


*Targeted Peer Support Model
Development and Evaluation for*

Caribbeans

Living *with* HIV/AIDS

(CHIVES): Case Studies





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The Demonstration is designed to create and assess the effectiveness of models of peer support for Caribbean immigrants living with HIV residing in the United States.

I. Introduction

The Special Programs of National Significance (SPNS) Targeted Peer Support Model Development for Caribbeans Living with HIV/AIDS Demonstration Program is a five-site initiative funded by the Health Resources and Services Administration's (HRSA) HIV/AIDS Bureau (HAB). Begun in 2003, the Demonstration is designed to create and assess the effectiveness of models of peer support for Caribbean immigrants living with HIV residing in the United States. The objectives of the models are to increase HIV+ Caribbean immigrants' knowledge of HIV infection; to increase their understanding of HIV treatment options and the service delivery system; and to increase their timely use of appropriate HIV medical care and ancillary services.

The SPNS program funded this Demonstration to focus health services research on individuals from the region that has the second highest HIV infection rate in the world after sub-Saharan Africa. Presently, AIDS is the leading cause of death among Caribbean adults aged 15-44 years.¹ There is a longstanding tradition of people of Caribbean heritage migrating between the US and their country of origin. Consequently, it is reasonable to assume that some of the migrants include persons who are HIV+. In the United States, poverty, lack of health care, language barriers, cultural norms, and the complexity of the health care system combine to restrict access to health care by vulnerable populations, including Caribbean immigrants.² While the Caribbean

¹UNAIDS. (2005). AIDS Epidemic Update. Geneva, December 2005.

²Wolf, R.C., Romaguera, J., Holloway, M., Colon, P., & Lago, M. (2002). Toward continuity of care between the United States and the Dominican Republic, Haiti, Jamaica, and Trinidad and Tobago: Lessons Learned from the Caribbean Migration Project. Presented at the XIV International AIDS Conference, July 7-12, Barcelona, Spain. Abstract ThPeE7930.

immigrant community in the United States has traditionally been very close knit, the stigma associated with HIV and concerns about safeguarding confidentiality are predictors of treatment preference among heterosexual men of Caribbean origin living with HIV.³

HRSA chose to focus on peer-support because the complexity inherent in effective HIV treatment calls for a cost-effective, culturally competent, community-based health intervention. Effective treatment programs featuring a peer-support component hold promise of being such an intervention.⁴ These programs employ peer-promoters to provide education regarding treatment options, adherence to care, accessing health and other support services, along with social support to individuals living with HIV in one-on-one or group settings. Peer-based HIV treatment interventions have been found to be less costly than other types of individual-level approaches, to effectively address social system factors that may shape risk behaviors, and to be effective in recruiting members of marginalized populations to enter and remain in the health care system as well as to adhere to care.⁵ More importantly, peer based interventions may also have critical credibility with people living with HIV in increasing their HIV knowledge, helping them manage stigma and disclosure, as well as, teaching about the benefits of entering and staying in regular HIV treatment.⁶ While there is a lack of studies that specifically address the effectiveness of peer support interventions among Caribbean immigrants in the United States, Wolfe *et al*² found that community norms and cultural beliefs are very important in shaping general health seeking behavior and HIV/AIDS related behavior among Caribbean individuals living with HIV/AIDS.

Four demonstration sites were located in New York and one in Florida: Brookdale University Hospital and Medical Center, Community Health Care Network (CHN), Lutheran Medical Center/Caribbean Women's Health Association (CWhA), Montefiore Medical Center and the University of Miami. The Academy for Educational Development (AED) served as the initiative's technical support and evaluation center, charged

with assisting the sites in the design of their interventions and leading the multi-site evaluation. Caribbeans Living with HIV/AIDS (CHIVES), the multi-site initiative's name, was designed to evaluate the effectiveness of peer support intervention models as a strategy to improve care-seeking behavior among Caribbeans living with HIV. The evaluation used both randomized and quasi-experimental designs in which clients were assigned to a comparison group with no peer support intervention and an intervention group with peer support intervention. Two of the sites (Lutheran and Miami) employed a randomized controlled design. The Demonstration began in October 2003 and concluded in August 2007.



Recruitment of clients, and therefore collection of baseline data ended in September 2006 - (the first client to be recruited was interviewed on December 14, 2004 and the last client was interviewed on September 15 2006).

The case studies that follow are intended to supplement the study's primary quantitative impact analysis and to provide practical insights on the contextual factors that the initiative has found critical to successful implementation of targeted peer support models.

³McDonald, R., Free, D., Ross, F. & Mitchell, P. (1998). Client preferences for HIV inpatient care delivery. *AIDS Care* 10:2, 123-35.

⁴Fogarty, L., Heilig, C., Armstrong, K., et al. (2001). Long-term Effectiveness of a Peer-based Intervention to Promote Condom and Contraceptive Use Among HIV-Positive and At-Risk Women. *Public Health Reports*, 116(1), 103-19.

⁵Broadhead, R., Heckathorn, D., Altice, F et al. (2002). Increasing drug users' adherence to HIV treatment: results of a peer-driven intervention feasibility study. *Social Science and Medicine*, 55(2), 235-46.

⁶Ross M., Harzke A., Scott DP, McCann K., Kelley M. (2006). Outcomes of Project Wall Talk: an HIV/AIDS Peer Education Program Implemented within the Texas State Prison System. *AIDS Educ Prev*, 18(6):504-17.

II. Case Study Methods

A. Objective

The purpose of these case studies is to describe the implementation of the CHIVES intervention at each site and the real life context in which CHIVES occurred. Case study is an appropriate method to examine the implementation of the CHIVES interventions because it can provide insight into “a contemporary phenomenon within its real-life context, especially when the boundaries between phenomenon and context are not clearly evident... [and when] contextual conditions [are] highly pertinent to [the] phenomenon of study.”⁷

The case studies highlight various process issues in the implementation of the CHIVES intervention at the study sites. Implementation characteristics vary by site just as the intervention and the context for the implementation vary by site. HRSA outlined the basic goals and requirements of the Demonstration but, each site responded with its own particular approach that met the general program criteria. Thus, while all sites addressed the common issue of timely health care seeking and used some version of peer support, each approach was to some extent, unique. For instance, the intervention periods were 3 months for the Miami and Brookdale sites, 6 months for the CHN site, 9 months for the Lutheran Medical Center/CWHA site, and 12 months for the Montefiore site. More importantly, the actual content and form of the peer interventions as well as the protocols used to recruit and retain clients in the intervention differed across the sites. Therefore, the case studies in this report are selected to highlight the range of issues that arise in the implementation of a peer support demonstration program in very different contexts.

Each case study illustrates an issue that is particularly relevant to the implementation of the CHIVES intervention at that site. While case studies can be used to explore the presumed causal links in real life interventions that are too complex for surveys or experiments, the case studies in this report do not attempt to do so. These case studies are simple illustrations of specific issues at each site and do not attempt to arrive at

broad generalizations about the implementation of the peer support interventions. On the other hand, in order to inform possible future efforts at replication, the case studies aim to arrive at important lessons learned in the implementation of such interventions.

B. Design

As described above, the case studies in this report are single-case designs with each site (or program) serving as a single illustrative case for a particular study question. The study questions and hypotheses that guided the development of each case report are presented in the section of the report addressing each site. The findings are then presented as specific responses to each of the case study questions.

In preparing the case studies in this report, AED employed several sources of data including:


- Program documents such as meeting notes and logic models,
- Recruitment and follow-up data, and
- In depth interviews with peer-promoters and site program personnel.

While some data were obtained specifically for the case studies, program personnel gathered other data during the execution of cross-site evaluation tasks and events such as:

- All-Site meetings,
- Program conference calls, and
- Site visits.

The evaluators collected both quantitative and qualitative data. In order to validate the findings, the researchers triangulated the data from the multiple sources described above. Also, since the success of such a complex intervention depends on the effective involvement of different actors, a multi-perspective lens was used to capture the views and voices of all stakeholders in the programs as well as to interpret findings from their vantage points.

⁷Yin, R.K. (2003). *Case Study Research: Design and Methods*. Third Edition. Thousand Oaks, CA: Sage Publications.

A photograph of two women embracing warmly against a solid orange background. The woman on the left is wearing a purple button-down shirt and has her arms around the other woman. The woman on the right is wearing an orange button-down shirt and has her hand on the first woman's shoulder. Both are smiling broadly. The woman on the right has visible tattoos on her fingers and is wearing a ring and a watch. The woman on the left is wearing a bracelet.

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Montefiore used a “community-based church outreach” approach to recruit clients into the study. Increasingly, public health interventions are utilizing and collaborating with faith-based institutions to provide services



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COME TO HIM

III. Case Study: Montefiore

A. Background

The CHIVES program at the Women’s Center at Montefiore Medical Center focused on English speaking Caribbean persons living with HIV or AIDS from Jamaica, Trinidad and Tobago, Guyana, Antigua, St. Kitts-Nevis, Barbuda, Montserrat, Barbados, St. Lucia and the US Virgin Islands. The Montefiore Women’s Center, located in the Bronx, NY, was established in 1987 and since that time has provided peer support services to clients living with HIV and their families. Montefiore’s intervention model was an adaptation of the original Women’s Center approach. A hallmark of that approach is the Center’s delivery

of comprehensive services including primary care, mental health services, housing assistance, meals, childcare, and transportation, case management, and escorted referrals to a wide range of ancillary services. Montefiore’s CHIVES team was relatively small and consisted of a principal investigator, a peer-promoter supervisor, four peer-promoters, a data manager, and a medical director. All these individuals had worked together before in the Women’s Center and they were supported, as needed, by other Women’s Center staff such as the social worker.

Among the five CHIVES sites, only Montefiore used a “community-based church outreach” approach to recruit clients into the study. Increasingly, public health interventions are utilizing and collaborating with faith-based institutions to provide services.⁸ A previous study has documented that churches can serve as institutions that provide social, economic and political capital to their community.⁹ More specifically, churches in African and in African Diaspora communities have a long tradition of expressing their communities’ challenges, advocating for social justice, organizing educational activities, mobilizing support for businesses, and promoting civil rights to address social needs.¹⁰

From a health perspective, studies have suggested that faith organizations, including churches, can provide a space where people can feel a sense of belonging, enabling them to cope with life’s stresses.¹¹ In 2004, the American Journal of Public Health published a systematic review of 53 studies of faith-based health programs in the United States and found these programs are effective in improving measurable health outcomes as well as improving disease knowledge, screening and healthy behavior.¹² The Center for Research on Religion and Urban Civil Society also conducted a systematic review of 25 studies and found that the activities of faith-based organizations have had positive health impacts.¹³ Faith organizations may be effective because they have garnered the trust of their congregations. For instance, a study on healthcare delivery in Black churches in the rural south of the USA concluded that churches can be used to effectively provide general or mental health education because of their

unique approach of conveying information and offering counseling along spiritual lines and providing support in a non-stigmatizing way.¹⁴

Despite widespread acknowledgement that churches can and do actively promote health and social services, there is very limited data examining their involvement in the HIV/AIDS service delivery with the exception of the few studies that point to shortcomings of churches in this area.¹⁵ A survey of churches in New York State found that less than 17 percent of congregations offered HIV/AIDS services including HIV/AIDS education, counseling and testing referral.¹⁶

While none of the above referenced research focuses specifically on Caribbean communities, Montefiore used churches in the Caribbean Bronx, NY community as its primary outreach venue for recruiting clients into the study. Montefiore’s recruitment strategy might be judged as successful, when considering the fact that it met 80 percent of its projected target sample and recruited 56 of the projected sample of 70 clients (Table 1). This raises the question: was this success due to the church-based approach of recruitment or due to some other factor(s)?

Montefiore’s Case Study Questions:

The following questions frame Montefiore’s case study:

- How did the project’s strategy for recruitment of clients using churches operate?
- What challenges and facilitators were encountered over the life of the strategy?
- How did the project’s church-based outreach model evolve over time?

Table 1: Client Enrollment

	Montefiore	Brookdale	Miami	CHN	Lutheran
Target Enrollment Numbers	70	200	200	152	140
Final Enrollment	56 (80.0%)	89 (44.5%)	88 (44.0%)	84 (55.3%)	40 (28.6%)

^{8&9}Swanson L, Crowther, M., Green, L., Armstrong, T. (2004). African American, faith and health disparities. African American Research Perspectives. Accessed at <http://www.rcgd.isr.umich.edu/prba/perspectives/springsummer2004/swanson.pdf>

¹⁰Caldwell, Greene & Billingsley, (1992). The Black Church as a Family Support System: Instrumental and Expressiveness Functions. National Journal of Sociology. 6, 21-40.

¹¹McRae, M. et al. “Black Churches as Therapeutic Groups. *Journal of Multicultural Counseling and Development* 27:4, 207-20.

¹²DeHaven, M.J., Hunter I.B., Wilder, L., Walton, J.W., & Berry, J. (2004). Programs in Faith-Based Organizations: Are They Effective? *American Journal of Public Health*. 94(6), 1030–1036.

¹³Johnson, B. (2002). Objective Hope - Assessing the Effectiveness of Faith-Based Organizations: A Review of the Literature. Philadelphia: Center for Research on Religion and Urban Civil Society.

¹⁴Blank, M. Alternative Mental Health Services: The Role of the Black Church in the South. *American Journal of Public Health*. 92:10, 1668-1672.

¹⁵Woldehanna, S., et. al. (2005). Faith in Action: Examining the Role of Faith-Based Organizations in Addressing HIV/AIDS. Washington, DC: Global Health Council.

¹⁶Tesoriero J. (2000). Faith Communities and HIV/AIDS Prevention in New York State: Results of a Statewide Survey. *Public Health Report*. 115:544-56.

B. How did the project's strategy for recruitment of clients using churches operate?

Who was responsible for outreach and recruitment?

At Montefiore, peer-promoters were the primary outreach workers responsible for client recruitment. There were four peer-promoters, two of whom worked with the program from its inception, with the other two joining shortly thereafter. Prior to assuming their responsibilities, the peer-promoters completed a lengthy (9-month) and intensive (5-days a week) training conducted by Montefiore staff.

From the outset, the Montefiore peer-promoters saw themselves primarily as service providers and thus they preferred to spend their time interacting with clients, delivering the intervention, and doing what they could to ensure that clients accessed care and other needed services in a timely fashion. This preference, however, had to be balanced with the need for the peer-promoters to conduct outreach so as to recruit clients. The principal investigator noted that she wanted to avoid a situation where one or two peer-promoters focused primarily on outreach while the other two delivered the intervention. She felt that all members of the peer-promoter team should be equally comfortable with all facets of the work so after discussions with the team the decision was made that all peer-promoters would share the outreach task. To facilitate this process, the program director monitored the success of the peer-promoters' efforts and adjusted their workloads accordingly so that no one was overburdened.

How was recruitment conducted?

Peer-promoters started out by making attempts to secure appointments with the pastors of small, local storefront churches that are typically frequented by Caribbean immigrants in the Bronx. Montefiore focused its outreach efforts on 30 such local churches. The Montefiore team noted that in order to gain entrée to the congregation, it was necessary to meet with the pastor whom they assumed was the gatekeeper. However, over the course of the study, they came to learn that often, despite the relatively small size of the congregations in question, there were several gatekeepers in addition to the pastor; for example, deacons, ushers, or church board members. Thus, the initial contact typically turned into several contacts aimed at securing the buy-in of all of the gatekeepers in order that the peer-promoters could receive permission to make a presentation about HIV and the CHIVES program to the church. The peer-promoters reported that on average it required four to six contacts in order to secure permission to address a congregation.

The Montefiore team was concerned about the interpersonal dynamics of peer-promoters going into churches where they were not known and presenting on the sensitive topic of HIV. Consequently, so as not to be an overwhelming presence, the team decided that peer-promoters would generally go solo to churches so that they could be an unobtrusive presence. Over time, they learned that entrée into the church was facilitated by attending church services that were held two to three times weekly so that they would become a known presence to the congregation. Then, at this point, they would be ready to make



the team learned that in many cases stigma prevented church members living with HIV from disclosing to anyone, including their minister

a presentation about HIV/AIDS, the Women's Center and the CHIVES program to the congregation.

The peer-promoters took great pains to present the CHIVES program as part of a holistic menu of services available at the Center so that the emphasis was not directly on HIV. This approach was taken in response to the profound stigma around HIV that persists in the Caribbean community. After the presentation, the peer-promoters would mingle with congregation members to give those who had questions or wanted to obtain literature about HIV and the program an opportunity to do so discretely. Again, the emphasis on discrete dissemination of materials and information was a direct response to the levels of stigma encountered in the community.

The principal investigator observed that because the peer-promoters were members of the target community, they were particularly adept at assessing the level of stigma in the various congregations they visited and tailoring their message accordingly. This is not to imply that they disguised their true intent but rather they took into account the sensitivities of their audience and adjusted as necessary so as to keep the congregation engaged long enough to have them find out about the available services. Some of the specific strategies the Montefiore peer-promoters used to counteract stigma during recruitment included: 1) Taking cards with their names and numbers to distribute to interested parties that might want to continue the discussion in private; 2) Presenting and distributing materials that addressed other diseases besides HIV so that congregants could feel comfortable approaching them, knowing that they did not have to restrict their inquiries to just HIV; and 3) Referring persons interested in being tested for HIV to the Montefiore Infectious Disease Clinic and/or Program Bravo – a local testing service.

C. What were some of the obstacles and facilitators to the project's recruitment approach?

The Montefiore team cited *lack of time* as the single most

important obstacle to recruitment. The church-based recruitment approach, while successful, was very time-consuming. *Stigma* in the community also posed a significant problem.

Time

From the outset, the Montefiore team was racing against the clock to make significant strides in recruitment within the timeline set by the Demonstration. Even if the program were not part of a demonstration, the amount of time spent conducting outreach would still have posed a considerable obstacle. As noted earlier, peer-promoters often had to contact a single church numerous times before gaining access to its congregation. This was necessary in order to build trust between the gatekeepers and the peer-promoters. However, a cookie-cutter approach could not work. Each church has its own hierarchy and so the peer-promoters had to treat each organization as a unique entity. In addition, building trust often required peer-promoters to attend church activities on a regular basis, which was very time consuming and labor intensive.

Once access was secured there was no guarantee on how long, if ever, it would take for any persons living with HIV in the congregation to agree to enroll in the program. As is detailed below, many of these persons had to overcome numerous challenges before they could enroll. In keeping with Montefiore's holistic model, the peer-promoters spent extensive amounts of time working with these persons, once they had come forward to express an interest, to assist them to resolve these problems. The holistic approach that addressed life issues and built trust, and the time involved, presented a challenge to the linear medical/health systems model which often narrowly defines health care needs as what can be addressed by western medicine and sets limits on the time and the amount of services that can be accessed. While the Montefiore team did have limits, these were kept as wide as possible and the range of situations in which the peer-promoters were prepared to offer assistance to potential clients was similarly expansive.

Peer-promoters reported much of their outreach interaction involved advising potential clients, who really wanted to enroll but were prevented from doing so by the need to resolve a variety of serious problems such as homelessness or domestic violence, on what they could do to remedy the situation in the short term thereby freeing themselves to enroll in the program. For example, the Montefiore team presented the following case at the January 2005 CHVES All-Sites meeting:

Client X came to the Women's Center with concerns about disclosure of her HIV status as well as many other psychosocial issues, e.g. employment, family matters, finances and housing. The Montefiore team helped the client address many of these issues by providing her with psychotherapy before she even enrolled in the CHIVES program. After the client was provided with assistance

to address her psychosocial issues, she experienced enough relief from her circumstances to increase her self-efficacy and began to feel more confident about her ability to participate in the CHIVES program. She eventually enrolled in the program and became an active participant.

Stigma

Staff indicated that discussing sexuality as it relates to HIV/AIDS in a church environment was a real challenge because the cultural barriers surrounding such topics in the Caribbean community were heightened in the church setting where values tend to be very conservative. Consequently, homosexuality, which is a particularly taboo subject in Caribbean culture¹⁷ tended to be openly condemned in the churches. Thus, stigma proved a potent obstacle to having people come forward and enroll in the program. Initially, the Montefiore team had hypothesized that individuals living with HIV would disclose their status to their ministers who would then provide them with information about the Demonstration and encourage them to contact the Montefiore team without disclosing the individual's status. This did not happen because the team learned that in many cases stigma prevented church members living with HIV from disclosing to anyone, including their minister. Although the medical director of the Montefiore team is also a pastor and has connections with many of the churches that were targeted in the outreach effort, the nature of his interactions with the various congregations did not permit him to discover the full extent of stigma within many churches. While the negative attitudes of some churches were readily apparent during the initial encounters that the medical director and the peer-promoters had with them, it took time in other congregations for their true stance to emerge. Furthermore, the team observed that while they and others often spoke of "the attitude of the church", in many cases the situation was more complex, with a range of attitudes being displayed by various members. It is also important to note that in many congregations there were formal and informal leaders who exerted varying degrees of influence on the congregations in question. As a result, in some churches while there was stigma, among individual members, the leadership was welcoming of the peer-promoters and the project; in others, the leaders may have demonstrated stigma while some congregants privately held more compassionate views. One of the ways that the peer-promoters sought to address this complex situation was to connect one-on-one with individual congregants, gain their trust, and acquire, over time, an understanding of how infected persons within the congregation perceived the congregation's reaction to them and use this information to determine how best to continue with the outreach effort.

In some cases, the team discovered that the stigma around HIV and fears around disclosure in some congregations resulted in the creation of networks of people living with HIV outside of these congregations. Therefore, the peer-promoters had to expand their efforts so as to identify and connect with these

¹⁷White R., Carr R. (2005). Homosexuality and HIV/AIDS stigma in Jamaica. *Cult Health Sex.*, 7(4):347-59.

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alternative networks outside of the church - these could take the form of informal gatherings at the home of infected person or at a social agency that catered to persons living with HIV. Finally, while recruitment within the churches was proving difficult, churches did help deliver the message about the intervention that eventually led to better outreach in non-church settings.

Montefiore identified four factors that facilitated their outreach approach and enabled them to overcome some of obstacles mentioned above: 1) small, stable, and cohesive team 2) prior experience with the target population 3) a holistic approach to offering care and 4) strong institutional support. It is important to note, however, that these factors are not directly related to the church-based strategy and could potentially be strengths in any context.

Small, Stable, Cohesive Team

Montefiore’s CHIVES implementation team consisted of four full-time peer-promoters and their supervisor who worked under the direction of the principal investigator and the medical director. Team members were trained and worked together almost a full year before service delivery began. From the outset, their interactions were characterized by frequent and open communication. The peer-promoters saw each other and their supervisor daily and usually the principal investigator as well. Cross training occurred naturally because of the team’s size, so all of the peer-promoters had some knowledge of their colleagues’ respective caseloads. For instance, peer-promoters had instituted a system of back-up peer-promoters whereby when a peer-promoter was not available, someone else cared for his/her clients.

According to one peer-promoter, “*the smallness of things makes it easier to manage...you know when things happen sooner and so you can stay on top of things.*” The smallness of the group also allowed for a rapid response to problems, for example, when it appeared that a lack of trust was preventing

entrée into the churches, the group quickly convened and decided that peer-promoters had to become more engaged in the churches and attend services so as to promote trust. Subsequently, when recruitment was still not progressing at the desired pace, the medical director met with the principal investigator and they formulated a plan to supplement the church-based recruitment with referrals from the Montefiore Medical Center (MMC) AIDS Center, the MMC HIV Counseling and Testing Program and with a nearby New York City Department of Health HIV Counseling and Testing AIDS clinic site.

In addition, the team experienced very little staff turnover (Table 2). In fact since the program’s inception, only one peer-promoter left. The longevity of the relationships between the team members was critical to their success over the course of the intervention. The full-time status of the peer-promoters also appears to have strengthened their individual commitment to the program. The peer-promoters reported that because of the amount of time they spent working they were able to follow clients from shaky beginnings to successful conclusions and this helped retain the staff in the program. In sum, the fact that the Montefiore program had a small group of highly committed staff that focused primarily on the CHIVES program rather than being spread across several programs facilitated not only outreach but also all program processes.

Experience with the Target Population

The peer-promoters’ experience with the target population was reflected in their ability to engage the clients. The peer-promoters employed specific communication skills that facilitate recruitment and engagement. For instance, in some cases, the peer-promoters would disclose their challenges with HIV and personal life issues and how they resolved them successfully so that the client perceived that others had faced and overcome the challenges that (s)he was currently facing. According to one peer-promoter, it was important to stress to clients during outreach and recruitment that HIV is not a death sentence, which is a complete contradiction to

Table 2: Peer-promoter Retention Patterns

	Montefiore	Brookdale	Miami	CHN	Lutheran
Total # of peer-promoters at beginning of program	4	11	2	4	4
Total # of peer-promoters as of Aug 2006	4	8	2	2	3
Highest # of peer-promoters at any time as of Aug 2006	4	11	2	3	5
Longest serving peer-promoter - length of time served through Aug 2006	3 years	36 months	25 months	8 months	3 years
Shortest serving peer-promoter - length of time served through Aug 2006	1 year and 2 months	5 months	25 months	1 month	3 months

what many had heard in the Caribbean and believed. Peer-promoters also served as a sounding board for prospective clients, allowing them to voice fears and concerns that many had kept suppressed for years while dealing with their HIV disease in secrecy. Peer-promoters noted that it was important to “*legitimize the pain*” that potential clients felt so that they could be assured that they and their feelings would be treated with respect if they were to enroll in the program.

A Holistic Approach to Offering Care

In addition to having a small and well-trained staff, the program was able to attract and retain its clients by offering comprehensive care. The Women’s Center, in which Montefiore’s program is housed, has always integrated its programs horizontally. So from its inception, there was already a network of supportive programming. In terms of its service delivery, the Women’s Center aims to be as comprehensive as possible, and the entire environment is designed to be therapeutic and to build community. There is co-location of primary and ancillary services so that these have a synergistic effect.

Potential clients were enticed to join by the wide range of services the program offered. For many potential clients facing a host of serious life issues, the program’s menu of services and the willingness of the staff to assist clients to access them appropriately were very attractive features of the program. Clients had on-site access to the Women’s Center’s mental health services, housing assistance, transportation assistance, food pantry, family therapy, support groups, and a children’s center with a specific focus on children infected with or affected by HIV. Where the Women’s Center did not provide a needed service, peer-promoters were trained to make referrals and, in most cases, would accompany the clients to ensure that they received needed services. High on the list of outside referrals were immigration services and so the peer-promoters took it upon themselves to learn about and create linkages with local immigration law services. The program managers also constantly encouraged the peer-promoters to update and augment their knowledge about available ancillary services so that they were better positioned to assist clients.

Strong Institutional Support

From the outset, the Women’s Center had strong institutional support for its CHIVES program from Montefiore Medical Center. The principal investigator was well respected at Montefiore and had established solid, longstanding relationships with key decision-makers within the Montefiore administration prior to the start of CHIVES. The Montefiore administration provided tangible support to the program by paying the salaries of some of the providers as well as providing the program with excellent physical space.

Ensuring that a comfortable space was available in order to conduct the intervention for clients was very important as, according to the Principal Investigator and program staff, clients needed to be exposed to an environment that was warm, caring and discreet. As stated by one of the peer-promoters “*They could come here but dem naw gon stay if they are not comfortable.*” The location of Montefiore’s CHIVES

intervention was designed to be physically and psychologically comfortable for clients. For example, the space allocated to the program was completely devoid of any reference to HIV or AIDS. Instead, the program offices were located on the first floor of an office building and the nameplate for the office suite simply states “PEAS Program.” On entering, one encountered a homey atmosphere with comfortable armchairs, bookcases with novels and other non-HIV related reading material, and soft lighting. The office space contained several private meeting areas so that peer-promoters could ensure that their interactions with clients were confidential. According to the peer-promoters, many prospective clients who were hesitant to enroll were won over by the office space. None of this would have been possible without the commitment of the Montefiore administration to the program.

D. How did the project’s church-based outreach model evolve over time?

The Montefiore team was able to achieve a balance between fidelity to the intervention and flexibility to respond to the needs of their target community. Thus over time, the model overall stayed stable with only a few changes being made to it.

Stability over Time


The Montefiore program was modeled after the peer-support model that the Women’s Center has used for over 18 years and that involves developing a supportive community of care. They adhered quite strictly to the model only deviating when the need to do so was obvious. This strict adherence was made possible by the fact that as a team they spent months identifying, discussing and refining the goals of the program. At the end of this process, everyone had the same understanding of what the program was intended to do. Staff was adequately trained, and their process of outreach was well thought out as they aimed to present their program in the church while integrating it with other healthcare information and resources in order to reduce stigma people might feel from receiving their services.

Flexibility to Change

While striving to maintain fidelity to the original model, the staff also strove to be flexible when necessary. For example, at the beginning of the outreach effort, two peer-promoters would visit a single church. However, they observed that they were not able to engage individual church members in this manner. It appeared that for church members living with HIV to feel comfortable coming forward, it would be necessary to engage them one-on-one and build their trust overtime. Therefore, peer-promoters began visiting churches singly and attending church activities on a regular basis so that they became known to the congregation in question and the attitude of individual members towards them became more trusting.

Expanding Enrollment to Other Caribbean Countries

Originally, Montefiore’s intervention was focused on Caribbeans of Jamaican origin. However, when recruitment proved slower than anticipated, the team discussed the problem internally and with church leaders. The leaders had previously questioned the HRSA requirement of restricting sites to serving



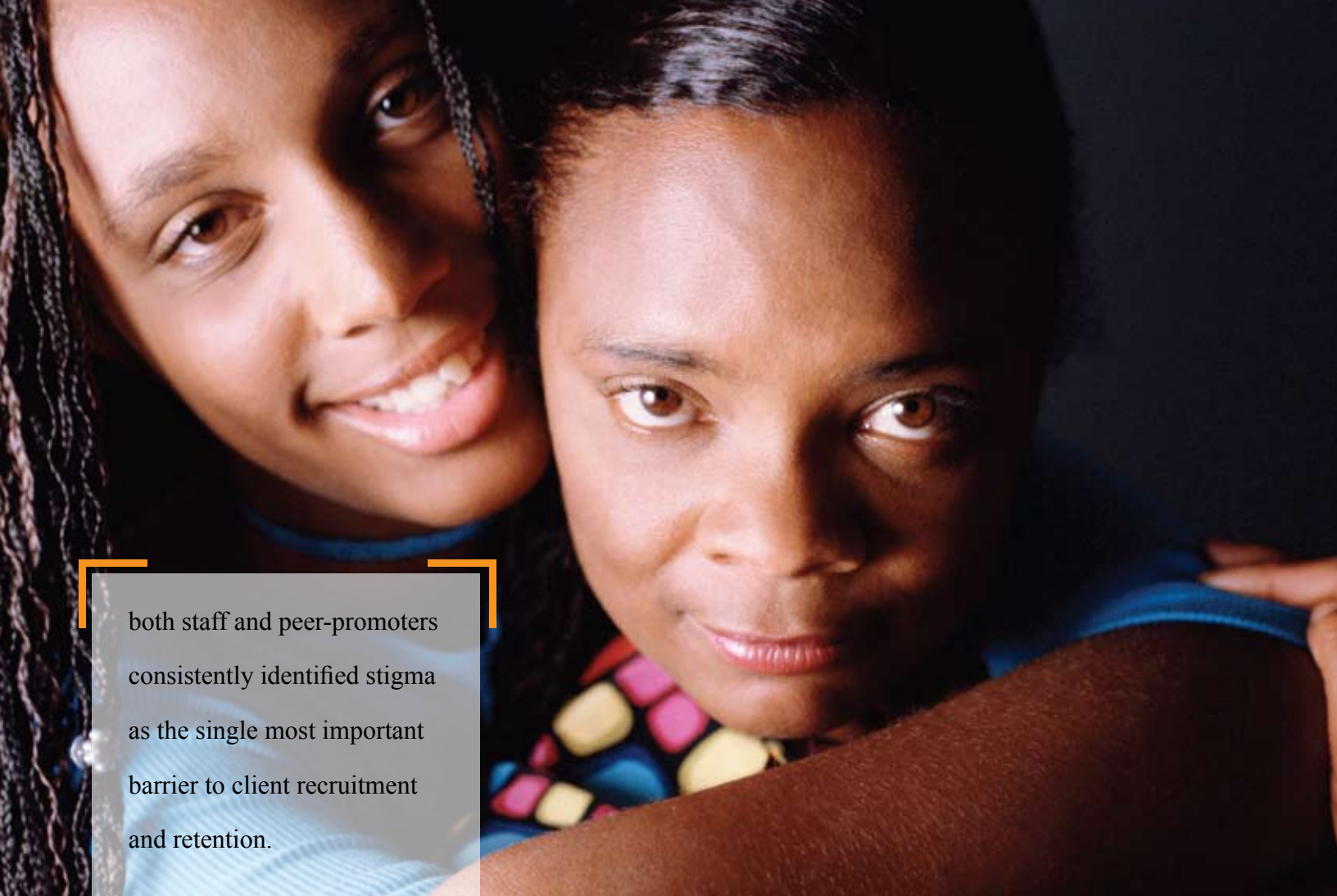
None of this would have been possible without the commitment of the Montefiore administration to the program

persons from just one country. They were concerned that the requirement was unfair to those deemed ineligible and might stigmatize the country whose nationals were being targeted. Thus when the team proposed expanding eligibility to include persons from other Caribbean countries, this decision was welcomed. The site requested and was granted leave by HRSA to recruit from other Caribbean countries. Ultimately, one third of the clients in Montefiore's program came from these other countries.

E. Conclusions

The church-based recruitment approach was hampered by stigma and other reservations voiced by church leaders. Thus, any successes that the site was able to attain were due primarily to the highly dedicated peer-promoters who persisted despite the obstacles and who were able to bond with potential clients and motivate them to enroll. Specifically, the peer-promoters' ability to understand the target population and their issues was probably the most important contributor to their success. At the core of the program there was a small cohesive team that received intensive attention from the principal investigator and the medical director. The longevity of the relationships between the team members was critical to their success. At the institutional level, having support to hire a smaller team of full-time staff and having space to conduct a holistic intervention provided the necessary foundation for successful outreach.

Where time is a factor, as is the case with all Demonstration projects, the church-based recruitment approach probably is best utilized in conjunction with another approach so that jointly the two strategies can reach the desired sample size. Six months into the implementation period Montefiore decided to make this change and began to recruit from HIV outpatient clinics and testing and counseling sites while still continuing to recruit from the churches. However, the Montefiore church-based strategy does provide useful lessons on how to gain entrée into a congregation, the amount of time needed to do so, the importance of building trust and ways to make that happen, and how ultimately to reach out to those living in secret with HIV and assist them to seek care appropriately. Specifically, the Montefiore peer-promoters developed an approach that allowed them to circumvent the stigma against HIV, that often resulted from opinions voiced by church leadership, by connecting one-on-one with individual members who were positive and gradually engaging these persons to the point that they were willing to enroll in the project and begin accessing health care.



both staff and peer-promoters consistently identified stigma as the single most important barrier to client recruitment and retention.

IV. Case Study: Brookdale

A. Background

The CHIVES project at Brookdale was located in the hospital's Treatment for Life Center (TLC), an AIDS designated center and part of the hospital's infectious disease division. Located in Brooklyn, NY, TLC has a staff of 40, including six physicians, nurse educators, and case managers and sees 1000 HIV+ patients annually, most of whom are African-American, Caribbean and Latino. The Center provides integrated outpatient and in-patient care, has 9000 outpatient visits a year and sees 150-170 newly infected persons each year. The majority of the patients that are living with HIV are minorities with a significant proportion coming from the Caribbean. Services provided to the patients include psychiatric care and HIV counseling and testing.

The CHIVES project at Brookdale served Haitians living with HIV or AIDS with a special focus on those residing in

Brooklyn, Queens and Long Island, NY. One of the barriers to care that Brookdale aimed to address in its intervention was HIV related stigma among Haitian immigrants. Homophobia in many developed countries has resulted in HIV/AIDS being a stigmatized condition. In Haiti where HIV infection has started to be diagnosed in heterosexual populations, such as women living in poverty, the stigma that was once directed solely towards homosexuals is now transferred to other vulnerable, infected groups.¹⁸ In addition, some of the prejudice towards people with AIDS has been reflected at an institutional level where efforts towards HIV/AIDS have centered on prevention rather than treatment, suggesting that there is less value in helping those who are already infected. While research on interventions to reduce stigma among Haitians is limited, studies have shown that improving clinical services as well as addressing internalized stigma that a client living with HIV may feel, can alleviate the impact of stigma.¹⁹

¹⁸Farmer P. (1992). *AIDS and Accusation: Haiti the Geography of Blame*. Berkeley: University of California Press.

¹⁹Walton, D.A., Farmer, P.E., Lambert, W., Léandre, F., Koenig, S., Mukherjee, P., et al. (2004). Integrated HIV Prevention and Care Strengthens Primary Health Care: Lessons from Rural Haiti. *Journal of Public Health Policy*, 25, 137-158.

At the start of their project, Brookdale staff identified stigma in the Haitian community as a significant barrier to the successful implementation of the study. The team’s prior experience working with Haitian faith leaders, members of the Haitian media, and the Haitian community in general indicated that while the community might be supportive of their proposed CHIVES intervention, stigma would be a real problem. In addition, just prior to launching the intervention, the team conducted interviews with key informants that reinforced the view that attempting to mitigate stigma would actually facilitate the implementation of their CHIVES intervention.

B. How did stigma impact the implementation of the project?

Brookdale’s Case Study Questions:

The Brookdale case study examines the site’s strategies to fight stigma in the Haitian community as a way to recruit and retain clients. The case study attempts to answer the following questions:

- How did stigma impact the implementation of the project?
- What strategies were employed to reduce stigma? How did the strategies evolve over time?
- What facilitators and barriers did the site encounter when addressing stigma?

Client Recruitment and Retention

Over the life of the project, both staff and peer-promoters consistently identified stigma as the single most important barrier to client recruitment and retention. By the time the recruitment period closed in September 2006, Brookdale had met only 45 percent of its client enrollment projections (Table 1). Subsequently only 60 percent of enrollees came back for their three-month follow-up appointment (Table 3).

According to the program staff, some potential clients, particularly those lacking formal education and unable to accept the stigma associated with the disease, denied the existence of HIV and attributed their illness to voodoo. Others with more formal education thought that HIV education and interventions were for the uneducated. Some infected persons from a higher social class that may have been eligible to participate in the study did not want the stigma of seeking care from services that also catered to persons from a lower class and so declined to participate in the intervention.

Stigma also affected how and where outreach occurred. In contrast to the other New York sites, where outreach workers specifically sought out clubs and other venues known to be frequented by immigrants from the target country, this type of direct approach was not viable at Brookdale. Although, the site where the intervention was conducted is in the heart of the Haitian community in Brookdale, the peer-promoters, who were the primary outreach workers, reported that they could not approach fellow Haitians in public settings with information about HIV. Doing so was bound to lead to active rejection by the targeted parties. Similarly, the peer-promoters noted that it was very difficult, if not impossible, to conduct outreach at clubs and parties known to be frequented by Haitians.

Keeping clients engaged after they had gone through the initial enrollment process was also challenging due to stigma. Peer-promoters reported that many clients were extremely afraid of whom they might meet at the service delivery site or who might see them entering the site. Some clients had extreme difficulty keeping their first appointment due to concerns that they might run into other Haitians at the clinic. One of the program staff, who is Haitian, reported that he spotted a newly enrolled client approaching him, and because he was aware of how much of a problem stigma was in his community, he consciously avoided making eye contact with the client so as not to prevent her from proceeding to her appointment for care. Another CHIVES team member recounted a case where a client recognized a CHIVES team member as someone she knew in Haiti and vowed, as a consequence, never to return to the clinic or the intervention. She was ultimately persuaded by the staff to change her mind and, from that point onwards, the team member in question pretended to ignore her so that having direct contact with him did not embarrass her.

Table 3: Three-Month Follow-up Rate

Recruitment Site	Follow-up Rate	Comment
Montefiore	89.1%	
Brookdale	60.7%	
Miami	55.8%	Includes clients that have deceased
CHN	51.2%	
Lutheran	51.3%	
SUNY ²⁰	62.5%	

²⁰SUNY - The State University Of New York’s Downstate Medical Center, recruits for the control arm of Brookdale and CHN

Effect on Peer-promoters

Despite the fact that the Brookdale peer-promoters all attended several trainings about how to reduce stigma, all of the peer-promoters reported that they personally had problems with stigma and disclosure. As a result, once the program started, the program coordinators had to be more involved in outreach activities than their counterparts at other sites. This was attributed to the peer-promoters' resistance to conducting outreach and possibly risking having to disclose their HIV status. When asked what they thought might happen if they encountered a Haitian they knew while conducting outreach, there was consensus that even if they did not disclose their status, because they were discussing HIV the person would likely suspect they were HIV+ and then, share that information with others in the Haitian community. Once others in the community knew or suspected they were positive they and their families would be ostracized.

The apparent contradiction in having peer-promoters that were afraid to meet their prospective clients is perhaps explained by the strategy that was used to recruit the Brookdale peer-promoters. TLC reviewed the data on broken appointments of current patients and placed all Haitian patients on a continuum. The most adherent were recruited as peers, while the middle category was identified as potential clients. So the Brookdale peer-promoters were indeed part of the target community that suffers from stigma.

Content of the Intervention

Initially, clients met with peer-promoters one-on-one. Then eventually the site started offering group sessions that were intended to provide clients with a support network. However, because of stigma, only 30 percent of the clients participated in the group sessions. A larger percentage of clients met in informal group settings every two months for purely social interaction during which HIV was not discussed.

C. What strategies were employed to reduce stigma? How did the strategies evolve over time?

Community Wide Education

Brookdale conducted community level activities in order to try to affect change and to help de-stigmatize HIV. Brookdale's community level intervention involved the education of faith and community leaders to foster social support networks and a media campaign to help de-stigmatize the disease. The project staff met with influential leaders in the faith and the general Haitian community in a series of dinner meetings and forums to discuss the impact of the disease on the community and how stigma was preventing the infected from accessing care. The team built on relationships that TLC had already established and conducted dinner meetings and one-on-one visits to the offices of Haitian physicians that belong to Association of Haitian Physicians Abroad (AMHE); Docs Tee Time; Haitian Psychiatric Association (HPA); and the Aesclepius Medical Society. They also followed up with some of the Haitian faith leaders that they had trained under a CDC funded initiative in 2003 and presented additional messages about stigma to this audience.

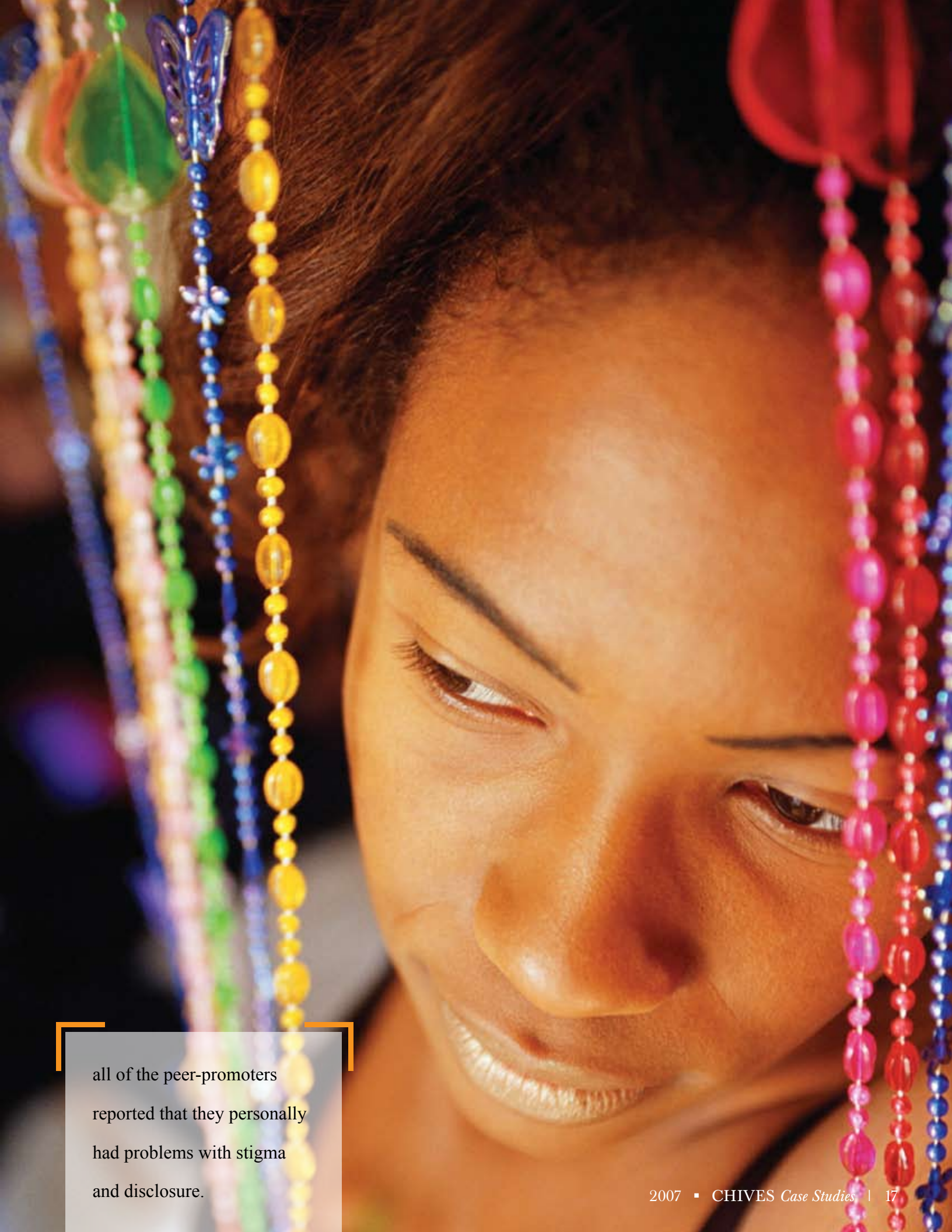
The Brookdale team placed public service announcements on the radio and in the print media that targets Haitians in New York. The principal investigator and another member of the project team were guests on local Haitian radio and television programs where they discussed the impact of the epidemic on Haitians and the effects of stigma. Brookdale also produced its own short video on HIV and stigma, which it presented at health fairs throughout the community. The team reported that the above-mentioned efforts were well received by their target audiences but there were no data on the actual impact these efforts may have had on stigma.

Recruitment of New Outreach Workers

Initially, Brookdale had specified that a key responsibility of peers was “*identify, coordinate and participate in community outreach projects, which provide HIV education to those living with HIV/AIDS, high-risk groups, community and faith leaders, and the Haitian community,*” and had hired Haitian Kreyol speaking individuals. However, after initial assessments revealed the internalized stigma that the initial group of peer-promoters was struggling with, program staff made the decision to hire experienced outreach workers that were not necessarily Haitian. The rationale was that this initial cadre of peer-promoters lacked the skills to conduct outreach effectively. Specifically, the peer-promoters were too hesitant about speaking in public about HIV and disclosing their status. As discussed above, staff observed that some of the peer-promoters did not “*want to be identified as HIV+.*” The newly hired outreach workers were all members of the Treatment for Life Clinic's Community Advisory Board (CAB) and had been trained on effective outreach strategies prior to being hired.

Initially there were some issues that needed to be resolved in this mixed group of peer-promoters/outreach workers. The Haitian peer-promoters were not as outgoing as their non-Haitian counterparts and were reluctant around outreach. In fact, the two groups did not understand each other. This lack of understanding was particularly problematic for the non-Haitian group since they were tasked with recruiting Haitians. They had to learn that an indirect approach worked best with Haitian clients and that public discussions of HIV and sexuality were essentially taboo.

The Brookdale project managers had to learn to give the peer-promoters time and space to work through their issues relative to stigma. It would appear that initially, the managers were influenced by reports from other CHIVES sites where the peer-promoters were all very comfortable conducting outreach and disclosing their status. Based on these reports, they expected their peer-promoters to do the same. Some eventually did but it took considerable time. In 2006, three years into the four-year project, one of the Haitian peer-promoters reported that he disclosed his status at a public meeting of Haitian religious leaders. When asked what prompted this action, he replied that being part of the CHIVES program helped him to have the confidence to disclose publicly.



all of the peer-promoters reported that they personally had problems with stigma and disclosure.



The complexity of stigma, coupled with all of the other challenges that the target community and even the peer-promoters faced, made it virtually impossible to make real headway in the time allocated...

Client Centered Services

In an effort to mitigate the stigma in the larger community, the site tried to ensure that potential clients felt their concerns around confidentiality would be addressed by the program. Clients were offered their choice of peer-promoters, and gender concordance between the peer-promoter and the client was arranged if requested. It is important to note, however, that disclosure by the peer-promoters began towards the end of year two of the project when they had become more comfortable with the issue of disclosure. Initially as discussed earlier, they were unwilling to take this risk. However, they attribute their increased comfort level to the training that they continued to receive as well as the motivational talks that the team's health educator gave them.

One peer-promoter recalled the initial situation of a prospective client who had been positive for several years but had not sought treatment, and when contacted had a T-Cell count of eight. Overcome by feelings of stigma, this individual cried for 15 minutes in the initial meeting and was only persuaded to schedule a primary care visit when the peer-promoter disclosed and explained that previously, he too had been in similarly dire straits. The peer-promoters reported that once clients understood and were convinced that HIV is not a death sentence and that the peer-promoters have faced similar challenges, they were willing to be engaged. Interestingly, the peer-promoters reported that they also motivated clients by helping them to set becoming a peer-promoter in the future as a personal goal. The peer-promoters explained that they had been selected to serve as peers because they represented positive examples of care seeking and could serve as role models to others. Several organizations in New York City have HIV peer-promoter programs and the Brookdale peer-

promoters encouraged their clients by reasoning that if the latter improved their care seeking then just like the Brookdale peer-promoters they might one day be recognized for this achievement and could apply to serve as peer-promoters in one of the peer-promoter programs in the city.

Anonymous Physical Space

The peer-promoter intervention services were delivered in a building that is separate from the main hospital and is located central to the Haitian community in Brookdale. This was done intentionally to eliminate any stigma that clients might feel about seeking care from TLC, a known provider of HIV services. However, program staff found that despite the fact that the building did not have signage that features "HIV" prominently, some clients preferred to seek care in settings located far away from the community so as to minimize the likelihood of encountering someone they knew. Therefore, towards the end of the Demonstration, the peer-promoters started to make home visits and conduct one-on-one sessions. At the time of writing of this report, nearly 10 percent of all peer encounters were happening in the client's home. By going to their homes, the program attempted to address the stigma associated with coming to the clinic for the intervention.

D. What facilitators and barriers did the site encounter in addressing stigma?

Site staff and peer-promoters identified factors that hindered and/or helped their efforts to combat stigma during program implementation. One factor facilitated Brookdale's fight to combat stigma. It is discussed next.

Culturally Competent Team

Brookdale's team was composed primarily of Haitians with strong ties to the target community. Of the roughly 200 Haitian patients living with HIV seen at TLC, the overwhelming majority was managed by the project's principal investigator. While, at times, concerns about stigma may have caused certain prospective clients to avoid Haitian providers, it appeared that for various reasons, particularly language, most Haitian patients at Brookdale ultimately preferred to be seen by Haitian providers. Nevertheless, stigma continued to create a constant tension such that at times clients appeared to be simultaneously avoiding and seeking help, while the project staff always tried to ensure that clients found a comfortable space to seek care.

While there were many characteristics of the Brookdale team and its efforts that facilitated the fight against stigma, there were also obstacles. This is not surprising given the deep-rooted nature of the problem. These challenges are discussed next.

One Country Focus

Some members of the Brookdale team were of the opinion that by focusing only on Haitian immigrants, their intervention might have worsened or helped to maintain the level of stigma already present in their target community. From the outset, TLC's Community Advisory Board (CAB) and some TLC staff questioned why enrollment was restricted to just Haitians. There was the perception that the project was attempting to make the point that HIV is a Haitian disease. Also because similar projects were not available for TLC patients and community resident from other countries, this also fueled the perception that Haitians were being stigmatized as "*the group with HIV.*"

To combat these perceptions, program staff engaged the wider community including other programs in the hospital and the Haitian community at large. At TLC, they always provided project updates at CAB and general staff meetings, and when the project held community meetings, the staff of other TLC projects was always invited to participate. Program staff, including peer-promoters, made a special effort to integrate themselves as much as possible in general clinic activities such as health fairs, World's AIDS day, and outreach events in the community so that they did not appear isolated and exclusionary.

Insufficient Time

Finally, as is the case with all of the CHIVES sites, insufficient time proved a barrier to Brookdale's reaching its goal of mitigating stigma in its target community. The complexity of stigma, coupled with all of the other challenges that the target community and even the peer-promoters faced, made it virtually impossible to make real headway in the time allocated for the Demonstration. As the project came to a close, the team felt that they were seeing signs of progress, as seen by

the example of the peer-promoter who had disclosed and a slight increase in the number of clients willing to attend group sessions. Unfortunately, the end of the project also meant the end of funding and the chance to see whether the signs constituted a real pattern of improvement.

E. Conclusions

Brookdale site staff had identified stigma as a key barrier to the implementation of their intervention. Their experiences demonstrate just how intransigent to change the problem of stigma can be. In some sense, Brookdale's decision to target stigma meant that it had to launch a two-pronged intervention – reduce stigma in the community and provide clients with a peer-support intervention. This effort was further complicated by the discovery that even the peer-promoters that were supposed to be assisting clients to overcome stigma were also grappling with the same issue. This discovery underscores the importance of careful prescreening to ensure that peer-promoters possess all of the necessary skills and attributes to feel comfortable in their role. Had this particular challenge been identified in advance perhaps Brookdale might have devoted more time to intensive training of their peer-promoters prior to the start of outreach, with a specific focus on stigma and disclosure.

Brookdale tried community wide education as a means of reducing stigma. These educational events were well attended, but it is not clear that there was a direct and significant association between these activities and referrals of prospective clients to the program. Also the peer-promoters never mentioned the community wide education as a factor in assisting them or their clients to address stigma. Again, the lack of time and resources to launch a wide and deep community education effort might explain this finding. It must be noted, however, that SPNS did not specifically fund grantees to conduct community education as part of this Demonstration -Brookdale made the decision to conduct community education as a means of mitigating stigma which it believed would be a significant hindrance to the successful implementation of their project.

The Brookdale team did attempt to make changes to those conditions that were under their control. They hired new outreach workers when it was clear that the peer-promoters' stigma prevented them from assuming this function effectively. They tried to offer as client-centered service as possible within the limitations posed by operating within a large, urban clinic.



The Miami site recruited clients daily through an in-reach process conducted in the inpatient wards at the Jackson Memorial Hospital

V. Case Study: Miami

A. Background

The Miami CHIVES site is a partnership between the University of Miami School of Medicine and Jackson Memorial Hospital. A key player as part of the Public Health Trust System of Dade County, Jackson Memorial Hospital is the only public hospital in the county and provides care for 40 percent of all patients living with HIV in the county. Nine HIV specialist physicians from the University of Miami School of Medicine staff HIV services at Jackson, hence the partnership that created the CHIVES program at Miami.

The Miami CHIVES intervention was informed by the Anti Retroviral Treatment and Access Study (ARTAS)²¹, a four-year interdisciplinary CDC funded project that aimed to assess and develop interventions to improve access to HIV care. The ARTAS project targeted English speaking, disadvantaged clinic patients living with HIV in four metropolitan areas—Atlanta, Baltimore, Los Angeles, and Miami. The intervention, which drew on social cognitive and empowerment theories that attempted to enhance participants' self efficacy, examined the effectiveness of a brief, intense case management strategy in improving care seeking among recently diagnosed clients living with HIV. The case management intervention consisted of two to five contacts designed to:

- Identify personal strengths and abilities that will encourage clients to seek care.
- Actively involve clients in identifying personal and system barriers to seeking care.
- Advocate with service delivery entities on behalf of clients.²²

One of the major findings from ARTAS was that those in the intervention group were 37 percent more likely to be in care than those in the comparison group. The Miami CHIVES intervention was a targeted peer-support model adapted from the case-management model of ARTAS.

Unlike the other CHIVES sites, the Miami intervention was hospital-based with recruitment²³ and the first peer-promoter client encounters occurring in an inpatient setting. The site only recruited from patients who had been admitted to the hospital and did not conduct outreach in outpatient and public settings, as did the other CHIVES sites.

Miami's Case Study Questions:

The Miami case study examines the site's hospital-based recruitment strategies. The case study attempts to answer the following key questions:

- How did the project's hospital-based recruitment and engagement strategy function?
- What factors facilitated and impeded hospital-based recruitment and engagement?
- What strategies did the project employ to overcome barriers to hospital-based recruitment and engagement?

B. How did the project's hospital-based recruitment strategy function?

Miami's strategy centered on three main components – the recruitment protocol that was used in the hospital, the peer-promoters who engaged the clients while they were still in the hospital, and the intervention that was delivered while the clients were still in the hospital. Each of these components was essential to ensuring the success of the hospital-based strategy.

Recruitment Protocol

The Miami site recruited clients daily through an in-reach process conducted in the inpatient wards at the Jackson Memorial Hospital. During a focus group interview with outreach workers, they stated that outreach mainly happened at “*the patient's hospital bedside*”. Prior to the start of the intervention, the Miami CHIVES principal investigator briefed fellow providers in the HIV clinic about the intervention and its eligibility requirements. The principal investigator also collaborated with providers to establish a system that would allow for random assignment of potential clients to the treatment and comparison arms of the study. By laying this foundation in advance, the team reported that the number of provider referrals to the project was higher than they otherwise might have been, given the high number of patients that the clinic treats on a routine basis. The providers referred potential clients to the CHIVES coordinator for eligibility assessment. If the patient agreed to participate in

²¹Gardner L.I., Metsch L.R., Anderson-Mahoney P., Loughlind A.M., del Rio C., Strathdeed S., et al. (2005). Efficacy of a brief case management intervention to link recently diagnosed HIV-infected persons to care. *AIDS*, 19, 423-439.

²²University of Miami Medical Center <http://ssrg.med.miami.edu/x27.xml>. Accessed on August 29th 2006.

²³Gross, C., Mallory, R., Heiat, A., & Krumholz, H.M. (2002). Reporting the Recruitment Process in Clinical Trials: Who Are These Patients and How Did They Get There? *Annals of Internal Medicine*. 137, 10-16.

the study, the CHIVES interviewer would enroll the client in the intervention. However, because the potential clients were already hospitalized, in some cases the client might be deemed too sick to begin the intervention and the CHIVES team would have to wait for notification from the provider in question as to when the client was strong enough to participate. Again, the close relationship that the CHIVES principal investigator established with other providers facilitated timely notifications in most cases.

Miami outreach workers reported that when approached few of the potential clients declined to enroll in the intervention. This was because all of these individuals were extremely sick and hospitalized. Many of them had been positive for quite a while but had not sought treatment or had not adhered to their medication regimen. As a result, they were often desperate for any assistance that was offered. The outreach workers presented CHIVES as a program that would help them avoid future hospitalizations by linking them to primary care that would improve their health. This offer was particularly appealing to this target population because for reasons of stigma many wanted to be released from hospital as soon as possible so as to minimize the possibility that someone they knew might find out they were living with HIV.

Peer-promoters

The Miami peer-promoters were selected based on their ability to navigate the hospital's care system. They were also required to speak English so that they could communicate effectively with the hospital providers that managed the CHIVES clients and speak Haitian Kreyol, the language that was used most often by clients. The Miami peer-promoters were recruited from the cadre of volunteer peer educators already working at Jackson. These individuals all had taken a three month course in Adult Immunology HIV/AIDS Education; completed the State of Florida's four hour HIV/AIDS 101 and 104 courses; agreed to maintain patient confidentiality at all times; and were mentally and physically fit to serve full time as a peer-promoter.

Delivery of the Intervention

Since the majority of Miami's patients were very sick, in most cases, the client's first encounter with a peer-promoter as part of the intervention occurred in the hospital. Subsequent contacts might be in the hospital if the client was hospitalized for a while or at a location of the client's choosing. The intervention consisted of five peer-promoter client encounters. The first interaction centered on building the relationship between the client and the peer-promoter. The second interaction focused on identifying and emphasizing the client's strengths that could motivate and facilitate the client seeking care. The third interaction taught the client how to make contact with the health care system in an effective manner. The fourth interaction reviewed progress because it was expected that by this time the client had made at least one successful effort to access HIV primary care. The final interaction provided the client with an overview of the successful transition to care seeking with an emphasis on strategies that work.

According to the peer-promoters, what happened in the encounters that took place in the hospital was crucial in determining whether or not clients would continue with the intervention post-discharge. Thus during the early interactions peer-promoters had to work hard to build trust, demonstrate the benefits of continued enrollment, and establish the type of rapport that would keep clients engaged. They were able to do this because of the knowledge that they had of the system and because as peers they could empathize with the clients. The peer-promoters observed that clients' greatest needs were tangible benefits such as assistance with housing and transportation and sympathy and empathy. When the peer-promoters were able to provide these in sufficient measure this increased the likelihood that once the clients were discharged they would keep in contact.

C. What factors have facilitated and/or impeded hospital-based recruitment?

As they were preparing their application to SPNS, the Miami team knew that it could count on some existing strengths to facilitate the implementation of its hospital-based strategy. Prior experience with the ARTAS project had demonstrated that although Jackson Memorial Hospital is a complex context in which to field an intervention for disadvantaged populations, the team could be successful in this endeavor.

Cohesive but Independent Team

The Miami team was relatively small – the principal investigator, the project coordinator who was responsible for the day-to-day management of the project and assisted part-time with recruitment, the lead recruiter, and two full-time peer-promoters. Team members' offices were in close proximity and the principal investigator reported that they saw each other daily. As a result, any problems that surfaced were addressed promptly and usually as a result of collective brainstorming by the team. There was virtually no turnover in the staffing except in the project coordinator position. However, because the rest of the team was so close-knit even the departure of the coordinators and the arrival of their replacements did not appear to have any noticeable effect on team dynamics.

Despite the close supervision that the peer-promoters and the recruiter received, they all reported feeling autonomous in their positions. They were not micromanaged and were allowed to use their knowledge of Haitian culture to respond to unanticipated challenges as they arose. Their input was respected and their status as professionals was undisputed.

Finally, the Miami CHIVES team's relationship with the larger organization— particularly the Infectious Disease Department - was strong. Physicians referred patients to CHIVES all the time. Several factors facilitated this strong relationship: (1) The intervention was designed within the clinical department by people working in the department; (2) project staff made grand rounds to present the project; (3) there was buy in from the head of the department and (4) there was daily contact between the CHIVES staff and the Department staff.



during the early interactions
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Focus on Haitians

According to the team, the Miami CHIVES' exclusive focus on Haitians made the program more successful than it would have been if the program had catered to more than one group. The single focus simplified administration and allowed the program to really stress cultural sensitivity. The recruiters and the peer-promoters were all Haitian. They all spoke Kreyol and used that language to communicate with their clients. Printed materials were translated into Kreyol. The logo for the project featured Haitian art. Later in this document, the negative effect of the hospital's physical environment is discussed and the staff believed that "*by being so Haitian when we present ourselves there is a wall that vanishes when we greet them in Kreyol and we approach them and get close to them physically*" and help breakdown this barrier.

Several issues impeded Miami's efforts at recruiting and engaging clients who were hospitalized. These are discussed next.

The System of Uninsured Care

Analysis of baseline data shows that of all the CHIVES sites, Miami had by far the highest percentage of uninsured clients - 70 percent of Miami's clients compared to 17 percent of clients from the other sites (Pearson Chi Square $P=0.000$). According to a 2004 Florida Health Insurance study, Miami-Dade County has the largest number of uninsured people under the age of 65 in Florida.²⁴ At the end of 2003, the number of uninsured in the county was estimated at above half a million. In Miami, health care for the uninsured is provided primarily through Jackson Memorial Hospital, which means the hospital has a significantly high load of uninsured patients²⁵.

The Miami CHIVES project was designed specifically to train patients on how to navigate the system of uninsured care. Nevertheless, Miami's principal investigator stated that one of the biggest challenges in the project was ensuring that clients were covered under the Ryan White Care Act. Securing coverage is a complex process that requires cutting through a great deal of red tape in terms of making certain they qualify. Patients need to provide a large amount of documentation – notarized documents, identification- and these requests often raise fears about immigration status. The rules were recently changed to require patients to be recertified every six months, which means that they need to produce documentation twice a year. Peer-promoters assisted clients with this process and even though the peer-promoters had considerable experience with the system, this still proved challenging.

Patients with Advanced HIV Disease

By choosing to target hospitalized patients, Miami recruited some of the most severely ill clients in the Demonstration. This was an unexpected challenge that the team said underscored for them the magnitude of the problem of inappropriate care

amongst disadvantaged Haitian immigrants living with HIV. Towards the end of the project, the principal investigator reflected that if he were to conduct a similar project in the future, given how ill clients were, the project should definitely include more of a medical intervention and perhaps have a provider make post-discharge home visits to assess severity of illness. Some of the clients that Miami enrolled arrived at the emergency room close to death. The death rate among those that enrolled into the study was very high – at the writing of this report 12 of the 86 clients had died; this is in sharp contrast to the other four sites, which saw three deaths combined across the sites.

This issue is a reflection and consequence of the target population not seeking medical care until it is too late - they are too sick, have more complications and are less responsive to medications. Staff reported that the notion of preventive care is not developed in the Haitian culture and people with no insurance were even less likely to go for care. In addition, at times, the stigma of HIV resulted in deep-rooted denial among those who have tested positive. They refused to believe that they have HIV, attributing the symptoms to various other conditions or even voodoo. For example, one patient who had suffered with diarrhea for months along with other serious symptoms was convinced that he had food poisoning and could not accept his HIV diagnosis, even after being admitted to the hospital. Consequently, the observation of one team member that, "*stigma is killing people*" was no exaggeration and the hospital-based nature of the CHIVES Miami project amply demonstrated this.

Hospital Physical Environment

Recruitment in patients' hospital rooms presented its own challenges. First, there was the issue of confidentiality. Although the lead recruiter always spoke in Haitian Kreyol to potential clients, he reported that many were convinced that they would be overheard and as result would be very hesitant to even listen to the recruitment message. Second, as stated earlier, the majority of patients had advanced disease. Those who understood and accepted their diagnosis and prognosis were often overcome with grief and a sense of loss. According to the recruiter, he encountered many people "*who were grieving for a life that could have been and grieving for a life that was.*" At times this profound grief affected their decision to enroll. Some felt that enrolling would mean that they would have a constant reminder of their HIV status during the three months of the intervention. Others, who were still in some denial about their status, thought that by enrolling they would be accepting that they in fact had HIV.

²⁴Garvan, C. W., Duncan, R. P., Porter, C. K. (2005). The Florida Health Insurance Study 2004: County Estimates of People Without Health Insurance. The Department of Health Services Research, Management and Policy, University of Florida.

²⁵Jackson, C.A., Pitkin, K., Beatty, A. (2003). Governance for Whom and for What: Principles to Guide Health Policy in Miami-Dade County. RAND Health.



Miami recruited some of the most severely ill clients in the Demonstration.

Third, although the voluntary nature of participation in the CHIVES program was clearly explained verbally and in writing at the time of recruitment, some individuals enrolled because they mistakenly believed that they were obliged to accept all services offered to them while hospitalized. The recruiter, who is Haitian, explained that in Haiti refusal to follow requests made by hospital staff could lead to poor care or immediate discharge from the institution. Consequently, some patients believed that the same could happen here in the US. Thus, these patients enrolled but then once they were discharged they withdrew from the program. Miami had five such cases.

Finally, the hospital setting was extremely impersonal and as a result hindered the development of trust between the peer-promoters and the clients. A visit to the patient wards revealed a very antiseptic, monochromatic, and cold environment, not unlike that found in any other large urban hospital that has a large uninsured patient load. The resources were simply not there to create the type of homey environment that patients found so attractive at Montefiore, another of the CHIVES sites described earlier in this report. Also oftentimes the length of the peer-promoter/ client encounter was determined by neither party but rather had to be squeezed in between client interactions with providers, going for lab tests, and other

activities that were part of the inpatient experience. Thus, in retrospect, the Miami team felt that the intervention should have mandated more peer-promoter contacts with clients since the debut in the hospital often did not forge the a bond of trust between the two parties.

Institutional Bureaucracy

The Miami CHIVES project was embedded in a department that itself is part of a very large bureaucracy. This created some obstacles for the CHIVES project. For example, the premise of CHIVES was that infected individuals should access HIV primary care regularly. However, Jackson Hospital's bureaucracy has created a system that requires patients to see on average 20 different individuals – mainly staff who verify that patients are eligible to receive services-before they see a doctor. These patients, as noted earlier, are in many cases not only physically ill but suffering the emotional strain of stigma and possibly other serious life issues such as homelessness, unemployment, and immigration problems. Thus the bureaucratic barriers made it that much harder for them and hence for the peer-promoters and the intervention to achieve the goal of a primary care visit within 90 days.

In addition, the hospital has a policy that requires case reviews every six months and if the review process is not done the patient cannot receive services. This requires a lot of documentation that the patient may be challenged to provide creating further burden on the client. The peer-promoters believed that care seeking would improve if these policies were changed but the project had no power to reform institutional policy at that level.

Competition for Resources

Resources are always scarce at a hospital like Jackson Memorial that has such a large volume of uninsured or underinsured patients. The Miami team recounted that once the CHIVES clients started attempting to access more services with increased regularity, they received reports that the project was placing a strain on hospital resources. For example, case managers complained that peer-promoters were creating more work by referring more clients to them. The case managers' frustration was understandable because there were no dedicated CHIVES case managers. Instead, CHIVES clients utilized the same case management services that were accessed by all of the other patients in the hospital. Some of the hospital staff that was concerned with the financial bottom line of the institution was of the opinion that the fewer patients living with HIV they have the better and there was encouragement to refer CHIVES eligible patients to other facilities.

Concerns about Confidentiality

One of the biggest barriers to study enrollment was that patients did not want to encounter another Haitian while at the hospital. The consent form explained that they could meet with other Haitians and this raised a lot of concern around confidentiality. Apparently, many who had experiences with Haitian providers in Haiti and in the United States had their personal information disclosed to others by these providers. The CHIVES staff was trained to inform clients that Jackson Memorial staff was required to observe the privacy laws, but the team said that clients often dismissed these assurances by recounting their experiences or those of others, where providers disclosed confidential information. As a result some clients did not want to share information within the hospital setting due to concerns that it might be passed on to others. Even the CHIVES peer-promoters seemed to share in this fear as they reportedly were concerned that the interviewer might reveal their status to clients during the baseline interviews.

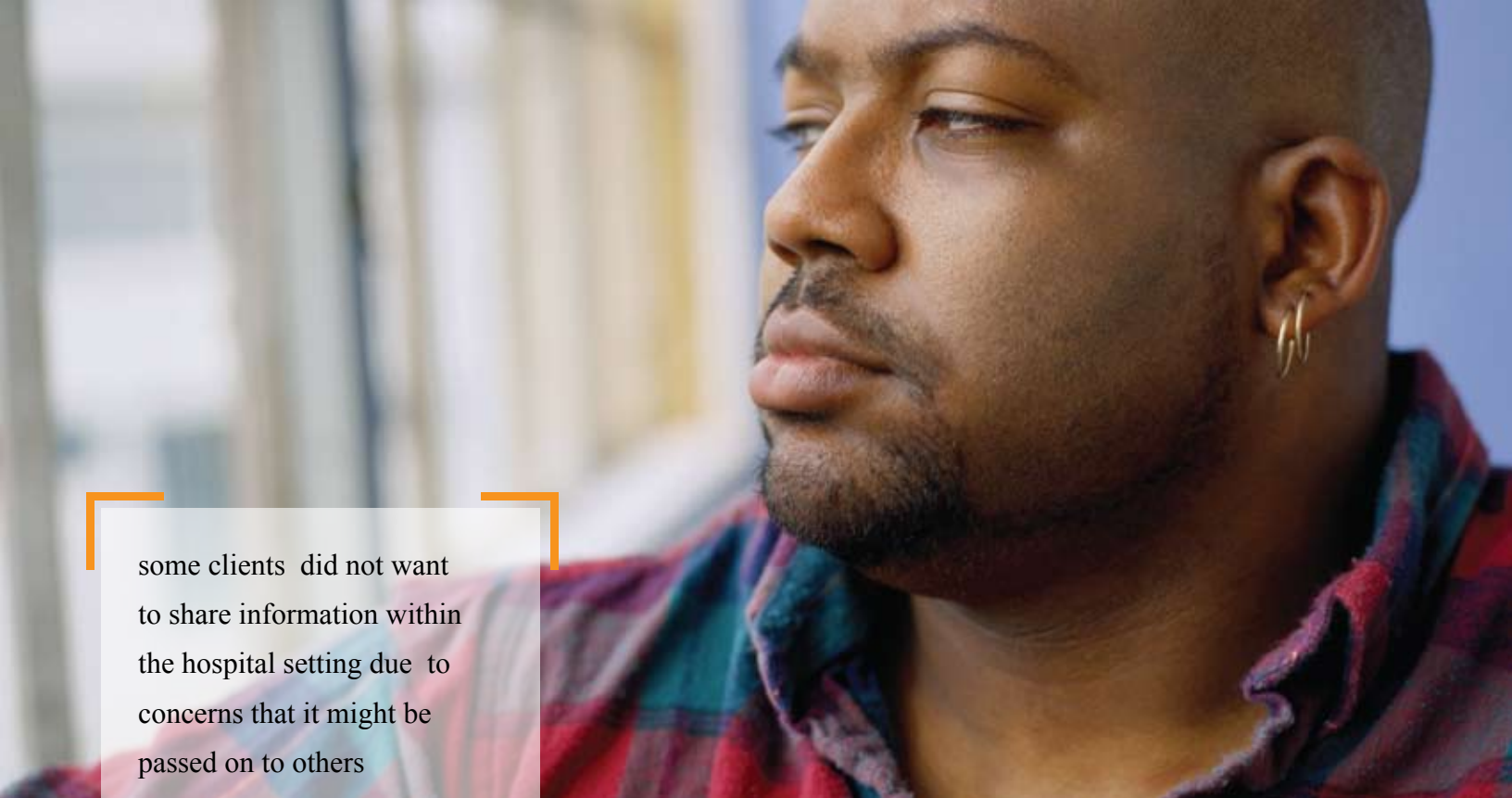
D. What strategies did the project employ to overcome barriers to hospital-based recruitment?

Miami's hospital-based recruitment and implementation strategy faced several challenges, as follows: the system of uninsured care, patients with advanced HIV disease, hospital's physical environment, institutional bureaucracy, competition for resources, and concerns about confidentiality. The CHIVES team was able to address some of these barriers while others were not amenable to resolution. For instance, nothing could

be done about the volume of eligible patients who were severely ill and unable to participate in the intervention. Their presence had to be accepted as a fact of life when one works in a hospital catering to a large uninsured patient load and, in the case of CHIVES, patients from a sub-population where the burden of stigma associated with HIV was particularly high. Similarly, since the CHIVES project had limited resources, the team could do nothing to address complaints that CHIVES clients were exacerbating competition for already scarce resources. This too is a fact of life at Jackson Memorial.

On a positive note, intensive training of the recruiter, the interviewer, and the peer-promoters proved very effective in overcoming the obstacles of the system of uninsured care, the hospital's physical environment, institutional bureaucracy, and concerns about confidentiality. According to the recruiter, it was absolutely essential that in his initial encounter with a potential client he be reassuring, compassionate, knowledgeable, and persistent. These qualities went a long way to assuaging fears about forced disclosure, the inevitability of death from HIV, and many other concerns shared by potential clients. Persistence was especially important because the severely ill individuals whom he was approaching often did not want to be bothered, but as he said "*I knew I had something good for them, something that would help them because I had been in their shoes and so I could not give up.*" Compassion was crucial because even though many of the fears expressed might have appeared illogical to someone who was familiar with the system, they were nonetheless very real and valid for those who expressed them. Above all clients appeared to need reassurance that their personal information would be kept private, that they would receive needed help that often went beyond primary care to include ancillary services that would address life issues, and that they might survive at least a little longer. Having well-trained recruiters both of whom are Haitian and one of whom is living with HIV increased the likelihood of potential clients being persuaded to enroll.

Knowledgeable and committed peer-promoters were key in assisting clients to navigate their way through the confusing Ryan White system of care. The fact that the peer-promoters were both former volunteers and were thoroughly familiar with the ins and outs of the system was an added bonus. For example, they both knew many of the staff responsible for verifying eligibility and thus could advocate on behalf of their clients. They also had personally faced the challenges of rude staff, long waiting times, and confusing forms and so they could reassure the clients that there was a way to deal with these challenges successfully. They could also count on their own experiences to minimize wherever possible the impact of bureaucracy. For example, one peer-promoter shared how she advised clients to maintain a folder with all of the documents required to show eligibility for services. Thus, every time a client was asked to produce documentation it was readily accessible.



some clients did not want to share information within the hospital setting due to concerns that it might be passed on to others

All of the staff worked together to constantly reassure clients that their confidentiality, at least as far as the team was concerned, was being maintained. Unfortunately, there was nothing that anyone on the team could really do to influence the behavior of providers whom clients rightly or wrongly suspected might be breaching their confidentiality. However, one of the recruiters thought of a compelling reason why concerns about confidentiality should not be allowed to prevent them from accessing care. He said he would tell clients that while it was true that they could encounter someone they knew, it was unlikely that the individual would be able to look at them and know they had HIV. However, if they did not seek care eventually they would become so ill that their physical appearance might betray their diagnosis or at least make onlookers begin to ask nosy questions; so then it would be better for them to just seek care regularly thereby maintaining their health and a healthy appearance as much as possible.

E. Conclusions

The Miami CHIVES experience captures many of the challenges that large urban hospitals with high numbers of uninsured or underinsured patients face. Competition for resources, bureaucratic hurdles, patients who present in the end stages of disease because they were not able to access care – these were but a few of the challenges that this site faced. Perhaps it might have been easier to conduct the study

outside of the hospital setting, but then the team cohesion that was observed at Miami might not have been present since the principal investigator and the implementation staff would have been in different locations. Besides given the aims of CHIVES, it was instructive and necessary that at least one site in the Demonstration serve the most affected of the target population that CHIVES sought to reach. Miami's approach of having highly trained and dedicated staff enabled them to minimize as much as possible the obstacles such as bureaucracy. However, their experience shows that the larger systems in which small programs like CHIVES are embedded will have to change if services are to become truly accessible to underserved populations. Programs like CHIVES identify where the blockages are, for example, overburdened case management services that become stretched to breaking point when clients with real needs and a right to the services present. Yet programs like CHIVES lack the clout necessary to solve the larger systems problems. At best they can do what the peer-promoters attempted to do- help clients navigate around obstacles.



CHN's implementation of its CHIVES project was significantly challenged by staff turnover

VI. Case Study: CHN

A. Background

The Community Healthcare Network (CHN) is composed of eight primary care health centers and three mobile units and is the largest HIV case management program in New York City. The centers provide integrated HIV and planning services including treatment adherence, substance abuse, social work, social support, nutrition, mental health, and linkages with over 500 agencies in the New York area. Two of the centers – Betty Shabbaz and Caribbean House, participated in the CHIVES study.

The CHIVES project at CHN served English-speaking Caribbean immigrants (from Antigua & Barbuda, The Bahamas, Barbados, Grenada, Guyana, Jamaica, St. Kitts & Nevis, St. Lucia, Trinidad and Tobago, St Vincent & Grenadines) living with HIV in Brooklyn, Queens, Bronx and Manhattan, New York. Clients in the intervention arm of the study were seen at several community clinics that are part of the Community Health Care Network.

CHN's implementation of its CHIVES project was significantly challenged by staff turnover which in turn depleted the number of staff who had participated in the project from its inception and had institutional memory of project goals, objectives and procedures. From the start of the project, however, the Demonstration's Technical Assistance and Evaluation Center conducted site visits to the project and was able to capture some staff perceptions on the turnover. Therefore, by analyzing the site visit data and also reviewing program documents, it was possible to draw some conclusions about the impact of the turnover. This case study explores the role of staffing in the successful implementation of a peer support demonstration project.

CHN's Case Study Questions:

The following questions frame CHN's case study:

- What were the project's initial staffing plans?
- How did the staffing evolve over time?
- What factors contributed to staff turnover?
- How did staffing issues impact the project?
How did the project compensate for staff turnover?

B. What were the project's initial staffing plans?

Organizational Matrix

The intervention was overseen by the principal investigator who delegated a high degree of managerial and operational responsibility to the CHIVES program manager in running the day-to-day activities of the project. The program manager was responsible for recruiting, supervising and training of the four part-time peer-promoters.

Hiring Peer-promoters

CHN planned to recruit its peer-promoters from the patient caseloads at centers in the CHN network. The site had a contingency plan in place for peer-promoter attrition, foreseeing the difficulty of retaining peers during the four-year life of the initiative. Peer-promoters that dropped out of the program were to be replaced by peer-promoters from other programs run by CHN. Implementation of cross training among CHIVES peer-promoters and the peer-promoters from other programs, would ensure that there would be a seamless transition when a peer-promoter left the CHIVES program.

Peer-promoters' Roles and Responsibilities

CHN's peer-promoters were fully responsible, under the supervision of the program manager, for the delivery of all aspects of the intervention. CHN's intervention consisted of six 90-minute 8-10 person group sessions to be convened once a week, as well as 12 individual sessions that were intended to provide clients with additional support. Group session topics included HIV education and myth deconstruction, navigation of the healthcare system, as well as coping skills and stigma discussion.

Peer-promoters were organized to work in teams of two, with each team assisting at least one client. The teams were assigned to one of the two CHN centers so that there would be continuity of care. The size of the peer caseloads would vary by intensity of patient need as well as by the rolling nature of enrollment. Clients were given a choice of a female or male peer-promoter.

Besides being responsible for delivering the intervention, peer-promoters were responsible for conducting outreach activities to enhance the recruitment of program participants. They were allowed to conduct outreach at restaurants, churches, health fairs, colleges, and other community forums known to be frequented by the target population. Peer-promoters also met weekly with the program manager to debrief, receive burnout counseling, and assess program progress.

Training

The initial cadre of peer-promoters attended a multi-site training that was held for the peer-promoters from all of the CHIVES sites. In addition, once they returned to CHN, the peer-promoters received additional site-specific training that was designed to reinforce their comprehension of topics covered in the multi-site training such as HIV transmission and prevention, interpersonal and group communication skills, counseling support, and service planning and decision making. The site-specific training was then augmented by having the peer-promoters attend numerous training offered by various non-profit HIV/AIDS service organizations in the New York City area.

C. How did staffing plans evolve over time?

The first critical turnover of staff was the departure, in June of 2004, of the program manager. This caused disruptions in the implementation of relevant first year activities including the refinement of the project's intervention and staffing plans that included the hiring of peer promoters. Still, the project developed intervention manuals that set forth the content of the intervention and how it was to be administered, as well as designed site-specific training for their peer-promoters, outreach plans and materials to market the project to the community. Peer-promoters were eventually hired and trained, and the program seemed poised for implementation.

Other delays involving its institutional review board prevented CHN from starting launching of the intervention in October 2004, as originally intended. In January 2005, the peer-promoters started the field implementation of the intervention. From the outset, progress in recruiting clients was slow and better and innovative methods of recruitment were clearly needed.

During the May 2005 site visit, the evaluators learned that two of the four peer-promoters had left their positions due to health reasons. The site recruited outreach workers from elsewhere in its network to assist the peer-promoters in conducting outreach. The interim program manager explained the staffing change as necessary to augment the manpower available to conduct outreach since the site's enrollment was so low and there were only two peer-promoters on staff. However, a senior manager, expressed the view that the peer-promoters were hesitant to speak directly about HIV and disclose to those they encountered while conducting outreach; hence the need to involve seasoned outreach workers that had experience conducting outreach to individuals living with HIV became evident. The Technical Assistance and Evaluation Center staff recommended that CHN take steps to retrain the peer-promoters to equip them with the skills necessary to overcome their internalized stigma.

In July 2005 the interim program manager resigned. A new program manager was hired in September 2005. During this transition, the morale and enthusiasm of the peer-promoters was highly affected as they lacked direct hands-on supervision on a daily basis. In March 2006, when the Technical Assistance and Evaluation Center staff paid a site visit, more

significant attrition had occurred on the project as, with the exception of the principal investigator, all of the original peer-promoters were no longer with the program. At that point, since the inception of the program, there had been eight different peer-promoters, of whom only three remained on staff.

D. What factors contributed to staffing turnover?

Individual

CHN provided the following reasons for staff departures:

- Poor health of two peer-promoters.
- Difficulty among some peer-promoters in retaining their welfare benefits as a result of part-time employment. For instance, despite the fact that the site limited the peer-promoters to working twenty hours a week so that they would not lose their benefits, one peer-promoter quit after receiving her first paycheck because her earnings reduced her monthly food stamps allocation to \$1.
- Discomfort among some peers in talking about HIV within the context of delivering the intervention due to stigma in the community. A CHN senior manager was of the opinion that staff turnover would continue to be a problem until peer-promoters were comfortable disclosing their status and speaking about HIV publicly.

Despite certain attitudes that proved to be barriers for recruitment, peer-promoters professed an enthusiasm for the work, were passionate about helping others develop positive care seeking behaviors and expressed the desire to be role models to their clients. While the above explanations are not without merit, it became clear that larger and more systemic issues were possibly the cause of the high staff turnover. These are discussed next.

Institutional

The departure of the program manager, who was also the director of HIV programs at CHN, early in the life of the CHIVES program created a supervisory vacuum that was very difficult to fill during the first half of the initiative. The subsequent program manager did not have the same degree of experience as the previous one or the connections that were needed to build buy-in and support from the CHN centers and departments that could have referred clients to the program, and lacked proactive supervision. This created some confusion among peer-promoters in understanding the direction of the project as well as in understanding their roles and responsibilities. Interviews with the peer-promoters in late 2004 and spring 2005 indicated that they did not seem to understand their real role or what the program was trying to accomplish. They also seemed to be somewhat rudderless and floundering while trying to make sense of their assignments. As a result the CHIVES Evaluation and Technical Assistance Center made recommendations to the team that included:

- *“Retrain staff involved in outreach to be more direct about addressing HIV in their efforts;*



During this transition, the morale and enthusiasm of the peer-promoters was highly affected as they lacked direct hands-on supervision on a daily basis



The space allocated for a project that involved recruitment and educational interventions seemed inadequate

- *establish procedures to monitor the level of effort and the effectiveness of the various strategies employed in outreach; and*
- *assure that the project staff receives adequate and consistent senior oversight and that the role and responsibilities of the local evaluator are clearly defined and respected.”*

In addition, as early as spring 2005, a CHN executive observed that at that point in the life of the intervention, the CHIVES program was not as integrated as it should have been within the CHN large network. Specifically, the CHIVES team had not established the type of working relationships that would lead to internal referrals. In addition, the executive observed that the program manager appeared to prefer to work in isolation and had not reached out to forge ties with colleagues in other CHN centers and departments that could have served as referral sources for clients for the intervention.

Physical office space was another plausible reason for high staff turnover and slow recruitment. The space allocated for a project that involved recruitment and educational interventions seemed inadequate. The space was small and poorly ventilated, lacked privacy, and had no secure storage in which to maintain client records. The space barely accommodated two full-grown adults in a seated position. Thus, when the program manager and the research interviewer were present, the peer-promoters

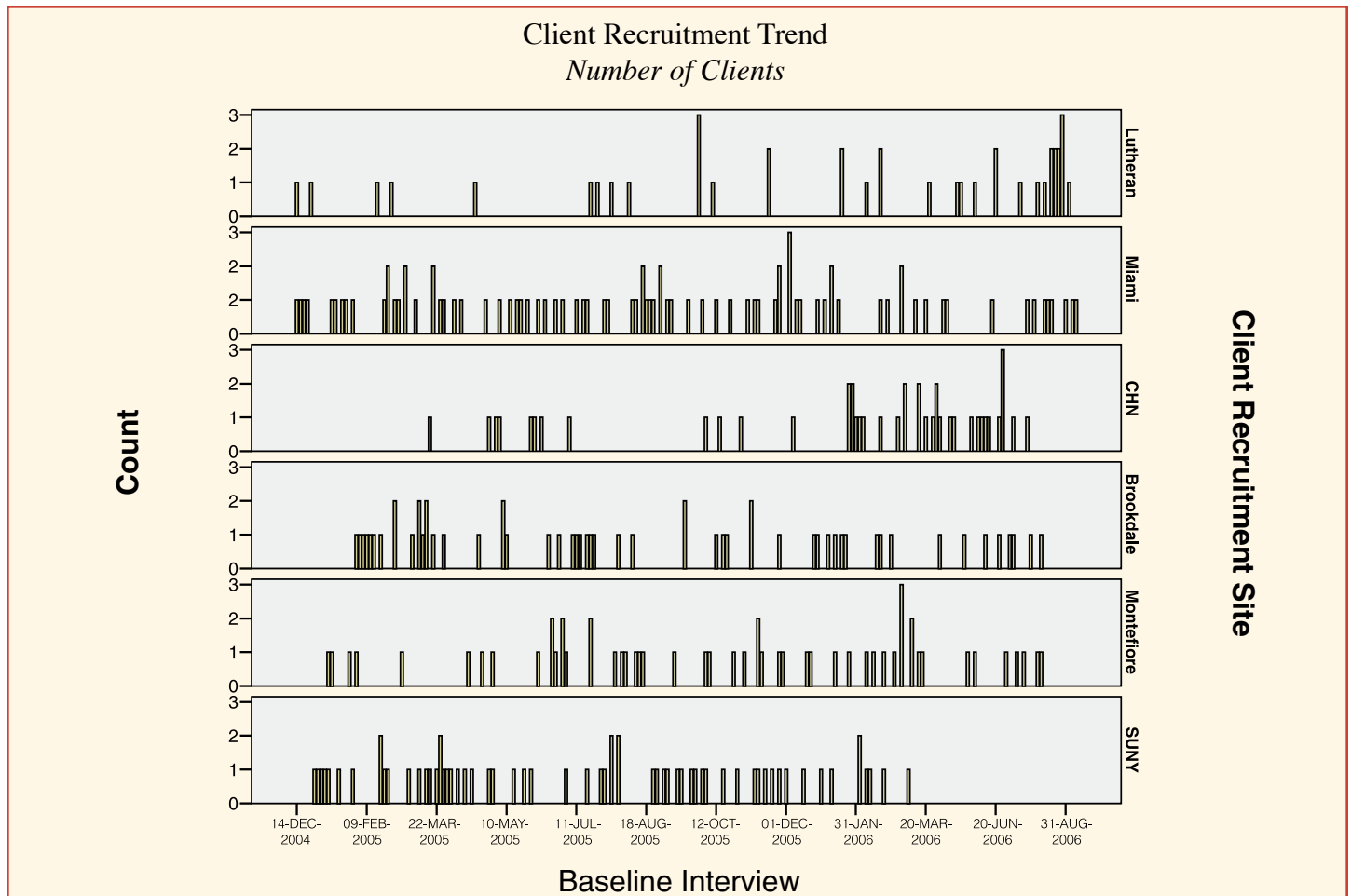
had nowhere to sit and were forced to wait outside in the corridor space or in the clinic waiting room. The problem of inadequate space was particularly acute when a peer-promoter and a client needed to meet for a one-on-one discussion as part of the intervention. The pair would take over the office space and the program manager, the interviewer, and the other peer-promoters would be forced to find somewhere else to sit until the discussion was over. There was no privacy for group discussions and in fact group discussions took place in space that was shared by the entire clinic. The program manager stated that given the cultural importance of space, décor and ambiance, the poor space sent a strong and wrong message to potential and existing clients. The peer-promoters concurred with this assessment and complained that the poor quality of the space sent a wrong message to clients that they were not valued and made it difficult for the peer-promoters to do their job.

E. How did staffing issues impact the project? How did the project compensate for staff turnover?

Low Recruitment

Lack of proactive supervision of the peers resulted in low recruitment numbers by the early part of 2005 (Figure 1). Peer-promoters reported going to restaurants, clubs, parties, and sporting events to conduct outreach, but it was not clear that these venues were frequented by people living with HIV. A CHN senior manager reported that in the first year and a

Figure 1: Client Recruitment Pattern at Different Sites



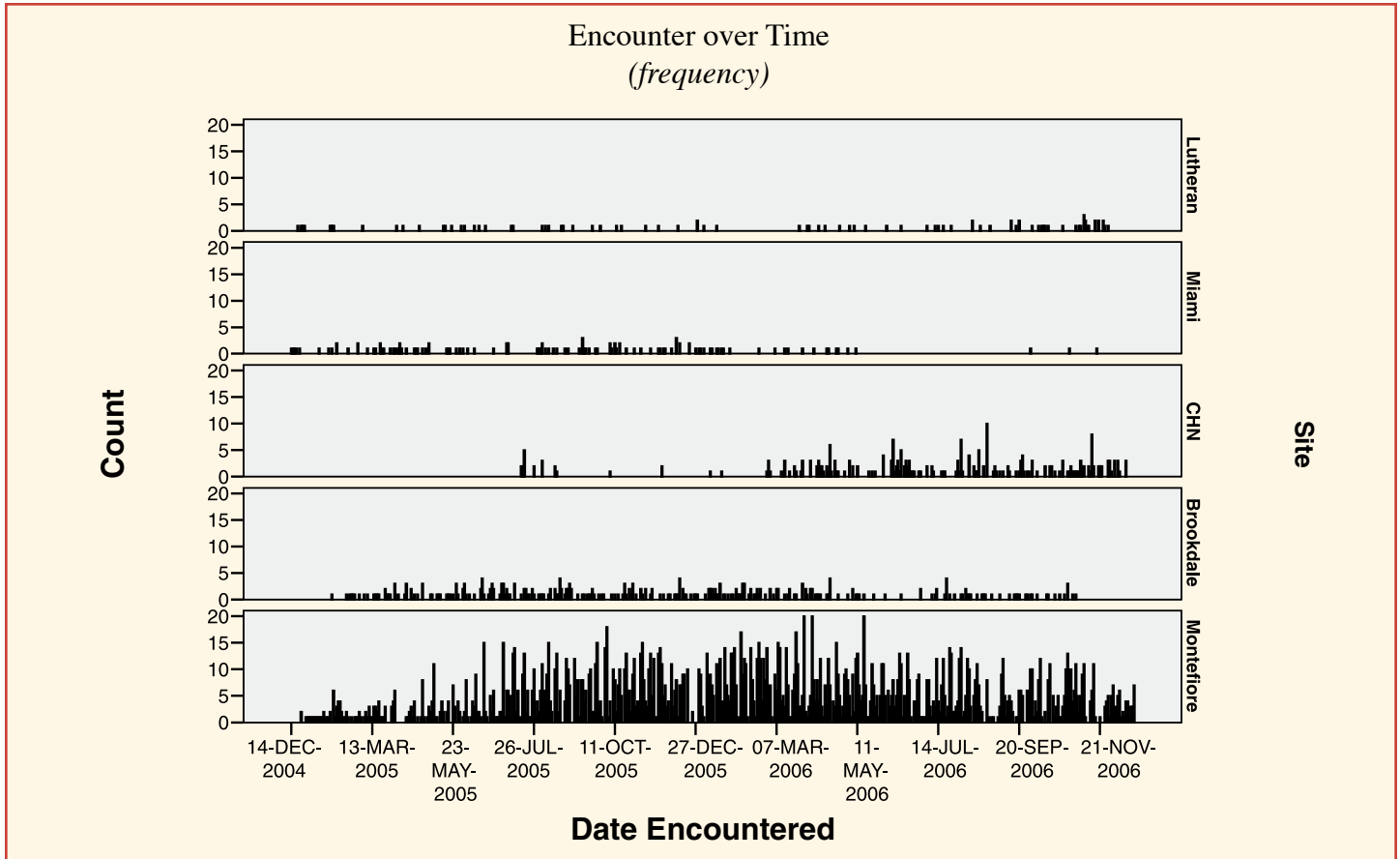
half, prospective clients had actually been discouraged from enrolling because they would go to the program office and find no one there.

Lack of Fidelity to the Intervention

Eight months into the project, the site was still unable to implement the group session intervention due to low recruitment (Figure 2). The site lowered the minimum number

about the impact of HIV and that they are at risk.” When asked about the intervention curriculum, the peer did not seem aware of it and apparently was not following any structured plan regarding client interactions. Also, the program manager complained that the intervention manual was too long and complicated and therefore, peer-promoters were adapting it as necessary, but no documentation of the adaptations appeared to have been made.

Figure 2: Intervention Administration Pattern at Different Sites



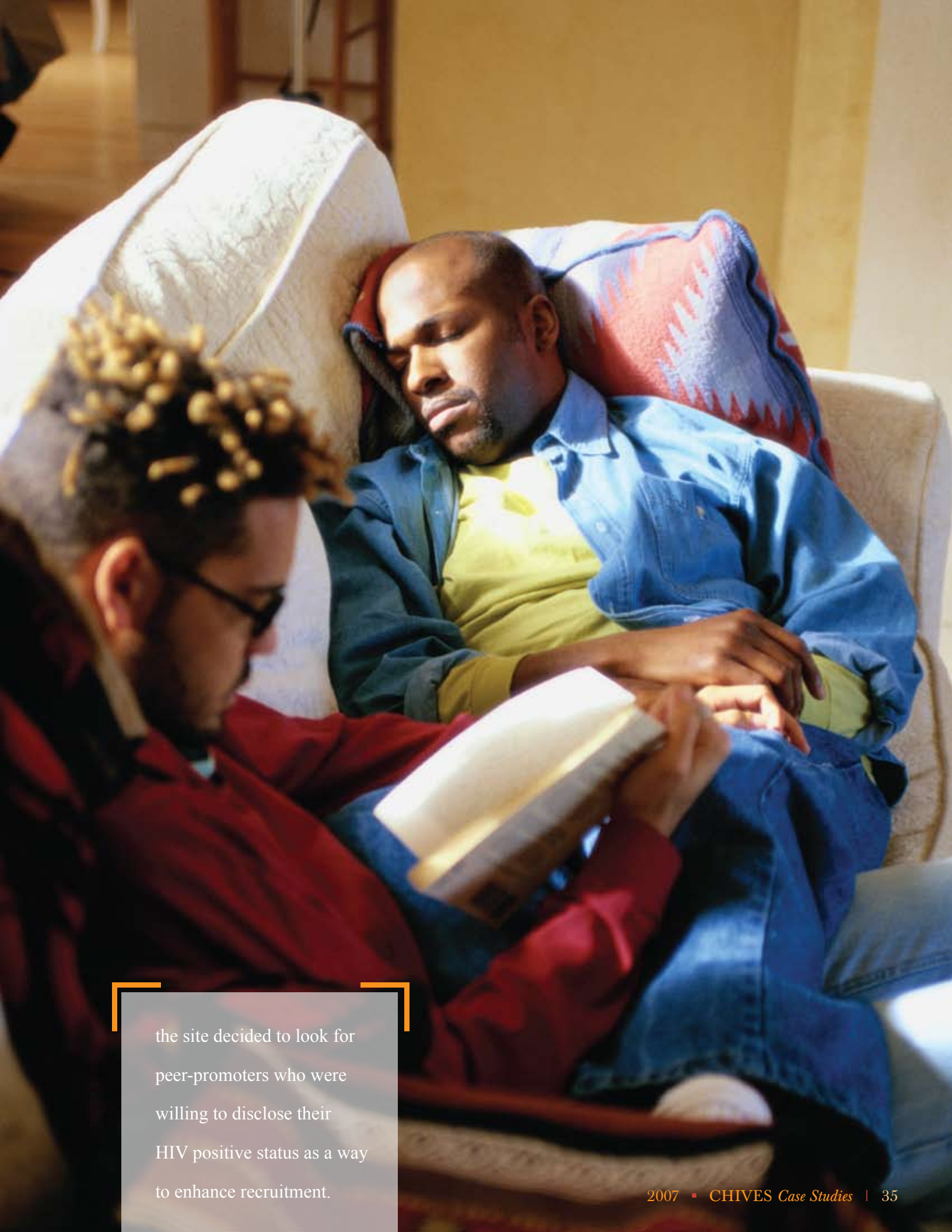
of participants required to constitute a group from six to five but still was unable to convene a group. The first client group session was held in March 2006, two and half years after the start of the project.

The original staff that had been trained at the multi-site training in 2004 was no longer with the project by the middle of 2005. New staff received the site-specific training by the fall of 2005. Institutional knowledge to effectively implement the intervention had thus been lost. Although their replacements had limited training when they were hired, it seems that this instruction did not suffice to make them adhere to the intervention manual. Also the frequent turnover among the peer-promoters prevented some from receiving training reinforcement. As a result, the later cohort of peer-promoters did not fully grasp the true aim of the program. In March 2006, a recently hired peer-promoter stated that the peer-promoter’s role was “to inform individuals in the Caribbean community

In spring 2006, the site decided to look for peer-promoters who were willing to disclose their HIV positive status as a way to enhance recruitment. Despite the fact the intervention called for Caribbean peer-promoters, CHN now hired an African American peer-promoter because, according to a senior manager, “American-born peer-promoters are not hung up about this (disclosure) and therefore can set the example that might motivate the Caribbean peer-promoters to disclose.” Project staff believed this strategy of using Americans-born peers would be more effective in reaching Caribbeans because of issues of confidentiality and lesser potential for recognition of clients in the Caribbean community.

Possible Redefinition of a Peer

HRSA required that peer-promoters enrolled into the projects be HIV positive and of Caribbean origin as a way of ensuring culturally appropriate peer-supported interventions among Caribbean people. A focus group in 2001 had shown the



the site decided to look for peer-promoters who were willing to disclose their HIV positive status as a way to enhance recruitment.



he tapped into his personal network and began inviting persons living with HIV to his home for dinner

Caribbeans who were living with HIV would feel more comfortable talking about HIV issues when approached by someone from their own background having similar disease status.²⁶ However, CHN's successful experience with an African-American peer-promoter challenged this notion. The data showed that the African-American peer-promoter was more effective at outreach than his Caribbean colleagues. This individual had been positive for many years and used to conduct outreach for HIV programs. He did not think that being an American working on a Caribbean initiative would be an issue because he was older and of retirement age and had substantial experience working with Caribbeans. He also thought that being American might be an advantage because he would not be drawn into inter-island rivalry that sometimes occurs when two persons from different Caribbean countries meet. The peer-promoter, himself, reported that he was prepared to disclose his status early in the interaction with clients because he found that this increased openness and the client's comfort level. Unfortunately because of his relatively brief tenure and the fact that at one time he was working solo it was impossible to do a thorough comparative analysis of his experiences with those of his colleagues. Nevertheless, the available data suggest that he was effective not only at outreach but at implementing the intervention. He reported, and the program manager concurred, that clients sought him out because of his long experience living with the disease, his knowledge of resources in the community that could help them, and because of his age. Caribbeans traditionally are raised to respect their elders and this peer-promoter was regarded by some clients as somewhat of a father figure.

Creative Problem Solving

On a positive note, when a new program manager came on board in September 2005, he instituted several creative measures to boost enrollment. This individual was well connected in the HIV/AIDS service arena, was aware of many agencies that served individuals who were potential clients, and thus redirected outreach efforts to focus on these agencies. Then he tapped into his personal network and began inviting persons living with HIV to his home for dinner and then using the opportunity to inform them of the program and ask them to refer any other positive persons they know to the program.

Staff reported that the recent outreach impact in the community had been great – they reported that the community invited CHN to be part of its HIV activities. For instance, it was reported that the Trinidadian Consulate had referred clients to the project and some other consulates invited CHN to participate in activities. In addition, through the manager's coordination, eventually all HIV services across the CHN Network learned to refer eligible clients to CHIVES.

The manager also established efforts to track the success of outreach efforts by venue so that these data could be analyzed

to identify the most productive venues and eliminate those that were not yielding clients. As a result of these measures, enrollment in the program increased rapidly in the last 12 months (Figure 1) and it would appear that had they been taken earlier CHN would have met its original enrollment targets. In the end CHN had recruited 88 clients and this is impressive considering their rocky start. In fact, staff reported that 13 persons came in to the program to enroll after enrollment was cut off.

F. Conclusions

The CHN experience amply demonstrates the importance of having solid, experienced supervision at the helm of projects as complicated as CHIVES. Many of the challenges posed by CHIVES were not of the sites' making, for example, the initial requirement to recruit clients from only one country or the fact that four of the sites were located in New York thus creating competition for clients. The fact remains however that the sites had to navigate through these obstacles, and the staff turnover at CHN hampered its ability to maintain a steady pace with recruitment and implementation tasks. Furthermore, institutional memory was virtually completely lost after the original program manager and the last of the original peer-promoters left. Even though there was a manual and a curriculum, the process for implementing the contents of these documents within the context of CHN was unknown to the replacement workers and there was no one there to advise them. Better institutional support would have remedied these problems early on but this did not materialize until later in the project. Such support might also have led to the allocation of better physical space and more thought being given to improving the orientation and training of replacement workers.

To its credit, however, the CHN administration did institute some changes later on in the project. The most beneficial was hiring a project manager who was not afraid to try creative ideas that were not in the manual to boost outreach – this ultimately solved the outreach problem and enabled CHN to get back on course. The decision to hire an African-American peer-promoter, although not in line with the original Demonstration guidance, perhaps provides the most interesting lesson learned that having a common disease status and not necessarily a common culture might be all that is needed to be an effective peer. This hypothesis warrants further investigation as it could have a great impact not only on the staffing but also the selection of target populations for programs like CHIVES.

²⁶Wolf R., Kemerer V., Magaz P., Romaguera R., Goldman T. (2003). Assessing the Impact of Caribbean Migration on HIV/AIDS Care: Ryan White CARE Act Consumer and Provider Focus Groups and Interviews. *Unpublished Report*



Some patients come from a distance to receive care at CAFHC because they do not wish to seek care in the communities where they are known

VII. Case Study: Lutheran/Caribbean Women's Health Association

A. Background

The Lutheran Medical System is composed of several ambulatory care clinics, one of which, the Caribbean American Family Health Center (CAFHC), was home to the Lutheran CHIVES program. CAFHC has been in existence since 1999 and has been actively providing outreach and education around HIV to the community it serves. The Center reports that almost all of its clientele are from the Caribbean and 45 percent are HIV+. The Caribbean Women's Health Association (CWAH) has provided HIV prevention and support services to Caribbean immigrants in Brooklyn since 1988. The services are specifically designed to be culturally appropriate, comprehensive and integrated. The agency serves over 7000 individuals annually through outreach, training, education, counseling and case management. CWAH's reputation in the New York City Caribbean immigrant community facilitates the inter-agency networking and referrals that are needed to recruit patients into the Lutheran/CWAH CHIVES program. CWAH and Lutheran have a long history of working together. The two organizations collaborated in establishing the Caribbean-American Family Health Center in 1988.

The CHIVES program at Lutheran/CWAH served persons living with HIV from Trinidad and Tobago, Jamaica, Guyana, Grenada, Barbados, St. Lucia, and Puerto Rico in the Flatbush, Crown Heights, and Bedford-Stuyvesant neighborhoods of Brooklyn, NY. The CHIVES program planned to identify clients by conducting targeted outreach into the community and in-reach into its existing patient caseload and the program's HIV counseling and testing program. However, the site encountered some challenges that made it difficult to reach these goals.

Lutheran's Case Study Questions:

The following questions frame Lutheran's case study:

- What was the project's outreach and recruitment plan?
- How did the outreach and recruitment plan evolve over time?
- What challenges and facilitators were encountered during outreach/recruitment?

B. What was the project's outreach and recruitment plan? /How did the plan evolve over time?

Only one of the five CHIVES sites included in its proposal to HRSA an outreach plan that was essentially followed throughout the Demonstration. This was Miami. The other sites, as anticipated by HRSA, proposed tentative plans that they then finalized during year one of the Demonstration. Lutheran's plan consisted of the same three main components as the other sites' plans – a target population, staffing and a recruitment strategy. These are discussed next.

Target Population

Lutheran proposed to recruit 140 Caribbean immigrants living with HIV who were either already in care or identified as needing care based on the results of rapid testing offered by the site. Clients would be recruited from various parts of the city as many CAFHC patients do not live in Brooklyn. Some patients come from a distance to receive care at CAFHC because they do not wish to seek care in the communities where they are known. The center initially had decided to target Trinidadians but eventually expanded outreach, with HRSA's approval, to immigrants from Jamaica, Guyana, Dominican Republic and Puerto Rico.

Staffing for Recruitment

The initial recruitment strategy called for outreach workers at both Lutheran and its partner, the Caribbean Women's Health Association. However, for reasons that are unclear, the community-base component of outreach never materialized. CWAH was apparently under the impression that rather than conducting targeted outreach focusing directly on Caribbeans living with HIV, it was instead supposed to conduct a community education campaign that would sensitize gatekeepers in the community who would then refer potential clients to the program. Some of CWAH's proposed strategies included mobilizing demonstrations in front of the Jamaican consulate in New York to protest the Jamaican government's response to HIV/AIDS; conducting outreach to members of various Caribbean professional groups; and developing a directory of Caribbean businesses that would feature the CHIVES message and would be disseminated throughout the Caribbean community.

It was clear that these strategies could be both time-consuming and costly, and they were not approved by the grantee. Lutheran maintained that their expectation of CWAH was that it would employ its existing outreach workers, who all



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had deep roots in the community and were well respected, to go out and find eligible persons for enrollment into the program. From the outset, the two organizations could not agree on the approach to outreach and recruitment, and from that point on the CWA workers were minimally involved, if at all. One outcome of the disagreement on the approach to outreach between CWA and Lutheran was that the bulk of the outreach fell on Lutheran's sole outreach worker. This individual was living with HIV and highly committed, nonetheless, it became apparent that her efforts needed to be supplemented and so the three Lutheran peer-promoters were asked to assist.

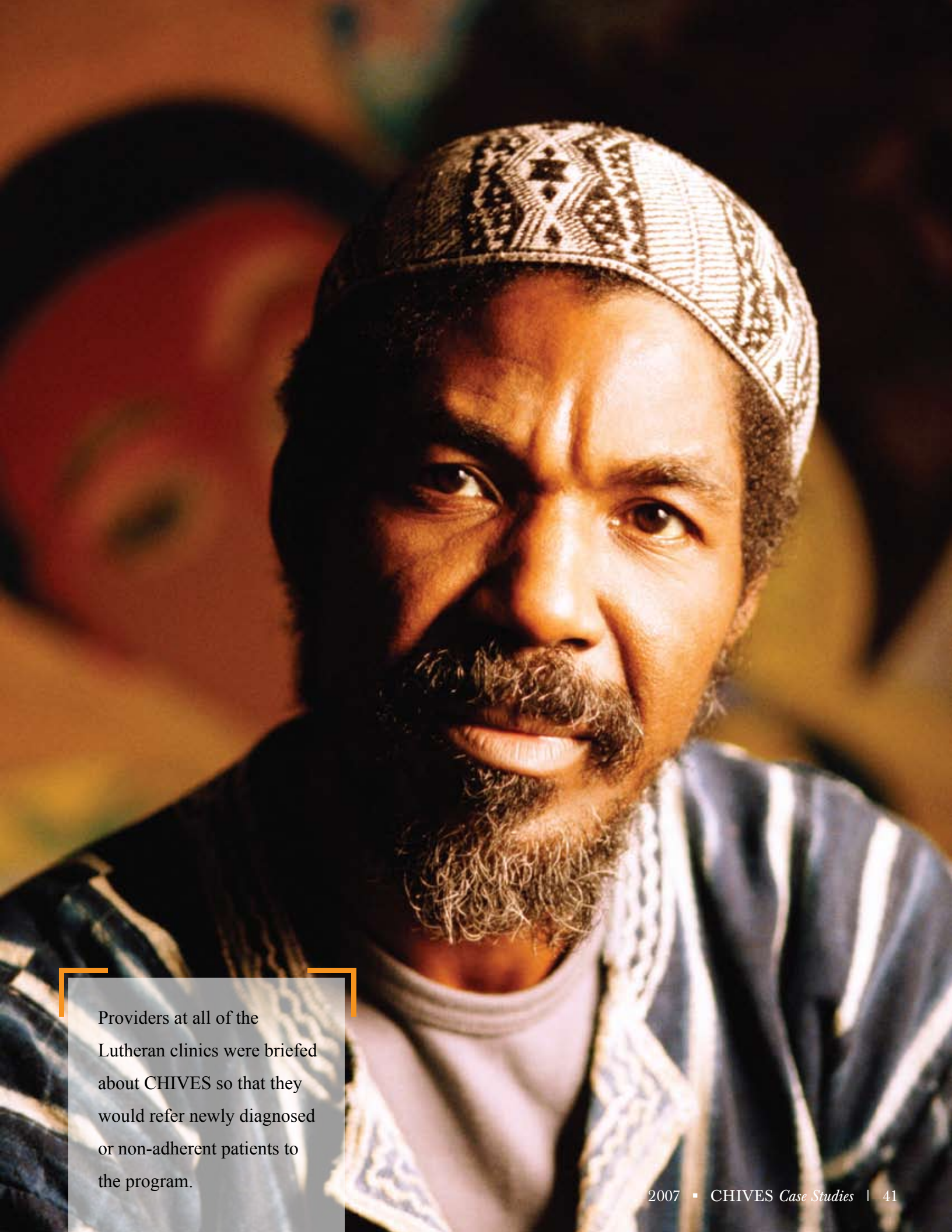
Later in the third year of the program, Lutheran tried a new strategy and enlisted four outreach interns to conduct outreach in the neighborhoods where they lived. The advantage of this approach was that these individuals knew their neighborhoods, were presumably trusted by their neighbors, and could be relied on to identify eligible persons and persuade them to enroll. Lutheran also considered that local churches could be powerful partners in fighting the stigma, a factor keeping otherwise eligible persons from enrolling. Therefore, the program retained the services of a faith-based coordinator to concentrate on local churches and educate pastors. Finally, the project established a referral network for patients coming from the study countries to the United States to seek care. For instance, the staff reported enlisting medical providers in Trinidad and Tobago to publicize CHIVES in those countries. The site also placed announcements about CHIVES in Caribbean targeted media in the United States and local media in the Caribbean. Unfortunately, the program did not collect quantitative data on the effect of these changes, but anecdotally they reported that they were marginally successful.

Recruitment Strategy

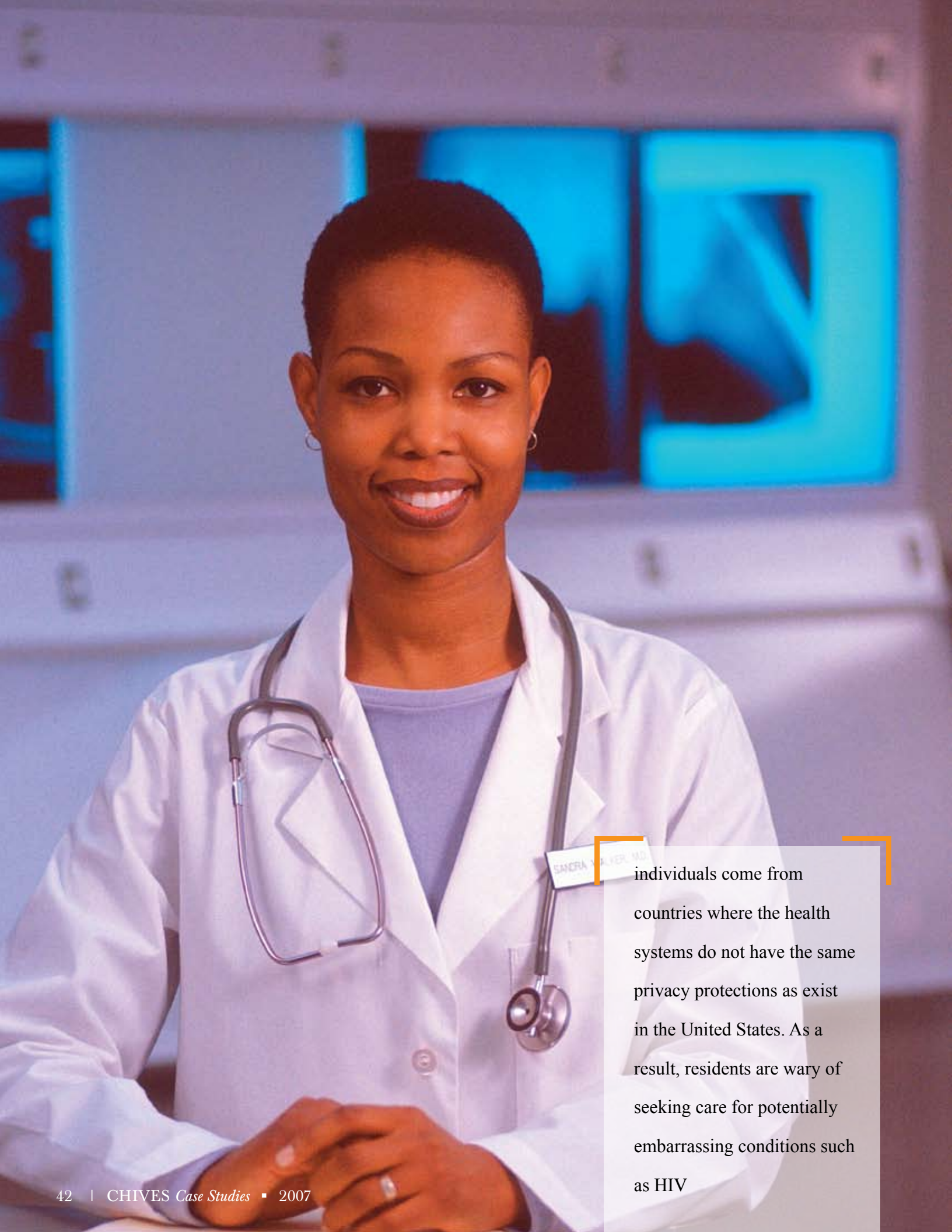
With respect to outreach into the community, Lutheran's strategy centered on having outreach staff encourage interested persons to find out their status by going to CAFHC for a free rapid HIV test using the technology OraQuick²⁷. The Lutheran outreach worker made the same offer to those that she met while conducting in-reach within the CAFHC waiting room. The other component of recruitment involved in-reach into Lutheran's existing health center network. Providers at all of the Lutheran clinics were briefed about CHIVES so that they would refer newly diagnosed or non-adherent patients to the program.

According to the Lutheran's outreach manual, Lutheran's outreach into the community would be facilitated mainly through community partners. The outreach workers were to "interact with community resource agencies to (a) inform them of project's scope of services, (b) identify and recruit eligible applicants, and (c) establish mutual collaborative agreements for the provision of services and/or joint ventures." Outreach workers would arrange group meetings and joint ventures with participating community organizations and service providers to present the project's purpose and to recruit prospective clients into the program. Program documentation also indicated that Lutheran Medical Center had linkages with media outlets, radio stations, small and medium sized businesses and churches that it would tap for outreach.

²⁷Greenwald J.L., Burstein, G.R., Pincus, J., & Branson, B. (2006). A Rapid Review of Rapid HIV Antibody Tests. *Current Infectious Disease Reports*. 8, 125–131.



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individuals come from countries where the health systems do not have the same privacy protections as exist in the United States. As a result, residents are wary of seeking care for potentially embarrassing conditions such as HIV

C. What challenges and facilitators were encountered during outreach/recruitment?

Lutheran faced several challenges in trying to implement the outreach and recruitment strategy that it had proposed. Some were beyond its control. Others related to institutional factors and to the assumptions that Lutheran chose to make about the target population. These challenges are discussed next.

Assumptions Underlying the Recruitment Strategy

One of the main contributors to Lutheran failing to meet its recruitment goal was the lower than expected number of Lutheran clients who were inconsistent users of care. While in-reach was supposed to contribute significantly to enrollment, in 2005 when staff reviewed clinic records, they found only 12 patients that fit the study's eligibility criteria – i.e. patients who sought care sporadically. Of these, four were out of the country and the remainder was resistant to enrolling because of confidentiality concerns (see below) and had yet to be convinced.

Besides the low numbers, program staff reported that the attitude of some Lutheran providers was also an obstacle to in-reach. Although they had been briefed extensively about the program and its eligibility criteria, some providers tended to unilaterally decide which patients might be interested in enrolling in the program instead of allowing patients to make the decision for themselves. Thus some persons who might otherwise have enrolled were never informed about the program and were allowed to continue with the regular regimen of care.

The outreach strategy did not fare that much better. According to program staff, the main outreach activities undertaken by outreach workers were talking to people in clinic waiting rooms and encouraging them to get tested, and talking to persons in public places where the outreach staff believed eligible persons might be found to encourage them to get tested. Persons encountered in clinic waiting rooms who agreed to be tested could usually be tested immediately at the clinic's on-site counseling and testing services. However, those met out in the broader community were given vouchers that entitled them to go to CAFHC to be tested. The problem was that people who agreed to be tested needed to be tested right away because any delays usually seemed to decrease their interest in the test. Project staff stated that the amount of grant funding allotted to outreach was insufficient. This is not surprising because the site did not anticipate the level of outreach that was required to recruit clients. Due to resource constraints, the program could not afford a mobile testing van. Therefore, staff had to rely on people remaining sufficiently motivated after their initial contact with the outreach worker to come to CAFHC to be tested, and that often was not the case.

There were also some administrative concerns that cropped up when the program seemed to be stressing testing more than it was its intervention. Since the tests were being offered free, an increase in the number of test takers meant an increase in the amount that had to be spent on testing supplies. Thus, although Lutheran actually was reimbursed for the cost of the test, some

administrators began to wonder whether test takers should not be charged a co-payment. This proposal raised concerns that potential clients would be discouraged from being tested, but this change was not instituted during the life of the CHIVES project.

The increased volume of test takers created a strain on the testers. As a result, in the first two years of implementation three different persons held the tester position. Institutional red tape then hampered the timely filling of the vacancy. At times, when the position became vacant, the CHIVES outreach worker was tapped to assume the task temporarily. This was a full-time position and therefore it hindered her ability to fulfill her outreach responsibilities.

The linchpin of Lutheran's outreach effort was testing. However, the CHIVES project had miscalculated the prevalence of HIV in the Caribbean immigrant population. Even assuming that the prevalence rate in the target community was as high as three percent, the project would have had to find hundreds of Caribbean immigrants willing to be tested in order to find just half of the treatment sample of 70 that they had proposed to recruit. The principal investigator observed that thanks to the CHIVES project, CAFHC increased the number of hours it conducted testing to 40 hours a month, and the number of persons being tested increased threefold from 40 persons a month to 120. Yet, these numbers were not sufficient to allow the site to reach its enrollment target.

Confidentiality

A significant obstacle to enrollment at Lutheran, as was the case at other sites, was potential clients' concerns around confidentiality. These individuals come from countries where the health systems do not have the same privacy protections as exist in the United States. As a result, residents are wary of seeking care for potentially embarrassing conditions such as HIV. When they come to the United States they have difficulty believing that their confidentiality will be respected. This concern was perhaps heightened in the case of Lutheran because its intervention was housed in a neighborhood with a very high concentration of Caribbean immigrants. In addition, the staff at CAFHC was mainly from the Caribbean, and while this may have promoted culturally competent care, it also raised concerns for some potential CHIVES clients that by seeking care at CAFHC they risked running into a provider they knew or who knew their family back in the Caribbean or someone else in their social network.

Additional concerns revolved around immigration. Some potential clients who were undocumented aliens believed that seeking care through the Ryan White system could put them at risk for deportation; particularly since, in their view, US immigration policy did not appear to be supportive of immigrants living with HIV moving to the US. During the life of the project there were several reports (not confirmed by the evaluators) of immigration raids where Caribbean immigrants were apprehended and sent to deportation facilities. Whether these reports were true or not, they appeared to have gained credence among the target population and as result, quite a few eligible persons were hesitant about enrolling in the CHIVES program.

Despite the severity of the obstacles discussed above, project staff has also identified assets that facilitated their outreach efforts. They reported that their commitment to the project and the support they received from the larger institution were instrumental in helping them achieve their final results.

Staff Commitment

In the face of low enrollment, the Lutheran staff remained committed to the program. Until the very end the outreach worker and the peer-promoters expressed passion and enthusiasm for the work and were prepared to go the extra mile when necessary. The outreach worker would spend all day in various clinics conducting outreach and then visit various clubs and social venues late at night looking for potentially eligible persons. The peer-promoters who were drafted to assist the outreach worker did so on their own time as volunteers and were not paid for their efforts.

Given the low numbers of eligible persons that they were finding, the staff focused on convincing those persons who had refused to join the program or who were hesitant to join to change their minds. This required numerous contacts with these individuals to listen to them and reason with them and help them overcome their fears. The staff reported that it often took up to two weeks of daily contact before these individuals could be convinced. For example, potential clients with deep concerns about possible breaches of confidentiality were reassured over and over again by the entire team that all Lutheran staff was required to observe privacy laws. In some cases staff disclosed to increase the comfort level of a potential client; according to the outreach worker: *“People are encouraged to see that someone that is just like them can make it.”*

The team also took other measures besides offering reassurance. The program also began offering the intervention at another Lutheran clinic and giving clients their choice of clinic locations so that those with privacy concerns could obtain care from a facility that was not in close proximity to their neighborhood. In addition the hours at the clinic were extended so that evening and Saturday care were available to suit clients with varying schedules. As a result there were what the program coordinator termed as *“outreach victories.”* In one case the outreach worker met a man who had been diagnosed HIV+ in 1992 and since that time had received no care. The worker described the man’s appearance as *“skeletal and being at death’s door”*. In addition, he was homeless and had substance abuse issues. Despite this daunting scenario, the outreach worker was persistent and eventually the man was persuaded to enroll in care. When the evaluators met with

him, he was on HAART and responding well. He had gained weight, had recently married, and was enrolled in college and working part-time. He attributed his success to the promises of confidentiality that he received, the nurturing approach of the outreach worker, and the kindness and acceptance that he encountered from the CHIVES team and all of the CAFHC staff.

Institutional Support


Project staff reported that outreach workers and peer-promoters were fully integrated into the Lutheran system and participated in all Lutheran staff meetings. Therefore, there was a seamless referral from the testing and counseling site to the Lutheran CHIVES site. The staff person who was the principal investigator for the first three years of the program also oversaw all HIV services at Lutheran and so was well positioned to establish solid referral linkages with all of the HIV services. He was also able to build buy-in and to convince staff in other centers that the CHIVES program was a positive and not a negative for the entire system and was not in fact creating extra work for existing staff. For example, he noted that when the number of requests for HIV tests went up as a result of the outreach effort, Lutheran hired additional counseling and testing staff to respond to this need.

D. Conclusions

The Lutheran CHIVES case study illustrates the importance of assessing an intervention after the grant award and prior to implementing the project in the community. In addition, the partnership between CWHHA and Lutheran, although longstanding, faltered because the partners did not have a shared understanding of the implementation approach. Although CHIVES was not intended to be an outreach initiative it turned into one for Lutheran because successful outreach is the lifeblood of a program like CHIVES that depends on voluntary enrollment to build a client base. This underscores the necessity to allocate sufficient time and resources for outreach, particularly when working in populations that are hard-to-reach and for whom there are no epidemiological data to permit reliable sampling calculations.



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VIII. Summary/ Lessons Learned

The findings from the case studies of the five sites in the CHIVES Demonstration project highlight several factors that potentially determine the success of outreach projects within stigmatized populations in general, and HIV/AIDS peer support programs in particular.

Stigma

HIV related stigma among Caribbean immigrants has proved to be the single most salient item that affected the way the projects evolved over time. At Montefiore, stigma was a barrier to church members living with HIV enrolling. Concerns about confidentiality reduced enrollment both in the in-hospital recruitment environment at Miami and in the outreach that Lutheran conducted into the outlying community. Even the peer-promoters at some of the sites suffered from internalized stigma that prevented them from being effective at their jobs; despite the fact that the Brookdale project had planned for mitigating stigma in the wider community, its peer-promoters were reluctant about conducting outreach for fear of having to disclose their status. Internalized stigma of CHN's peer-promoters was credited with their reluctance to conduct outreach in public.

Sites' creativity and flexibility in dealing with the various issues that were a manifestation of stigma in part determined their success at implementation. At Montefiore, outreach workers made sure that they talked about other health issues in addition to HIV/AIDS in order to give potential clients a comfortable cover to approach them. Brookdale and Lutheran made sure that they offered services in anonymous buildings that would eliminate any fears that clients might feel about seeking care. With regards to peer-promoters, while Brookdale decided to hire other experienced outreach workers and give the peer-promoters space to confront their fears, CHN continued to struggle with peer-promoter turnover since it did not have the organizational integrity to deal with such issues as they came up. CHN eventually took a bold step, in the final phases of the program, by hiring an African-American peer-promoter who turned out to be very effective.

Team Cohesion and Experience

The value of a cohesive team with dedicated staff was demonstrated in most of the case studies in this report. For instance, some of Montefiore's successes were attributed to peer-promoters that were very well trained and consistently supported by the principal investigator and other senior staff. At Miami, a small and close-knit team resulted in virtually no turnover and ensured that any problems that surfaced were addressed promptly; well-trained staff was key in overcoming the various institutional obstacles the site encountered during implementation. In contrast, most of CHN's early problems are attributable to a dysfunctional team that lacked the proper supervision.

The peer-promoters' experience with the target population as well as their communication skills were key in recruiting and engaging clients. Hiring people that met the basic requirements and then training them to have the skills necessary to fulfill a challenging role was central to Montefiore's success and their retention figures demonstrate that. At Brookdale, culturally competent staff that was trusted by the target population helped potential and enrolled clients to overcome strong stigma and take the risk of participating in the program. At Lutheran, a dedicated and passionate staff stayed the course despite poorly planned program. On the other hand, CHN provided instructive lessons on the importance of staffing in terms of the implementation of the project and fidelity to the intervention curriculum.

Institutional Support

Another factor that was essential in determining success across all five sites was institutional support for the program. At Montefiore, the project enjoyed the unstinting support of the larger institution and was in fact able to use services offered by the larger organization to attract and retain clients. Strong institutional support contributed to a strong and cohesive team at Brookdale. While institutional support ensured a comfortable space for conducting intervention at Montefiore, sites without such support sometimes had less than adequate space. In some cases, institutional bureaucracy resulted in barriers to care but integration into the larger institution ensured a seamless referral from testing and counseling to the Lutheran CHIVES project.

Understanding Community/Cultural Dynamics

The sites' abilities to understand and adapt to the community dynamics in which each project operated can have a significant impact on the project. For instance, members of the target communities at both the Brookdale and Montefiore sites expressed concerns that by focusing on persons of one nationality the projects might be perceived as acting unfairly toward those of other nationalities. While at Brookdale, the project addressed the community's concerns by meeting with its Community Advisory Board on a regular basis to show how the project was benefiting the larger community and not just Haitians, the Montefiore project decided to broaden recruitment to more groups and even changed its random assignment strategy so that individuals from the same network would receive the same intervention. On the other hand, in a different context, in Miami where the community was not as intimately engaged in the hospital setting, a focus on one ethnic group was an asset – the staff was able to tailor the intervention to one group and was able to serve this group well.

Time

Finally, the importance of building in sufficient time for navigating through the various anticipated and unanticipated context related issues was demonstrated in all cases. Cultivating trust in an environment of high externalized and internalized stigma is time consuming as illustrated by the problems encountered in Montefiore's church-based recruitment strategy. At Brookdale, time was needed to make any real headway in the Herculean task of mitigating stigma in the community. At CHN, time was needed to work through the internal problems that plagued the project from the outset and make the mid-course corrections that set it on the right track; it seems that if the last program manager had had just six to nine more months in which to oversee outreach and recruitment, CHN might have achieved its original recruitment targets. In Miami, the project team would have liked more time to forge the needed bond between clients and peer-promoters that would have facilitated delivery of the intervention.

In the end, while the Demonstration project may or may not achieve its goals of finding effective peer support models to encourage HIV care seeking, the lessons above identify factors that future efforts in peer support for persons living with HIV may wish to consider during implementation. When targeting vulnerable populations the issue of stigma will be encountered and should be addressed upfront wherever possible. Doing so requires knowledge of the community and, because the community is constantly changing, respectful consultation with the community. In addition, the sites showed that it is important to take into account the many manifestations of stigma and to develop different creative and flexible strategies to address them. Institutional support is critical as it provides the foundation that supports the project and is often instrumental in enabling the project to secure needed resources that are beyond its individual budget.

Time emerged as a key factor affecting implementation and the sites' experiences underscore the need to build sufficient time for outreach particularly if the outreach has to address issue of stigma in order to recruit clients. Time is also needed to facilitate the peer-client bond once clients are enrolled so that the latter remain engaged and peer-promoters' ability to deliver the intervention is maximized. Finally, time should also be allotted to allow the program team to bond, particularly if they have not worked together before because team cohesion and stability facilitate implementation. Dedicated, quality peer-promoters who are well trained facilitate implementation. However, peer promoters in some cases may need extra time to grow into their roles and achieve their full potential.



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We would like to thank all the peer promoters and clients, without whose dedication, altruism, and courage this study would not have been possible.



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