training. These service providers shared from their own experiences in which such skills were taken for granted, especially in agencies without much experience in incorporating paraprofessionals.

One-third (33%) of all service providers interviewed discussed at great length the need for a different type of program *supervision* when implementing peer-based programming. An administrator made the following statement regarding what she saw as the single most important aspect of peer-based programming:

How much supervision there is...You know, peers can be the greatest, greatest people to deliver an intervention, but if you don't have the right people supervising it can blow up in your face one day. A lack of good supervision can destroy a program.

Service providers at all levels – administration, supervision, and peer – articulated the need for a special type of supervision when dealing with peers. Supervisors must be available at all times, "whenever things come up," and they must be ready and willing to supply "any support peers might need." As one service provider succinctly stated, "The nature of employing paraprofessionals requires strong, intensive, and intentional supervision, for sure."

Regarding *recruitment*, 19% of service providers referenced the importance of "finding the right people" to serve as peers rather than rushing into program implementation. They discussed the time it takes to cultivate and prepare their clients/patients for the work of peer service provision, and they shared lessons learned about how hiring "just anyone who is HIV-positive" can negatively affect

implementation and ultimately program outcomes. One supervisor talked extensively about the type of recruitment and interviewing her program utilized:

Not all consumers qualified. They had to bring experience to the table. They were asked questions in the interview like: "How do you deal with your diagnosis?" and "What is your knowledge of HIV and AIDS?"

Several more service providers also discussed the challenges of recruitment throughout the interviews; therefore, I also reference this theme in the findings related to program replication later in this chapter.

A final consideration for peer-based program implementation was identified by 19% of service providers—the need for *flexibility* in the way the PwP program is implemented. These service providers referred to achieving a balance between "the science" of the intervention (i.e. evidence-based interventions or DEBIs), which they often termed "going by the book," and allowing for "an element of flexibility around helping support [peers] to make the program their own." One peer described the way his program achieved this flexibility in program implementation, saying:

And then how we covered [the content] was up to us, using the workbook as a guideline. Some people never opened the books and some people followed everything. A lot was dependent on the patient themselves, and a lot was based on the style of the peer.

Especially given the trend toward evidence-based interventions in the field of HIV prevention as well as the documented success of incorporating scripted content into PwP programs, informants often raised the challenge of achieving balance as a relevant concern for current and future peer-based PwP programs to consider.

# Obtaining Buy-In

Service providers were asked to reflect specifically upon the process they went through during the start-up phase of their peer-based PwP program with regard to obtaining buy-in from the larger agency. They were asked to describe their experiences and perceptions about how higher level administration, medical providers, and other professional staff responded to the idea of incorporating peers as service providers. Table 13 shows the breakdown in responses, with an overwhelming majority of service providers (71%) stating entirely positive experiences obtaining agency buy-in for the peer-based model. Service providers articulated a number of reasons for the positive responses of their agencies.

Table 13: Experiences Obtaining Buy-In for Peer-Based Model

Obtaining Buy-In	# (%) of informants		
Positive Experiences	15 (71%)		
Challenging Experiences	3 (14%)		
Obtaining Buy-In Required Justification	3 (14%)		

First, several service providers attributed support for the peer-based model to the agency's historical involvement in consumer advocacy. Several of the programs in the sample were, in fact, founded upon models of consumer-driven activity. One informant stated.

The genesis of [name of agency] was a peer-based model, and so I think it's been easy to translate that, well I shouldn't say easy, but there's never really been a negative reaction to the peer-based model.

Secondly, several service providers shared stories which indicated that strong support for the peer-based model came from the agency's genuine desire to its clients/patients do well:

It wasn't hard to get buy-in from the clinic because there were their patients, these were people they wanted to see do well, they had a familiarity with them already and they were confident in the insider knowledge they brought to the table.

Finally, a few service providers joked about it being easy to garner support from medical providers and other service staff for the incorporation of peers because it meant that their own jobs were made easier because, as one peer stated, "We do half of their work."

While comments like these were intended to be taken lightly, several service providers did make statements which emphasized that their positive experiences in obtaining agency buy-in for the peer-based model were based on a genuine recognition of the contribution peers can make to the process. For example, one supervisor explained,

I think if anything, by and large the staff really felt like that was a valuable resource and something really, really helpful and a perspective they could not necessarily provide. So they were happy. I think that part was probably the least difficult.

The service providers who shared more challenging experiences in obtaining agency buy-in (14% of those interviewed) referred more to misunderstandings throughout the agency regarding what the peers' roles would be than to instances in which the agency was simply opposed to the idea of incorporating peer service providers. One program supervisor stated,

I think it would be hard for us to find many people in the field who would be opposed to this idea theoretically of having people living with HIV being involved in program design and delivery. What was frustrating to me was just that people didn't really understand what that meant.

Another service provider who recounted a similar experience acknowledged that agency administration was also initially concerned about issues of confidentiality in dual relationships (as clients/patients and co-workers).

As Table 13 shows, another 14% of those interviewed indicated that the process of obtaining buy-in for the peer-based model included a period of time during which the program had to provide justification to legitimize the work of their peers. These experiences reflected change over time in the amount of agency support and buy-in for the peer-based model as the program began to demonstrate strong outcomes data. One such program conducted an actual 6-month pilot phase prior to implementation, during which they collected data

...and then we used that data first to show, based on this intervention, that clients were actually getting connected to more services and service providers than prior to the intervention. We were able to also show the program's feasibility.

Experiences like the one described above indicate the importance of collecting evaluation data for peer-based programs in order to garner agency buy-in and also ensure sustainable funding in the future. One administrator's response to the question of obtaining buy-in summarizes these experiences of justification over time:

I would say that we did not necessarily have a lot of buy-in initially, but eventually we developed it. I think that we have buy-in now. The historical use of peers at our agency was a quite decentralized, not good. It lacked supervision and was not well-documented. So, the agency had a bitter taste in their mouths, it started with a bad reputation. But, I came in and really centralized the program. I hired peers and I hired [a supervisor] to specifically oversee and supervise them. We took the time to develop a strong Code of Conduct for our peers as well. That was really important. After we did these things, there was a big change in how the staff understood the peers and saw a better quality of services we provided.

These stories of programs achieving buy-in over time through the demonstration of quality services and positive results indicate the importance of collecting and reporting

program outcomes not only for the benefit of the program funders, but also for the justification of the program to agency staff and administration.

### **Describing Service Provision**

# Defining Successful Programs

When I interviewed service providers for the purpose of understanding specific aspects of PwP programming, I initially asked each individual, "Do you consider your program to be a successful peer-based program?" Only one service provider, out of the 21 interviewed, responded that her program was not successful. The other two service providers from the same program indicated that they *did* see their program as a success. This begs the question: how do service providers define success? In other words, how do peer-based service providers define the success of their programs, and what types of program outcomes do they measure to determine success? Table 14 summarizes the various ways in which service providers went on to describe their programs' success.

Table 14: Service Providers' Definitions of Success

Definition/Measure of Success	# (%) of informants
Measures of Social Outcomes	9 (43%)
Retention of Clients	8 (38%)
Improved Clinical Health Outcomes	7 (33%)
Strong Reputation of the Program	3 (14%)

Note: some service providers referenced multiple types of success, which is why the numbers yield a cumulative percentage greater than 100%.

While clinical outcomes are more easily measured as evidence of program success, it was actually more common (43%) for service providers to share examples of *social outcomes* as justification for their programs' success. Social outcomes included

clients/patients who state they are "better able to control their lives on their own" and are more "self-sustaining." These measures are less tangible and less objective outcomes, but service providers exhibited a clear sense of pride and a belief in the value that peer-based programming adds to the lives of their clients/patients. These social outcomes included anecdotal feedback from program participants regarding the impact the program had on their lives as well as evidence of increased levels of empowerment and self-sufficiency. As one service provider said,

When you have people come back and tell you how good they feel. And what a difference we have made in their lives. So they can go and share the love with somebody else. That's an excellent experience.

Several service providers talked about success in terms of positive feedback and stories told by clients/patients that illustrate the ways their lives improved because of the program. For example, one informant shared,

They come back to us, I mean scores of people you know, how it was really meaningful and how it changed their lives and how they are working or something or how their lives are different.

Especially given the emphasis that many of the peer-based programs place on empowerment, it came as no surprise during interviewing that service providers clearly value such anecdotal accounts of success and positive change in their clients/patients' lives. One service provider asserted,

I think they walk away with not only more knowledge of HIV and treatment but feeling more self empowered and able to cope with the issues that surround HIV treatment.

The stories that seemed to resonate most strongly with service providers as evidence of programmatic success related to increased comfort with disclosure of one's HIV status, as the example below describes:

One of the ladies from one of the sessions said, "I'm going to share, disclose my diagnosis to my 30 year old daughter." And she had been living with HIV now for 10 years. So that weekend she did it and then she came back to the following week and shared it with the group that she did disclose. And then based on her sharing her story, there was another lady in the group that said she was thinking about disclosing to her family.

These client-reported measures of success were deemed relevant by service providers because they evidenced ways in which the programs made a significant impact on the lives of their clients.

More than one-third (38%) of service providers also referenced a second indication of successful programming, that of achieved *retention* in the program over time. Citing the longevity and number of individuals engaged in the program as evidence of the program's success, service providers made statements like, "It must be good if they keep coming back" and "Patients come back year after year." One service provider explained it thus:

Really there are people here that have been coming to the group for 10 years. And, we know that there are other groups that offer more than we do, they offer food and they offer money and we don't have any of that to offer. However, people continue to come, so I think that [the program] must provide something for them.

Another service provider who defined success as retention said this:

How we know that we are successful is that we have patients that come back. Again and again and again. If a patient did not feel that they were treated with dignity and respect, if they didn't feel that they were getting the best quality of care and service, I don't think they would frequent it. They would say, "I would never come back to this place again." I think because we are connected, we put the patient first, that we have a high turn around and we do have patients that

come back. You know, time and time again. And it's been so, so successful, and just so prominent for years.

One-third (33%) of all service providers referred to some type of *clinical* outcomes as evidence of their program's success with statements like, "When you see folks' health get better, that says to me that this is a successful program." These medical outcomes measures included improvements in lab work (CD4 and viral load counts) as well as other indications of improved health status. One service provider declared,

I think the most important thing is that we are seeing changes, positive changes in people's lab work. When they learn about it here, compliance to medication and understand how important that is, then we are seeing a really, good, sharp increase in valuable, clinical markers.

Service providers talked extensively about and attributed the work of their peers through their PwP programs to perceived improvement in health outcomes:

We are seeing a higher level of engagement in their medical care, a higher level of medical comprehension, so they [patients] get what's going on or they get the importance of what is going on. So they understand the importance of coming in for routine labs, they understand what the lab values mean when they get the results back. They have the space to ask about side-effects and negotiating side effects so we are seeing an adherence with medications as well so that means better overall health.

Lastly, three service providers (14%) mentioned a fourth indication of program success. These responses pointed to the established *reputation* of their programs throughout the broader community and/or nation as a factor in determining successfulness. Several programs in the sample have had the opportunity to share their models for peer-based programming at national HIV conferences and trainings over the years, which also suggests a level of success.

# Benefits of the Peer-Based Model

Throughout the interviews, service providers spoke of the benefits of the peerbased model; the themes that emerged relate to three types of benefits: benefits to clients, benefits to agencies, and benefits to the peer providers themselves.

## Benefits to Clients

As Table 15 shows, service providers identified five unique benefits to clients of peer-based programming. Many service providers identified more than one benefit throughout their interviews; hence, the total percentage of responses is greater than 100%.

Table 15: Thematic Codes Regarding Benefits of Peer-Based Programming: To Clients

Code	# (%) of informants		
Shared Experiences	18 (86%)		
Hope	7 (33%)		
Safe Space	7 (33%)		
Caring	3 (14%)		
Orientation	2 (9%)		

A clear majority of service providers spoke of the value of *shared experiences* between the peer and the patient/client, saying things like: "I'm just like them," "peers are on the same level," "I've been in their shoes," and "it's a normalizing factor." Service providers point to the benefit to clients who meet with a peer and can then say, "It's not just me" and "They really understand me." As one peer explained:

They seem more comfortable talking, especially if I tell them, "I know what you are going through right now because I was in that position a couple of years ago." And so, you know, the level of confidence and relief increases a lot when you are working at a peer level.

Service providers talked extensively about peers being uniquely equipped to help clients/patients because their perspective is unique and cannot be duplicated by the expertise of "professionals." In fact, one service provider spoke candidly of the ways "shared experience" can be more important than the factual presentation of HIV prevention messaging:

I think it's because a lot of peers, they've been there. They know it is one thing to have numbers and a lot of data and stuff. But they have the feelings attached, you know, the day-to-day stuff that people don't think about.

Another of the most commonly expressed benefits to clients of the peer-based model is the unique ability of peers to provide a model of *hope* for clients/patients, which was specifically cited by one-third (33%) of all service providers. One peer described this model of hope by saying, "We are walking, talking, living examples—to show people that you can live with this virus." According to some theories of hope, hope is most often built and instilled in people through relationship with others (Dufault & Martocchio, 1985; Farran, Herth & Popovich, 1995). The service providers in this study see peers as uniquely equipped to provide that hope to clients/patients at just the right time—especially when an individual is initially diagnosed with HIV, as described by one service provider:

I think for some folks, let's say they test positive, they might be the only person that they know that is HIV positive, it's like very isolating. They might not have family members, they might not have friends, they don't know anyone else that is HIV positive, and to meet someone else that is openly HIV-positive that is healthy, you know, isn't sick on a day-to-day basis, it can be a really powerful experience. That's remarkable—it's a source of normalizing it for folks as well as providing a sense of optimism that there's more there after the diagnosis.

In describing the benefit of hope, service providers frequently spoke about peers being able to demystify the diagnosis of HIV, overcome feelings of internal shame in a powerful way, and combat the "death sentence" mentality many people latch onto once they learn of their diagnosis.

You know, when they meet someone who has been living with HIV for 10, 15, 20 years, they say, "Oh, I'm not going to die, so I have to figure out how to live with this."

Service providers cited this personal model of hope as a source of much-needed inspiration, especially for the most high-risk populations.

It was really helpful to them, you know? It was nice to be able to sit down with someone who was maybe further along in the journey than them and doing well, and hearing that this person has a good life, and so they were able to relate to that and see that as a source of inspiration.

About a third of service providers mentioned another benefit to clients of the peer-based model. These service providers described how meeting with a peer quickly fosters the creation of a *safe space* where patients/clients feel more comfortable talking about highly-stigmatized issues. Several service providers, like the one quoted below, saw this benefit as especially significant for vulnerable and diverse populations because of the common ground the peer relationship provides:

I think there's lots of people that benefit from peer-based interventions, but the folks that I think most often do are people who may be distrustful of medical systems, distrustful of western medicine. These are folks who sometimes their providers don't necessarily match them—culturally, racially, ethnically—so there is maybe kind of a hesitation in that sense. So to be able to talk to somebody who looks a little more like them or talks a little more like them, there is a level of buy-in that they can jump on board with.

The safe space created within the peer relationship benefits clients by affording them a new level of trust, one that is often much deeper than they are able to achieve with their medical provider, case managers, or counselor. The following comments from two different service providers capture the benefit of safe space and trust in powerful ways.

More times than not, what we found out doing this whole program is that we [the peers] were the only place that a lot of the patients could turn to and just open up and talk. Without any fear of judgment or stigma or anything like that. They would open up and tell us things that a lot of times they did not share with their provider.

Sometimes I think having the peer was more important than the intervention itself. That just having someone to talk to them about what's going on with them, they just kind of let down their guard and didn't feel like they had to, you know, put on a good face.

This safe space can actually be seen as a benefit to both the clients (because it increases their level of comfort and ability to ask questions and get information) and to agencies (because peers are therefore able to better assess for risk and gain an understanding of patient/client lifestyle).

Some service providers talked about the *caring nature* of the peer provider relationship with clients/patients. These responses indicated ways in which peers would "go the extra mile" for clients/patients, making them feel genuinely cared for and supported. Service providers described this kind of caring as something medical providers and other helping professionals would like to be able to exhibit, but often cannot because of time constraints. Peers indicate to clients/patients that "we are still here" and "we are working hard to make sure [clients] are comfortable." One program supervisor shared a story that illustrates the benefit of caring particularly well:

You know there is one story that I still do remember where one of our patients who was in an abusive relationship and you know literally got a lot of support from the peer who had also been through something similar and said, "Look, I changed my life." And this person actually ended up making a lot of changes, getting a job at the hospital, and making huge changes in her life. None of which we may have necessarily measured.

The two service providers who discussed the benefit of *orientation* to services were both from a program that utilizes peers in the role as patient navigators. Under the

patient navigation model, clients benefit from having a peer who literally "walks them through" their first few clinic visits at a large institution where orientation to services can be daunting.

### Benefits to Agency

Table 16 shows five additional aspects of peer-based programming that service providers identified as benefits to the agencies themselves. Only one service provider—a peer---acknowledged the relative cost-effectiveness of peer-based models, stating that "peers are cheaper than social workers." So, while the lower cost of peer-based programming did not seem to be a main draw for agencies, several other benefits received significant attention throughout my interviews with service providers. Again, because some providers cite more than one benefit to the agency, the percentage total is greater than 100%.

Table 16: Thematic Codes Regarding Benefits of Peer-Based Programming: To Agencies

Code	# (%) of informants
Added Value to the Agency	11 (52%)
Flexibility of Time	4 (19%)
Peer Input	3 (14%)
Increased Honesty	3 (14%)
Cost	1 (5%)

Over half (52%) of all service providers spoke specifically of the *added value* peers provide to their agencies, which was referred to as: "a good way to bridge services," "a part of the buffet of options we provide," "a very value added thing," "an added dimension," and "a way to go beyond the clinical aspect of HIV prevention." In essence, service providers who cited the added value of incorporating peers felt that peers

helped their clients/patients become better equipped to make decisions about their health than they would have been without the presence of peers. Additionally, these service providers saw utilizing peers as a way to expand the breadth and depth of the services offered, to increase engagement, and improve efficiency of care. One service provider described his agency's approach this way:

The client will meet with the peer first and kind of get prepped for the visit. Then, they'll go meet with their provider, and then they'll come back and they'll be able to debrief with the peer. To be able to like digest all the information, ask more questions, clarify things. They may have heard some medical jargon in the medical visit that they don't understand, and they can come back and kind of make sense of it with the peer.

The way in which the peer-based model can be utilized to extend and enhance existing clinical HIV prevention services and traditional models of care is perhaps best articulated in the words of one peer who said,

I think that the peer-based model is one of the best models that we currently have available to help with behavior science. And I think that it shouldn't clash with non-peer-based models or professional models or however you want to say it. I think that they are actually made to work well together. There are often things that will be discussed with a peer that would not be discussed with a provider. And so the two of those working together will probably give the best results to the clients.

Another benefit to agencies acknowledged by about one fifth (19%) of service providers is that of the accessibility and *flexibility of time* that peer providers have to offer patients/clients. While this is also a benefit to the clients/patients themselves, service providers who spoke of this benefit identified it more closely as a benefit to their agencies, in that peer providers were able to shoulder the bulk of necessary HIV prevention conversations. Several service providers spoke of the challenge and expense medical providers incur in order to buy out even fifteen minutes of their time to engage in

an HIV prevention discussion with a patient, whereas peers are able to meet with patients for longer periods of time. As one peer described,

I think that it's just that the staff and the physicians sort of have to shoulder a lot. They are always walking the short rope of time, you know? They have so many people to see, and so they want to be able to offer some behavioral advice and moral support and all those kinds of things and they don't always have time to be able to do that.

This benefit to agencies means their services can be enriched through the incorporation of peers.

A few service providers (14%) cited the benefit of *peer input*. The peers' unique perspective enabled them to anticipate "where the problems were going to be." Peers were described as "vocal about stuff [administrators] wanted to put in place that just didn't make any sense." One administrator spoke quite candidly about the value of the peer perspective throughout the process of program design and evaluation, saying: "I think they do have a very intimate knowledge of the issues that the programs are dealing with, and I think that's invaluable." Interestingly, a peer articulated this benefit to agencies in much the same way:

I think probably a benefit would be that there is also feedback you can get from your peers for your program. Like, you know, a peer has a different perspective on things, so they can give you what it's going to be like coming into an agency HIV-positive, walking in through the door. And I think that's helpful because that's a very different perspective than you get from a provider or case manager.

One additional benefit to agencies, which also appeared as a benefit to clients within the safe space created by peers, is the level of *honesty* patients/clients exhibit in interactions with peers, which is often greater than the level of honesty they may provide in the context of a conversation with a medical professional. A number of service providers (14%) acknowledged this as a benefit to agencies, urging them to utilize a

multi-disciplinary team approach to their HIV prevention programming in order to glean wisdom and insight from the peers to attain a clearer picture of the patient/client and his or her risk factors.

#### Benefits to Peers

The sentiments of the administrators and peers quoted above certainly indicate the contribution a peer can make to an agency. While the focus of this study is to look at the programmatic level and understand the process of peer-based programming implementation and service delivery, I feel it is important to recognize the benefit to peers who serve as peer providers. Twenty-eight percent of service providers specifically mentioned the reciprocal benefit to peers. Peers themselves often made statements like: "I'm helping them, and they're helping me too," and "You grow as a person, you grow as an individual, and you also grow as a person living with HIV." The reciprocal benefit peers receive from being involved in this type of work aligns with the tenets of Empowerment Theory and should be underscored as an additional rationale in support of more agencies considering the addition of peer-based programming.

#### Challenges of the Peer-Based Model

Just as service providers discussed a number of benefits related to incorporating peers, they also shared wisdom and experiences related to the challenges inherent in the peer-based model. Tables 17 and 18 provide a breakdown of the themes service providers discussed related to challenges for agencies and challenges for peers themselves, respectively. It is important to note that, even when directly asked to consider clients/patients for whom a peer-based approach might not work well, none of

these service providers mentioned challenges for clients who receive services from peer providers.

# Challenges to Agency

As service providers described their peer-based programs, they referenced three specific aspects of peer-based service provision as uniquely challenging to agencies.

Not surprisingly, the issue of *funding* was raised by more than half (52%) of all service Table 17: Thematic Codes Regarding Challenges of Peer-Based Programming: To Agencies

 Code
 # (%) of informants

 Funding
 11 (52%)

 Management
 8 (38%)

 Confidentiality
 2 (9%)

# providers, in statements like:

The challenge is that we need more money for funding [laughs] so we can keep our peer program running. Those are the main challenges, we are continuously working and fighting for grants to keep our program going.

A number of service providers made similar references to their program's need for more funding: "We could do things, but we don't have the funding," "I'm supposed to show movie clips, and there's no TV," and "I have a lot of women in the group, and we have no space big enough to meet."

Related to the need for more funding, service providers mentioned the need for specific resources like those named above. They also talked about the challenge of funding sustainability over time. Many service providers shared similar stories about times when their programs were operating well under a specific grant funding cycle, only to have to close the program completely once that time-limited funding ended. One

service provider said simply, "We've never been able to make our program sustainable". The general consensus among service providers seemed to be that providing peer-based services in the last ten years has required agencies to chase grants and be ready to open and close programs according to ever-changing funding availability.

Over one-third (38%) of service providers spoke about the *management* challenges associated with operating a successful peer-based program. Their comments acknowledged the ways in which a person living with HIV, especially one who is similar in demographic and lifestyle characteristics to the clients being served, can be challenging to manage. One supervisor said,

You know, people bring with them their own lives and a certain amount of challenges, and so when you are coming from a community that has a lot of challenges, the people you are recruiting may carry those same things. So that's kind of hard as a manager.

Program supervisors in particular spoke of the challenges they face in getting "them [peers] to stick to the protocol." A number of service providers made statements like, "There was a lot that went on to managing that program" and "There is a lot of oversight that has to be given for the process to work." Related specifically to the burden of supervision for peer staff, the informants underscored many times that there must be "a dedicated person who is going to have management oversight because coordination of peers can be quite challenging."

Two service providers, both administrators, mentioned the issue of *confidentiality* as a unique sticking point when employing peer providers. Both of the individuals who referenced this challenge were speaking specifically about the dual nature of the peers' relationship to the agency, as both providers of services to clients/patients and receivers

of the agency's services themselves. The challenge for agencies in situations like these is to clearly establish rules and practices to ensure confidentiality of both the client/patient and the peer, which can be "a slippery slope" at times, especially when the peer providers have personal affiliation with the clients/patients outside of the agency environment.

### Challenges to Peers

Service providers, including peers themselves, articulated a number of ways in which serving as a peer provider can be challenging for the peer. About half of service Table 18: Thematic Codes Regarding Challenges of Peer-Based Programming: To Peers

Code	# (%) of informants	
Balancing the Peer's "Own Stuff"	10 (48%)	
Managing Boundaries	6 (29%)	
Newfound Professionalism	6 (29%)	

providers (48%) talked about the challenges that arise from the peers' own situations. Coded as "own stuff" in the qualitative code book, this category refers to the ways in which issues within the peer's own personal life can be "triggered when working with people" and their private lives can get "tangled up with the life of being a provider of services at the agency." One program supervisor spoke pointedly about the need to anticipate and manage this phenomenon when incorporating peers:

I don't think we often create a whole lot of space for peer-based staff to get the clinical support that they need around what offering services in this community intervention brings up for them. And what I think can happen is people begin to be triggered or engage in risk-taking behaviors because they're hearing so much about it as they are offering an intervention for their peers.

The peer from the same program as the supervisor quoted above acknowledged the support he receives from his superiors and the overall agency:

We [peers] have our own therapist. We meet regularly to talk about any issues and concerns we may have so that we are healthy on a mental level to be the best that we can be for our community.

Almost one-third (29%) of service providers specifically discussed the challenge peers face in establishing and maintaining professional *boundaries* with clients/patients. In particular, these comments referred to "the boundary between being a friend and being a peer leader." By way of example, one peer shared:

You know, occasionally there can be some days where you feel like professional boundaries are being crossed. Someone is sharing all this stuff, we're developing a rapport, and they've forgotten that the peer's doing their job and they're not just a friend—or a potential date [laughs]. There were a few instances where you have to set boundaries.

Service providers identified the challenge of managing boundaries as especially problematic for peers who live in the same community as the patients/clients they work with. One supervisor spoke candidly about this challenge and the types of situations agencies must anticipate:

One thing that came up a lot with us is that people were living in the community, so they would see each other out. And, what do you do when you see someone? What do you do if you know something, or vice versa, what if the patient knows something about the peer or the peer's family? How do you handle that? I see it as very sticky. Very, very sticky.

While the questions posed by the supervisor above may, be ethical questions most helping professionals have already asked themselves, peers—especially paraprofessional peers—will not necessarily have been trained in how to behave in such situations. This relates to another challenge acknowledged by 29% of service providers, which concerns developing the *professionalism* of peer providers. Most of the comments related to professionalism focused on the challenges peers face in navigating the professional world, often for the first time. As one program supervisor stated, "We often forget that

they [peers] haven't had these opportunities their whole lives, so this [the work environment] is a really weird kind of structure to throw them into." So, while peers may be eager to enter the agency workplace, they often face challenges when they do not receive the supervision and support they need to transition into their new roles.

While many service providers spoke at length about these challenges to peers, almost all of them also acknowledged that these challenges can be easily overcome as long as the agency is committed to providing quality, caring supervision and avenues for peers to engage in self-care activities.

## Looking Ahead to Replication

Advice to Others Implementing Peer-Based Programs

Toward the end of each interview, I asked service providers, "If you were approached by someone from another agency who was considering developing their own peer-based HIV prevention program, what advice would you give them?" Table 19 shows nine categories of advice cited by service providers in response to this question.

Table 19: Thematic Codes Regarding Service Providers' Advice to Others Considering Incorporating Peers

Code	# (%) of informants	
Recruitment	11 (52%)	
Respect Peers	9 (43%)	
Structure	7 (33%)	
Community Involvement	6 (29%)	
Supervision	5 (24%)	
Training	2 (9%)	
Buy-in	2 (9%)	

This portion of the study, perhaps more so than any other, reflects the true practice wisdom of peer-based service providers—in their own words. Every service provider

interviewed shared at least one piece of advice. While many of their comments and pieces of advice duplicate findings mentioned in earlier sections of this chapter, all nine categories are covered in the discussion which follows in order to demonstrate the full-range of advice which can and should inform future peer-based PwP programming.

The most common (52%) piece of advice given by service providers to others considering a peer-based model was to engage in a process of intentional, in-depth recruitment of the "right" peers for the job. "Choosing carefully and wisely" during the recruitment and interviewing phase was cited as of critical importance to the ultimate success of the program. As one peer stated,

The staff that you put together is very important. Just because someone is living with HIV, it doesn't mean that they are able to be a peer. It's very important that you choose the right people to put into those positions.

The idea that HIV-status alone is insufficient as a means of suitability for work as a peer provider was echoed by many service providers. They advised that beyond the individual's HIV-positive status, hiring supervisors should look for individuals who "are emotionally ready," "have an interest and a willingness to learn," "are passionate for the work," "have outgoing and friendly personalities," and "are willing and able to disclose their status to others." One administrator spoke of the importance and time-intensive nature of the recruitment process:

These aren't naturally positions we post on Career Builder and hope for the best [laughs]. There is a lot of intentionality done behind the recruitment. If you get the wrong person, even if you have the best model on earth, you can do a lot of damage.

Several service providers mentioned specific action steps they would recommend to new peer-based program staff to aid them in recruiting the best peers for the job. These

strategies included requiring letters of reference from the peer's doctor and/or case manager, and asking pointed interview questions such as, "When you had a problem with your medical provider or health care, how did you navigate it?"

The second most common (43%) piece of advice service providers shared was to "respect the peers" for their expertise and the life experience they bring to the table. The belief in the leadership potential of their peer providers was evident in the advice many supervisors and administrators shared; these service providers articulated a commitment to their peers, "wanting them to develop their talents and leadership skills" in their roles at the agency. Toward that end, one supervisor urged future peer-based program staff to

let the positive individuals create the majority of the program...I dare say that if our program was run by HIV-negative folks, we just wouldn't have the success or get the attention that we have been getting.

Another supervisor spoke even more directly about her approach to engaging her peer providers in the design and day-to-day operations of the program:

My approach was this: I have these degrees in public health, I have learned how to set up health education programs and implement them. But I'm looking for the peers to really help me relay this information to people's lives. And it is a collaboration. So on my end, I have some of the skills that can help them understand the information and how to convey it and run the group, and they're bringing some other skills to the table. It's just, you know, to really look at it as a collaboration not just someone being thrown out there."

While this collaborative approach may not come naturally for program administrators, many service providers in this study clearly believe that respecting the expertise of peers serves to strengthen programs over time.

One-third (33%) of service providers advised peer program planners to ensure their programs have a *strong infrastructure* and clear guidelines from the beginning. At times, this seems contradictory to the previously quoted comments related to allowing

peers the flexibility to make the program their own. While many service providers did place value on flexibility, several informants warned about the difficulties face by peers in terms of maintaining program fidelity. As one service provider stated, "it can never be assumed that because it's a peer-based program it can just be very organic." Rather, program planners must be intentional in their program design, having a well-defined program structure from the beginning. Several service providers stressed the importance of structure, making statements like:

There has to be very clear guidelines, and protocols in some ways—like having a computer based model to work off of was really helpful—because you don't want a lot of leeway with what kind of information can be given out.

On a related note, 24% of service providers also gave advice to peer-based program planners regarding the central importance of strong *supervision* and training. When the responses regarding structure are combined with those emphasizing supervision, the advice to new peer-based programs seems to be to begin with a well-structured program (clear outcomes, evaluation plan, guidelines, scripted content, etc.) and then utilize supervision as a time where innovation and creativity of the peer can be explored.

Twenty-nine percent of service providers commented on the importance of *involving the community* (those living with HIV) in the design and evaluation of a peer-based program. As one service provider advised,

The population that you are serving needs to be involved in the entire process, from the very beginnings, from thinking to starting a program like this to evaluating and implementing the program as well. Folks need to be used throughout the entire process, and there should be many focus groups used to test the way the information is being presented as well as what information is being presented.

The individuals who shared this advice regarding the benefits of intentional community involvement alluded to many reasons for its importance, including improving the reputation of the agency, ensuring programs meet individual needs, capturing new lessons that HIV-negative people may not consider, and empowering people living with HIV by giving them a voice. Related to this last reason, one service provider said,

Make them feel included and that they are equal partners at the table when you are developing what you're rolling out. And that their voice is important, and they get to participate in your program in a real way.

In addition to ensuring a level of community involvement, which allows for consumer *buy-in* for the peer-based program, two service providers also advised future peer-based programs that "the institution needs to buy-in and have a commitment to" the peer-based model.

This collection of advice from existing peer-based service providers to prospective peer-based service providers reflects some of the major themes seen throughout the findings of the study as a whole—especially the concepts of recruitment, supervision, and innovation in program design. In the chapter which follows, I discuss the key findings as they relate to informing current and future peer-based programming.

#### CHAPTER SIX

#### DISCUSSION AND IMPLICATIONS

I think one of the best things about [our program] is that clients get to work with **positive peers--** peers who also have HIV and are much further along in developing positive coping mechanisms for their HIV diagnosis and the emotional issues that come along with it. So, to me, the most important part of it is that they become better able to deal with becoming positive.

~ Stated by a program supervisor in this study

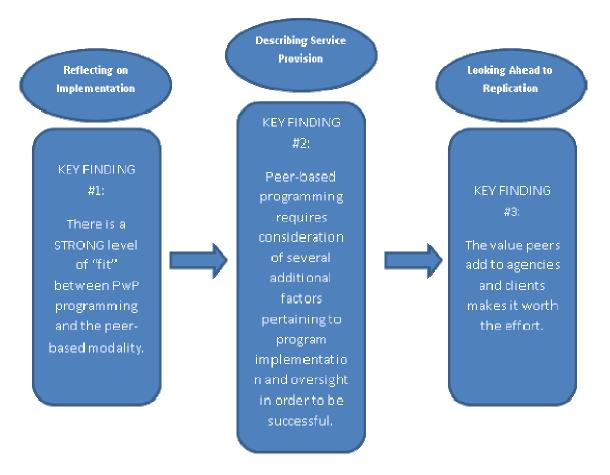
In Chapter One, I acknowledged the assumptions guiding my pursuit of this current study on the peer-based model of HIV service provision. Based on my own years of experience in direct service and program administration of HIV services, and in particular my observations of HIV-positive individuals whom I have had the privilege to work alongside, I engaged in this study with the assumption that peer-based programs work. Still, I developed a rigorous study and engaged in a process of coding and data analysis that included multiple bias checks. The presentation of the study's findings in the previous chapter reflects both the strengths and the challenges service providers associated with the peer-based service model. What follows in this final chapter is my summary of the three key findings of this study, a careful presentation of the study's limitations, and a conclusion with my thoughts regarding its implications for social work practice and research. I am pleased, albeit not at all surprised, to be able to report that my

assumption is generally supported by the data. As the program supervisor quoted at the beginning of this chapter so eloquently states, "positive peers" make a difference.

# **Three Key Findings**

The Conceptual Framework for this study was first presented toward the beginning of Chapter Five to illustrate the structure used for qualitative data analysis. The framework categorizes the themes that emerged in my conversations with service providers into three areas: implementation, service provision, and replication. After

Figure 3: Conceptual Framework's Application to Study's Key Findings



reviewing the data analysis and findings, I have identified three overarching key findings; each key finding aligns with one of the three categories in the Conceptual Framework

(see Figure 3). The first key finding relates primarily to the quantitative data and concludes that there is a strong level of "fit" between Prevention with Positives (PwP) programming in general and the peer-based model in particular. The second key finding acknowledges the challenges and cautions many service providers spoke about related to the peer-based model of service delivery, summarizing them by stating that peer-based programming requires a good deal of "extra effort" on the part of the agency and the program supervisor in order for the program to be successful. The third key finding serves as an important overarching conclusion from all of the data in the study and establishes that—all factors being acknowledged—the value peers can add to an agency's services makes the incorporation of a peer-based program a worthwhile endeavor. I will now elaborate further on these key findings and their implications.

Key Finding #1: There is a strong level of "fit" between PwP programming and the peer-based model.

One of the most innovative components of this study is the way in which existing literature and research evidence is utilized to understand the nuances of the peer-based programs in the sample. As described in Chapter Three, I chose this methodology carefully in order to achieve a level of triangulation of established data with new data. The key program characteristics drawn from the PwP literature formed a template of sorts by which to measure the level of fit between traditional, established PwP programs and more recent peer-based models of PwP programming. As the data presented in Chapter Five confirms, the overall level of fit between those program characteristics and the peer-

based programs in the study's sample was found to be very strong; programs in the sample fit with the entire set of program characteristics 84.08% of the time.

While this overall percentage reflects a strong level of fit overall, the data also suggest that several of the key program characteristics from the literature are actually expanded upon and have been made *better* through the application of a peer-based approach to service provision. For example, one of the key program characteristics cited in the PwP literature referred to the need for programs to have established methods for ensuring community involvement, meaning they should involve individuals living with HIV in the design and evaluation of their programs. More than 85% of the peer-based programs in the sample stated that their programs included such community involvement. And, perhaps more significantly, nearly one-third of all service providers also spoke specifically about the benefits their program experienced as a result of strong peer input into their program's design, ongoing implementation, and evaluation planning. The importance and value of the peer "voice" at the table has also been cited in the peer-based PwP literature (Raja & Glick, 2007).

In addition to the strengthened community involvement present in peer-based PwP programs, the strong level of fit can be seen—perhaps most notably—in relation to the characteristics of rapport and duration of relationship. As a reminder, service providers were asked, "Do peers in your program establish strong rapport with clients?" and "Do peers in your program have an ongoing relationship with clients, as opposed to seeing them on a one-time basis?" As noted in Chapter Five, these two program characteristics comprise the Relationship category, and the level of fit among the study's

sample in that category was 100%. This means that every service provider from every program in the sample stated that these two characteristics were present in their programs and were of particular importance to their program's success. Throughout the qualitative portion of the interviews, 14% of service providers spoke specifically about the ways in which the relationship between a peer provider and a client was strengthened because peers have more flexibility with their time and are able to dedicate more time to clients' needs. Other research on peer-based HIV prevention programs has also found this to be true (Downing et. al., 1999; Raja & Glick, 2007).

Beyond the duration of the relationship, the ability of peer providers to establish and maintain strong levels of rapport with clients is found to be the key strength of the peer-based model. Not only did all service providers state the presence of rapport and the importance of rapport to be particularly high, but several of the most common themes found in the qualitative data analysis of interviews relate directly to the development of rapport between peers and clients. As the literature suggested (Adelman & Frey, 1997; Albrect & Adelman, 1987; Brashers et al., 2004), service providers in this study identified having a peer provider as integral in creating a safe space for clients to feel open to share their risk factors and life stories honestly and without judgment. One-third of all service providers referenced this strength of the peer-based model. Additionally, as the theories of hope (Dufault & Martocchino, 1985; Farran et al., 1995) described in Chapter Two propose, one-third of all service providers in the current study described ways in which the relationship with a peer served to instill hope in clients in a way that non-peer providers cannot. This suggests that rapport is more easily established between

a peer and a client than between a "traditional provider" and a client, because the peer brings shared experience upon which they can build a relationship. In the qualitative data analysis, as described in Chapter Five, a majority (86%) of service providers interviewed referenced the value of that shared experience between the patient/client and the peer.

Therefore, it is clear from this study that peer-based models of service provision fit very well with established program design of PwP programs. In fact, there are several indications from the data that the utilization of peer service providers may meet the needs of clients receiving PwP services in a way that non-peer-based programs simply cannot. This is especially true because peer-based programs have an inherent commitment to incorporating peer input into their program design, are better able to ensure adequate time can be spent with clients in need, and naturally serve to establish meaningful and hope-filled relationships between clients and peer providers who can share their experiences and empower clients accordingly.

Key Finding #2: Peer-based programming requires consideration of several additional factors pertaining to program implementation and oversight in order to be successful.

A review of the qualitative data from interviews reveals the service providers' references to the challenges and time-consuming aspects of providing peer-based services. These issues provide a clear warning to future peer-based service providers to carefully consider their commitment to and capacity for implementing a peer-based program that may encounter these challenges. As Chapter Five describes early on in the qualitative findings, service providers articulated several key program characteristics of a peer-based program which were not included in the list of characteristics found in the

literature. Three of the four additional program characteristics that peer-based programs must consider were related directly to implementing a peer-based program. Those characteristics were: intentional and thoughtful recruitment of peer providers (stated by 19% of service providers), strong supervision (stated by 33% of service providers), and intensive initial training of peer staff (stated by 48% of service providers). In addition to these three considerations, another similar theme emerged later in the interview data and emphasized the challenges associated with the overall management and oversight of a peer-based program.

The service providers in this study raised the method of recruiting and hiring peer providers as a matter of critical importance. In fact, when asked what advice they would give to someone considering starting a new peer-based PwP program, the most common answer (52%) was to recruit well. The challenge of peer recruitment has also been cited in other studies of peer-based HIV prevention programs (Bettencourt et al., 1998; Raja et al., 2008). Chapter Five includes a number of quotes from service providers which summarize the importance of recruiting the "right" people for the job. The general consensus among service providers was that an HIV diagnosis alone does not mean that a person will be a good peer provider. When asked how they recruited their peer providers, most program administrators and supervisors answered that their recruitment process was internal—utilizing referrals from medical providers and case managers—rather than via open job postings. While one program supervisor did speak at length about the specific types of interview questions she uses to gauge an individual's readiness for a peer provider position, others simply stated that recruitment is a challenge.

Once peer providers have been hired, challenges continue. Over one-third (38%) of service providers stated that the primary challenge to agencies employing peers is the amount of management and oversight that peer-based programs require. Once again, this finding has also been well-documented in the peer-based PwP literature (HRSA, 2005; Koester et al., 2007; Marino et al., 2007; Raja & Glick, 2007; Raja et al., 2008). Management issues raised by service providers most often referred to the challenges faced by supervisors and administrators to ensure that peer providers (who are most often lay educated and unfamiliar with program fidelity and evaluation) remained true to the protocol of the intervention and/or program. Service providers stressed that managing a peer-based program requires an extra degree of oversight.

This "extra effort" relates directly to a third theme regarding the considerations necessary for a successful peer-based program—the need for close and intentional supervision of peer staff. Nearly one-quarter of service providers' primary advice to would-be peer-based program implementers was to anticipate the need for a heightened level of supervision. The challenges peer service providers articulated for themselves relate to difficulty maintaining personal/professional boundaries and general unfamiliarity with workplace expectations. These challenges, also cited in the peer-based HIV prevention literature (Bettencourt et al., 1998; Raja et al., 2008), will require the attention of a supportive supervisor. In fact, several program supervisors in this study stated explicitly that there must be a dedicated staff person whose sole responsibility at the agency to supervise peer staff. This will be especially important during the initial stages of the peer-based program and any time a new peer is hired, because nearly half

(48%) of all service providers talked extensively about the time-intensive nature of initial training for peer staff.

Service providers made it very clear that there are challenges associated with the management and administration of peer-based programs. Responding to those challenges with the necessary considerations will require extra effort on the part of program administrators. The time required of agency staff who choose to implement a peer-based PwP program must be anticipated from the onset. Thoughtful and thorough recruitment of peer staff must be followed by intensive training and then ongoing supervision. As such, peer-based programs cannot and should not be seen as simply "add-on" support services to be implemented and then left to run on their own. In order to develop and maintain a successful peer-based PwP program, service providers must be ready and willing to commit to an intentional process of program implementation and on-going oversight.

Key Finding #3: The value peers add to agencies and clients makes it worth the effort.

Despite the extra effort required of program administrators and supervisors to achieve success with a peer-based program, the data from this study clearly demonstrate an overall affirmation of the benefits of peer-based programming. I have remained cognizant of my own bias toward the peer-based model throughout the design, interviewing, and analysis of this study, and I have therefore made every effort to represent all sides of the issue. As the data discussed in the second key finding illustrate, there *are* challenges and negative aspects of implementing a peer-based program, and service providers in this study spoke quite candidly about them. However, when I asked

each service provider, "Do you believe more agencies should be incorporating peers into HIV prevention services?," everyone responded "Yes." Even the most jaded and critical service providers I spoke with responded "Yes," which suggests that 100% of peer-based service providers believe that despite the challenges, the added benefit of incorporating peers makes the model worth the effort.

Table 20, below, outlines data taken from the qualitative code book and data analysis in a way that essentially weighs the pros and cons of the peer-based model based on the comments and themes of service providers. As described in Chapter Five, I categorized the benefits and challenges of the peer-based model into three groups: benefits/challenges to clients, benefits/challenges to agencies, and benefits/challenges to peers. The table shows the number of codes for each category as well as the number of quotes referencing each. Looking strictly at the bottom line, service providers identified Table 20: Pros and Cons of the Peer-Based Model: Evidence from Qualitative Coding

	Benefits of Peer-Based Model		Challenges of Peer-Based Model	
	# Codes # Ouotes			
		# Quotes	# Codes	# Quotes
To Clients	5	45	0	0
To Agencies	5	31	3	27
To Peers	1	7	3	24
TOTALS	10 Codes	83 Quotes	6 Codes	51 Quotes

10 different benefits of the peer-based model and spoke of those benefits 83 times; by contrast, they identified only six challenges of the peer-based model and spoke a less

frequent 51 times regarding those challenges. While these numbers alone do not necessarily reflect the service providers' rationale for arriving at the conclusion that it is worth it for more agencies to incorporate peers, I believe the data serve as evidence that the pros *do* outweigh the cons.

I would offer a few observations which might provide further explanation as to why service providers recommend the peer-based model in spite what might seem like significant challenges. First, it is interesting to note that one of the three codes regarding challenges to agencies is the task of obtaining sustainable funding; in fact, 12 of the 27 quotes regarding the challenges to agencies were in reference to funding issues. The lack of funding opportunities for peer-based HIV PwP programs are real, and those which do secure temporary funding often do not sustain it for long periods of time due to grant cycles and changes in funding priorities. It seems that service providers in this study, when responding to my question about whether or not more agencies should incorporate peers, were indicating that more peer-based programs *should* exist—and should, therefore, be given more credence by potential funders.

The challenges to peers also warrant attention in order to understand the overwhelming support of service providers for future peer-based programming. The three codes regarding challenges to peers all refer to ways in which peers can feel ill-prepared for the task at hand. The majority of related comments centered around the peers' difficulty maintaining personal/professional boundaries and navigating the professional workplace environment. As discussed in the second key finding, these challenges can and should be addressed adequately if the agency is committed to

providing the initial training and ongoing supervision the peer-based model requires. Therefore, while the 24 quotes regarding challenges to peers certainly raise legitimate concerns, service providers seem willing to recommend the peer-based model to others in spite of these challenges—as long as agencies are aware of the challenges, anticipate them, and plan to overcome them through supervision and program oversight.

Overall, service providers recommend the peer-based model to their colleagues in spite of the challenges they cited in the interviews because the benefits outweigh the challenges. These are service providers with years of experience providing some of the very first peer-based PwP programs in the country. They speak of the benefits they see for their clients. These are benefits that cannot be easily measured: empowerment, hope, relationship-building, and social support. They also speak of the benefits their agencies have experienced as a result of having peers on staff. They see the ways in which peer input has made their programs stronger and more relevant to the needs of the communities. They have seen the ways in the health of their clients has improved because of the time peers can spend with them and the level of honesty between clients and peers. Fifty-two percent of all service providers in the study referred specifically to the added value the peer-based program provides to their agency as a whole; peer-based programming was described as a "bridge in services," an additional item in the "buffet of services" they offer, and an "added dimension" of clinical care that goes "beyond" traditional models. As 100% of service providers indicated, their experience with the peer-based model compels them to suggest that other agencies do the same.

#### Limitations

I undertook this study as an important first step in what will likely be a careerlong research agenda aimed at program description and evaluation of HIV services and
peer-based models in particular. While I believe the findings and discussion included in
this study are rich in lessons learned, implications for program design and
implementation, and the potential for peers to make an even more powerful impact on the
lives of people living with HIV, this study is not without its limitations. Below I
acknowledge and account for several of the most evident limitations; I also state, when
applicable, the steps taken to minimize each limitation as much as possible.

First, the lack of a representative nationwide sample of all peer-based PwP programs limited the study's ability to conduct statistical tests to determine the influence of variables such as: geographic region, target population, HIV risk factor, experience of the agency, and community representation. The contextual analysis provided in Chapter Four of the peer-based PwP programs included in the sample represents my best attempt to acknowledge at least some of those variables. In their nationwide study of PwP prevention messaging, Morin et al. (2004) found no significant difference in program outcomes based on geographical region. This may suggest the same could be assumed of the present study as well. Still, the sampling strategy employed in this study limits its generalizability. Additionally, because the methodology of this study did not include a thorough look into patient/client outcomes, its findings are limited to qualitative lessons learned rather than measures of program effectiveness. While the diversity of program models, as described in Chapter Four, provides some assurance that there is little reason

to suspect the sample to be atypical, broader empirical generalization cannot be concluded. I do, however, believe this study presents a strong level of theoretical generalizability (Mason, 2002, p. 196), given the expertise and firsthand direct service knowledge informants were able to provide.

One additional note regarding the sampling strategy and the size of the sample which relates to the limitations of this study must acknowledge the possibility of selection bias. As described in Chapter Three, 42% of the total number of peer-based PwP programs I was able to identify agreed to participate in the study. I did not look into the differences which may exist between those programs who agreed to participate and those who did not. Therefore, it is possible that the peer-based PwP programs in the sample may not be reflective of the entire set of peer-based PwP programs. Especially since no incentive was provided to study participants, it is possible that those who participated may have a stronger commitment to the research process and/or greater familiarity with participating in research studies. Additional research would be needed to better understand the differences between those programs in the sample and those who are missing from the sample.

Ensuring common, shared definitions of the PwP key program characteristics among informants was, at times, difficult. While some of the program characteristics asked about in the interview are straightforward (e.g. "Does your program have established written procedures?"), others are more subjective and open to interpretation (e.g. "Is your program well-integrated with other agency services?"). The lack of consistent definitions from one informant to another is an inherent limitation of this

study, especially related to the Messaging characteristics (as alluded to in Chapter Five). To address this limitation, I returned to the original research articles citing each of the program characteristics in order to understand exactly how they were originally conceptualized. I then coupled that language with the collaborative feedback of the EPPEC evaluators and SPNS grantees (in some cases they were also the original authors of the studies in question) to choose the wording for this study's Interview Tool (see Appendix C). I also attempted to clarify informants' understanding of various program characteristics in the context of the interview; when an informant rated any program characteristic particularly high or low (on the 1-10 scale of importance), I asked an openended follow-up question which allowed the informant to describe what their program does in their own words.

The semi-structured and organic nature of the interviews in this study, and the process of recording and transcribing interview content, also present a set of limitations. The Interview Tool was not utilized as an exact script for my interaction with informants. Rather, my "guided conversations" generally covered each of the main elements of the Tool at some point, but often I did not ask each and every question of each and every informant. This approach to the interview process resulted in a degree of inconsistency. It is for this reason that I utilized the technique of cross-sectional indexing (as opposed to question-based coding) in the coding phase of the data analysis, which allowed me to capture themes as they occurred in the course of the entire conversation instead of limiting certain codes to certain question responses. Additionally, transcriptions always carry a limitation in that some content, especially non-verbal, may be missed or

misinterpreted. I asked the transcriptionist to include all verbal utterances in the transcripts as a way for me to read into such content. I believe I was able to interpret some of the subtle content because I was the person both conducting the interviews and coding the data.

In retrospect, I have some regret about not recruiting a slightly larger sample, which would have allowed for much more in-depth data analysis to capture the variation in informants' perceptions and experiences with peer-based programming based on staff type. In Chapter Five I present some data which point to discordant responses from peers, supervisors, and administrators within the same program, as well as some differences in perceptions of program characteristics found among peers, supervisors, and administrators. However, little conclusion can be drawn from that variation due to the small sample size. Replication of this study with a larger set of informants could be advantageous.

### **Implications for Social Work and Next Steps**

Despite the limitations of the current study, I believe the study's employed methodology and its key findings offer several important implications for social work practice and research. In the most recent set of accreditation standards set forth for social work academia, the Council on Social Work Education (CSWE) describes the type of research and practice social work students and faculty alike are to pursue. The 2008 Educational Policy and Accreditation Standards (EPAS) call for students and faculty to engage in "practice-informed research and research-informed practice" (Standard 2.1.6, CSWE, 2008). It is my belief that studies such as this one exemplify the type of research

CSWE calls for. I am hopeful that this EPAS statement points to a trend throughout the social work profession toward better integration of practice wisdom into empirical research, which (as described in my Philosophy of Research in Chapter One) is something I wholeheartedly believe in and have sought to model throughout the methodology and analysis of this study. In these few final pages, I will summarize what I see as several important implications for social work practice and research as well as some of my personal "next steps" in continuing to build this research agenda around peer-based models of HIV service provision.

#### **Practice Implications**

First and foremost, the key findings of this study provide a compelling case for social service providers and agencies to consider challenging the "traditional" roles of formally-trained helping professionals and lay-educated paraprofessionals. Seeing that the peer-based PwP programs included in this study aligned quite closely with established non-peer-based PwP programs—and in some instances were heralded by service providers as *better* equipped for the task of HIV prevention messaging—should urge us to be open to more innovative thinking in program design. For some practitioners who read this research, the idea of employing peer staff may have been met with resistance in the past. It is my hope that this study, and the words of service providers throughout, will cause some to pause and consider a new way of thinking in future program development.

Related to future program development, the key findings of this study hold strong implications for those of us likely to engage in social work consultation and/or program evaluation work with agencies. In particular, Key Finding #2 (related to the "extra

effort" required of program administration and staff in order to design, implement, and deliver quality peer-based services), presents an entire set of considerations which consultants may wish to discuss with agencies preparing to begin a new peer-based program, or for those who are looking to evaluate and improve their existing peer-based services. This research suggests implications for peer-based programs to consciously implement "extra" measures related to aspects of program management, supervision, and training. These themes emerged strongly enough throughout the current study to suggest an opportunity might exist for social work researchers to engage in consultative roles with interested agencies in order to set their programs up for success. Additionally, consultants or program administrators should also look for ways to engage these peerbased programs in developing well-structured evaluation plans to describe and accurately measure the programs' successes. As described in Chapter Five, peer-based PwP programs purport several different types of success (social, medical, etc.); while service providers can often speak anecdotally of their program's success, many of these types of outcomes are challenging to measure. I suggest the use of logic modeling as one way to engage program staff in describing their programs and considering specific outcomes of interest to their agencies and funders. Yet, this process can be daunting for evaluation novices; it is my hope that the program characteristics and findings from this study may assist consultants and program designers to better articulate, conceptualize, and describe their programs in more evaluation-friendly ways.

Toward that end, I am personally committed to addressing the need for a concrete deliverable which will translate this study's findings into some sort of meaningful guide

for agencies. While I have made a conscious effort throughout the course of this study and its analysis to present the findings in a way that is both academically rigorous and practically applicable, I am keenly aware that most practitioners simply do not have the time to sift through current research to find such studies. Therefore, I intend to summarize the findings of this study into a series of clear action steps and concise considerations for current and future peer-based HIV programs. While I will be engaging in such work as it relates to this particular study, I would be remiss if I did not encourage other social services researchers to engage in similar projects that would translate other "practice-informed research" back into a format that could be made readily available to those who informed the research in the first place.

#### **Research Implications**

It is my hope and desire that the methodology employed in this study, as well as the ways in which I have attempted to summarize and present its key findings, will serve as a model for other researchers as they consider how "practice-informed research and research-informed practice" can be done. As a researcher committed to a lifetime of this type of applied program-oriented research, I cannot overemphasize the belief I have in the value that practitioners bring into the research arena. Their "practice wisdom" can and should continue to be included in our research as much as possible. One of the main implications of this study's methodology is the way in which such practice wisdom can be coupled with existing research evidence and literature. I sought the answer to Research Question #1 (dealing with how well peer-based program adhere to established PwP program characteristics) by triangulating the existing research evidence on PwP

programs with the practice wisdom gleaned from my discussions with a particular set of peer-based program service providers. This is just one example of the potential for including practitioners' voices into our rigorous research agendas.

As I conclude, I must also mention a number of important implications drawn from this study for future research on peer-based models of HIV service provision. First, one of the most talked about aspects of providing these peer-based PwP services was the topic of training. As mentioned in Chapter Five, service providers in the study spoke extensively about the need for substantial amounts of initial training when employing paraprofessional peer staff. While I did probe into this program characteristic somewhat further, I believe more research is needed to explore the type and format of this initial training. For example, service providers who spoke of this need for initial training reflected on a range of training topics including skills-building, HIV knowledge development, establishing professional boundaries, and workplace etiquette—just to name a few. More research can and should be done in order to better understand the training needs of peers as well as to describe current training practices of peer-based program supervisors and administrators in more depth. Such research could result in the development of usable training curricula and manuals for peer-based programs to use as well as identifying the most effective ways to deliver training content.

Another aspect of this study's findings, which could benefit from additional research, would be to further the discussion among service providers regarding the challenge of peer recruitment. As discussed in Chapter Five, service providers of all types acknowledged the delicate and challenging task of finding and hiring the "right"

peers for the job. Several of the service providers spoke quite articulately about this, stating that efforts must be made by the agency to be sure that being HIV-positive is not seen as the *only* characteristic which qualifies someone to serve as a peer service provider. While a few of the service providers in this study did mention specific ways in which their agencies attempted to recruit peer providers thoughtfully, I believe much more must be done to research this particular aspect of peer-based service provision.

Toward that end, future research could and should explore how existing programs engage in peer recruitment as well as begin to develop best practices for peer recruitment moving forward.

Lastly, the peer-based model of service provision is not unique to the field of HIV. In fact, as mentioned earlier in this study, much of the current HIV peer-based programs credit the field of breast cancer research as being among the first to suggest the value of the peer-based approach. Certainly, there are a number of examples which indicate that peer-based models are becoming more and more commonplace. In the field of addictions, for example, many substance abuse recovery programs are staffed by recovering addicts themselves—and the AA/NA programs are based entirely upon the concept of addicts helping addicts. In the course of my research, I have encountered similar examples including post-partum depression support groups facilitated by women who struggled with the condition themselves, and gang violence prevention groups which utilize former gang members to spread their messages. All of this leads me to believe that this study and others like it, which focus specifically on HIV peer-based service provision, can and should play a part in a much larger research agenda—one that seeks to

define a set of best practices for peer-based models of care among any number of populations in which struggling men and women might benefit from knowing others like themselves who have succeeded in becoming "positive peers."

# APPENDIX A ELIGIBILITY SCREENING QUESTIONS

### **Eligibility Screening Questions**

"Hello. My name isa	and I am a research assistant from Loyola University – Chicago. I				
received your contact information from, and I was hoping to talk with you for a few					
	e are doing which focuses on peer-based HIV prevention services.				
suggested that you and your agency might fit with the focus of this study. Do you have a					
few minutes?					
I have just a few questions about ye	our program that will help us determine if your program is the type of				
program we are focusing on. If so, I would like to ask about your willingness to participate in the study.					
1) Has name of program provious	ly received or is it currently receiving funding as a designated Prevention				
	y received of is it currently receiving funding as a designated Frevention Y/N				
If Yes, funded by:	HRSA				
if Tes, funded by.	CDC				
	Other:				
If Yes, is name of program	m primarily a peer-based program? Y/N				
	nese questions, end questioning here. Ask about interest and willingness See continued script below). n 2.				
2) Is name of program primarily designed as a primary prevention program? By this, we mean: Is the program specifically focused on providing HIV prevention messages to those already infected with HIV. $Y/N$					
3) Does <u>name of program</u> include primary goals of either: reducing risk taken by HIV-positive clients/patients or reducing negative health outcomes for HIV-positive clients/patients?  Y/N					
NOTE: If Yes to either 2 of that this program may not	or 3, continue to question 4. If No to both 2 and 3, inform the individual the eligible for this study.				
4) Does name of program utilize H	IIV-positive peers as a primary means of delivery of prevention services				
to clients/patients?	Y/N				
to offering puncting.	±/±1				

*NOTE:* If Yes, ask about interest and willingness to be a part of the study.

## EXPLANATION OF PARTICIPATION IN THE STUDY:

Based on your answers to these questions, your program does meet the eligibility criteria for this study. Let me explain a bit more about what your participation in the study would require. This study will be conducted through phone interviews with service providers like yourself. We estimate the interview will take approximately 45 minutes. For each program in the study, we will be asking to interview three separate staff members: an executive-level administrator, a mid-level program supervisor, and a direct service peer. The lead researcher, Allison Tan, will be conducting the actual interviews, and prior to the interviews we will send the participants a document that will help to anticipate and prepare for the types of questions we will be asking. The interviews do not ask for any personal identifying information. The focus of the interview is to inquire about the experience of service providers in operating peer-based programming.

Does this study sound like something you and your program are willing to participate in? If Yes, collect contact information for the three individuals to be interviewed. (Track in Excel document.)

If Maybe, ask if Allison might call the person at a later date to answer any remaining questions and follow up.

# APPENDIX B INTERVIEW PREPARATION DOCUMENT

#### INTERVIEW PREPARATION DOCUMENT

Hello, You are receiving this document in preparation for our upcoming phone interview, which is scheduled for, 2011 at PM, CST.
At the time of the scheduled interview, I will contact you. The interview will last approximately one hour. While you most certainly do not need to prepare any type of formal response in advance, it is my experience that interviewee's often benefit from knowing what types of questions to expect.
SAMPLE QUESTIONS:
Tell me about the nature of the peer-based program? How many peers participated? Can you walk me through the way the intervention works with clients/patients? How were peers recruited and trained for this program?
What can you tell me about the process for obtaining buy-in from the agency for this peer-based program?
Describe what you believe to be the greatest benefits of providing peer-based services. For clients? For staff? For the agency overall?
Describe the greatest challenges or drawbacks of providing peer-based services. For clients? For staff? For the agency overall?
Would you say that this program was a success in delivering peer-based HIV prevention services?
What are the unique elements/contributions of the peer-based model? Why was a peer-based model a good choice for your agency?
What specific advice or caveats would you want others who are considering implementing a peer-based program to know? Why should (or shouldn't) more agencies be incorporating peers into service delivery?

Should you have any questions prior to the scheduled interview, do not hesitate to contact

me at: apizzi@luc.edu. Thank you, and I look forward to talking with you soon.

Allison Tan, MSSA Loyola University - Chicago

# APPENDIX C

INTERVIEW TOOL

#### PEER-BASED PREVENTION WITH POSITIVES INTERVIEW INSTRUMENT

Agency ID	 Date of Interview/
Agency Name	 Staff Type
	(A) (S) (D)

#### INTRODUCTION

Good (morning/afternoon). I want to thank you for taking the time to talk with me today about your experiences and thoughts about providing peer-based HIV Prevention with Positives services.

I asked that you set aside about an hour for this interview today. It may not take that long, but I wanted to be sure that you had enough time to fully express your thoughts and experiences. If during our conversation, you need to take a break, please let me know.

After the interview, all the notes and recordings will be sent out for transcription. A preliminary copy of the transcript from this interview will be provided to you for your review and approval before any final reports are disseminated from this study. In the final written report and any subsequent publications, all quotes will be anonymous. Please be assured that anything we talk about in the course of this interview will be held in the strictest confidence.

Are you ready to get started?

#### \*\*\*SECTION A- FIT WITH BEST PRACTICES\*\*\*

The first part of this interview asks you to speak about several specific key characteristics of your peer-based program.

I will begin by asking you about the characteristics of your program. These first questions are the same as those I emailed you earlier. You can follow along if you'd like. First, I will ask whether your program includes each characteristic. Then, I will ask you to rate the importance of that characteristic to the successful functioning of a peer-based Prevention with Positives program – on a scale from 1-10 (1 being NOT AT ALL important and 10 being ESSENTIALLY important).

In this first section of the intervention, you can limit your responses to Yes or No and 1-10. We will return to some of these characteristics in more detail throughout the rest of the interview, during which you can share with me the specifics of how your agency has accomplished each element and why you believe them to be important or not important.

# Let's begin.

1) theorie	Is your program based on Behavior Change and/or Motivational In	terviewing
theorie		Y/N/DK
	How important is this to a successful peer-based PwP program?	
2)	Does your program hold to a harm reduction model?	Y/N/DK
	How important is this to a successful peer-based PwP program?	
3)		
assessi	ment questions, educational information, etc.)?	Y/N/DK
	How important is this to a successful peer-based PwP program?	
4) MSM,	Is your program targeted and tailored to any specific subgroup (for IDU, youth, women, etc.)	example:
	Which Populations:	Y/N/DK
	How important is this to a successful peer-based PwP program?	
5) future?	Does your program specifically address the client/patient's personal	l goals for the
		Y/N/DK
	How important is this to a successful peer-based PwP program?	
6)	Are program staff, especially peers, provided ongoing opportunities	s for training? Y/N/DK
	How important is this to a successful peer-based PwP program?	

7) and res	Are there established, written procedures for the program which desponsibilities of staff?	escribe the roles
		Y/N/DK
	How important is this to a successful peer-based PwP program?	
8)	Is your program well-integrated with the other programs and service offers?	ces your agency Y/N/DF
	How important is this to a successful peer-based PwP progr	ram?
9)	Does your agency, as a whole, support the importance of HIV prev	rention? Y/N/DK
	How important is this to a successful peer-based PwP program?	
10) design	Has the community (including those living with HIV) been involve, planning and/or evaluation of your program?	ed in the Y/N/DK
	How important is this to a successful peer-based PwP program?	
11) Does the client/patient typically have an ongoing relationship provider (that is, do the client and peer see each other regularly, as opencounters)?		*
,		Y/N/DK
	How important is this to a successful peer-based PwP program?	
12) mainta	Do you feel the peer providers in your program are typically able to the client/patient?	o build and Y/N/DK
	How important is this to a successful peer-based PwP program?	
These	next few questions refer to different types of statements or mess	sages a peer

These next few questions refer to different types of statements or messages a peer provider might say to a client. I will give you two choices. Please indicate which of the two your program is more likely to use.

Is a peer provider in your program more likely to say:  "Tell me about what you think you can do to better protect yourself."  Or
"Are you being good?"
How important is this type of HIV prevention message (the one you have chosen as most likely to be used by your program) to a successful peer-based PwP program?
14) Is a peer provider in your program more likely to say:  "If you don't use clean syringes, you could get hepatitis."  Or
"If you use condoms, you will protect your sex partners."
How important is this type of HIV prevention message (the one you have chosen as most likely to be used by your program) to a successful peer-based PwP program?
15) Is a peer provider in your program more likely to focus on: the importance of the client's own personal health Or
the public health of others.
How important is this type of HIV prevention message (the one you have chosen as most likely to be used by your program) to a successful peer-based PwP program?
16) Is a peer provider in your program likely to use altruistic prevention messages, like: "Consider the responsibility you now have for protecting your current and future sexual partners."
Y/N
How important is this type of HIV prevention message to a successful peer-based PwP program?  The remainder of the interview asks a series of questions about your experience in
providing peer-based HIV Prevention with Positives services.
***SECTION B - STAFF EXPERIENCES***
1. First, let's begin with an update on the status of ( <u>name of program</u> ). Is the program currently active?

How long has the program been in existence?

If yes,

*If no*, When did the program end? What is your understanding of why the program ended?

2. Tell me about the nature of the peer-based program? How many peers participate(d)?

How were/are peers recruited and trained for this program?

NOTE: If respondent rated the question about adequate training opportunities for peers HIGH or LOW, then ask:

If HIGH, You mentioned earlier that providing staff of programs like yours with training is extremely important. Please tell me about the type of training and ongoing education peers employed by your program receive. And, tell me why you believe this to be particularly important to a successful peer-based HIV Prevention with Positives program.

If LOW, Earlier, you rated training of peer staff relatively low in terms of importance for a successful peer-based HIV Prevention with Positives program. Can you tell me more about why you rated that characteristic so low?

3. Can you walk me through the way the intervention works with clients/patients?

NOTE: If respondent said "yes" to any of the following characteristics (scripted content, client personal goals, or strong rapport), be sure these elements are explained in the response to this question. If not, probe for more information about how the program does each.)

4. What can you tell me about the process for obtaining buy-in from the larger agency for this

peer-based program? Were administration and other service providers supportive of this type

of program? What steps did the program staff take to explain the peer-based program to the larger agency?

NOTE: If respondent stated 'yes' to any of the following questions (support of agency, written procedures, integration of services, community involvement), be sure these elements are explained in the response to this question. If not, probe for more information about how the program does each.)

*NOTE:* If respondent rated any of the following characteristics HIGH or LOW, ask:

*If HIGH*, Earlier you indicated that \_\_\_\_\_ was particularly important to a successful peer-based HIV Prevention with Positives program. Can you tell me more about why you rated this characteristic so high?

*IF LOW*, Earlier, you rated \_\_\_\_\_ relatively low in terms of the importance for a successful peer-based HIV Prevention with Positives program. Why did you rate this characteristic so low?

- 5. Describe your most positive experiences with providing peer-based services.
  a. What have you seen to be the greatest benefits of your program to clients? Can you think of a patient for whom this program worked particularly well? Tell me about him or her.
- b. What have you seen to be the greatest benefits of your program to staff and the agency as a whole? How did you change for the better as a result of this program?
- 6. Describe your most challenging experiences with providing peer-based services. a. What have you seen to be the greatest difficulties or draw backs of your program to clients? Can you think of a patient for whom this program did not work particularly well? Tell me about him or her.
- b. What have you seen to be the greatest difficulties or challenges of your program to staff and the agency as a whole? If you could do things over again, what would you do differently?
- 7. Would you say that this program was a success in delivering peer-based HIV prevention

If yes, Tell me why you have come to view it this way. What does 'success' mean for you?

*If no,* What do you think could have gone better?

- 8. What do you see as the unique elements/contributions of the peer-based model?
- a. Why was a peer-based model a good choice for your agency?
- b. What specific advice or caveats would you want others who are considering implementing a peer-based program to know?
- c. Why should (or shouldn't) more agencies be incorporating peers into service delivery?
- 9. Is there anything we haven't covered about the peer-based model of services that you think is important?

Thank you so much. Now, I would like to ask you just a few demographic questions about yourself as we conclude the interview. These questions are asked only to describe our sample. If you do not wish to provide any of the following information, simply say so.

#### \*\*\*SECTION C - DEMOGRAPHICS\*\*\*

Position Title: Years	s Employed at Agency:
Years in Current Position:	Gender: M/F/T
Race/Ethnicity: African American Asian	American Caucasian Hispanic Other
Highest Level of Education Completed:	<ul><li>1- High school only</li><li>2- Some college</li><li>3- Associates degree</li><li>4- Bachelors degree</li><li>5- Masters degree</li><li>6- Doctoral degree</li></ul>

Thank you so much for your time. As I said in the beginning of our conversation today, you will receive a full copy of the transcription of this interview before any data are pulled from it for inclusion in the final report from this study. I hope you will take the time to review the transcript to be sure I have accurately reflected your responses. If, at that time, there are any points you feel need to be clarified, feel free to contact me directly. I really value your feedback.

# APPENDIX D

CONSENT SCRIPT

# SCRIPT & ORAL CONSENT FORM FOR TELEPHONE INTERVIEW

Hello, I am \_\_\_\_\_ from Loyola University and I am calling to conduct the interview about your program and the peer-based HIV prevention services it provides. Are you still available to talkat this time?

If No: Is there a better time for you?

If Yes: Schedule the day and time and thank them.

If No: Thank them and give them the name of the primary researcher and her phone number to call if a time becomes available.

If Yes: Good. Now I am going to read you some information by way of informed consent for participation in this interview. At the end I will ask if you understand and agree to the information. If you do please respond yes or ask any question you have. Is that clear?

If No: Answer any of their questions and read the informed consents ask for their Oral Consent.

If Yes: Read the informed consent and ask for their Oral Consent.

"You are being asked to participate in a research project conducted by Allison Tan at Loyola University Chicago. Your participation in this study will be in the form of a telephone interview.

The purpose of the research is to understand the specific experience of providing peer-based HIV prevention services. This information will help us to identify the strengths as well as the challenges associated with providing these services. Several of the questions will you be asked are based on documented successes of other HIV prevention programs.

During the interview, you will be asked about the nature of your peer-based HIV prevention program. Some questions focus specifically on key program characteristics. Other questions ask for you to provide examples and information about your program. Throughout the interview, you will also be asked to rate certain program characteristics in terms of your belief about their importance to a successful peer-based program. The interview may last up to one hour.

Participation in the interview is voluntary and your decision to participate or not will have no adverse affects. Also, you may choose not to respond to any question or to withdraw participation from the interview at any time without consequence. The Loyola University- Chicago researcher will make every effort possible to ensure that your identity and any information provided during this interview are kept confidential. Any

written or other records of interviews will be kept in a locked file cabinet or locked computer file for the duration of the project. None of the responses will be attributed to you personally, and the researchers will report the results of the interviews in summary form, with no personally identifiable information. Before any findings are analyzed or reported from this study, you will receive a transcribed version of this interview for your review and approval. For that reason, this interview will be audio-recorded.

You will not receive any direct benefits from the research project. There could be a benefit to you as a professional and to people working in the field of HIV as this research has potential use in informing planning and policy of future HIV prevention services. There are minimal risks to you as a result of this research study. Your participation in this interview will in no way affect your position at your agency or program.

If you have any questions about the purpose of the research, how responses will be used, or any issue related to this interview, you may email Allison Tan at apizzi@luc.edu to have questions addressed. Additionally, you may call Loyola University Chicago's Office of Research Services at (773) 508-2689 in case you have questions about your rights as a research participant.

*If you agree to participate, please answer yes to the following question:* 

"Are you over the age of 18 and freely and voluntarily consent to participate in this research project?"

If they consent, thank them and begin the interview. Check the box on the interview as well indicating they have given consent.

If they do not consent: Thank them for their time.

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#### **VITA**

Allison Tan earned her BSW from Taylor University in Upland, Indiana and her MSSA/MSW from Case Western Reserve University in Cleveland, Ohio. Prior to returning academia to complete her PhD in Social Work, she worked for nearly ten years in the field of HIV & AIDS. She began her HIV service in program administration and supervision of a multidisciplinary team of service providers in a community health center setting on Chicago's west side. Following the 2006 reauthorization of the Ryan White Treatment Modernization Act, Ms. Tan was hired as a consultant by the AIDS Foundation of Chicago to help design and implement a new medical case management model citywide. Drawing from these experiences, she has recently transitioned her professional skills as a free-lance consultant to non-profit organizations – offering technical assistance, training, and grant development in areas including program design and evaluation, strategic planning, professional development, and grant writing.

While completing her doctoral work at Loyola University Chicago, Ms. Tan has also served as the editor-in-chief of *Praxis*, the student-run journal within the School of Social Work. She is currently an adjunct instructor at both Loyola and Dominican Universities, teaching a range of classes including the social policy series. In addition to her HIV prevention research, Ms. Tan has done extensive writing and presentation on the topic of best practices for working with the LGBT population from a Christian perspective.