IN MEMORIAM

To those transgender women and men who we lost in the HIV epidemic,
and especially the dozen participants who died
during the course of our initiative.

We Remember You!
CONTENTS

Introduction ........................................................................................................................................1

Chicago House: TransLIFE Care ........................................................................................................5

CHN Family Health Center: T.W.E.E.T. Care .................................................................................26

Howard Brown Health Center ...........................................................................................................44

The Alexis Project ..............................................................................................................................61

PHI: The Princess Project ..................................................................................................................81

SUNY: The INFINI-T Project .............................................................................................................101

APIWC/SFDPH: TransAccess ...........................................................................................................119

BIENESTAR: TransActivate ............................................................................................................143

The Brandy Martell Project ..............................................................................................................156
INTRODUCTION

HIV Disparities. Transgender women (people who were assigned male at birth and have a female gender identity and/or feminine gender expression) are at high risk of having HIV and of contracting HIV. In a recent meta-analysis conducted worldwide, the HIV prevalence rate among transgender women in high-income countries such as the United States is approximately 22%, but transgender women regardless of country wealth were approximately 49-times more likely to be living with HIV compared to all adults of reproductive ages. Transgender women of color, especially African-Americans and Latinas, experience disproportionately high rates of HIV. A 2008 meta-analysis of 29 regional US studies found that race was a significant mediating factor to HIV status among transgender women. For example, HIV prevalence among African American transgender women is approximately 56%, whereas the prevalence among white transgender women is approximately 17%.

The higher HIV prevalence among transgender women compared to other high risk groups may be due to many environmental and social contexts including multiple stigmas (transphobia, racism, sexism, HIV, sex work, and towards immigrants); substance use; recurrent incarceration and victimization in the criminal justice system; homelessness and marginal housing; relationship and other forms of violence; institutional inattention, indifference, and mistreatment; mental health issues; lack of economic opportunities; and other issues.

Disparities in HIV care. Transgender women are more likely to have unstable housing, exhibit symptoms of mental illness, and use substances than the general population. These factors can result in late entry or avoidance of entry into HIV medical care, and consequently they can lead to poorer health outcomes than those with earlier care entry. However, disparities in treatment engagement exist along social, economic, gender, and racial/ethnic lines. Researchers have documented that transgender women living with HIV are less likely than other populations to be taking ART. Transgender patients receiving Ryan White HIV/AIDS Program-funded care were 85 to 90 percent less likely than others to engage or remain in safety net-funded primary medical care. Transgender women who initiate ART, are less confident about integrating

their treatment regimens into their daily routines, and are less likely to report positive interactions with their providers\(^8\). It is particularly difficult for transgender women to find healthcare providers who respect their gender identity and with whom they can have honest discussions about hormone use and other practices\(^9\), resulting in low levels of satisfaction with and trust in their providers and poor health outcomes\(^10\). In fact, discrimination of transgender women by healthcare providers has been reported in many studies\(^{11,12,13}\) and many transgender patients seem to know more about their own healthcare than do their physicians\(^14\). Even disrobing in healthcare settings may result in unsafe situations and expose transgender women to insensitivity and hostility from healthcare providers resulting in avoidance of seeking healthcare.\(^{9,11,13,15,16,17,18,19}\)

For transgender persons, constrained access to culturally competent health care and social services, experiences of stigma and discrimination, vulnerability to violence and exploitation, social barriers to maintaining a stable income and safe housing, and intersecting experiences of social marginalization all contribute to negative health outcomes.

**This Initiative.** In response to these HIV disparities, the Health Resources and Services Administration’s Special Programs of National Significance (SPNS) funded nine demonstration projects in four US urban areas in 2012 to implement innovative, theory-based interventions for transgender women of color living with HIV in their jurisdictions. The SPNS initiative also funded one national Transgender Evaluation and Technical Assistance Center (TETAC) at the University of California San Francisco, Center for AIDS Prevention Studies (CAPS) which partnered with UCSF’s Center of Excellence for Transgender Health.

This manual describes each of these interventions, including:

---


• The local epidemiology and the unique needs of the populations served
• A description of each organization
• Key components of each intervention including outreach, recruitment, and retention strategies
• A logic model and/or a description of how each key intervention component addressed various stages of the HIV Care Continuum (e.g. linkage, retention, ART adherence, and viral suppression).
• Core intervention staff
• Description of community partners, when appropriate
• Staffing requirements and cost estimates
• Program planning and development needs
• Preliminary programmatic outcomes
• Important lessons learned

Four of the nine demonstration sites were agencies that do not directly provide clinical services. These sites were:

• Bienestar Human Services in Los Angeles, CA. Bienestar’s program was called TransActivate, and it provided multiple services (e.g., navigation, outreach, use of social networks) to improve engagement in care among Latina transgender women living with HIV.

• Chicago House in Chicago, IL. Chicago House started the Trans Life Center to reach transgender women of color living with HIV through outreach, a drop-in center, and access to a variety of programming including housing and employment support, legal services, linkage to care services, and social support in addition to the provision of transgender cultural competency trainings.

• Friends Research Institute in Los Angeles, CA developed The Alexis Project that used social network recruiting and engagement, peer navigation, and contingency management to reach and engage transgender women of color living with HIV who were previously unaware of their infection.

• Public Health Institute in Oakland, CA created The Princess Project that used health educators to reach African American transgender women living with HIV with motivational enhancement interventions sessions and health promotion workshops in a safe project space called the Butterfly Nest.

Five demonstration sites were providers of direct medical care in addition to a variety of other support services. These sites were:

• Community Healthcare Network in Queens New York. The T.W.E.E.T. (Transgender Women Entry and Engagement To) Care Project reached transgender women of color living with HIV by mobilizing peer leaders to conduct outreach and “teach back” sessions to link participants to care.

• Department of Public Health in San Francisco, CA partnered with a local community based organization (CBO) to create The Trans Access Program that provided HIV primary care at the CBO.
in a welcoming environment in addition to community outreach and linkage to care services to reach transgender women of color living with HIV.

- **Howard Brown Health in Chicago, IL** created their **After Hours drop-in clinic** to reach transgender and gender non-conforming people in a trans-only community space and offered support groups both for young and adult transgender women of color living with HIV.

- **SUNY Downstate in Brooklyn New York** created **INFINI-T** to attract and retain young transgender women of color living with HIV using a youth-focused “one-stop shop” model, including outreach, a community advisory board, and a group level intervention called JOG (Just One of the Girls).

- **Tri-City Health Center in Fremont, CA** created **The Brandy Martell Project** to serve Latina and African American transgender women living with HIV with a combination of legal services, skills-building group sessions, and healthcare enrollment facilitation.

These short descriptions do not do justice to the comprehensive services provided at each of the nine demonstration sites. We hope that you will take the time to read more about each program in the following chapters. The sites worked incredibly hard, in partnership with their local communities, to develop, implement, and evaluate their programs. This initiative may be the largest of its kind ever to focus on the unique needs of transgender women of color living with HIV. We hope that this effort will contribute to the development and implementation of new culturally-appropriate, high-quality services to improve engagement in care for transgender women of color living with HIV across the US and beyond.

**The TETAC Team:**

Greg Rebchook, PhD  
JoAnne Keatley, MSW  
Starley Shade, PhD  
Madeline Deutsch, MD, MPH  
Jae Sevelius, PhD

Andre Maiorana, MA

Deepalika Chakravarty, MS

Sam Ferguson, LCSW

Luis Gutierrez-Mock, MPH, MA

Omar Sahak

**Health Resources and Services Administration**  
**Office of Training and Capacity Development**  
**Demonstration and Evaluation Branch**  
**Special Projects of National Significance (SPNS) Team:**

Adan Cajina, MSc  |  Chief, Demonstration Evaluation Branch

Chau Nguyen, MPH  |  Public Health Analyst

Natalie Solomon-Brimage, MPH  |  Public Health Analyst

Melinda J. Tinsley, MA  |  Public Health Analyst

Jessica M. Xavier, MPH  |  Health Scientist
Lisa M. Kuhns, Ph.D., MPH

Josie Lynne Paul, MA, LCSW

Judy Perloff, MSW, LCSW

Corresponding Author:
Josie Lynne Paul, MA, LCSW, Director of TransLife Care Program
Chicago House and Social Service Agency
1925 N. Clybourn Avenue, Suite 401, Chicago, Illinois 60614
773.248.5200, x317 (p)
jpaul@chicagohouse.org
LOCAL EPIDEMIOLOGY

While local epidemiological data in Chicago for HIV infection among transgender (or “trans”) women are limited, a meta-analysis of 29 studies focused on U.S. transgender women found a prevalence of 27.7% laboratory-confirmed HIV infection (four studies).\(^1\) New cases of HIV infection in the City of Chicago are concentrated among men (83.2%) and men who have sex with men in particular (MSM; 78.3%).\(^2\) It is likely that a percentage of cases reported as MSM are trans women, who are incorrectly or inconsistently reported with regard to sex and gender identity. The City of Chicago has included “current gender identity” in its case report form since 2010, however these cases are widely believed to be underreported, which renders current surveillance data ineffective for tracking these cases. Two prior studies of HIV prevalence among young transgender women in Chicago, based on both self-reported and laboratory confirmed HIV infection, suggest that approximately one-fifth of young transgender women are infected with HIV \(^3,\(^4\). These studies also report high rates of social and economic marginalization among trans women, including high levels of homelessness, unemployment and history of incarceration, which are noted as driving factors in the local HIV epidemic.

---

PROGRAM DESCRIPTION

THE ORGANIZATION

Geographical Makeup

The TransLife Care (TLC) Program is situated in Chicago, Illinois. The estimated population of Chicago and its surrounding counties is about 5.2 million people who represent nearly 66% of the population of the state of Illinois. The Chicago Eligible Metropolitan Area (EMA) encompasses about 1,600 square miles and reflects urban, suburban, and rural communities. Chicago, the largest urban center in the area, is the nation’s third most populous city. In the beginning of the epidemic, HIV/AIDS cases were concentrated in the North Side Community Areas of Chicago along the lake. Though prevalence in these areas remains high, the epidemic has now spread throughout Chicago and highly impacts African American and Hispanic populations living in community areas on the South and West sides of the City of Chicago. These high prevalence areas coincide with the city’s distribution of both high-risk and impoverished populations.

The TransLife Care Program serves the transgender population living on the north, west and south side of Chicago, which encompasses about 235 square miles. The TLC programming is strategically located along public transportation to allow for easy access.

Organizational Context

The mission of Chicago House and Social Service Agency (Chicago House) is to serve individuals and families who are disenfranchised by HIV/AIDS, LGBTQ marginalization, poverty, homelessness, and/or gender non-conformity by providing housing, case management, employment services, HIV prevention and medical linkage and retention services, legal services, and other supportive programs. As a provider of HIV housing and social services since 1985, Chicago House has been at the forefront among Chicago’s community-based AIDS service organizations in acknowledging the profound impact that social and economic factors such as housing, employment, and income can have on citywide HIV prevention efforts and the health of those living with HIV/AIDS. With non-medical factors accounting for as much as 40% of health outcomes, the provision of social services that help people prioritize prevention, engagement in medical care, and adherence to medication for those living with HIV must be central to comprehensive HIV prevention efforts. In 2016, Chicago House served more than 1,800 people – including nearly 200 adults and more than 40 children living in our residential and/or scattered site housing programs, and more than 1,000 adults accessing our prevention, case management and employment services.

While Chicago House has designed a comprehensive array of services to help address the many barriers to healthcare, housing, and employment that HIV-impacted individuals may experience, we recognize that no
one agency is able to provide everything that a person might need in order to achieve self-sufficiency and wholeness. Therefore, over the past 30 years, Chicago House has developed close working relationships with a broad network of agencies in order to provide our clients with a comprehensive array of support services. These partnerships create a strong referral network that allows us to not only reach vulnerable members of the community, but to provide our clients with the best possible care by offering them referrals for services not available at Chicago House.

The TransLife Care program is a “one stop shop” service center within Chicago House for the Chicagoland Trans community where life-saving services are provided, including help with housing, legal assistance, employment counseling and job readiness, social support and outreach-based health services.

THE INTERVENTION

Theoretical Basis and Guiding Principles

The TransLife Care (TLC) Program provides a transgender affirming environment and programming that addresses the social and structural determinants of health, which evidence suggests drive HIV infection in marginalized communities and are most commonly experienced as challenges within the transgender community. The project is rooted in a set of core clinical philosophies including: (1) Trauma-informed Services, (2) Client centered care, (3) Strengths-based approaches, (4) Systems theory, and (5) Harm reduction. Additionally, based on feedback from trans-identified staff members and individuals on our community advisory board, services were developed, organized, and delivered using the following guiding principles: (1) Trans specific, (2) Accessible and barrier free, (3) Stigma-free inclusive eligibility criteria, (4) Bundling of services, (5) collaboration, and (6) Relationship and connection.

Key Components of the Intervention

The intervention inputs, activities, outputs, and outcomes are detailed in the TransLife Care Project logic model (see Appendix, Figure 1). The TransLife Care Project creates multiple opportunities to meet the target population “where they are” and provides them with meaningful and necessary services, support, and access. The intervention is structured to provide trans women of color with “no wrong doors” to services and medical care. Participants may choose any of the services offered when they are ready in any order, through the TransSafe drop-in or directly through Chicago House and community service providers. The components of the intervention are detailed in the Flowchart for TLC (see Appendix, Figure 2) include:

---

• **Community Outreach** – Event- and street-based outreach to engage the community in the meaningful services offered within TLC, specifically targeting trans women of color who are unaware of their HIV status, newly diagnosed, or out-of-care.

• **Drop-in Center** – Portal providing low-threshold access to services to engage members of the trans community women of color in services

• **On-site medical, housing, legal, employment, and HIV services** – Agency and subcontracted staff provide health education, medical care, housing linkage and referral, legal, and employment services in client-centered trans-specific environments. Housing, legal, employment, and HIV services are programming offered by Chicago House but not covered specifically under this SPNS-funded intervention.

• **Navigation** – Supporting trans individuals to access necessary, affirming, and inclusive services, particularly trans women of color connections to HIV related medical care.

• **Trans-competency trainings** – Systems level trainings with medical providers and support staff to provide affirming and inclusive HIV care.

---

**TLC Program Model (Intervention Components)**

**Community Outreach**

The TransLife Center employs community outreach strategies to engage trans and gender non-conforming individuals within the most marginalized communities. The purpose of this outreach is to inform potential participants about services offered through the TLC as well as to empower them to engage in these services. Each outreach venue is selected based on regular attendance of trans individuals within these settings in under-served communities. Examples include Cook County Jail, TaskForce Prevention LGBT youth drop-in on the west side of Chicago, and the south side sex work stroll popular with trans women. Each outreach venue is reviewed for potential outreach effectiveness as well as outreach worker safety.

The TLC utilizes Peer Outreach Coordinators to conduct outreach in many of these settings. The TLC conducts a Peer Outreach Training with all peer outreach workers, recognizing the need to provide professional development opportunities for these peers and members of the community served. Outreach efforts focus on two primary strategies.

1. **Building Relationships** - Outreach workers attend outreach venues on a consistent basis, in order to build trust with the host organization as well as the trans identified individuals who frequent these settings.

2. **Offering Access to Meaningful Services** – Outreach workers provide community members information about effective and easily accessed services that meet the needs and wants of many, including the most marginalized in the transgender community.
**TransSafe Resource Drop-in Center**

The TransSafe resource drop-in centers provide trans-affirming space where trans-identified and gender non-conforming individuals can find social support and safe harassment-free space, as well as direct access to housing resources, legal services, employment services, and trans-affirming health education and linkage to medical care. The drop-in is held once weekly from 1:00 to 5:00 PM. TLC participants self-select the services they desire and receive, following a client-centered approach. Additionally, alongside access to specific services in one accessible and flexible drop-in setting, trans and gender non-conforming individuals can also find access to HIV linkage to care for those new to care or fallen out of care, retention in care for those currently in care in need of assistance to adhere and remain in care, and HIV prevention services such as testing, counseling, and pre-exposure prophylaxis (PrEP) information, navigation, and provider linkage.

When TransSafe participants attend the drop-in for the first time, the TLC staff conducts an intake with the participant, gathering basic demographic information including preferred name and legal name, date of birth, preferred gender pronouns, racial and ethnic identity, estimated monthly income, and contact information. Staff also screens new participants for interest in the services offered as a part of the TransSafe Resource Drop-in Center and orients new participants to the space. All drop-in attendees sign in and select which services they are interested in receiving, and service providers use the sign-in list both to ensure they see all interested participants and to record that services were provided that day. Additional staff encourages drop-in participants to network with other participants while not with service providers.

TLC staff review client needs for all those who engage in services through TransSafe and a Peer Outreach Coordinator is assigned to assist with connection and follow through with resources.

**TransHealth Services**

TLC contracts with Heartland Health Outreach (HHO), a company of Heartland Alliance in Chicago, to provide medical services to TransSafe participants at our TransSafe drop-in. If a participant is seeking medical care for the first time and is interested in hormone treatment, qualified clinical staff first meet with the participant to complete an informed consent assessment and education prior to seeing the medical provider. An HHO medical tech registers each patient, and the Nurse Practitioner meets with each patient after that. While patient visits focus on the presenting complaint, the medical provider also conducts a general health assessment, including sexual health risk assessment and need for HIV prevention and treatment services as a part of the initial visit. The provider makes appropriate recommendations for any additional care, including HIV testing, HIV prevention care such as PrEP, or HIV treatment services.

**TransHousing Services**

Participants seeking housing services first meet with the TLC Project Coordinator to assess homelessness and housing instability and contributing factors such as physical health and mental health, substance use, HIV status, as well as risks to the individual's well-being related to housing instability and homelessness.
When appropriate, the Project Coordinator lists the client on the Chicago Central Referral System (CRS) List, which the citywide homeless services system uses to allocate appropriate housing opportunities as they become available. The Project Coordinator will make additional referrals as appropriate to the Trans Housing Case Manager or to Chicago House Housing Specialists as well. After assessing housing stability and taking appropriate action, the Project Coordinator also assists participants with linkage to other TLC service providers. If participants receive housing via the CRS List system, Peer Resource Navigators assist the client with obtaining the documentation needed for permanent supportive housing programs.

In addition to housing linkages and referrals, TransHousing provides 15 scattered site, community-based, permanent supportive housing (PSH) units for transgender and gender non-conforming individuals that are accessed through the CRS List. PSH clients pay a portion of rent equal to 30% of income. TransHousing clients receive intensive case management services from the Chicago House TransHousing Manager.

**TransLegal Services**

The Staff Attorney conducts an intake with all transgender individuals seeking legal services, including basic demographics, presenting concern, and legal services sought. Clients receive an overview of the scope of legal services offered through the TransLegal program, including name change and gender marker change on identifying documents, record expungement and sealing, direct representation in employment and housing discrimination, direct representation in seeking public benefits such as SSI and unemployment insurance, and misdemeanor defense. Based on intake information gathered, the TLC attorney informs the client of the program’s ability to meet the client’s legal needs. Clients receive information on next legal steps indicated by the nature of the legal case. If the client’s legal concerns fall outside of the scope of the TransLegal program, they are referred to alternative legal counsel. In most cases, specialty legal services, often pro bono, can be arranged through the vast network of the TransLegal Advisory Council that meets quarterly and is comprised of attorneys and law firms from an array of practice specialties.

**TransWorks Employment Services**

The TransWorks Employment Program offers job readiness workshops, resume assistance, computer access, job search skill development, career counseling, and mentorship programming for transgender and gender non-conforming individuals. The TransWorks Coordinator meets with interested TransSafe participants to determine the level of employment services sought by the client, and to discuss the scope of employment services offered. Potential TransWorks clients at the TransSafe drop-in are offered assistance in the computer lab with more limited immediate resume and job search assistance as well as full participation in the job readiness workshop, and coaching with an employment specialist. Those who opt for participation in the full TransWorks program complete intake and assessment with the TransWorks Coordinator.

**HIV Related Services**

An HIV Prevention and Care Coordinator attends the TransSafe Drop-in, available to all TransSafe attendees. The HIV Coordinator provides referrals to CLEAR (Choosing Life: Empowerment! Action! Results!), an evidence-based health promotion intervention for persons living with HIV/AIDS or at high risk; HIV testing...
or referral to testing services, risk reduction counseling, linkage to PrEP for those who are HIV negative and indicated for PrEP; and linkage to care for transgender individuals living with HIV who are newly diagnosed or out-of-care. The HHO medical provider can also provide HIV-related medical care, within the TransSafe Drop-in as well as at the HHO clinic sites, to those living with HIV who are newly diagnosed or out of care, and PrEP to interested negative TransHealth patients.

**Transgender Cultural Competency Trainings**

Transgender individuals face discrimination and marginalization in many systems, including legal, health care, social services, and employment. TLC attempts to positively impact these systems and the care of trans persons within these systems at a macro level by providing Transgender Cultural Competency trainings. The TLC Director and Care Coordinator provide trainings to medical systems and clinics, social service providers, schools, and universities. These trainings are evaluated with a pre- and post- test protocol. The TransWorks Coordinator and TransLegal Director provide trainings to employers and legal systems, respectively.

**Collaborative Partners**

The TLC operates with the support of community partner organizations, both medical and non-medical, that provide a range of complementary services to the core services provided at the TLC.

Our medical partners include Heartland Health Outreach (HHO) and Ann & Robert H. Lurie Children’s Hospital of Chicago (Lurie Children’s). They provide expertise in transgender medicine as well as on-site health services. Medical and mental health providers from HHO and Lurie Children’s helped shape the vision for the site-based health services and protocol for linkage to medical care. HHO conducts patient consultation, basic health triage, and linkage to medical care at HHO clinics or other local medical providers for transgender-specific medical care and hormone therapy, as well as HIV Primary Care and preventive health screening and services. Preventive health services include, but are not limited to, screening for sexually transmitted infections (STIs), with plans to expand services to include PrEP. On-site transgender-specific health education and consultation is provided for gender transition, hormone therapy, and access to transgender medical services. Basic triage services include assessment of current health complaints and referral to treatment, as needed.

Our non-medical partners are the Center on Halsted on the North Side of Chicago, University of Chicago The Villages on the South Side, and TaskForce Prevention on the West Side of the city. We partner with these organizations to provide education and outreach, support group sessions, and mobile versions of TLC services in their locations for transgender or gender non-conforming consumers.

**Core Intervention Staffing Requirements**

Staffing of the Core Intervention Consists of:

- **1 Full-Time Program Director.** Supervises Project Manager as part of Core Intervention as well as oversees operations and service provision for the TransSafe, TransLegal, TransHousing, TransHealth, and TransWorks components.
• **1 Project Manager.** Supervises Peer Resource Navigators as part of Core Intervention, as well as supervising part-time TransSafe Coordinator. Conducts outreach, provides services at TransSafe Drop-in, provides linkage to HIV care for transgender women who are newly diagnosed, new to care, or out of care.

• **4 part-time (1.25 FTE equivalent) Peer Resource Navigation.** Assists with operations of TransSafe Drop-in and assists participants in navigating services and linkage to HIV care for transgender women who are newly diagnosed, new to care, or out of care.

Additional Staffing through Internal or External Partnership:

• **TransHealth Medical Provider** (approximately 4 hours per week)

• **TransHousing Case Manager** (approximately 4 hours per week present to assist at TransSafe Drop-in with housing information and referrals)

• **TransWorks Employment Specialist** (present during TransSafe Drop-in and full time case load)

• **TransLegal Attorney** (present during TransSafe Drop-in and full time case load)

• **Part-time TransSafe Coordinator** (20 hours per week)

• **HIV Coordinator Testing/Navigation/Linkage-to-Care Specialist** (approximately 4 hours per week at TransSafe drop-in).

**PROGRAM PLANNING AND DEVELOPMENT**

**START-UP STEPS**

The initial steps taken to start up the program focused on hiring and training staff, development of MOUs with our collaborative partners, and identifying meaningful and effective recruitment strategies.

**Hiring and Training of Staff**

It is important to the project’s success to hire staff members who are reflective of the community (trans-identified individuals) and who organically understand why the program is needed and can champion its mission. The Chicago House Community Advisory Board (CAB) was a vehicle for informing the community about the staff openings. Members of the CAB were also invited to participate in the interview process. Initial training of staff included the agency’s core clinical philosophies: Trauma informed care theory, client centered care, and strengths based and systems theories. All new staff members were required to attend the agency’s Harm Reduction Clinical trainings. Staff shadowed those in similar positions and were assigned a “Staff Mentor” to monitor the onboarding process and promote staff retention. Finally, staff members were trained on the
program process and outcome objectives. Weekly individual supervision of staff was maintained, and TLC departmental meetings were held bi-weekly to review the project’s progress towards achieving outcomes.

Development of MOUs

Project partners were specifically chosen because of their experience serving transgender individuals in a variety of disciplines. Partners were embedded in geographical locations that provide multiple points of access to services for transgender women of color on the North, South, and Central areas of Chicago. The project agreed to provide transgender-focused cultural competency training to any staff of the partner agencies that lacked necessary skill sets to provide trans affirming care/services. Formal MOUs were drafted and update annually to make adjustments in the deliverables based on the previous year’s output and success.

Development of Recruitment Strategies

Initially, the project met weekly to develop recruitment strategies. Staff attendees included key line staff directly responsible for recruitment and their managers. Recruitment was an activity that was believed to be the responsibility of all staff, no matter the staff position or title. The philosophy was that all staff members were stakeholders in the project and as such, all needed to leverage their connections and community to spread the word about the project and its benefits. This approach also helped to remove the pressures on the few and distribute it among all. Weekly meetings allowed for discussion on the successes and challenges for each strategy and whether or not staff should continue to implement a particular strategy. In general, the rule of thumb was to give strategies three months before abandoning them. Weekly recruitment meetings were also an important time for staff to support each other, and to offer positive affirmations for the good work they were doing.

MODIFICATIONS MADE TO ORIGINAL PLAN

The following are changes or modifications made to the original intervention design.

1. Drop in location

Originally, the TransSafe drop-in program took place in the lower level of one of the agency’s housing residential buildings. Although accessible by public transportation, the building was in a traditional residential neighborhood and drop-in had to be a very intentional activity since there were no other reasons to be in the area. The lack of neighborhood activity contributed to a low attendance rate. In addition, there was inevitable tension between the housing residents and the drop-in participants who were experienced as intruding on the residents’ living space. The TransSafe program was moved after about one year to the LGBTQ Center that allowed the program to grow by serving individuals who were reluctant to travel to a residential neighborhood as well as those who happened to be at the LGBTQ Center for other needs.
2. Program Expansion

The TransSafe program was situated on the north side of Chicago, a high prevalence community for HIV infection. Some transgender women lived on the south or west sides of town and would not travel to the north side for services. Even with the provision of transportation cards, some individuals did not feel safe traveling from one side of town to the other. Modifications were made by adding two new drop-in programs, one each on the south side and west sides of the city. The two additional resource drop in programs did not offer the full range of services as the north side program but served as an introduction to the TransSafe model with the open invitation to visit the larger program with more services, whenever the participant felt ready.

3. Increase in Peer Staff

Additional peers were added to further distribute workload as the program expanded as well as to ensure that program participants felt connected to more than one staff person, in case of staff turnover. Due to the high level of participant mistrust and fear of providers, developing trust with participants took time and dedicated effort. If the participant developed a trusting relationship with more than one staff, the likelihood of the participant dropping out of services in the event that a particular staff leaves decreased. Ideally, program participants would feel connected to both staff and program.

4. Peer Navigation

Participants’ engagement waned once their initial expressed need was met. Since retention in care is something that occurs over a long period of time, maintaining a strong relationship with individuals over time was essential to support their long-term health. Towards this end, the role of the peers expanded from recruiter and linker to also navigator. As navigator, the peers are able to work with participants around their life-needs and priorities, connecting them to transgender-specialized resources at various points of their involvement with the program. This on-going involvement enables the peers to organically step in when an individual encounters challenges with care adherence.

FACILITATORS TOWARDS IMPLEMENTATION

The 6 primary facilitators that lead to successful implementation include:

1. Trans Specific

The TransLife Care intervention is transgender specific. Unlike many drop-in services where services are general or focused more broadly on lesbian, gay, bisexual and transgender (LGBT) individuals, the TLC intervention reflects trans-specific programming. TLC services are designed first and foremost for the trans community and by the trans community. Wherever possible, care is given to hire qualified professional trans-identified staff.
2. Accessible and Barrier Free

The TLC intervention is designed to be highly accessible and barrier free to participants. The TransSafe space is a “no appointment necessary” drop-in space where participants can access housing resource, medical, legal, employment, HIV, and other referral services, when they feel ready and when they feel sufficient trust in relationships built. The TLC intervention has the service providers present and ready when the client is ready, as opposed to the client needing to be ready when the provider is available. Every effort is made to partner and co-locate TLC services with agencies in locations where trans identified individuals most in need have safe passage, transportation, and a familiar environment.

3. Stigma-free Inclusive Eligibility Criteria

The TLC intervention eligibility criteria are designed to be broad and inclusive in order to reduce the stigmas associated with gender, race, age, and HIV status. For many marginalized individuals and communities, restrictive program eligibility can be experienced as targeting, tokenizing, and stigmatizing. HIV status specific interventions often create issues around potential participants feeling like the program is only focused on HIV and that others will see them as HIV Positive or at risk simply by their participation. For the TLC intervention, the eligibility criteria are very simple:

(1) age 18 or older; and
(2) self-identified as transgender, transsexual, or gender non-conforming.

4. Bundling of Services

The primary portal to the TransLife Center intervention is through the TransSafe resource drop-in program. Most participants first engage with TLC in this space, where they find all of the TLC service components and providers immediately available and accessible to them. This bundling of services – the creation of a trans affirming “one stop shop” – maximizes individual participants’ agency and autonomy regarding when, where, and how they access services.
5. Collaboration

The TLC intervention is collaborative in nature, relying on community partnerships to build the fullest array of trans affirming, accessible, and meaningful services in a “one stop shop.” Even with a significant array of service providers employed directly by the Chicago House TLC, we rely on partnerships with appropriately sized and located drop-in space, health services providers, and full network of housing, legal, medical, and employment providers.

6. Relationship and Connection

While the TransSafe resource drop-in centers serve as portals to TLC services, stigma, isolation, mistrust, and provider fatigue represent significant barriers to accessing services. Therefore, outreach efforts focus on relationship building as well as disseminating information about program services. TLC Staff provides persistent presence in outreach venues such as other drop-in spaces, clinics, events, and clubs. The strength of the relationships built through outreach activities brings highly vulnerable trans individuals into TransSafe and other services.

BARRIERS TOWARDS IMPLEMENTATION

The three primary barriers that impact implementation include:

1. Staff Turnover

Hiring and maintaining competent and talented staff greatly impacts the success of the intervention. Many individuals in the trans community have experienced stigma and discrimination from providers, been denied access to medical care, and/or report being verbally harassed or physically assaulted in social service or health care settings. These experiences traumatize the victims and they perpetuate fear among transgender women who remain wary of care providers. This mistrust of the care system and care providers in general leads to challenges with participant engagement, and necessitates a model of service delivery heavily reliant on relationship building built on trust and availability. When staff leave the program, that relationship between the participant and the program becomes vulnerable and at risk of disruption.

2. Accessible and Adequate Space

Successful programming is dependent on the location of the services being in an area that is accessible via transportation but also in an area of the city/town where trans individuals feel safe to travel without fear of harassment and abuse. Space that is located in an area frequented by the trans community is ideal as well as is space that is embedded in a location that is trans affirming and culturally competent.
Both will ensure greater program participation. The space must allow for program participants to fully express themselves in a manner that feels culturally authentic to them, which may include boisterous behavior and language that some might consider otherwise vulgar or crass, as long as such behavior is not threatening or violent and the language is not disrespectful to others. Program participants’ need for space that allows and validates their socialization norms must be a value also shared by program staff. Space also needs to be large enough to hold one large meeting area and a minimum of three private meeting areas where private conversations can be held with the onsite providers.

3. Access to Hormone Therapy

A large majority of women (in one study, more than 80%) access hormone therapy during their lifetime. Many participants in the TLC prioritized hormone therapy over other needs, be that other medical care, mental health services, or even housing. Initially, the TLC program did not provide an easy pathway to hormone therapy. Attendance dropped off when transgender individuals learned that TLC was not a place to access hormones easily and seamlessly. Participation increased as soon as the onsite medical provider in the TransSafe space began adjusting their hormone protocols that reduced barriers to hormone prescriptions.

ONGOING STAFF TRAINING AND DEVELOPMENT

The Project Manager, whose original title was Program Coordinator, attended HRSA Grantee Meetings and Intervention related trainings and conferences in years two through five of the project. As staffing numbers and complexity increased, TLC capitalized on the opportunity to build the supervisory skills and experiences of the Project Coordinator and her promotion to the Project Manager Description.

Staff Training and Development focused on the professional development of contractual Peer Resource Navigators by providing an Outreach Training developed by the program director utilizing frameworks from other SPNS Grantee models, and training through Midwest AIDS Training & Education Center as appropriate. Where possible and appropriate, the Peer Contractual Staff were promoted to other TLC regular employee positions as they became available through attrition or additional grants. When budget permitted, Peer Resource Navigator compensation was increased to provide closer to a living wage.

TLC INTERVENTION OUTCOMES

Data regarding enrollment and uptake of the intervention over the evaluation period indicate it is both feasible and acceptable to the target population (HIV-positive adult transgender women of color). Over the course of the HRSA-funded TLC accrual period, December 1, 2013-August 31, 2016, program staff
enrolled 122 participants in the program evaluation. Two participants were withdrawn from the evaluation due to duplicate enrollment at another site, resulting in a final sample size of 120. TLC participants range in age from 18-64 years old with a mean age of 30.6 (SD=9.5) and average length of time since HIV diagnosis of 7.2 years (SD=7.1). Given the mandate of the HRSA SPNS initiative to target women of color, 100% of participants described their race as Black or African/American. Participants were largely of low socioeconomic status, consistent with the target of the HRSA-funded TLC program: to reach transgender women of color living with HIV who experience social and economic marginalization. A total of 94% of participants reported being unemployed at baseline, 97% earned less than $11,500/year, and 77% reported a lifetime history of homelessness. Interim analysis of data as of February of 2015 (N=100) indicate strong engagement with TLC intervention components with 72% of the sample reporting exposure to at least one component of the intervention between baseline and 6-month follow-up, declining slightly to 63% between 6-month and 12-month visits. Intervention efficacy (i.e., to promote engagement and retention in HIV medical care) will be evaluated at the end of the project funding period.
INTERVENTION COSTS

The following annual cost estimates are based on two years of operating the intervention after the model was finalized and in full operation.

<table>
<thead>
<tr>
<th>Category</th>
<th>Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Salaries</td>
<td>$140,000</td>
</tr>
<tr>
<td>Admin</td>
<td>$15,000</td>
</tr>
<tr>
<td>Program Director</td>
<td>60,000</td>
</tr>
<tr>
<td>Project Coordinator/Manager</td>
<td>40,000</td>
</tr>
<tr>
<td>Peer Navigators</td>
<td>25,000</td>
</tr>
<tr>
<td>Benefits</td>
<td>38,000</td>
</tr>
<tr>
<td>Travel – Local</td>
<td>500</td>
</tr>
<tr>
<td>Supplies</td>
<td>10,500</td>
</tr>
<tr>
<td>Program Supplies (includes office)</td>
<td>1000</td>
</tr>
<tr>
<td>Program Food</td>
<td>500</td>
</tr>
<tr>
<td>Drop-in Supplies</td>
<td>8000</td>
</tr>
<tr>
<td>Computers</td>
<td>1000</td>
</tr>
<tr>
<td>(includes food and transportation)</td>
<td></td>
</tr>
<tr>
<td>Contractual</td>
<td>31,000</td>
</tr>
<tr>
<td>Drop-in Spaces</td>
<td>20,000</td>
</tr>
<tr>
<td>Health Care Provider</td>
<td>10,000</td>
</tr>
<tr>
<td>IT Support</td>
<td>1000</td>
</tr>
<tr>
<td>Other Operations</td>
<td>4500</td>
</tr>
<tr>
<td>Rent – includes utilities</td>
<td>3000</td>
</tr>
<tr>
<td>Cell Phones</td>
<td>1500</td>
</tr>
<tr>
<td>TOTAL ANNUAL COST ESTIMATE:</td>
<td><strong>$224,500</strong></td>
</tr>
</tbody>
</table>

LESSONS LEARNED

**Relationship, Relationship, Relationship**

At the outset of the program, there was an assumption that due to the high degree of marginalization and need for services by transgender women of color (TWOC) that distributing materials promoting the trans-specific nature of the services would result in a high level of engagement in the TLC program. This
was not the case. Many trans women of color experience a high degree of distrust of systems of care and service fatigue from having to negotiate burdensome systems. TLC had to acknowledge this distrust. The remedy for distrust was relationship building, which required a consistent and persistent presence at outreach venues throughout the intervention period. Hiring trans women of color who were from the target community (“Peers”) helped in relationship building, but was not sufficient, as Peers must also have professionalism and appropriate relationship building skills, such as a trauma informed approach, to be successful. Finally, relationship building cannot rely on a single staff person for long-term success. The program must foster and mentor multiple staff members and their relationship with the agency and program as a whole.

Integration with Community Partners

Relationship building with partnering agencies requires as much attention as relationships with program participants, which was facilitated by a patient, persistent, and consistent presence within the community partner systems. Often, community partners have as much distrust as trans women of color participants. Partnerships must offer clear benefits to the community partner and the clients they serve, whenever possible with minimal or no expectation or demand for outcomes and scopes in return, placing the emphasis on benefits to community over meeting of research or funder goals. While outreach is most effective in underserved communities, effective partnerships must also bring resources to the under-resourced partner organizations.

Meaningful Services

Another important factor in engaging participants involved providing services that trans women of color find meaningful to their lives. Within the TransSafe drop-in, housing, legal employment, and health care services are bundled so that participants can access desired services as well as learn about additional services offered without any pressure to engage in any particular programming. This entirely client centered approach included HIV services as a matter of participant choice and, as a result of not focusing on HIV as the primary service, participants became more willing to discuss and engage in HIV prevention and care services.

Short-term Intervention Fosters Engagement, Not Retention

With a client centered, choice driven drop-in intervention, participants often feel like they have “completed” the intervention once successfully linked to the service initially sought (e.g. housing or name change). This created short-term participant/provider relationships and lacked the longer term engagement often important for following retention in HIV care and medication adherence. While the trans-affirming safe space and networking opportunities offered at TransSafe lead some participants to continue drop-in attendance and program connections, introducing ongoing peer navigation services enhances duration of engagement in intervention for those wanting more limited services at point of initial program participation.
**INTERVENTION APPENDIX**

**Figure 1: TransLife Care Logic Model**

### INPUTS

- **Funding**
  - HRSA Funding
  - In-Kind Contributions

- **Lead Agency**
  - Chicago House

- **Partners**
  - Lurie Children’s Hospital
  - Heartland Health Outreach Center
  - University of Chicago Task Force Prevention

- **Systems**
  - Ryan White Case System
  - Chicago Police Department
  - Department of Corrections

- **Programs**
  - Outreach/Case Finding
  - Resource Navigation
  - Drop-in Services
  - Legal Services
  - Housing Services
  - Medical Services
  - Employment Services
  - HIV Testing
  - Linkage to Care Services

- **Staffing**
  - F/T Program Manager
  - P/T Care Coordinator
  - P/T Resource navigators (4)

- **Facilities**
  - Chicago House Offices

- **Materials/Supplies**
  - Incentives

### ACTIVITIES

- **Outreach** (Client Level)
- **Identification**
- **Drop-in** (Client Level)
- **Linkage, Retention, Adherence**
- **Engagement into Services** (Client Level)
- **Peer Navigation** (Client and Structural Level)
- **Retention, Adherence**
- **Trans Competency Trainings** (System Level)
- **Identification, Linkage, Retention, Adherence**

### OUTPUTS

- Transgender women will attend TransSafe Drop-in
- Transgender women will engage in at least one TLC service through drop-in attendance
- HIV-positive transgender women who are out-of-care will be identified through TransLife Care Program Services
- Transgender women who have been newly diagnosed with HIV or who have fallen out of care will enroll in linkage into care services
- Peer Navigation (Client and Structural Level)
- Retention, Adherence
- Trans Competency Trainings (System Level)
- Identification, Linkage, Retention, Adherence
- Care providers and case managers will receive competency training on working with transgender populations

### INITIAL OUTCOME

- 89% of transgender females receiving HIV testing will test negative and 100% will be referred to prevention services
- 11% of transgender females receiving HIV testing will test positive and 100% will be referred to linkage into care services
- 100% of HIV positive out-of-care transgender females will be referred to linkage into care services
- 80% of transgender females provided linkage into care services will complete at least one medical appointment within 30 days of program enrollment
- 90% of transgender individuals who completed an initial medical appointment will continue to receive linkage into care services and support
- HIV-positive transgender individuals will remain in care as a result of receiving support, educational, vocational and/or housing services at TLC
- Care providers and case managers will receive competency training on working with transgender populations
- 95% of all training participants will demonstrate an increase in knowledge about providing culturally-affirming HIV care to the transgender community

### FINAL OUTCOME

- Transgender females will remain HIV-negative and will lead healthy lives
- Transgender individuals living with HIV are engaged in specialty medical care that is culturally competent and results in these individuals experiencing improved health and quality of life, which then also decreases their risk of infecting others
Figure 2: TransLife Care Program Flow Chart

Outreach, Recruitment and Retention: Care Coordinator, Peer Leads, Program Director

Connect to TransSAFE Resources Drop-In Center

Screening Care Coordinator & Peer Leads

Housing Needs
Community Resource Needs
Employment Assistance Needs
Legal Needs
Healthcare Needs
HIV Services

Connect to TransSAFE
Connect to TransWORKS
Connect to TransLEGAL
Connect to TransHEALTH

Currently Homeless
Advocacy
Linkage to Care
Testing
Prevention: Condoms, Counseling, PrEP

Shelter
CRS List
Trans Housing
Figure 3: TransLife Center TransLEGAL Flyer
Community Healthcare Network: TWEETCare

CHN FAMILY HEALTH CENTER: T.W.E.E.T. CARE
COMMUNITY HEALTHCARE NETWORK
FAMILY HEALTH CENTER:
T.W.E.E.T. (Transgender Women Engagement and Entry To) CARE PROJECT

Luis Freddy Molano, MD

Jessica Contreras

Matthew Weissman, MD, MBA, FAAP

Sabina Hirshfield, PhD

Corresponding Author:
Luis Freddy Molano, M.D., VP of Infectious Diseases and LGTBQ Programs and Services
Community Healthcare Network
60 Madison Ave, 5th Floor, New York City, NY. 10010
fmolano@chnnyc.org
212-545-2460
CONTENTS

Local Epidemiology ............................................................................................................................. 28
Program Description .......................................................................................................................... 30
Program Planning and Development ................................................................................................. 39
Intervention Outcome ......................................................................................................................... 40
Lessons Learned ................................................................................................................................... 41
Intervention Appendix ........................................................................................................................ 43

LOCAL EPIDEMIOLOGY

This intervention took place in an urban, clinical setting. Community Healthcare Network’s (CHN) Family Health Center is located at 90-04 161st street, Jamaica NY. The nearby Jamaica Station is the largest transit hub on the Long Island Railroad (LIRR), and provides direct access to John F. Kennedy Airport. In addition to the LIRR, the clinic is within a 10-minute walking distance of the E, J, Z, and F trains on New York City’s subway transit system. Additionally, there are at least eight MTA New York City buses serving the area. Jamaica’s varied transportation options make it easy to access the clinic even without private means of transportation. The Jamaica area is one of the busiest upcoming neighborhoods in Queens County. This area has become one of the most sought after destinations of the immigrant community. Many individuals from Central and South America are living and working in Jamaica and the undocumented have found a safe space in a neighborhood that is diverse and accepting with options for informal workers, such as day laborer and sex workers.

Jamaica, Queens hosts a large and diverse population. According to 2015 census data, the population is made up of 236,745 people. The population is primarily composed of African Americans, with a sizable representation from Hispanic, Asian, and White inhabitants. ¹ Recent data from the New York City Department of Health shows

¹ Source: U.S. Census Bureau, 2011-2015 American Community Survey 5-Year Estimates
that the Jamaica neighborhood has the third highest number of new HIV diagnoses in the borough, second only to West Queens (Jackson Heights, Elmhurst, and Woodside) and Long Island City-Astoria.²

### Unique needs

Research has shown that transgender women (TW) face higher rates of HIV infection than non transgender people,³ and that African American TW face higher rates of HIV infection than those of other races and ethnicities.⁴ With these discrepancies in mind, it is important to note that in a 2015 survey of over 27,000 transgender people in the United States, almost one-quarter reported that at some point in the past year they needed health care but did not seek it due to fear of discrimination for being transgender.⁵ The needs of the population are categorized in two groups: Medical and Supportive Services.

### Comprehensive Medical Care

Securing access to quality medical care is challenging for TW. Due to persistent stigma, there are very few medical providers that are affordable as well as culturally and clinically competent in trans issues. There is a severe distrust of the medical community, and many in the medical field see people of trans experience as a different set of individuals that do not believe in established medical facilities. Access to HIV treatment and adherence counseling, gender reaffirming surgery, hormonal treatment, and mental health requires medical professionals who are competent, knowledgeable, and able to identify and overcome barriers to care that are unique to people of trans experience.

### Poverty

Too often, a lack of legal protection leads to unemployment for transgender people. The National Transgender Discrimination Survey (NTDS) found that 15 percent of respondents were living in severe poverty, defined as making less than $10,000/year. For transgender people of color, those rates were even higher, with 34 percent of Black and 28 percent of Latina/o respondents reporting severe poverty. As a way to meet every day necessities transgender engage in sex work as a means of employment.⁶

---

² Source: NYC/DOH 2015 data
Homelessness is another critical issue for transgender people: one in five transgender individuals have experienced homelessness at some point in their lives. Family rejection and discrimination and violence have affected many LGBTQ identified youth who are homeless in the United States, a community that makes up an estimated 20-40% of the more than 1.6 million homeless youth.7

Housing and food security rank high among the needs of this community. This becomes more urgent in women living with HIV/AIDS. Having a storage place for their medications, adequate sleeping areas, and access to quality food has a direct impact on their medical outcomes.

**Legal services**

According to demographic data from the T.W.E.E.T. intervention, 78% of participants are of Latin American descent and have an undocumented status. Many participants have fled from countries in Latin America due to extreme persecution and violence for being gay and/or transgender. These stigmas make it more likely that transgender women will engage in sex work for survival, making them even more vulnerable to violence, police arrests, drug use, evictions, and personal disputes with colleagues. These women greatly benefit from a comprehensive network of legal aid.

As a result of the high volume of cases, the T.W.E.E.T. program has collaborated with numerous legal agencies and pro bono firms to assist patients in obtaining asylum, U Visa (a nonimmigrant visa which is set aside for victims of crime, and their immediate family members, who have suffered substantial mental or physical abuse and are willing to assist law enforcement and government officials in the investigation or prosecution of the criminal activity), and T Visa (a nonimmigrant visa for current or former victims of human trafficking).

**PROGRAM DESCRIPTION**

**ORGANIZATIONAL CONTEXT**

The Special Projects of National Significance (SPNS) Program Enhancing Engagement and Retention in Quality HIV Care for Transgender Women of Color initiative was a multi-site demonstration project providing funding to support organizations to design, implement, and evaluate innovative interventions to improve timely entry, engagement, and retention in quality HIV care for transgender women of color living with HIV. This grant was awarded to Community Healthcare Network (CHN) in 2012. The T.W.E.E.T (Transgender Women Engagement and Entry To) Care Project provides the following services to people who are 18 years of age and older to:

---

7National Center for Transgender Equality  http://www.transequality.org/issues/housing-homelessness
Identify newly diagnosed transgender women of color and link them to care
Identify HIV-positive transgender women of color who are currently out of care and link them to care
Enroll identified clients into the TL-Teach Back Intervention
Identify and utilize Peer Leaders, who will be members of the target population that receive the requisite training in the identification, engagement, linkage to and maintenance in care for transgender women of color

CHN is a not-for-profit federally health qualified network with a mission to provide access to comprehensive community-based primary care, mental health care, and social services for diverse populations in underserved communities throughout New York City. Comprised of eleven community health centers and a medical mobile unit, CHN services federally-designated, medically-underserved areas in the Bronx, Brooklyn, Manhattan, and Queens. CHN’s community-based centers provide comprehensive primary and preventative care, reaching over 75,000 individuals each year. More than 95% of CHN’s patients are people of color, approximately 35% are uninsured, and 77% have incomes below the federal poverty level.

Additional services provided on site at the Family Health Center are:
- Dental
- Podiatry
- Wellness
- Nutrition
- Sexual and Reproductive Health
- Health Homes Care Coordination

THE INTERVENTION

The two interventions that serve as the foundation for the T.W.E.E.T. Care Project are the Popular Opinion Leader and the Teach Back interventions. These interventions are evidence-based and supported by substantial research that shows the effectiveness of these programs. The Popular Opinion Leader has been shown to be effective at systematically indentifying, recruiting, training, and engaging the popular opinion leaders (POLs) of a population to serve as behavior change endorsers.

Program staff decided to implement TL-Teach Back intervention based on the strong theories, content, and structure of this evidence-based intervention. In the context of the T.W.E.E.T. Care Project, the teach back intervention was re-named Transgender Leaders Teach Back (TL- Teach Back) to emphasize the role of participants who became Peer Leaders and to customize the intervention to the population.
Theoretical Basis

Social Cognitive Theory

- This learning approach underscores the importance of observation, imitation, reward, interaction and sharing in learning and adopting new behaviors.
- The program employs the use of peers so that clients are able to observe and imitate their success.

Trans-theoretical Model

- This approach explains or predicts a person’s success or failure in achieving a proposed behavior change.
- Individuals move through a series of five stages (pre-contemplation, contemplation, preparation, action, maintenance) when adopting healthy behaviors.
- The individual advances through the stages, making progress, relapsing and losing ground, learning from mistakes made over time, and using those gains to move forward.
- Motivational interviewing is a method that works on facilitating and engaging behavior change within the client. Motivational interviewing is a goal-oriented, client-centered counseling style to explore and resolve client ambivalence around changing their lifestyles.

TL-Teach Back has two main goals:

- To facilitate entry and retention in care for group participants through educational activities and observation of peers
- To improve the quality of life of our patients and to stop the spread of the HIV/AIDS and sexually transmitted infections, with specific focus on achieving HIV viral load suppression

The core elements of the interventions are as follows:

- Group topics can vary, but must be included in one of these five areas:
  A. HIV/AIDS and STDs
  B. Sexual Health
  C. Transitioning
  D. Wellness
  E. Mental Health
- Group sessions are divided in two parts: educational portion and group discussion
- Group sessions are held at CHN’s Family Health Center which provides primary care services (appointments can be scheduled on days the group meets)
- Group sessions are facilitated by a Peer Leader who was previously a group participant
• Peer Leader collaborates with staff to encourage access and retention in care
• Participants complete a pre- and post-test at each session. Tests are evaluated prior to being delivered to participants to ensure that proper health literacy levels are utilized
• Groups sessions are held weekly
• A minimum of 5 completed sessions (one for each area) is required to become a Peer Leader
• Staff provides technical assistance to Peer Leader while preparing for the group session through coaching sessions.

**Sessions**

### AREA A: HIV/AIDS AND STIs

<table>
<thead>
<tr>
<th>Core focus</th>
<th>Optional focus</th>
<th>Example of additional information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Difference between HIV and AIDS</td>
<td>Pre-exposure prophylaxis and post-exposure prophylaxis</td>
<td>History of HIV/AIDS infection</td>
</tr>
<tr>
<td>Prevention of HIV</td>
<td>HIV life-cycle</td>
<td>HIV connections</td>
</tr>
<tr>
<td>Treatment of HIV/AIDS</td>
<td>HIV medications</td>
<td>HIV and heart diseases</td>
</tr>
<tr>
<td>Symptoms</td>
<td>Syphilis</td>
<td>Opportunistic infections</td>
</tr>
<tr>
<td>CD4/VL</td>
<td>Hepatitis A, B and C</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Gonorrhea</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Herpes</td>
<td></td>
</tr>
<tr>
<td></td>
<td>HPV</td>
<td></td>
</tr>
</tbody>
</table>

### AREA B: SEXUAL HEALTH

<table>
<thead>
<tr>
<th>Core focus</th>
<th>Optional focus</th>
<th>Example of additional information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Oral, vaginal and anal sex</td>
<td>Sex work</td>
<td>BDSM</td>
</tr>
<tr>
<td>Sexual harm reduction</td>
<td>“Partying and playing”</td>
<td>Role-playing</td>
</tr>
<tr>
<td>Anal health</td>
<td>Sexual risk continuum</td>
<td>Eroticizing safer sex</td>
</tr>
<tr>
<td>Condom use</td>
<td>Sexual health myths</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Serosorting</td>
<td></td>
</tr>
</tbody>
</table>
## AREA C: TRANSITIONING

<table>
<thead>
<tr>
<th>Core focus</th>
<th>Optional focus</th>
<th>Example of additional information</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Hormone therapy</td>
<td>• Local and community resources</td>
<td>• Voice training</td>
</tr>
<tr>
<td>• Defining the identity process</td>
<td>• Non-surgical procedures</td>
<td>• Coming out to sexual partners</td>
</tr>
<tr>
<td>• Sexual reassignment surgery</td>
<td>• Name and gender marker change</td>
<td>• Coming out at work</td>
</tr>
<tr>
<td>• Silicone injections</td>
<td>• Access to gender segregated facilities</td>
<td>• Coming out to friends and family</td>
</tr>
<tr>
<td>• Labs serum monitoring</td>
<td></td>
<td>• Body image</td>
</tr>
<tr>
<td>• Insurance</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

## AREA D: WELLNESS

<table>
<thead>
<tr>
<th>Core focus</th>
<th>Optional focus</th>
<th>Example of additional information</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Communication skills</td>
<td>• Disclosing (HIV status and trans-experience)</td>
<td>• Eating disorders</td>
</tr>
<tr>
<td>• Develop self-efficacy</td>
<td>• Living with HIV</td>
<td>• Goal settings</td>
</tr>
<tr>
<td>• Self-advocacy</td>
<td>• Problem solving</td>
<td>• Writing a CV</td>
</tr>
<tr>
<td>• Cultural and professional competency</td>
<td>• Coping skills</td>
<td>• Community involvement</td>
</tr>
<tr>
<td>• Bi-lateral sensitivity training;</td>
<td>• Working with a case manager</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Access to care and insurance</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• How to talk to medical providers</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Annual medical check-up</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Job readiness</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Housing</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Immigration</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Back to school</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Nutrition</td>
<td></td>
</tr>
</tbody>
</table>
**AREA E: MENTAL HEALTH**

<table>
<thead>
<tr>
<th>Core focus</th>
<th>Optional focus</th>
<th>Example of additional information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Depression and anxiety</td>
<td>Relationship with sexual partners</td>
<td>Eating disorders</td>
</tr>
<tr>
<td>Abuse</td>
<td>Anger management</td>
<td>Holiday blues</td>
</tr>
<tr>
<td>Substance use</td>
<td>PTSD</td>
<td>Overview of drugs</td>
</tr>
<tr>
<td>Gender Identity Disorder contradiction</td>
<td>Discrimination</td>
<td>Dealing with stigma and discrimination</td>
</tr>
<tr>
<td></td>
<td>Domestic violence</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Harm reduction</td>
<td></td>
</tr>
</tbody>
</table>

**Intervention Process**

1. Potential client is referred to the weekly TL Teach-Back sessions from outreach activities (see T.W.E.E.T. CARE PROJECT Recruitment Strategy).

2. Potential client attends TL Teach Back session facilitated by Peer Leader (client can enter TL Teach Back cycle at any point, whether the group is on in area A, B, C, D, or E).

3. Potential client is encouraged to come back the following weeks and continue attending TL Teach Back sessions.

4. Potential client is enrolled in the project after attending at least two sessions.

5. Client can decide to remain a group participant and attend the weekly sessions for unlimited time. Client is referred to staff member for primary care services.

6. Client is encouraged to become Peer Leader. To become a Peer Leader the consumer must attend at minimum one group session for each area.

7. A client that becomes Peer Leader has the following responsibilities:
   a. Choose a topic and facilitate at least one (and up to three) group sessions;
   b. Meet with a staff member for three individual coaching sessions while preparing the group session;
   c. Participate in outreach activities (see T.W.E.E.T. CARE PROJECT Recruitment Strategy);
   d. Refer potential client to the project;
   e. Encourage referred clients to make and keep medical appointments.

8. Peer Leader meets with staff member for coaching sessions.

9. Peer Leader participates with staff in outreach activities.

10. Peer Leader prepares and presents group session to clients.
11. Group participants complete a pre- and post-test. To increase patient’s involvement, feedback on results will be discussed with the group.

12. After presenting the group as Group Leader, she will receive a certificate of completion and a gift card.

13. Participants have the chance to receive accurate and important information from one of their peers.

14. Participants can become future Group Leaders.

15. Cycle restarts from point 1.

Staff may facilitate and present the group in the following cases:

- First group session for each area
- Group Leader is not able to participate
- Emergencies
- Absence of a Group Leader for a given week
Intervention Components

Outreach

• Staff conducted weekly nontraditional outreach events such as visiting night clubs near known high-sex trafficking areas. Staff walked the streets handing out safer sex packages that include program materials, condoms, and lubricant.

• Ongoing monthly recruitment activities linked patients to care and developed partnerships based on trust. To stay in contact with patients, staff members diffused health education and promotion on internet-based social networks (such as Facebook, Twitter, and Instagram). Facebook is a great tool to use to maintain contact with participants. Features used in this intervention are private messaging to remind patients of appointments, weekly educational groups, and upcoming events. Peer-led activities and special events allow patients to design and execute their own ideas for outreach and recruitment efforts.

Recruitment

• Staff planned special events such as celebration of Trans PRIDE, Trans Day of Remembrance, Miss Trans Latina, and holidays. Peers who were already enrolled received small incentives for bringing people in their own social networks. Those individuals who attended weekly workshops on a consistent basis were chosen to assist in planning and running the event alongside CHN staff.

• Peers learned how to properly approach attendees, explain the services of the program, establish boundaries, and maintain a safe environment. Staff then provided the peers with certificates of appreciation and references for those who applied for employment. After receiving this training, many peers felt prepared and empowered to apply for paid positions with CHN.

Retention

Retention strategies were based on how quickly new patients and existing patients were linked to services and referrals. Supportive services were a key component to maintain high retention rates. Staff focused on what patients considered to be priority, and not only on medical needs in order to understand the population and what they experience on a daily basis.

Supportive services included:

• Assistance with name change, gender marker, referrals for gender reassignment surgeries (to knowledgeable and skilled providers)

• Assistance with online or in-person application for benefits such as SSI and cash and food vouchers
- Accompanying patients to appointments, including surgical, legal, and housing appointments
- Referral to trans-sensitive shelters and housing specialists
- Referrals to comprehensive legal services

It was important for the staff to build on the family environment that was forming through this intervention. During the winter, staff collaborated with the owner of a social club and hosted numerous events. During the summer, events such as Trans by the Sand (beach picnic), Trans by the River (state park picnic), and an End of Summer Event were held. At these events, staff and participants celebrated all the accomplishments the participants achieved, both professional and personal.

Community Partners

Our work is based on the development of strategies and collective leadership. That is why CHN has strived to maintain alliances with friendly organizations who can in turn make referrals to us. Our community partners include business establishments and community based organizations. A mapping of the community was conducted, scouting sites for social gatherings, and/or agencies that provide services to the target population (housing, legal, job readiness, advocates, free services.)

In order to establish a solid relationship with a community partner, a meeting is scheduled for staff to discuss the benefits of the collaboration with intent to help the community. Past partnerships have included small business owners, pharmacies, and local community board members who can provide and disseminate information to the target population.

Staffing

Principal Investigator (PI) oversees the staff and deliverables during the planning and implementation phases. PI participated in the needs assessment of the target community. PI meets regularly with Program Manager and staff and provides technical assistance and referrals to trainings both in/out of CHN. The PI is involved directly in outreach activities, program evaluation and program promotion during the intervention and represented CHN in related meetings.

Program manager is responsible for compiling evaluation data; administering evaluation tools; reviewing the caseload; tracking and enrollment; providing a comprehensive assessment for each client; scheduling follow-up sessions as appropriate; creating monthly group workshops; submitting petty cash and transportation reimbursement; staff supervision and development, establishing and maintaining linkages with CBO’s such as Bronx Community Services (BCS), Center for Court Innovation (CCI), Human Trafficking Intervention Court HTIC (AP8) and Immigration Equality.
**Patient Services Specialist** is responsible for enrolling patients, including intake, scheduling appointments with providers and social workers; administering survey tools; entering notes (Individual Level Interventions (ILI)) into the medical record database; updating T.W.E.E.T. tracking; referrals for legal and name change; attend human trafficking intervention courts; preparing letters for patients for court, gender marker, and work authorization; assisting patients with insurance and housing benefits; scheduling supervision with staff to discuss plans for the week and case conferences.

**Retention Specialist** is responsible for new enrollments; referrals for name change, medical, supportive and legal services; developing client-centered service plan with each client and conducting appropriate follow up as determined by the client’s assessed level of need; establishing relationships with community partners to provide promotional services; and ensuring patients’ compliance with appointments and data collection as well as reviewing data integrity.

**Peer Educator** is responsible for group facilitation; providing coaching sessions to Peer Leaders; creating monthly flyers for weekly groups; maintaining tracking of all Peer Leaders and group encounters; ensuring social media (Facebook) is updated with program workshops and events.

**Court Navigator** duties are attending court sessions on Fridays when referrals are made, meeting with patients, providing details for intakes; scheduling sessions to coincide with groups; providing completion letter to judge, District Attorney, attorney, and patient; maintaining tracking of all referrals and services provided; assisting patients to navigate through court to recover documents for asylum cases. This role is crucial for program development and it must come from the targeted community in order to create a safe environment where patients feel non-threatened, non-judged and have a sense of community.

**PROGRAM PLANNING AND DEVELOPMENT**

During the program planning, a community needs assessment was done to identify gaps in the community. The program hosted two community forums to elicit input. At this time, several “leaders” were identified as well as culturally and clinically competent potential employees. After staff members were identified, each staff was assigned a section in designing the curriculum for the Teach Back Peer Leader intervention.

**IMPLEMENTATION AND MAINTENANCE**

During the intervention implementation, the only modifications made were related to staff structure and the number of groups per week. The initial staffing structure included a Program Manager and a Patient Services Manager. After the initial Patient Services Manager resigned, the role was re-designed to focus solely on patient services and not on managerial functions. The role of Patient Services Specialist was created, and the Program Manager assumed all managerial tasks. The new Patient Services Specialist was a
member of the community being served and focused on navigating barriers for patients to engage and stay engaged in care.

The intervention quickly became very popular in the community. In the original work plan, we stated the group would consist of 8 to 12 participants. By year two, groups consisted of 20 to 25 participants weekly. The clinic conference room was not equipped to host any more than 20 to 25 people at a time and the number of people who wanted to attend the group caused a potential fire hazard. The same topic was held twice a week to accommodate the community's interest. More people were provided with information and regardless of the small space, all participants felt safe. The participants acknowledged that the intervention became a family setting.

Ongoing supervision took place with staff. Corrective plans were put in place to make sure all staff actively engaged with participants and did not lose focus of their task. The large case load required the work be equally shared between the team in order to avoid overwhelming any one staff member. Communication between Project Investigator and staff members was crucial to keeping morale high and also providing solutions to any potential issues as they arose.

Staff attended annual trainings about HIV prevention, medication management and adherence, motivational interviewing, administering surveys, trouble shooting methods, and other innovative methods to enhance medical care to high-risk individuals.

Staff turnover was not a hindering factor in this intervention. There was only one instance of staff turnover and the remaining staff is still part of the intervention.

**INTERVENTION OUTCOME**

**INTERVENTION COSTS**

Among the 163 HIV-positive transgender women of color who were enrolled, participants were ages 24-55, with an average age of 35. Thirty percent of participants identified as African American and 65 percent as Hispanic. Countries of origin included Mexico, Ecuador, Peru, Dominican Republic, Puerto Rico, El Salvador, Honduras, and Colombia. An additional nine percent identified their race/ethnicity as “other”.

At the end of the intervention:

- **83% (135/163)** of participants were either in active care or had pending appointments
- **17% (28/163)** were either non-compliant or lost to follow-up due to substance abuse, depression and/or other social factors.
- **79.2% (107/135)** of those participants who were either in active care or had pending appointment reached viral load suppression
- **Rates of sexually transmitted infections were less than 4%**
Legal Outcomes:

- **93** name changes
- **85** asylum cases won
- **42** U Visas granted (for victims of violence in their country of origin)
- **50** T Visas granted (for victims of human trafficking, used as “drug mules” and/or sex work)
- **70** Trans women obtained Work Authorization (needed for work permit approval)
- **30** Trans women received work permits

Approximate cost of the intervention annually (not including evaluation costs)- **$266,000**.

LESSONS LEARNED

One of the recommendations for the replication of this program in future activities or organizations is that community dialogue is fundamental to the response to HIV. The program must understand the needs and respond to the concerns, questions, and doubts that are generated in the target community. A staff member summed up this recommendation well by stating “keep an open mind and an open heart.”

One of the most essential things is to be able to keep the promise that leadership comes from the community so that participants feel that they are part of the initiative and the impact it makes. The implementation of the initiative in the trans community was difficult, but showed substantial success and promise. Part of our commitment to the execution of the project was community empowerment, so participants were able to become their own advocates and were able to disseminate and replicate the information to the rest of their peers in the community. It is important to create more programs that are trans-specific, trans-inclusive and trans-directed.

Best Practices

- Identify support systems for the patients
- Discuss safety in the clinical setting
- Provide behavioral health referrals if needed
- Discuss survival sex, HIV, and its transmission
- Assess transition plan and aid in the planning process
• Assess level of comfort
• Think about the patient as a person not as another number or rare case
• Assess sexual behavior in a professional manner, differentiating between medical necessity and curiosity
• Remember that behavior does not equal identity
• Create corresponding policies and procedures

Establishing a team that is motivated by the same focus is important to implement an intervention of this magnitude. CHN supports and advocates for equality and justice in order for every human to be equal.
Figure 1: TWEETCare Logic Model

**Figure 1: TWEETCare Logic Model**

### INPUTS → ACTIVITIES → OUTPUTS → SHORT-TERM OUTCOMES → LONG-TERM OUTCOMES

**INPUTS**
- Staff
- Peer Leaders
- Positive standing in transgender community
- Funding
- Research/best practices
- Community Partners

**ACTIVITIES**
- **Training**
  - Train providers in culturally competent, quality HIV care
  - Train Peer Leaders in group facilitation & outreach
- **Recruitment**
  - Develop online outreach modalities
  - Identify traditional and non-traditional outreach settings
  - Recruit clients using 4 outreach modalities
- **Group Sessions**
  - Provide peer-led educational group sessions on 5 topic areas
- **Individual Level Support**
  - Conduct assessments
  - Link to onsite and external medical, supportive and ancillary care
- **Clinical Care**
  - Test patients of unknown HIV status
  - Provide quality clinical care to patients with HIV
- **Sustainability**
  - Enhance community partnerships, networks and collaborations
- **Evaluation**
  - Develop and implement monitoring system
  - Develop Intervention Manual

**OUTPUTS**
- **Training**
  - Providers trained
  - Peer Leaders trained and supervised (60)
- **Recruitment**
  - Clients recruited (163)
  - Clients successfully enrolled (163)
- **Group Sessions**
  - Sessions conducted (1,883)
  - Participants in sessions (87 Peer lead groups)
- **Individual Level Support**
  - Clients assessed (163)
  - Clients linked to onsite medical support (120)
  - Clients referred externally (43)
- **Clinical Care**
  - Patients tested for HIV (100)
  - Newly diagnosed and out-of-care patients linked to HIV care (30)
  - HIV primary care visits (837)
- **Sustainability**
  - Community partnerships and linkages established (45)
- **Evaluation**
  - Evaluation criteria tracked and benchmarked
  - Intervention Manual

**SHORT-TERM OUTCOMES**
- **Clients**
  - Increased participation in peer support groups and networks
  - Increased knowledge & self-efficacy that promotes health-seeking and safer sex behaviors
- **Providers**
  - Increased capacity of CHN providers to serve transgender women of color
  - Increased capacity of CHN providers to serve HIV+ patients
- **CHN**
  - Reduced barriers to HIV care
  - Increased number of HIV+ patients identified and enrolled
  - Increased linkages to ancillary services & networking with local agencies

**INTERMEDIATE OUTCOMES**
- **Clients**
  - Increased level of engagement in care continuum
  - Receives support and ancillary services as identified in assessment
  - Reduced HIV transmission risk behaviors
- **Providers & CHN**
  - Increased ability to engage and retain patients in culturally competent, quality HIV care
  - Increased capacity to offer linkage to continuum of community-based care for supportive services
  - TWEET program sustained
  - Permanent evaluation system in place

**LONG-TERM OUTCOMES**
- **Sustained patient engagement in HIV primary care**
- **Improved patient health outcomes**
- **Improved patient quality of life**
Kelly Ducheny, Psy.D.

Trisha Holloway

Corresponding Author:
Kelly Ducheny, Psy.D., Senior Director, Behavioral Health Services
Howard Brown Health Center
4025 N Sheridan Road, Chicago, IL 60613
773.388.1600
KellyD@howardbrown.org
LOCAL EPIDEMIOLOGY

Men and women of color are disproportionately affected by HIV/AIDS in Chicago, with higher rates of new HIV diagnoses. In Illinois, there is a 0.61% HIV infection prevalence among persons living in Cook County (where Chicago is located), compared to the Illinois prevalence of 0.32%. Within the City of Chicago, the HIV prevalence rate is 868.5 per 100,000, dramatically higher than the Cook County rate. In addition, while Chicago’s HIV/STI surveillance report does not capture local epidemiological information related to transgender individuals, national studies demonstrate that transgender women have HIV prevalence rates from 22% to 28%, with African American transgender women testing positive for HIV more frequently than any other demographic.

Program Description

Howard Brown Health (Howard Brown) is a Chicago-based, federally qualified health center (FQHC) that specializes in providing care to gay, lesbian, bisexual, transgender and gender non-conforming (TGNC) people, and people living with HIV with six clinic sites across the city, one of which is a designated youth

2 County Health Rankings and Road Maps, 2016
center (Broadway Youth Center). In 2016, Howard Brown served over 12,900 primary care patients through 40,120 patient visits. Howard Brown provides primary care, behavioral health services, HIV care and case management, HIV testing and counseling, alternative insemination, TGNC health care and outreach to some of Chicago’s most underserved communities. Forty percent of patients served receive state Medicaid; 20% are uninsured and living at or below 200% of the federal poverty level. Howard Brown serves a primarily urban population, although patients travel from several neighboring states and rural areas of Illinois to access affirmative care at our locations. Howard Brown is serving a progressively larger number of TGNC people; the agency initiated an informed consent hormone protocol for adults in 2010, revising it to further reduce barriers to care in 2014. Since 2009, the number of TGNC patients served in primary care increased 660%, from 467 patients, 65 of whom were HIV positive (2009) to 3091 patients, 236 of whom were HIV positive (2016).

THE INTERVENTION

The specific aim of our intervention is to provide culturally relevant, tailored TGNC-affirmative services to HIV positive Transgender Women of Color (TWOC) with a goal of successful engagement and retention in primary medical care and adherence to HIV-specific care. The intervention includes a specialized drop-in clinic that offers an informed consent hormone prescription process, as well as innovative community programming, support groups, peer outreach, and organizational initiatives to improve staff ability to offer TGNC affirmative care across the agency.

While focused on the recruitment and retention of HIV positive TWOC, the intervention was open to all TGNC people, regardless of their HIV status or identity in the TGNC community. Howard Brown believed that community trust-building would be most effective if all TGNC people were visibly welcomed and included, allowing TGNC peer groups and chosen family networks to access care together, regardless of HIV status and gender presentation. This approach also offered potential patients the greatest privacy, since people could participate in the intervention components for many different reasons and resources, one of which was HIV care.

The intervention was designed to sit on top of Howard Brown’s preexisting, comprehensive Ryan White primary care and behavioral health, linkage to care, retention in care, and case management services, some of which are specifically designed to engage and retain transgender women in HIV care. The intervention did not duplicate preexisting elements of care, but instead created unique community-based entry points to engage TGNC patients in accessing care or resources at Howard Brown, and, when ready, guide TGNC patients into our established systems of HIV care.

Our intervention is predicated on the value of community-tailored health intervention programs that create safe spaces for transgender women to comfortably discuss issues related to health, gender history, depression, sexual risk, and substance use (Nemoto, 2005). By building authentic community trust and
involving community members in programming and outreach, our intervention offered HIV positive TWOC and all TGNC people an opportunity to develop a relationship with Howard Brown’s health care system on their terms, in their time, with their priorities validated and supported. This approach reduced the fear of discrimination in health care that many TWOC experience, especially when seeking HIV care or HIV testing (Bockting, 1998; Clements, 1993). Through improved relationships and trust with our health care system, TWOC living with HIV and all TGNC people are more effectively engaged and retained in care, and more able to re-engage in health care after being absent or out of care.

The intervention had three primary goals:

1. Offer meaningful, engaging, low-barrier, community-driven programing and resources to attract TGNC people, with a focus on TWOC, to Howard Brown and into care
2. Deepen the TGNC and TWOC communities’ trust of Howard Brown and our ability to provide TGNC affirmative care
3. Systematically improve Howard Brown’s ability and investment in providing TGNC affirmative care

The intervention achieved its goals through six key components:

4. A biweekly Friday evening TGNC-only drop in called “After Hours” that provided medical, pharmacy and behavioral health care, staff and community led programming, insurance counseling, dinner, and other resources (i.e., clothing, hygiene, letter writing)
5. A weekly TGNC youth support group called “TYRA” that provided staff and community led programming, dinner and other resources for youth 14-24
6. A biweekly TGNC adult support group called “T-Time” that provided staff and community led programming, dinner and other resources for adults 25 and up
7. TGNC specific community and health center based outreach
8. In-house initiatives to develop trans-affirmative care capacity and to deepen internal agency trans-competence
9. A TGNC specific needle exchange called “SHINE” offered during After Hours. SHINE is not federally funded and was not part of SPNS funded programming but was offered as an additional, concurrent resource at After Hours.

Staffing

The intervention required 0.1 FTE of a director, 0.8 FTE of a program manager, 1.5-2.0 FTE of outreach staff, and 0.5 FTE each of 2 additional program staff. All staff outside of the director are TGNC, many of
whom are TWOC. The program manager oversees all staff, administratively coordinates After Hours Drop In staffing and resources, and takes the lead in partnering with other departments in the agency to provide increasingly TGNC affirmative care at TGNC specific programming and in service provision at Howard Brown as a whole. The outreach staff create relationships with individuals, social networks, and groups to introduce services at Howard Brown and personally invite potential participants to attend programming to obtain resources, medical care, hormone prescription, and community connection. The outreach staff reach possible participants through social media and through a visible presence in the community at known hang outs for TWOC, houses, and social networks (i.e., balls, bars, social events, other TGNC Drop-Ins). The outreach staff also coordinate and create programming for T-Time, the adult support group, and the After Hours Drop In. The 2 other staff (each .5 FTE) assist the outreach team in creating personal relationships and inviting people to participate in programming, coordinate and create programming for TYRA, the youth support group, and the After Hours Drop In. These two staff also organize a series of community events (i.e., health fair at Miss Continental Plus, summer cook outs, holiday parties, transgender day of remembrance activities). Four to five other TGNC staff or consistent volunteers assist the program staff by co-leading groups, facilitating programming at the After Hours Drop-In, and by participating in speaker panels, educational programming or HIV testing events.

Key Components of the Intervention

After Hours Drop-In

The After Hours Drop In occurs on the first and third Friday of each month from 6-9 p.m. Participants start to arrive in the waiting room at 4:30 p.m. for programming, and first come, first served medical appointments that begin at 6 p.m., and continue to appear throughout the evening. Attendance ranges from 15-50 participants of all ages, some who bring family, friends, or significant others to participate in their health care. After Hours is open to any TGNC participant. Participants access any or all of the available services at drop in, staying in drop in for as long or as short a time as they would like. Staff dedicate the first floor of a Howard Brown clinic to drop in, providing medical, behavioral health or other care in some areas, and community programming in others. Programming occurs in either the waiting room (for large crowds and when non-TGNC family or friends are included) or in the TGNC-only programming space. On the following page is a floor plan that shows which services are provided in each space.

After Hours Drop In activities were built to accommodate available space. While it is critical to have some TGNC-only programming space, it is optional to have activities in separate rooms. Space should be used to maximize flow and conversation, and reduce participant isolation or the need for de-escalation.

After Hours was designed to house a specialty medical clinic offering full primary and HIV care and wrap around services specifically tailored for TGNC people. The medical clinic and its supportive services are not SPNS funded programming. Medical clinic staffing includes 4 primary care providers, 1 behavioral
health consultant, 1 nurse, 2 medical assistants, 1 phlebotomist, 1 insurance enroller, 1 volunteer producing gender marker change letters for provider signature, 1 STI/HIV test counselor, and 2 patient service representatives (PSR, front desk). Staffing also includes two collaborative pharmacies that remain open during After Hours and directly communicate with the medical providers about patient care and prescriptions. The embedded medical clinic offers new patient and return appointments, with many TGNC people initiating care at After Hours and then scheduling return appointments with their provider during standard clinic hours. However, if patients find it easier to access care only at After Hours, they can obtain primary and HIV care solely in this way.

**Program staff responsibilities at After Hours include:**

- 1 staff member helps After Hours participants fill out basic registration paperwork as they enter the lobby and assists the PSRs as they register patients for medical care or insurance enrollment counseling. This person acts as a greeter, explaining available services and ensuring participants understand that After Hours serves TGNC people only.

- 1 staff member coordinates the clothing and hygiene supplies.

- 1 staff member coordinates dinner and participants’ interaction over food.

- 1 staff member and 1-2 volunteers coordinate SHINE, the trans specific needle exchange program.

- 1 staff member acts as a runner between the front desk, TGNC only programming space and the medical clinic. This person gets patients from programming space if they are running late for their medical appointment, and coordinates late requests for medical appointments, gender marker letters, or prescription refills. This allows participants to enjoy programming and other activities while waiting for their medical or insurance enrollment appointments rather than spending hours in the waiting room. This person also coordinates volunteers, presenters and programming.

- 1 staff member oversees the clinic schedule and appointment flow in the medical clinic and communicates with the pharmacy to resolve any prescription issues.

After Hours Drop-In programming examples include: game night, a panel of TWOC discussing their experience in prison and how they survived, a local TGNC artist discussing her work that was displayed at the agency, a group vocal coaching experience, Trans Day of Remembrance observation, self-defense presentation, Know Your Rights/records expungement presentation, RAD Remedy on-line service reviews, PEP and PrEP presentations, presentation on how to navigate police violence, discussion of being trans and in your 20’s, panel of TWOC staff working in the TGNC community discussing how they got their position and what it’s like to do that work, planning meetings to approach the Chicago-based Mexican Consulate and request improved support for gender marker change on national identification documents, Strong Professional TWOC panel, and an open mike night that welcomed TGNC people's vocal and musical performances.
Youth Support Group (TYRA)

TYRA is a weekly, 2-hour evening drop-in support group for TGNC youth, 14-24. This group is held at the Broadway Youth Center (BYC), Howard Brown’s designated youth program. The group is led by 2-3 staff members with attendance ranging from 2-15 youth. The group is embedded in the BYC and is offered at a time that allows participants to utilize other BYC services for wrap-around support. Group members can access medical, behavioral health and resource advocacy support before, during and after group programming (similar to After Hours). Staff create innovative programming and facilitate supportive discussion over dinner. While staff create an outline for each evening’s programming, they are flexible and allow room for change and improvisation as the needs of the youth each evening become clear. Staff regularly ask youth about programming that they need, want and value to create a group that celebrates, supports and educates the participants. Resources are provided to participants, including transit cards, information about accessing care at Howard Brown, and housing referrals. Programming has included guided discussion about job searching and resume creation, PEP and PrEP, hormone prescription, passability and safety, what is your ideal relationship, how to maintain love and happiness with a partner, disclosure to potential partners, how passability influences relationships with other TWOC, and bullying. In addition, the group viewed a movie call Mal Mala about transgender women in Puerto Rico who marched on the capital to demand their civil rights and impacted change and participated in a community gathering and memorial for a TWOC youth who passed.

Adult Support Group (T-Time)

T-Time is a biweekly, 2-hour evening drop in support group for TGNC adults, 25 and above. The group is led by 2-3 staff members with attendance ranging from 6-20 people. Staff create innovative programming and facilitate supportive discussion over dinner. As with TYRA, staff prepare programming for each group but adapt and improvise as the needs of the participants each evening become clear.

Programming has included guided discussion of current events, makeovers and beauty education, hormone prescription and accessing surgery, remembrance of TWOC who have passed, the impact of being visible, dating and relationships, myths of transition, self-appreciation and self-love, and the creation of a collage representing the person you envisioned yourself to be pre-transition and discussion about whether who you aspire to be has changed.

TGNC Specific Outreach

Two to three outreach staff plan and implement weekly outreach activities. Activities include 1) participation in community social events (Black Pride March, Trans Day of Remembrance, summer picnics, holiday parties), 2) attending community social events held by other organizations (bars, balls, award and celebration events, drop ins, gay family events), 3) visiting hang out locations or spaces TWOC congregate for work or community, and 4) individual and small group communication via Facebook, email and
phone. Outreach activities occur during regular business hours and from 8 p.m. until 2 a.m. Through all activities, staff discuss services offered at Howard Brown, invite participants to access services or attend programming at Howard Brown, and offer referrals to other resources should they match participant needs.

**In-House Initiatives**

Staff were involved in a range of in-house educational activities and initiatives to 1) have the agency make TGNC cultural competence and improved service provision for TGNC people a publicly articulated priority, 2) assist patient-facing (i.e., medical, linkage to care, front desk) and staff-facing departments (i.e., finance, HR, communications) improve their ability to respectfully communicate with and serve TGNC people, 3) support all staff members to develop TGNC cultural competence and respectful communication skills, 4) create systems that hold staff accountable for the consistent development and implementation of TGNC culturally competent and respectful communication with TGNC people for themselves and their supervisees, and 5) provide agency resources for TGNC affirmative care and staff development of TGNC cultural competence. Across the years of the project, these initiatives evolved in intensity and comprehensiveness. Examples of some initiatives include:

- The creation and implementation of a 2-hour Gender Appropriate Language training required of all staff at the agency
- The addition of a required competency area on which all agency staff are evaluated on the annual evaluation that includes consistent TGNC affirmative communication as a requirement to meet job expectations
- Development of pronoun buttons (5 options) worn by staff and provided to patients to facilitate respectful pronoun use
- Introductions at agency meetings/events include staff members’ name and gender pronouns
- Updates on transgender health initiatives provided at quarterly All Staff meetings
- The CEO and COO publically identifying TGNC health as an agency priority at All Staff meetings
- External advocacy efforts led by the agency to improve Medicaid coverage of hormones and surgery
- Internal advocacy efforts to improve the coverage of staff PPO/HMO insurance to cover hormones and surgery
- Creation of a TGNC specific patient satisfaction form with promotional materials in all clinics and buildings
- Creation of a TGNC Patient’s Rights document displayed in all clinic spaces with a TGNC specific process for gathering feedback on the care received at the agency
- Creation of a Visionary Task Force made up of staff from different clinic locations and positions to assist the executive leadership team in visioning the future of TGNC health at Howard Brown
- Incorporation of TGNC specific goals and initiatives in agency strategic plan
TGNC Specific Needle Exchange

SHINE is a needle exchange program developed by and for TGNC people with a special focus on providing supplies for injectable hormone use. It is offered at each After Hours from 6-8:30pm in TGNC specific space and coordinated by one staff member and 2 volunteers. A safer injection presentation is offered at each After Hours and syringe/needle options are coordinated with medical providers so participants can obtain their prescribed sharps for free through SHINE. SHINE was not funded through SPNS programming but was developed to be a complimentary service offered during After Hours.

PROGRAM PLANNING AND DEVELOPMENT

In reflecting on process and experience, these are the recommended steps to prepare to launch the program described above.

STEP 1: Obtain and continue to build administrative and leadership buy-in. Leadership buy-in was critical to the success of our program. Developing active involvement of agency leaders and administrative heads and their clear articulation of the priority of the program’s services paved the way for larger agency cooperation and investment. Find and/or build champions in each department.

STEP 2: Hire TGNC and TWOC identified staff who are well respected in and well connected to the TGNC community. This is critical in establishing trust with the TGNC and TWOC communities and engaging potential participants in programming. Hiring TGNC and TWOC identified staff and assessing their reputation in and connection with the community may be difficult if there are not already a number of TGNC staff at your agency who can facilitate applications, and vouch for the safety of the professional environment and the genuine intention of the agency to provide affirmative care to TGNC people. Create a staff with a blend of gender identities so potential participants will find a person or gender presentation that will facilitate connection.

Hiring TGNC staff may take longer than filling similar positions in other programs. Staff that possess the relationship and community cultivation skills needed may not have traditional office skills and may need intentional mentoring by managers to develop those skills and help TGNC staff to thrive. In addition, job descriptions and required credentials should be adapted to remove unnecessary requirements (i.e., requiring a college degree, barring staff with criminal records) to reduce barriers and increase access for excellent staff hires with less traditional backgrounds.

STEP 3: Assess the readiness of the agency or organization to respectfully welcome and provide care to a larger number of TGNC people. Gather feedback from TGNC staff, cisgender staff/allies, and TGNC community members. Explore what you need to improve and/or what initiatives you need to undertake to authentically say that you offer TGNC affirmative programming and care. Most systems, even systems that consider themselves affirmative, have a fair amount of agency evolution and growth that must occur before outreach staff will be able to authentically represent your services as truly affirmative in the TGNC community.
STEP 4:  Train providers and patient-facing staff in TGNC affirmative care and respectful communication. Train programming staff in drop in models, de-escalation techniques, and support group facilitation. In addition, proactively plan to provide TGNC staff with professional development that expands their skills and knowledge beyond the immediate project and prepare them to launch into other positions in the agency.

STEP 5:  From the beginning, position the After Hours Drop In as a standard expansion in the clinic schedule, not as a special program for which comprehensive staffing is optional or a ‘favor’. Laying this foundation integrates the program into a system’s standard care structure and, while a higher level of TGNC competence may be required to be effective in the clinic, this holds departments accountable for consistently staffing the drop in with staff that have been prepared and are performing drop in duties within their standard work hours.

STEP 6:  Initially, develop a core group of staff members and providers to staff the After Hours Drop In. As you establish smooth work flow and develop basic community trust, rotate new staff into the drop in with mentorship and modeling from existing staff and providers to increase the number of people available to work the After Hours shifts. Provide staff with context and initial training before their first shift, initially helping them understand how this clinic shift differs from other shifts and then helping staff generalize skills they learn at After Hours to other clinic times and activities.

STEP 7:  Develop outreach strategies and lay groundwork for implementation.

IMPLEMENTATION AND EVOLUTION

Staff recommend a needs assessment and preparatory training as start-up steps from experience, not because Howard Brown began its program after completing these steps. Howard Brown launched its programming and discovered areas of need as it progressed. Because Howard Brown is an LGBTQ health center and provides care that is much more TGNC affirmative than most care systems in our area, many staff assumed a higher level of agency wide TGNC competence than existed. The agency made an inaccurate assumption that because we provided care that was more TGNC affirmative than other places, the care we provided was already excellent and as TGNC affirmative as it needed to be. Staff leading support groups and conducting outreach were told by a range of community members and current/past patients about Howard Brown’s errors and missteps and were challenged to improve the systems of care. TGNC program staff struggled to defend the agency in their attempts to engage community members and potential participants without knowing if the consistency of TGNC affirmative services would improve. TGNC staff reported similar struggles with their own care and with internal agency systems that failed to treat them with consistent respect. Through reflection, deep discussion and a series of meetings, the program team met with agency leadership to clarify the areas of need, articulate the high cost of maintaining the status quo, and identify the opportunity of improving the care offered to TGNC people. Agency leadership committed to improving the consistency of TGNC affirmative care in all aspects of Howard Brown, including all patient-facing and staff-facing segments of the organization. These meetings launched many of the in-house initiatives described above and, across 2-3 years, had a significant rippling impact across the agency.
Across time, staff developed work flow improvements in the After Hours Drop In clinic. After 6 months, the agency added a phlebotomist during After Hours since many patients were starting hormones and the need for bloodwork was more concentrated than in a usual clinic shift. After 18 months, to avoid delays in accessing prescriptions and to enhance the experience of starting hormones, Howard Brown began administering a patient’s first hormone injection free of charge, using this as an opportunity for safer injection teaching. This process reduced the delay that occurred when a patient left the clinic to fill their prescription and then returned for injection teaching/first dose. Patients could obtain their first injection in an intimate injection teaching moment with friends and family and then shift into TGNC only programming space for special congratulations and support if they chose. Patients told staff this process dramatically improved their experience and the support they felt in their care. Howard Brown distributed hormone consents at the front desk at check-in and had sets of consents available in clinic for providers. Having a behavioral health consultant during the After Hours clinic was an important enhancement given the high levels of depression, anxiety and suicidal ideation seen in at-risk TGNC and TWOC patients. Having TGNC affirmative HIV/STI testing and counseling was a critical support at each After Hours as well.

As work flow improved and as staff were more prepared to offer TGNC affirmative services, staff and providers at Howard Brown started to identify After Hours Drop In as one of their favorite shifts. At present, eight medical and behavioral health rotate through After Hours with a team of nurses, medical assistants, front desk staff, insurance counselors, case managers, HIV/STI test counselors and front desk staff. New staff and other community providers that Howard Brown is training will shadow in the clinic to learn about TGNC affirmative care as well.

As community trust grew in Howard Brown and as participants began identifying the After Hours Drop In as providing the highest standard of TGNC affirmative care, conflicts occurred quickly if a new staff member was struggling with respectful communication or care. For the first 3 years, program staff met with every new staff member working After Hours, coaching on respectful communication and basics of TGNC affirmative care. As in-house agency initiatives increased and as all departments were given tools for greater accountability, departments began preparing and mentoring the staff they assigned to After Hours Drop In and beginning TGNC competency increased.

In 2010, Howard Brown launched its 3-step informed consent hormone protocol. After gathering data on the protocol for 5 years, the agency revised the protocol to further reduce barriers and enabled hormone prescription in 1-2 steps. The revised protocol was developed by a multidisciplinary team and piloted in the After Hours Drop In before being rolled out to the entire agency in 2015.

The approach to outreach evolved across time. Staff tried different models of staffing and discovered that an outreach team that included someone that was trans masculine and someone that was trans feminine was most effective in reaching TWOC. In addition, having someone on the team who was Spanish speaking expanded agency ability to engage and retain Latinx participants. Across time, the focus of our outreach deepened, having the team place less emphasis on traditional social venues (bars, balls, events, dating websites) and more emphasis engaging networks that were deeply embedded in the TGNC
and TWOC community. Rather than interrupting potential participants as they enjoyed social events or activities, the team identified settings and events that offered more intimate time to talk (social media, social networks, going into gay families) and gave them opportunities to introduce resources as a peer rather than as a representative of our larger agency.

The program experienced a lot of staff turnover. Most staff who left the program shifted to jobs in other departments at Howard Brown (billing, development, linkage to care, front desk), launched into other higher paying jobs in research, or went to graduate school. While the program would lose some momentum after each departure, remaining staff quickly rebuilt relationships and links and retained ties with the community. The team continually tried to connect potential participants with the program and not a specific staff member, bridging relationship to other staff they knew through the support groups and at After Hours to retain relationship.

**INTERVENTION OUTCOMES**

In the five years since the intervention began (2012-2016), the number of TGNC patients served in primary care at Howard Brown increased 325%, from 953 patients, 96 of whom were HIV positive (2012), to 3091 patients, 236 of whom were HIV positive (2016).

<table>
<thead>
<tr>
<th>Year</th>
<th>TGNC Patients</th>
<th>TGNC Patients Receiving Hormones</th>
<th>TGNC HIV+ Patients</th>
<th>TGNC HIV+ Patients Receiving Hormones</th>
</tr>
</thead>
<tbody>
<tr>
<td>2009</td>
<td>467</td>
<td>135 (29%)</td>
<td>65 (14%)</td>
<td>10 (15%)</td>
</tr>
<tr>
<td>2010</td>
<td>557</td>
<td>201 (36%)</td>
<td>74 (13%)</td>
<td>16 (22%)</td>
</tr>
<tr>
<td>2011</td>
<td>695</td>
<td>292 (42%)</td>
<td>85 (12%)</td>
<td>27 (32%)</td>
</tr>
<tr>
<td>2012</td>
<td>953</td>
<td>517 (54%)</td>
<td>96 (10%)</td>
<td>47 (49%)</td>
</tr>
<tr>
<td>2013</td>
<td>1332</td>
<td>1019 (77%)</td>
<td>129 (10%)</td>
<td>79 (82%)</td>
</tr>
<tr>
<td>2014</td>
<td>1797</td>
<td>1191 (66%)</td>
<td>180 (10%)</td>
<td>163 (90%)</td>
</tr>
<tr>
<td>2015</td>
<td>2311</td>
<td>1052 (46%)</td>
<td>198 (11.7%)</td>
<td>150 (76%)</td>
</tr>
<tr>
<td>2016</td>
<td>3091</td>
<td>1165 (38%)</td>
<td>236 (13%)</td>
<td>176 (75%)</td>
</tr>
</tbody>
</table>

In those same five years, the number of TWOC served in primary care increased 272%, from 156 patients, 105 of whom were HIV positive (2012), to 425, 147 of whom were HIV positive (2016). While the number of TWOC and TWOC living with HIV patients increased every year since 2010, the positivity rate reduced
every year (45% to 35%) and the percentage of TWOC living with HIV who received hormones increased every year (58% to 84%) even with the Delestrogen hormone shortage in 2016.

<table>
<thead>
<tr>
<th>Year</th>
<th>TGNC Patients</th>
<th>TGNC Patients Receiving Hormones</th>
<th>TGNC HIV+ Patients</th>
<th>TGNC HIV+ Patients Receiving Hormones</th>
</tr>
</thead>
<tbody>
<tr>
<td>2010</td>
<td>112</td>
<td>71 (63%)</td>
<td>50 (45%)</td>
<td>29 (58%)</td>
</tr>
<tr>
<td>2011</td>
<td>143</td>
<td>82 (57%)</td>
<td>61 (43%)</td>
<td>39 (64%)</td>
</tr>
<tr>
<td>2012</td>
<td>156</td>
<td>105 (67%)</td>
<td>62 (40%)</td>
<td>45 (73%)</td>
</tr>
<tr>
<td>2013</td>
<td>225</td>
<td>135 (60%)</td>
<td>86 (38%)</td>
<td>63 (73%)</td>
</tr>
<tr>
<td>2014</td>
<td>297</td>
<td>181 (61%)</td>
<td>111 (38%)</td>
<td>81 (73%)</td>
</tr>
<tr>
<td>2015</td>
<td>352</td>
<td>243 (69%)</td>
<td>132 (38%)</td>
<td>105 (80%)</td>
</tr>
<tr>
<td>2016</td>
<td>425</td>
<td>283 (67%)</td>
<td>147 (35%)</td>
<td>123 (84%)</td>
</tr>
</tbody>
</table>

In 2014, there were 121 After Hours ‘visits’, with 400 visits in 2015 and 454 visits in 2016. In 2016, 65% of the visits were by participants aged 25-54, 28% by participants aged 18-24, 6% aged 55 or above and 1% aged 17 and below. In 2014, 14 unduplicated TWOC attended After Hours, with 45 unduplicated TWOC attending in 2015 and 36 in 2016. Participation in TRYA, T-Time and After Hours specific programming and medical care alone does not explain the increase in TWOC and TGNC medical patients at Howard Brown. Instead, the implementation of After Hours in combination with the in-house initiatives created a repeating cycle of deepening community trust and continually improving affirmative care. The agency as a whole evolved the quality of care it provided and TGNC people engaged in care through every care access point available.

LESSONS LEARNED

Throughout the project, the team kept a list of lessons learned. Lessons that were hard won in the early years of the project became second nature as our workflow, staffing and program structures evolved. Several lessons learned were integrated into program development and highlighted above. Listed below are the additional lessons the team would like to share.

**LESSON 1: Your front line TGNC staff are the face of your organization in the TGNC community.**

They are absolutely critical to community building and to your successful engagement of participants. Engagement is primarily word of mouth and shared through social contact. TGNC staff are putting their reputations on the line whenever they vouch for the services your organization offers or the trustworthiness of your staff or systems. Your organization needs to work very hard to earn TGNC staff and community trust and to provide care of which your TGNC staff will be proud.
LESSON 2: Creating silo-ed TGNC expertise can result in deflection of shared responsibility for TGNC affirmative care. For the first 18 months, our program had two TGNC/TWOC patient navigators. The patient navigators were overwhelmed by the extremely high demand for their services (each worked with 500-700 people). Not only was there a high community need, but we discovered that internal systems and staff were deferring the needs of TGNC people to the patient navigators rather than providing affirmative care themselves or developing the skill or knowledge they needed to provide that care. We discontinued the patient navigation structure and instead focused on building internal systems to prepare each department and staff member to develop fundamental knowledge and skills in respectful communication and TGNC affirmative care. As confidence and internal accountability increased, staff skills and patient satisfaction increased.

LESSON 3: Emotional labor is a huge cost when working with TWOC and TGNC communities. Being a TGNC person and working with the TGNC community takes a significant toll on staff. Staff work to create strong, trusting relationships with community members to engage them in programming and in care. Those relationships are not restricted to working hours and open the staff member up for contact at all times, with requests for support and resources that the staff member may or may not be able to access. The intensity of emotional labor for this staff group was higher than any other staff group at the agency. Job responsibilities would sometimes need to be reorganized to support staff in managing the constant need for support by participants and staff regularly had discussions about how and when to assert personal boundaries with participants. The emotional labor of our team was also intensified by the organizational evolution we helped to lead.

LESSON 4: Telling staff why the community needs TGNC affirmative care and offering staff concrete things to say or do to communicate respectfully can make a huge difference. New staff want to provide affirmative care but they are often frightened or overwhelmed about how to do so. Midway through an After Hours Drop In, we gave some staff a handout with simple guidance on how to respectfully communicate with TWOC and TGNC people about pronouns. Staff immediately shifted their behavior and became more effective in the clinic.

LESSON 5: Create systems to intentionally focus on the at risk groups in larger populations. Our approach to engaging and retaining TWOC in HIV care focused on building agency wide competence on providing care to the TGNC community. We found it very useful to remind ourselves about the critical need to ensure that services, outreach and programming specifically reached TWOC.

LESSON 6: Many TWOC receive care at multiple health centers, moving between them to obtain the most accessible care or new resources, struggling to maintain care, or shifting in the search for more affirmative, empowering care. It can be very difficult to get a whole picture of care and frequently systems have incomplete medical data to best understand progress and sustained engagement.

LESSON 7: Conflicts and cultural competence within the TGNC community had to be regularly navigated in programming, planning, and community outreach. As TGNC people became more comfortable receiving care at Howard Brown, the racial, age, gender presentation, gender identity, and
transition experience of people receiving care in shared spaces dramatically increased. This sometimes created tension, conflict and misunderstandings between TGNC community members. For example, some participant groups with a binary gender identity would mis-gender non-binary participants or devalue their experience/identity. There was sometimes conflict between youth and older adults, Black and Latinx women, and White and people of Color groups. Staff needed to create safe space amongst participants as well as between participants and staff. We instituted safe space rules, modeled affirmative behavior and had ongoing discussions with participants and small groups to broaden awareness, understanding and support of others’ experience and identity.

LESSON 8: As agency competence improved and as staff and participants held Howard Brown to a higher level of accountability, the systemic lack of competence demonstrated by outside entities became more obvious and concerning. Specialists, referral sources and interpreters struggled to provide respectful, affirmative care to our TGNC participants. TGNC participants and staff, in turn, called upon Howard Brown to take a greater role in helping to evolve and inform the TGNC competence in these outside systems.

LESSON 9: Participants told us that TGNC-only programming space was of profound benefit. Some participants had never been in a TGNC devoted space and experienced a meaningful connection to community and a sense of relief. Cisgender staff and volunteers had to adapt to being restricted from entering some TGNC-only areas, and to the inability to participate in, contribute to or share in some TGNC-specific programming.
THE ALEXIS PROJECT
ENHANCING LINKAGES TO AND RETENTION IN HIV PRIMARY CARE FOR TRANSGENDER WOMEN OF COLOR: THE ALEXIS PROJECT

Cathy J. Reback, Ph.D.¹ ², Kimberly Kisler, MPH, Ph.D.¹ and Jesse B. Fletcher, Ph.D.¹

¹Friends Research Institute, Inc., Los Angeles, CA 90028
²David Geffen School of Medicine, Semel Institute of Neuroscience and Human Behavior,
University of California, Los Angeles, 90095

Corresponding Author:
Cathy J. Reback, Ph.D.
1419 N. La Brea Ave.
Los Angeles, CA 90028
ph: (323) 463-1601
fax: (323) 463-0126
reback@friendsresearch.org
In Los Angeles County (LAC), the HIV seroprevalence rate among trans women is estimated to be 21%,¹ a rate comparable to that among trans women across the United States and other high-income countries,² and 40% greater than that observed nationally among men who have sex with men.³ In LAC, trans women of color have the highest estimated seroprevalence rates; African Americans/Blacks, Latinas/Hispanics, Asians/Pacific Islanders, and Native Americans comprise 90% of transgender individuals living with AIDS.⁴ Despite comprising only a tiny fraction of the total population in LAC, transgender individuals are estimated to make up nearly 5% of all HIV-infected individuals not linked into HIV care in the County.⁵ The LAC HIV Prevention Plan identified the following co-factors that contribute to trans women's high risk for HIV infection: substance use, incarceration, sex work, mental health issues, unemployment, STIs, poverty, stigma and discrimination, transphobia, racism, immigration status, language, educational attainment, violence and sexual assault, and homelessness.⁶

---


PROGRAM DESCRIPTION

THE ORGANIZATIONAL CONTEXT

LAC is an urban, metropolitan city, is both geographically large and populous, and covers over 4,700 square miles with over 10 million residents. It is estimated that 14,428 trans individuals live in LAC with a range of 7,214 to 21,642 dependent upon the definition of “transgender.” The estimated ratio of trans feminine and trans masculine individuals is 1:1.

Friends Research Institute, Inc. (FRI) is a 501(c)(3), private, non-profit corporation established in 1955. Friends Community Center, a division of Friends Research Institute, is the community research center, located on the border of Hollywood and West Hollywood in LAC, where The Alexis Project was implemented. LAC is divided into eight Service Planning Areas (SPA); SPA 4, which includes the Friends Community Center site, has an annual rate of 24 per 100,000 population of persons diagnosed with AIDS, which translates to 38% of total new AIDS cases annually — the highest rate across all SPAs. Additionally, Friends Community Center is located in the 90028 “hot spot” zip code, an area of current and emerging HIV prevalence.

THE INTERVENTION

Theoretical Foundations

The Alexis Project incorporated three proven models, Social Network Recruitment and Engagement (network), Peer Health Navigation (individual), and Contingency Management (structural), into one multi-leveled project to optimize HIV health outcomes for trans women of color (see Figure 1). The two behavioral interventions, Peer Health Navigation (PHN) and Contingency Management (CM) were utilized, in concert, to ensure success in treating and retaining trans women of color in HIV care to improve their health outcomes.

Social Network Recruitment and Engagement: Social networking methodology is theoretically based in Respondent Driven Sampling (RDS), which provides coupons that incentivize participants from “hidden populations” to recruit peers into the study. RDS is maximally preferable when the population in question is not only hidden, but relatively closed (i.e., social networks tend to exclusively contain members from the same group), as transgender communities tend to be.7 Closed network status is especially salient among trans women, as viral loads are commonly high.8

---


**Peer Health Navigation:** The PHN intervention in The Alexis Project was based on the mechanisms of Social Cognitive Theory, a theory which posits interactive causal relationships among personal determinants, behavior, and environmental influences,\(^9,10\) and is designed to create improvement in participant self-efficacy. Low self-efficacy is associated with increased HIV risk in sexual minority populations\(^11\) and sub-optimal HIV healthcare outcomes in trans women.\(^12\) The PHN sessions helped to (1) identify the barriers to HIV care for each particular participant, (2) identify and link participants into other auxiliary needed services, and (3) increase participants’ self-efficacy in working with HIV care providers and other social service and treatment facilities. Peer Health Navigators did not provide counseling or psychotherapy; rather, they worked with participants to successfully navigate complicated health care and social service systems.

**Contingency Management:** CM is guided by the theoretical framework of behavioral economics, which is the application of contingencies to motivate individuals toward health-promoting behavior change. A behavioral economics intervention has particular promise when adapted for low/no income, marginalized and disenfranchised populations.\(^13\) The primary element of behavioral economics captured in CM is providing a direct and immediate reinforcement for health behaviors. The principle of conditionality, i.e., making the reward contingent upon the operant behavior change, distinguishes CM from just providing a traditional incentive.\(^14\)

**Key Components of the Intervention**

**Peer Health Navigation:** As part of the PHN component of the intervention, a Peer Health Navigator met with each participant to develop a client-centered treatment plan and directly link the participant to HIV primary health care and/or other needed physical, mental health, and/or psychosocial services (e.g., hormone therapy, dental care, hepatitis testing/care, TB testing/care, mental health counseling and/or psychotropic medication, substance abuse treatment, needle exchange, legal services, job training/development, transportation assistance). PHN is a tool that combines the individualized and well-rounded approach of individual case management with the specific goal of removing barriers that can impede access to and retention in HIV care. PHN, based on a client-centered philosophy, works to reduce obstacles that inhibit a

---


participant in obtaining health-promoting behaviors, focusing particularly on the multiple and complex co-
factors that often make it difficult for trans women of color to be linked and retained in HIV care.

During each session, Peer Health Navigators completed the Needs and Barriers Assessment (NBA) tool with
each participant; after each session, supplemental progress notes were written to capture the nature of the
session and further detail about experiences reported by the participant. At the first session, Peer Health
Navigators conducted an assessment of participants’ health care history (including past HIV care), unmet
service needs and barriers to health care, and the Peer Health Navigator answered any questions a participant
had about peer health navigation. Peer Health Navigators reminded each participant of her upcoming
appointment and, if necessary, transported and accompanied her to each scheduled appointment.

Participants were encouraged to have ongoing contact with their Peer Health Navigator (i.e., approximately
two to three times per week during the first weeks of the relationship). In most cases, the frequency
of contacts titrated down after the first quarter of care. Once the Peer Health Navigator-participant
relationship was well-established with a consistently maintained treatment plan as well as the removal of
barriers to auxiliary services, Peer Health Navigators then worked with participants to become more self-
sufficient, building self-efficacy for sustained healthy behavior change. However, participants were able
to contact their Peer Health Navigator at any time for information, guidance, and/or support or if another
service was required that was not part of the original client-centered treatment plan.

**Contingency Management:** CM served to increase health outcomes by specifically targeting HIV primary
care appointments and HIV milestones for positive reinforcement. Increasingly valuable reinforcers were
connected with HIV care visits and reaching and sustaining HIV milestones (see Figure 2). The escalating
reinforcement schedule of the CM intervention was structured to serve as a motivator for HIV care-seeking
behavior, such that HIV milestones were expected to be achieved with regard to retention in regular HIV
care visits, treatment, and medication adherence. Assuming an appropriate regimen (i.e., potent and to
which the virus was susceptible) was chosen by the treating provider, the trajectory of HIV RNA decline
should be clear and continuous. The Department of Health and Human Services (DHHS) guidelines note
that virologic “failure” should be defined by HIV RNA >200 copies/mL measured twice after 24 weeks (6
months) on therapy, and once “undetectable” (below the limits of assay detection, variably 20-75 copies/
ML), should remain undetectable. Interim milestones were chosen on the basis of ART-naive treatment trial
aggregate data and guidance from DAIDS-funded AIDS Clinical Trials Group protocols, based on sensitivity
analyses of a number of possible milestone definitions.\(^\text{15}\)

Providing incentives to reinforce both clinic attendance and HIV milestones in the care and treatment of
HIV, and using objective biomarkers was found to be highly effective at accomplishing goals of linkage and
maintenance in longitudinal care with on-treatment and successful virologic suppression. Participants who

achieved all of the targeted HIV health-promoting behaviors accumulated $500 in CM reward points. CM rewards were redeemable for goods or services that promoted a healthy, prosocial lifestyle (e.g., gift cards to grocery stores and department stores, a bus ticket to travel home for the holidays, shoes, umbrellas, wigs and cosmetics, payment of a phone bill and utility bill, DMV for legal documents). No cash was provided.

**Intervention Logic Model**

See Figure 1.

**Core Intervention Staff**

The Alexis Project core intervention staff included the Principal Investigator (PI), a part-time Project Director, two full-time Peer Health Navigators, a part-time Process Evaluator, a part-time Data Manager, and a part-time Medical Consultant (a MD who specialized in HIV care). The PI met with the full team on a monthly basis and met with the Project Director on a weekly basis. The PI was available for consultation throughout the project as issues arose, and provided direct supervision of the Project Director and the Data Manager. The Project Director assisted with development of most intervention materials, including assessment tools and databases, assisted in training all project-related staff, drafted all progress reports, communicated with partnering agencies and clinics, supervised all project-related staff, and oversaw the project’s day-to-day operations. The Project Director provided direct supervision to the Peer Health Navigators and the Evaluator. The Peer Health Navigators worked individually with each participant on-site as well as transported and accompanied participants to project-related appointments in the field. The Peer Health Navigators also collected project-related data through the initial extensive needs assessment and ongoing abbreviated needs assessments, kept progress notes on each participant interaction, maintained locator forms, and performed outreach to recruit new participants as well as locate existing participants to aid in retention. The Evaluator assisted in building systems to collect and track project-related process data, conducted weekly quality assurance reviews on all paper and electronic participant files, generated weekly and monthly reports on project progress, and managed all process data. The Data Manager built the databases, ensured quality control of data management, developed statistical routines for analyzing the data, and performed all data analyses. The Medical Consultant provided annual trainings to update all project staff on any changes to HIV medical care guidelines or protocols, as well as provided a refresher course on how to read labs. The Medical Consultant was also available via phone or email to answer questions related to lab work or HIV treatment options.

**Intervention Components including Outreach, Recruitment, and Retention Strategies**

Several outreach and recruitment strategies were utilized including: (1) a community-wide social network recruitment and engagement methodology (i.e., Respondent Driven Sampling; see above); (2) venue- and
street-based outreach whereby the Peer Health Navigators conducted outreach in places such as food lines, bars, street corners, and other locations where trans women tend to congregate; (3) dissemination of project flyers, including a postcard-sized flyer and a business card-sized flyer that folded over to fit into a person’s wallet or pocket; (4) in-reach was conducted through other programs at Friends Community Center (see Illustration 1); (5) in-services were conducted at local agencies that provide services to trans women; and, (6) community partners, including the two HIV medical care clinics, referred potential participants to the project.

Retention was ensured through the design of the intervention. Peer Health Navigators provided participants with 18 months of unlimited PHN sessions to address any barrier(s) that impeded their ability to be linked and retained in care. By working with participants on tasks such as helping secure housing, gain access to substance abuse treatment facilities, find gender affirming clothes and hygiene products, access food, and a number of other barriers impacting their quality of life, participants wanted to remain in the intervention because their basic and most critical needs were being met.

Additionally, retention was boosted through the rapport built between the participants and Peer Health Navigators. Peer Health Navigators were true peers, trans women of color living with HIV, which allowed the participants to feel safe in having frank, honest discussions about barriers to linkage and retention in care, as well as issues related to medication adherence.

**Description of the Community Partners**

Friends Community Center has numerous community partners that offer additional services to trans women of color including access to HIV medical care, free or low-cost hormone therapy, legal services, residential substance abuse treatment, mental health screening and treatment, primary medical care, housing, and transportation. Friends Community Center staff use their knowledge of the community partners to match the participant with services to meet her needs. In order to remain knowledgeable about culturally appropriate agencies and services, and to maintain personal relationships with our community partners, Friends Community Center staff made site visits to agencies, in pairs of two, on an ongoing basis throughout the implementation of The Alexis Project.

As Friends Community Center is a non-clinical site, formal partnerships with two medical clinics that provide HIV primary care was essential to the success of The Alexis Project. Memoranda of Understandings were established with each clinic. Although the clinics required various documents in order to enroll a participant into HIV medical care, many of the participants did not have this required documentation (i.e., government-issued ID). Therefore, the Peer Health Navigators worked in conjunction with the clinics to ensure participants obtained the required documentation to enroll in medical care as well as assisted the clinics in reminding participants of upcoming medical appointments,
transported participants to appointments, assisted participants with picking up medications, and even accompanied participants to medical appointments to enhance health literacy and assist the participant in understanding how to be an advocate for her health.

**Core Intervention Staffing Requirements**

**Principal Investigator (PI):** The PI was responsible for the overall management of the project; project implementation; participant safety; oversaw all program management tasks; assisted with staff hiring and training; attended Community Advisory Board (CAB) meetings; worked with the Project Director, evaluation team, and CAB in the development of the PHN manual; worked with the evaluation team, project staff, and CAB in the interpretation of findings; worked with the evaluation team in preparation of conference presentations and manuscript development.

**Project Director:** The Project Director was responsible for the day-to-day operations of the project; assisted with staff hiring and training; supervised and coordinated all project activities; oversaw program monitoring activities including program performance indicators; reviewed participant files for quality assurance; conducted in-service trainings at local CBOs and networked with community gatekeepers to enhance community awareness of The Alexis Project; substituted for absent Peer Health Navigators; maintained all program and intervention supplies; worked with the CAB and project staff on the development and implementation of project materials; facilitated CAB meetings; worked with the PI, evaluation team, and CAB in the development of the PHN manual.

**Peer Health Navigators:** The Peer Health Navigators provided peer health navigation to trans women of color living with HIV through multiple and ongoing sessions; linked all participants to HIV care; linked participants to up-to-date and culturally appropriate ancillary services and provided transportation, as needed; maintained fidelity to the intervention protocols; administered assessments to participants; maintained accurate and complete participant files; maintained accurate written reports, logged all program activities, and wrote daily and monthly staff reports; maintained an accurate and complete up-to-date, culturally appropriate referral list; and, attended CAB meetings.

**Process Evaluator:** The Process Evaluator oversaw all aspects of the program evaluation including operationalizing process and outcomes indices analysis design and revision; worked with the PI, the Project Director, and CAB in the development of the PHN manual; attended CAB meetings; worked with the PI, Project Director, Data Manager, project staff, and CAB in the interpretation of findings; worked with the PI and Data Manager in preparation of conference presentations and manuscript development.

**Data Manager:** The Data Manager supervised data management staff and activities; worked with the PI, the Project Director, and CAB in the development of the PHN manual; worked with the PI, Project Director, Process Evaluator, project staff, and CAB in the interpretation of findings; worked with the PI and Process Evaluator in preparation of conference presentations and manuscript development.
Medical Consultant: The medical consultant provided medical consultation; trained project staff on basic HIV medical case management including annual booster sessions; was available to read medical records provided by the collaborating medical providers; reviewed hormonal treatment profiles and ART choices, as needed; provided advice to project staff and other HIV providers on possible drug-drug interactions; consulted with project staff on participants’ treatment plans; and, answered questions and addressed concerns regarding participants’ treatment experiences and health outcomes.

PROGRAM PLANNING AND DEVELOPMENT

START-UP STEPS

Staff Hiring, Initial Training and Development, Developing MOUs and Partnerships, Developing Administrative and Provider Support and Buy-In, Developing Recruitment Strategies

The start-up for The Alexis Project included but was not limited to the identification of appropriate staff, considerable training for all levels of staff, the development of data collection processes and program materials, and establishing MOUs with partnering HIV clinics. It was vital that trans women of color living with HIV be an integral part of the staffing as the Peer Health Navigators, and have received ongoing training and support throughout the project. Upon hire, all staff received a six-to-eight-week multi-tier training consisting of: (1) in-house trainings by senior staff; (2) outside presentations and seminars provided by community professionals; and; (3) field observations and role plays with senior paraprofessionals and quality assurance through mock assessments.

The PI, Project Director, Process Evaluator, and Data Manager worked closely to develop all program materials and data collection processes including an in-house process evaluation spreadsheet for the Peer Health Navigators to record data on intervention exposure, viral load and medical visits, and CM payouts. Participant-Centered Treatment Plans and progress notes were also used by the Peer Health Navigators to record participant progress and the content of PHN sessions. All paper and electronic files were reviewed for Quality Assurance purposes on a weekly basis to ensure accuracy and completeness.

Provider buy-in was initiated by having the entire project team, from the PI to the Peer Health Navigators, visit each clinical site and hold an informational meeting with all clinic staff (from the front desk to the medical providers). These meetings took place right before project implementation and continued on a quarterly basis throughout the life of the project.

Friends Community Center has a long-standing trans-specific CAB that was utilized to guide project planning, design, implementation, and recruitment, to provide input for ongoing project improvement, and to address any barriers encountered during project delivery. The CAB was multicultural and composed of both trans
women living with HIV and high-risk negative trans women, current and past participants, community members including gatekeepers and stakeholders, local service providers, and members of local community planning and advocacy groups. CAB meetings were held on a biannual basis and all recruitment materials and project progress were reviewed at these meetings. CAB members provided ongoing feedback on the development of recruitment materials, implementation and process monitoring activities, client recruitment strategies and outreach, enrollment, and key project activities. Throughout the delivery of the project, the CAB monitored the cultural appropriateness of the project and modifications were made, as needed.

IMPLEMENTATION AND MAINTENANCE

Barriers and facilitators towards implementation

The greatest barrier to retention in The Alexis Project was the high rate of short- and/or long-term incarceration experienced by the participants. Although these participants were immediately provided with HIV care while incarcerated, upon release they needed to be linked to a HIV care provider to maintain medication adherence. Additionally, while incarcerated these participants often missed a follow-up evaluation time point. However, the Peer Health Navigators developed a strong rapport with the participants and, thus, most of the incarcerated participants returned to The Alexis Project site immediately, often within a day or two, upon release to reestablish their project participation.

Ongoing/refresher Training, Staff Development, and Retention Strategies

There was no turn-over of Peer Health Navigators throughout the implementation of The Alexis Project. This consistency was a testament to the commitment the staff felt toward the project, and the commitment Friends Community Center had toward maintaining high-quality staff. This consistency also ensured continued rapport with the participants, which enabled high retention in the project.

Continuing education and training was greatly valued and continued throughout the duration of the project. In addition to the mandatory human subjects and Good Clinical Practice/Good Research Practices trainings, all staff at Friends Community Center attended regular annual trainings on relevant topics. These onsite trainings included Outreach Strategies, The Foundation of Harm Reduction, Empowerment When Working with High-Risk Populations, Ethnography as Street-Based HIV Prevention, HIV Treatment 101, Substance Use and the Brain, Steps to De-Escalate Stressful Situations, The ABCs of Hepatitis, Bloodborne Pathogens, Treatments for Co-Occurring Substance Use and Mental Health Disorders, Marijuana and Synthetic Drugs, Medical Marijuana and HIV: What Clinicians Need to Know, Dealing with Difficult Clients/Red Flags, Effecting Change through the Use of Motivational Interviewing, Self-Care for Addiction Professionals, and Disaster and Safety Policy and Procedures Training. Offsite trainings included HIV/AIDS 101, STD 101, Tuberculosis, One-to-One: Individual Level Approaches to HIV Prevention, Synthetic Drugs, Outreach and Linkage to Care, Clearview COMPLETE Training, and the LAC LGBT Community Police Academy.
In addition to onsite and offsite trainings, staff attended national conferences such as the Transgender Leadership Summit in Oakland, the Transgender Health Conference sponsored by the UCSF Center of Excellence for Transgender Health, and local conferences such as the Trans* Health Summit hosted by the Los Angeles County Commission on HIV. Also, staff were encouraged to attend webinars on relevant issues (i.e., hosted by CDC, HRSA, local CBOs) and to attend monthly Transgender Service Providers Network meetings to maintain up-to-date changes in local transgender and HIV services. Finally, the Medical Consultant provided an initial training upon implementation on the basics of HIV treatment (i.e., medications, how HIV affects the body) and how to read HIV lab work such as CD4 and viral load. After the first year of implementation, the Medical Consultant provided annual refresher booster courses as well as offered one-on-one technical assistance to staff on an as-needed basis.

INTERVENTION OUTCOMES

REPORT ON CERTAIN OUTCOMES

From February 2014 through August 2016, 139 participants enrolled in The Alexis Project. Participants self-identified their race/ethnicity as African American/Black (n=57; 41.0%), Hispanic/Latina (n=44; 31.7%), multi/other (n=30; 21.6%), and Native American/American Indian (n=8; 5.8%). The age range was 19 through 59 years (median = 34.7), with a mean age of 36.2 (SD=9.7) years. Participants identified their sexual identity as heterosexual (52.4%), gay (25.8%), bisexual (6.5%), lesbian (3.2%), and pansexual/asexual/don’t know/other (12.1%). Just over one-third (38.7%) reported less than a high school education, one-third (32.9%) reported a high school diploma or a GED as their highest educational attainment, one-quarter (26.3%) reported some college-level education, and 2.2% reported a college degree (n = 137). More than one-third (38.9%) reported that they lived in their own house or apartment (either owned or rented), and just over one-quarter (26.6%) reported currently experiencing homelessness or living in a homeless shelter.

At baseline, 11 participants were unaware of their HIV positivity and, thus, the project’s new positivity rate was 7.9%. At baseline, 26% (33/128) of the participants had never been in HIV care and, among those who had previously been in HIV care, 41.9% (n=36/86) had dropped out. Furthermore, at baseline, 48.2% (n=67/139) of participants were in need of an ART medication prescription, and 51.1% (n=71/139) had an ART medication prescription but were medication non-adherent. Time from enrollment to linkage to HIV care ranged from 0 to 467 days (SD=103.2 days). At intervention completion, i.e., August 2017, 84.9% (n=118/139) of the participants were linked to care and 60/135 (44.4%) had achieved and/or maintained viral load suppression.

On average, participants attended 6.7 (SD=6.5) PHN sessions (range 1 to 31 sessions, median = 4 sessions), and 88.4% of the participants attended more than one PHN session. Participants earned a mean of $143.60 (SD=$139.63) in CM rewards (range $0 to $500.00, median = $90.00).
APPENDIX 1
The Annual Cost of Operating the Intervention

The annual cost for operating The Alexis Project, excluding staffing and office space was approximately $19,500. This included the cost for printing materials (approximately $1,000), office supplies (approximately $2,000), risk reduction supplies (approximately $1,500), and incentives for CM rewards (approximately $15,000). The maximum CM rewards was $500 for reaching all targeted HIV health-promoting goals. If a project enrolls approximately 50 participants annually, and approximately 60% achieve all HIV health-promoting goals the annual cost for CM rewards would be $500 x 50 x .60 = $15,000. For scalability purposes, a site might also require a graphic artist to design recruitment materials and advertising costs. Ongoing staffing would include a Project Director at 50% effort, and two Peer Health Navigators both at 100% effort. Additionally, each site and geographic location will have a different cost for operating supplies, CM rewards, incentives, salaries, fringe benefits, indirect costs, and rent.

LESSONS LEARNED

Although there were many challenges throughout the implementation of The Alexis Project, the project successes far outweighed the challenges. Through this process several “lessons learned” became evident.

Maintaining Boundaries

Peer Health Navigators required ongoing training, guidance, and support in understanding the personal and professional boundaries that were needed in order to work effectively. Given that the Peer Health Navigators were truly peers, they had experienced many of the same issues the participants were currently experiencing. Thus, the emotional weight of working with the participants and the frustration in not being able to solve every issue experienced by the participant was particularly trying for the staff. Very early in the project it became clear that the Peer Health Navigators would benefit from clinical supervision. A clinical psychologist was retained as a consultant to provide bi-weekly clinical case conferencing for the Peer Health Navigators. Having a clinician to discuss specific participant situations as well as the inherent difficulties of working with trans women of color living with HIV was extremely helpful for the Peer Health Navigators. Through trainings and clinical supervision, the Peer Health Navigators learned to set appropriate boundaries and how to be of assistance to the participants without taking on the weight of their worries.

Training Up the Medical Providers

The HIV clinics required a tremendous amount of assistance in providing culturally competent services to trans women of color. Even though both partnering HIV clinics had a long history of serving trans
patients, the HIV clinics still required a tremendous amount of feedback and staff meetings to ensure that each practitioner was providing the trans patients with the best possible culturally appropriate care. This process included: 1) creating posters with trans women of color living with HIV (see Illustrations 2 and 3) that were placed in clinic waiting rooms and assessment rooms as neither clinic had health promotion materials posted that specifically featured trans women; 2) arranging for a medical doctor who specializes in trans health care to provide grand rounds presentations to clinic providers on how to deliver trans-specific health care services (e.g., hormone therapy, sex-specific screenings and exams that do not match the participants’ gender expression); 3) providing “Trans 101” trainings to all clinic staff, from the front desk receptionist to the pharmacist to the lab technician to the medical provider; and, 4) assisting the administration in creating or updating trans-affirming policies and procedures such as creating new categories for gender identity on all medical paperwork and in the Electronic Medical Records, and moving from an outdated protocol for the initiation of hormone therapy to an informed consent model.

**Adopting a Client-Centered Approach**

Recruitment and retention strategies required the Peer Health Navigators to use a client-centered approach and “meet the participant where she is at.” This often translated into patience, requiring the Peer Health Navigator to have multiple sessions with a participant before she was ready to make a significant lifestyle change. To that end, it was beneficial for the Peer Health Navigator to disclose her own HIV-positive status to participants, which helped the participant relate to and build trust with the Peer Health Navigator. Additionally, the Peer Health Navigators would often use the knowledge gained in trainings to educate the participant about hormone replacement therapy and ART medication. Many participants would initially prioritize gender confirmation therapies over HIV therapies. The Peer Health Navigators used client-centered language such as “protect your beautiful body” to explain why gender confirmation therapies and surgeries could be ineffectual if she was not adherent to her ART medication. Prioritizing HIV care is living a trans positive life.
### Figure 1: The Alexis Project Logic Model

<table>
<thead>
<tr>
<th>TARGET POPULATIONS</th>
<th>INPUTS</th>
<th>ACTIVITIES</th>
<th>OUTPUTS</th>
<th>IMPACTS/OUTCOMES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Trans Women of color</td>
<td>Service collaborations with medical providers for HIV care (AIDS Healthcare Foundation (AHF), LA LGBT Center)</td>
<td>Conduct social network recruitment for HIV testing and social network engagement with those who are aware of their HIV status</td>
<td>10 trans women will become volunteer recruiters for the SNT program</td>
<td>Increase in direct linkages to service providers that provide HIV services, substance abuse, mental health, hormone therapy primary care, support groups, housing, youth-specific services for those 25 and other supportive services</td>
</tr>
<tr>
<td>Ages 18-65</td>
<td></td>
<td>Provide HIV counseling and testing as part of social network testing (SNT)</td>
<td>60 trans women of color will receive HIV counseling and testing</td>
<td></td>
</tr>
<tr>
<td>Living in Los Angeles County, CA</td>
<td>Service collaborations for other agencies</td>
<td>Provide HIV prevention through existing programs for trans women</td>
<td>139 HIV-positive trans women of color will be linked to a Peer Health Navigator (PHN)</td>
<td></td>
</tr>
<tr>
<td>African American, Latina, Asian, Pacific Islander, Native American, multi-ethnic, and other races/ethnicities</td>
<td>Volunteer social network recruiters</td>
<td></td>
<td>85% of those linked to a PHN will be linked to HIV medical care</td>
<td></td>
</tr>
<tr>
<td>HIV-positive</td>
<td>2 Full-time Peer Health Navigators (PHN)</td>
<td>Provide additional support services including mental health, primary care, hormone therapy, support groups, housing, and youth-specific at partner agencies</td>
<td>70% of those linked to HIV medical care will be retained, i.e., at least two completed HIV-related medical visits 3 months apart</td>
<td>Increase in percentage of newly diagnosed trans women of color linked to, re-engaged in or retained in care</td>
</tr>
<tr>
<td></td>
<td>1 Part-time Project Director</td>
<td>Link those who test HIV-positive to a PHN</td>
<td>100% of HIV-positive trans women linked to care will receive a Contingency Management reward for attending a HIV care appointment and achieving a HIV milestone</td>
<td>Increase in percentage of already diagnosed who were never or not in care trans women of color linked to, re-engaged in or retained in care</td>
</tr>
<tr>
<td></td>
<td>1 Part-time PI Process Evaluator</td>
<td>Link HIV-positive trans women of color to HIV care</td>
<td>70% of HIV-positive trans women linked to HIV medical care will report &gt;95% adherence to ART, and an undetectable VL or VL&lt;200</td>
<td>Decrease in viral load among trans women of color engaged in care</td>
</tr>
<tr>
<td></td>
<td>1 Part-time Data Manager</td>
<td>Implement combined Peer Health Navigation and Contingency Management intervention</td>
<td>85% of HIV-positive trans women will complete quarterly follow-ups to monitor engagement in care and HIV outcomes</td>
<td>Increased viral load suppression</td>
</tr>
<tr>
<td></td>
<td>Consultant, Medical Consultant</td>
<td>Provide Contingency Management rewards for attending HIV care appointments and achieving HIV milestones, i.e., reduced or suppressed viral load (VL)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Figure 2: The Alexis Project Study Design

Social Network Recruitment and Engagement (Respondent Driven Sampling)

HIV Status Unknown

HIV Testing & Counseling

HIV-

Known HIV+

HIV+

Retest in 3 months

Existing HIV Prevention Services

Peer Health Navigation + Contingency Management

Follow-up at 6, 12, 18, 24, 30, and 36 months post-enrollment

Health Outcomes:
- Increased Linkage & Retention in HIV Care
- Increased HIV Milestones
- Increased Viral Load Suppression
Figure 3: Combined Peer Navigation and Contingency Management Intervention

TIMEFRAME: 0-2 months  3-5 months  6-7 months  8-9 months  11-13 months  17-19 months

VISIT:  1  2  3  4  5  6

EVALUATIONS: Baseline  6-month follow-up  12-month follow-up  18-month follow-up
Illustration 1: Recruitment Flyer

The Alexis Project combines Peer Health Navigation and Contingency Management interventions into one program.

**Eligibility**
- Newly diagnosed HIV-infected trans women of color.
- HIV-infected trans women of color who have never received HIV medical care, or have dropped out of HIV medical care.

**Peer Health Navigation**
The Peer Health Navigation component of the program works with participants to identify HIV medical care services and other needed services, develop an individual client-centered treatment plan, remove barriers to those services and access those services. A Peer Health Navigator works with each participant to link her into HIV medical care by helping her make medical appointments and, if needed, providing transportation to and from HIV medical appointments. A Peer Health Navigator provides information and emotional support as she works with each participant to address her needs and barriers to accessing HIV medical care.

**Contingency Management**
The Contingency Management component of the program provides increasingly valuable incentives for attending HIV medical visits and reaching and maintaining HIV milestones. Each participant may earn up to $500 in incentives if she attends every HIV medical care appointment and reaches every HIV milestone.

**Follow-up evaluation assessments are conducted every 6-months throughout the entire project.**

The goal of The Alexis Project is for each participant to reach viral load suppression after regular, sustained HIV medical care visits and adherence to HIV medications.

For more information, call or text Angelina or Miranda at 323-793-4645. Or call our office at 323-512-7014.

The Alexis Project is named after Alexis Rivera who died on March 28, 2012, at the age of 36, from complications related to HIV. Alexis was a proud Latina trans woman, a community activist, a peer advocate and a gatekeeper.

A project of Friends Community Center. Funded by Health Resources and Services Administration.
Illustration 2 and 3: Posters Developed with Strong Images of Trans Women of Color Living with HIV for the Medical Clinics
Positively TRANS Positively Healthy


A project of Friends Community Center, a Service of Friends Research Institute. Funded by Health Resources and Services Administration. Call 323-465-1801.
PUBLIC HEALTH INSTITUTE:
THE PRINCESS PROJECT

Jamie Fuega

Tooru Nemoto, PhD

Mariko Iwamoto, MA

Sabrina Suico

Corresponding Authors:
Jamie Fuega, M.P.H
Address: 405 14th St., #162, Oakland, CA 94612
Phone: 510-978-9429
Email: Jamie.Fuega@phi.org

Tooru Nemoto, Ph.D., Research Program Director
Public Health Institute
405 14th Street, Suite 162, Oakland, CA 94612
Tel: (415) 602-6925
tnemoto@phi.org
Princess Project aims to enhance engagement and retention in quality HIV care through implementing innovative outreach and intervention programs in collaboration with the Public Health Institute (PHI), East Bay AIDS Center (EBAC), Community Advisory Board (CAB), HIV/AIDS service organizations (ASOs), Public Health Departments, health and social service agencies, and targeted transgender community members in Oakland/Alameda County, California. Our project team has been providing culturally and transgender-sensitive community outreach, HIV/AIDS prevention services, support groups, and gender transition feminization medical services (e.g., electrolysis and laser hair removal). In addition, we have been providing referrals to comprehensive HIV care, which may increase adherence to HIV treatment, as well as improve retention in health services for African American transgender women who are living with HIV.

LOCAL EPIDEMIOLOGY

HIV Incidence and Prevalence:

Despite a lack of valid and reliable national surveillance data on HIV/AIDS prevalence and incidence among transgender people, local data have shown high HIV sero-prevalence and risk behaviors among transgender women. The Alameda County Office of AIDS Administration (OAA) reported a cumulative total of 3,426 AIDS and 2,013 HIV cases as of December 31, 2008 and 430 newly diagnosed AIDS cases in Alameda County from Jan 1, 2007 to December 31, 2008.¹ These AIDS cases were dominated by African Americans (46.5%). The 2010 Oakland TGA (Transitional Grant Areas) Needs Assessment reported only 0.9% of the cumulative AIDS cases (n=31) were transgender persons.² Similarly, the San Francisco Department of Public Health (SFDPH)...

¹ Alameda County Public Health Department, Harder&Company Community Research. 2010 Oakland Transitional Grant Area HIV/AIDS Health Services Needs Assessment 2010.
² Alameda County Public Health Department, Harder&Company Community Research. 2010 Oakland Transitional Grant Area HIV/AIDS Health Services Needs Assessment 2010.
reported 399 cumulative AIDS cases among transgender women. However, these numbers are unreliable and under-reported because a transgender category in AIDS cases was not introduced until 1996 in SFDPH and transgender women tended to be categorized as MSM. Also, these surveillance data on HIV/AIDS cases do not match the results of a recent meta-analysis on the HIV prevalence among transgender women in the U.S.; which ranged from 0.5% to 60%, with an estimated prevalence of 28% (CI=25% to 31%).

We conducted a study that revealed high HIV sero-prevalence [46.5% of African American, 24.8% of Latina, 18.4% of Caucasian, and 13.2% of Asian and Pacific Islander (API) participants] based on a sample of 573 transgender women in San Francisco and Oakland. Our study is the only one, to our knowledge, which has investigated HIV risk behaviors among African American transgender women in Oakland and identified a high HIV prevalence (46.6%) among 123 study participants. Transgender women are categorized as one priority population at high risk for HIV in the Alameda County OAA Needs Assessment report. Our study also revealed that 49% had engaged in sex work in the past 6 months; 29%, 10%, and 16% had engaged in unprotected receptive anal sex (URAS) with primary, casual, and commercial sex partners in the past 30 days, respectively; 60% drank alcohol, 58% used marijuana, 11% snorted cocaine, 12% used methamphetamines, and 37% used ecstasy in the past 30 days. Compared with African American transgender women in San Francisco, those in Oakland reported significantly higher risk behaviors, such as URAS with commercial sex partners and ecstasy use. In addition, African American transgender women in Oakland revealed significantly higher unmet needs, in terms of basic assistance and mental health and other health care services.

PROGRAM DESCRIPTION

ORGANIZATION

Public Health Institute (PHI), incorporated in 1964, is an independent non-profit organization dedicated to promoting health, and well-being, and quality of life for people in California and elsewhere (see www.phi.org). A number of community-based health promotion projects funded by federal and

6 Nemoto T, Iwamoto M, et al. Racial and ethnic differences in HIV risk behaviors among transgender women in the U.S. Presented at Int’l AIDS Conference 2008; Mexico City, Mexico
state governments and private foundations have been conducted at PHI through the collaboration of researchers, service providers, policy makers, community stakeholders, and consumers. The quality programs and projects of PHI improve the health of people and communities and inform the development of public policy. In our project’s targeted area, Oakland/Alameda County, a few service agencies provide HIV primary care and treatment services to transgender women of color. The East Bay AIDS Center (EBAC) has been providing HIV counseling and testing and HIV primary care at Alta Bates Summit Hospital, as well as referrals to needed ancillary services for people who live with HIV. EBAC has also been providing PrEP for MSM and other high-risk populations in Oakland. Our project team initiated the Mariposa Project in collaboration with Health Right 360. The Mariposa Project recruited high-risk transgender women of color in San Francisco and Alameda County into a comprehensive counseling program to reduce substance abuse and HIV risk behaviors, as well as the Transgender Recovery Program at Health Right 360. Our project team, Health Intervention Projects for Under-served Populations (HIPUP), has established supportive and referral networks for clients among local CBOs, hospitals, and service agencies specific to the Princess Project (e.g., AIDS Healthcare Foundation, AIDS Project of East Bay, Highland Hospital, Trans Thrive/API Wellness Center, Tom Waddle Health Clinic, Tri-City Health Center, and San Francisco General Hospital). We have established a Community Advisory Board (CAB) for the Princess Project. HIPUP is well respected by local transgender communities and has made a significant impact on improving health, well-being, and human rights for transgender people in the Bay Area. The team’s dissemination efforts through publications and presentations have also contributed to research and knowledge about interventions to improve health for transgender people. Our project office (Butterfly Nest) is located in downtown Oakland and is the site for delivering intervention activities, health promotion workshops, and support groups for transgender clients.

PROJECT STAFF

Project Director. The Project Director provided leadership for the Princess project; developing the protocol, monitoring interventions; collecting, maintaining, and reporting data; conducting staff training, evaluation and dissemination; assuring human subjects protection, and securing ongoing funding for the project.

Motivational Enhancement Intervention (MEI) Supervisor. The MEI supervisor assisted the Project Director in developing the MEI protocols and curricula for the Princess Project; as well as providing training for transgender Health Educators on the fidelity of curricula, human subjects issues; outreach, scheduling, and implementing MEI; providing referral services, crisis intervention, and incidence reporting.

Clinical Advisor. The clinical advisor provided “transitioning feminization medical care” (e.g., electrolysis, waxing, and laser hair removal) for the Princess Project to attract African American transgender women who had not utilized HIV/AIDS care and prevention and other services.

Project Coordinator/Evaluator. The PC/Evaluator assisted the Project Director with evaluation, maintenance, and reporting; performance evaluation of MEI, dissemination of project findings, and training of transgender staff for
The SPNS Transgender Women of Color Initiative Interventions Manual

PHI: The Princess Project

Data collection, maintenance, and reporting to UCSF/TETAC (Transgender Evaluation Technical Assistance Center).

Transgender Health Educator. Under the supervision of the PC/Evaluator, the Transgender Health Educator conducted outreach, recruitment, MEI sessions, follow-up sessions (e.g., monitoring HIV primary care and other services), baseline and follow-up assessments, and reported data to Ms. Iwamoto.

Four Transgender Health Educators. provided culturally sensitive transgender specific services for African American transgender women in Alameda County. All of these project staff provided services for the Princess Project spanning multiple years over the life of the project.

THEORETICAL BASIS FOR MEI

MEI, the theoretical basis for the intervention, is aimed to increase adherence to HIV medication and improve retention in HIV care and other services; as well as to facilitate well-being and quality of life and provide continuous monitoring and follow-up of client status in the program. MEI or Motivational Enhancement Therapy is one of the National Registry of Evidence-Based Programs and Practices (NREP) and well-established substance abuse treatment program that has shown effectiveness for racial and ethnic minorities and for different types of problems (e.g., alcohol and drug abuse, smoking, diabetes management, and hypertension) at various treatment and non-treatment settings. The theoretical rationale for MEI is that mobilizing motivation for change is a key for addressing substance abuse and other health problems. Research studies have shown that the individual level of motivation is a strong predictor of reduction and cessation of substance use and of maintenance of abstinence. Motivation-enhancing techniques, such as motivational interviewing, are associated with increased participation and retention in treatment and treatment outcomes, such as reduction and abstinence and better social adjustment. MEI is a client-centered therapy building a therapeutic relationship between clinicians and clients with respect for clients’ autonomy and self-efficacy and empowerment. MEI has been mainly used for substance abuse treatment, however recently MEI has been utilized for substance use and HIV risk

reduction, HIV testing promotion, and improvement of HIV medication adherence.\textsuperscript{17,18,19,20,21,22,23} We chose MEI for the Princess Project because of its effectiveness in increasing adherence to treatments and reducing substance abuse and HIV risk behaviors; as well as its principles emphasizing self-motivation, self-efficacy, and empowerment; all of which are of presumed benefit to high-risk African American transgender women who are consistently exposed to racial discrimination and transphobia.

**KEY COMPONENTS OF THE PRINCESS PROJECT**

The Princess project is based on evidence-based theories and adaptation of our previous HIV prevention intervention projects and has three major components: Outreach, Intervention, and Building and Sustaining Capacity.

**Outreach**

- Conduct community outreach to identify high risk African American transgender women in Alameda County
- Facilitate enrollment of eligible transgender women into the Princess Project, utilizing motivational interviewing technique
- Recruit participants using referral coupons
- Recruit through social networks using the Internet
- Identify and recruit participants through a network of collaborating medical, social, and other service providers (in-reach method)

**Intervention**

- Provide comprehensive MEI delivered by transgender Health Educators (See figure below). Participants in the Princess Project complete the baseline assessment. Immediately after the assessment, they participated in the first MEI session. After the first session, they were asked to schedule the following 2 MEI sessions in a month. After completion of the 3rd MEI session, they completed monthly MEI

sessions during the following 6 months (total 6 MEI sessions). They also completed 6-month follow-up assessment from baseline. Follow-up assessments were conducted every 6 months for up to 2 years. Participants were paid incentives ($20 for each MEI session and $25 for each assessment).

- Provide comprehensive in-hand referrals to needed services at EBAC and the collaborating agencies (e.g., mental health and substance abuse treatment, housing, and employment)
- Monitor and retain clients in MEI; monitor quality of HIV care and other necessary services based on prompt process evaluation and feedback.
- Provide a weekly support group at the Butterfly Nest to increase retention and follow-up with participants.

**Figure 1: Participants Flowchart**
BUILDING AND SUSTAINING COMMUNITY CAPACITY

Princess Project was developed in collaboration with the targeted African American transgender communities and aimed to sustain community capacity after the project ended.

- Operate the Butterfly Nest in collaboration with community members
- Provide support groups for the project participants and their significant others
- Provide health promotion workshops for the participants and community members
- Collaborate with the CAB members who monitor all project activities, including human subject protection
- Seek to sustain the Princess Project after HRSA’s support ends in collaboration with CAB, community members; and local, State, and national government agencies

LOGIC MODEL

We have fully utilized the inputs and resources of our team’s expertise and experience in the field of HIV/AIDS care and prevention and other services for transgender communities, as well as institutional support from PHI. The enthusiasm and commitment in the targeted transgender communities are vital resources for successfully implementing the Princess Project. The activities and interventions include community outreach with multiple methods to recruit African American transgender women living with HIV. Through referrals and outreach to the collaborating agencies (in-reach methods), those who are HIV positive, but have never enrolled in or dropped out of HIV care were identified by our Health Educators and were enrolled in the Princess Project and provided with MEI to increase adherence and retention in HIV primary care and other services. We have utilized the Butterfly Nest where health promotion workshops and support groups have been held. HIV testing and counseling, HIV prevention programs, HIV/STI/HCB treatment and other medical care, including gender transition medical care services have been provided by the collaborating local service agencies. Under the supervision of the Project Director, the Evaluator developed local measures to conduct process and outcome evaluation to examine the efficacy and impact of the Princess Project. We have disseminated project findings and experience through community forums and professional meetings and sought funding to sustain the Princess project after HRSA support ends. The Princess Project has made a significant impact on improving health and well-being among participants and their partners, as well as in transgender communities in Alameda County that have been historically neglected in HIV/AIDS care and prevention services, despite their high HIV prevalence and incidence.
INPUTS/RESOURCES

- African American transgender Health Educators’ and the CAB members’ enthusiasm and commitment to enhancing the community capacity
- Our project team’s extensive experience in providing substance abuse and HIV prevention programs for transgender communities in the Bay area
- Collaborating CBOs’ community-oriented, comprehensive, and culturally competent service and support programs for African American communities in Alameda County
- Collaborating health service agencies’ HIV primary and other medical care services (e.g., transitioning medical care services) specific to transgender women
- CABs and already functional and efficient collaboration networks for HIV primary care and other services

ACTIVITIES/INTERVENTIONS

- **Outreach**: Utilize multiple methods (e.g., community outreach using referral coupons, social network using the Internet, and in-reach methods)
- **MEI**: Provide assessment and intensive MEI sessions to increase clients’ retention in HIV care and other services, improve quality of life, and increase protective behaviors against HIV transmission and re-infection
- **Service Linkage**: Provide prompt and individualized referrals to HIV primary care and other services at the collaborating agencies
- **Evaluation and Feedback**: Collect local and SPNS measures, evaluate data, and provide feedback to Health Educators and project team
- **Community Involvement**: Monitor cultural and transgender sensitivity and community acceptance of the project by CAB
- **Safe Community Space**: Create the Butterfly Nest where participants and community members come to relax, take workshops, and participate in support groups.
- **Dissemination**: Disseminate project experience and results of process and outcome evaluation through community forums and professional meetings, and sustain the Princess Project in collaboration with CAB and local, state, and national agencies.
PROGRAM PLANNING AND DEVELOPMENT

START-UP STEPS

• **Staff Hiring**
  In year 01, we completed hiring of all project staff, including Project Coordinator/Evaluator, Health Educators, and Project Assistant. All Health Educators were members of the transgender community and had extensive experience in providing services to the communities. Having front-line staff who were members of the community and have been active in their community was essential to implement project.

• **Initial Training**
  Our MEI Supervisor had provided MEI training sessions for Health Educators in terms of the MEI curriculum, motivational interviewing techniques, behavioral change plan, and incorporating baseline survey results into MEI sessions. At the 2-day MEI training (2-3 hours per day), the Health Educators learned about the techniques of Motivational Interviewing through role playing - how to efficiently deliver MEI techniques, such as reflection, open questions, developing and acknowledging discrepancies, rolling with resistance, feedback, engaging in ambivalence, and supporting self-efficacy. Other critical trainings were also provided.
  - Protection of human subjects and confidentiality
  - HIV progress and treatment training by Consultant
  - Health concerns related to hormone use among transgender by Consultant

• **MEI Curriculum Development**
  In early FY2, the MEI curriculum was finalized. All project team members met numerous times to share ideas and modified the curriculum to improve its appropriateness and sensitivity to transgender women who are living with HIV. The curriculum focused on ways to motivate participants to increase access to and retention in HIV primary care, as well as skills to handle life issues surrounding HIV care. We made the curriculum user-friendly, including check boxes, sample phrases, and progress tables that the Health Educators could easily monitor the progress of clients during MEI sessions.

• **Opening of the Butterfly Nest (storefront office):**
  Although establishing the Butterfly Nest was substantially delayed due to the prolonged financial review process within our agency, we were able to open the space to public in mid-FY2. The Butterfly Nest is easily accessible by public transportation (located in downtown Oakland), which facilitates participants to
come to the space. The Butterfly Nest played an essential role in implementing and attaining the project goals and objectives through various activities (e.g., MEI sessions, assessments, and support groups).

- **Developing MOUs and Partnerships:**
  We established collaborative working relationships with health clinics and CBOs that provide services for transgender women living with HIV in Alameda County. For our project (non-clinic site), the collaboration was essential to expand our capacity to provide better services and effective implementation of the project (e.g., recruitment, referrals, and follow-up). We were able to have frequent communication with clinical social workers to assist clients who tended to miss the medical appointments by escorting them to the clinic. In addition, through the collaboration, we were able to smoothly refer our clients to collaborating clinics and other necessary services in a timely manner to enhance their HIV care (e.g., substance abuse treatment, legal, and housing services, etc). Below is a list of agencies with which we had established MOUs: East Bay AIDS Center; Tri-City Health Center; AIDS Health Foundation; Asian Health Services. Other collaborators (without MOUs) included: HealthRIGHT 360; East Bay Community Legal Center; Summit Merit University, Nursing Program; Trans Employment Program; TransLife at San Francisco AIDS Foundation; Transgender Law Center; AIDS Project of East Bay; TransHealth at Asian and Pacific Islander Wellness Center

**Community Advisory Board (CAB)**

The CAB members consisted of transgender community members and staff of social service agencies that provide services for transgender people in the Bay Area (e.g., San Francisco Department of Public Health, St. James Infirmary, Asian and Pacific Islander Wellness Center, Bay Area Youth Centers, Hi Fi, Transgender Law Center, City College of San Francisco, Transgender Employment Services, and HealthRIGHT360). There was careful consideration about selecting the CAB members who had experience and knowledge about transgender communities in the East Bay and HIV primary care for African American transgender women. We held CAB meetings quarterly to prepare for the project implementation. We provided updates on the project progress, obtained feedback from the CAB members about project materials and outreach plans.

**IMPLEMENTATION AND MAINTENANCE**

**Modification Made to the Original Plan**

- **Inclusion Criteria Change:** We expanded our inclusion criteria to include any transgender women of color who are living with HIV, regardless of their utilization of HIV primary care in order to enhance linkage and retention to HIV primary care.

- **Intervention Design Revision:** We originally considered including HIV-negative trans women of color in the program; however, by anticipating challenges in recruitment and retention due to the
participants’ transient lifestyle, we decided to only focus on participants who were living with HIV in order to increase retention in the Princess Project and enhance adherence to HIV primary care.

- **Respondent Driven Sampling (RDS) Methods**: We originally planned to use RDS to recruit participants, but then reconsidered this decision due to feasibility concerns. Therefore, we decided to eliminate RDS and implemented multiple types of outreach, such as direct community outreach, utilization of social networks and internet, and referrals from collaborating CBOs.

- **Subcontractor**: Originally, we planned to collaborate with a local AIDS service agency that provides HIV testing and care in Oakland. The agency also used to have a transgender program that provided health promotion and support groups for African American transgender women. After about one year of collaboration with the agency, we realized that the collaboration efforts in recruitment and implementation of the intervention programs did not efficiently work to achieve the project goals and objectives. Unfortunately, we came to a conclusion to terminate the subcontract agreement with the agency. We subcontracted with another AIDS service agency in FY2 for delivering HIV primary care and other services to clients in the Princess Project who were living with HIV.

- **Referral Coupons**: In FY3, we added a “referral coupon system”. Participants could refer up to three transgender women living with HIV to the Princess Project and receive a $20 gift card for each successful referral for a transgender woman who completed the intake assessment.

- **Clinic Visit Incentives**: In FY3, we added “clinic visit incentive” in our intervention to increase access to care for those out of care clients. During the 1st 3 MEI sessions, the Health Educators worked with clients to set up a medical appointment at the collaborating health clinic and prepared for the 1st clinic visit using MEI techniques. When clients successfully visited the clinics chaperoned by the Health Educators, they received a $50 gift card for completing the clinic visit for HIV care (including medical check-up and blood work). Through MEI sessions, the Health Educators assisted clients to keep future appointments and adhere to their prescribed medications.

**BARRIERS AND FACILITATORS TOWARDS IMPLEMENTATION**

- **Identifying new clients**: The Health Educators and project team members sought the collaboration with new venues and agencies throughout the project years (e.g. attending various community events and actively encouraging our clients to distribute the referral coupons for their eligible transgender friends). Although fewer clients utilized the referral coupon than we expected, we found that those referred clients were less connected with the transgender community and did not frequent places where the Health Educators conducted outreach. The referral coupon system for the recruitment worked well to recruit “hidden” or “hard-to-reach” participants.

- **Stigma toward revealing HIV status**: We found that stigma toward revealing HIV positive status exists strongly in the targeted African American transgender community. The Health Educators
emphasized the confidentiality issues to clients and took time to build trusting relationships; however, we encountered several cases in which clients hesitated about revealing their HIV positive status. To overcome this barrier, we added a referral coupon system; we thought that knowing that their friends had actually enrolled in the project would ease this anxiety regarding HIV positive status.

- **MOU establishment**: Our initial meetings with clinic staff to discuss collaboration proceeded smoothly. However, the process to obtain the authorized signatures on the contract (MOU and subcontract agreement) took an extremely long time. For one agreement, it took almost 2 years to finalize. Due to the prolonged process, we were not able to establish MOUs with large county operated hospitals.

- **Retention in HIV Care and Intervention Programs**: We have observed that many unmet basic needs in our clients’ lives tend to be a barrier to access to care or trigger them to fall off from care. Among our clients, unstable housing and substance use were commonly seen as obstacles to adhere to ART medication, as well as retention in HIV primary care. During the MEI sessions, the Health Educators helped the clients identify these obstacles, actively provided referrals and skills to eliminate the obstacles, and helped them to re-engage in care following the MEI curriculum.

- **Turnover of Project Staff**: We have experienced project staff turnover during the 5-year project period. Turnover was a huge setback to our project team to lose staff who were trained, experienced, and well-connected with clients. In most cases, the incidence of staff-turnover was promptly handled by appointing transgender staff who were working for our other projects and had experience and knowledge about HIV prevention and care for transgender communities in the targeted area. The Project Coordinator also worked to ensure a smooth transition. She guided the Health Educators to complete the ongoing intervention sessions before the Health Educators resigned and guided them to inform all their clients that newly appointed Health Educators would contact them for the follow-up assessments. Although it was inevitable that project activity was slowed down due to staff turnover, we were able to minimize the impact on the project implementation.

**ONGOING TRAINING, STAFF DEVELOPMENT AND RETENTION**

- **MEI Consultation Monthly Meeting**: The MEI Supervisor provided monthly consultation meetings with the Health Educators throughout the project period. The monthly consultation meetings provided opportunities to refresh the MEI techniques and discuss any issues or concerns while providing MEI sessions.

- **Staff Retention Strategies**: To prevent staff turnover, the project management team continuously supported project staff (Health Educators and Project Assistant) and closely monitored their workload to reduce stress. MEI Supervisor also continuously hosted monthly consultation meetings with Health Educators and addressed their possible burnout issues. Additionally, the management team provided staff opportunities to grow as professionals (e.g., learning presentation skills at conferences, etc).
INTERVENTION OUTCOMES

RECRUITMENT AND FOLLOW-UP COMPLETION

<table>
<thead>
<tr>
<th>Year</th>
<th>Baseline (40)</th>
<th>3 MEI</th>
<th>3 Monthly MEI</th>
<th>6 MO</th>
<th>12 MO</th>
<th>18 MO</th>
<th>24 MO</th>
<th>30 MO</th>
<th>36 MO</th>
</tr>
</thead>
<tbody>
<tr>
<td>FY2</td>
<td>37</td>
<td>21</td>
<td>7</td>
<td>10</td>
<td>7</td>
<td>8</td>
<td>7</td>
<td>10</td>
<td>2</td>
</tr>
<tr>
<td>FY3</td>
<td>10</td>
<td>6</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>-</td>
</tr>
<tr>
<td>FY4</td>
<td>16</td>
<td>7</td>
<td>5</td>
<td>8</td>
<td>3</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Total</td>
<td>63</td>
<td>34</td>
<td>13</td>
<td>19</td>
<td>10</td>
<td>8</td>
<td>8</td>
<td>11</td>
<td>2</td>
</tr>
</tbody>
</table>

** As of January 31, 2017. 6 duplicated clients with other SPNS sites are included in total 63 participants above (2 in year 02, 3 in year 03; 1 in year 04)

34 out of 63 clients (54%) completed 3 required MEI sessions

13 out of 63 clients (21%) completed 3 additional monthly MEI session

- 1,496 outreach contacts during the project recruitment period
  (0 in year 01; 834 in year 02, 183 in year 03; 479 in year 04); Preparation period in year 01; no outreach was conducted

- Throughout the project year, our Health Educators provided 280 MEI sessions.

- Our Health Educators provided 3,856 total hours with clients outside of intervention, such as accompanying clients to service agencies (outside hours was tracked since FY3).

LINKAGE TO CARE AND SERVICES

- 33 out of 63 participants recruited had never enrolled in or had previously dropped out of HIV primary care at the intake

- 11 participants enrolled in HIV primary care though the Princess Project

While we had been encouraging clients to access or re-engage with care, we often observed that many unmet basic needs in the clients’ lives were a barrier to access to care or triggered them to fall
off from care. As a part of the strategy in increasing access/re-engagement with care, the Health Educators actively provided referrals for clients to appropriate and necessary services during the MEI intervention sessions. Throughout the project years, the Health Educators made 78 referrals as indicated below. Out of 78 referrals, 26 referrals successfully connected clients to services.

### Characteristics of our Clients

The demographic information here is based on 60 transgender women.

#### Gender Identity*

- Female/Woman 23%
- Transfemale/Transwoman/Transgender Woman 25%
- Transsexual Woman 12%
- Transgender 43%

#### Age

- 20-29yrs 13%
- 30-39yrs 32%
- 40-49yrs 23%
- 50-59yrs 27%
- 60-69yrs 5%

Note: * = mutual exclusive responses

### Referrals by Venue

<table>
<thead>
<tr>
<th>Referrals by Venue</th>
<th># of Referrals made</th>
</tr>
</thead>
<tbody>
<tr>
<td>Resource/Drop-In</td>
<td>37</td>
</tr>
<tr>
<td>HIV Primary Care</td>
<td>11</td>
</tr>
<tr>
<td>Housing</td>
<td>10</td>
</tr>
<tr>
<td>Substance Use</td>
<td>5</td>
</tr>
<tr>
<td>Legal Assistant</td>
<td>3</td>
</tr>
<tr>
<td>Mental Health</td>
<td>2</td>
</tr>
<tr>
<td>Food Assistance</td>
<td>2</td>
</tr>
<tr>
<td>Other (Employment, etc)</td>
<td>4</td>
</tr>
</tbody>
</table>

*Note: * = mutual exclusive responses*
**Race**
- Hispanic 7%
- White 3%
- African American 92%
- American Indian 10%
- Asian 2%

**Education (n=59)**
- Less than High School Degree 39%
- High School Diploma/GED 29%
- Some college 29%
- Bachelor's Degree 2%
- Graduate Degree 2%

**Relationship Status (n=59)**
- Single 76%
- Living together 10%
- In a relationship, not living together 12%
- Other 2%

**Annual Income (n=44)**
- Less than $600 11%
- $600-$2,999 32%
- $3,000-$5,999 2%
- $6,000-$11,490 36%
- $11,491-$15,282 11%
- $15,283-$35,999 7%
**Income Sources (past 6months)**

- Part/Full time Job 13%
- Selling Drugs 20%
- Sex Work 33%
- Panhandling 20%
- SSI/SSDI 38%
- Spouse/Partner 12%
- Other Family Member 8%
- Foreign Born 2%

**LONG-TERM OUTCOMES/IMPACT**

Data analysis is ongoing, and we plan to evaluate the effect of the Princess Project comparing the outcome variables at baseline with those at 6-month follow-up (e.g., enrollment in HIV primary care, viral load, CD4 count, substance use and sexual risk behaviors, and psychosocial outcomes). We will examine the following outcome variables:

- Improved quality of life and health and well-being among clients enrolled in MEI: quality of life measures, CD-4 count, viral load, and other medical and sociocultural measures (e.g., transphobia, self-esteem, social support, and depression)
- Increased protective behaviors against HIV re-infection and transmission and health promotion behaviors among participants
- Increased HIV/AIDS awareness and knowledge about HIV care and other health care services among clients, their partners, and community members through support groups and community activities
- Increased the capacity of African American transgender communities and service providers in Alameda Co.
- Increased participation in transgender community activities among clients and their partners

**APPROXIMATE INTERVENTION ANNUAL COSTS**

Average annual intervention costs, including personnel effort (FY1 to FY4): **$307,610**

(Personnel: $774,659, Travel: $8,361, Other Cost: $4,981)
LESSONS LEARNED

Implementation of Intervention at Non-clinic/Non-CBO sites: Since we are a non-clinic/non-CBO site, we don’t provide direct services to clients. Therefore, we had to actively seek other ways to find clients and design our program to attract them.

Partnership with other agencies: As described in the previous section, collaboration with other clinics and service providers was one of the key components of our intervention activities, allowing us to expand our recruitment capacity and efficiently provide linkage to care services. We made the Butterfly Nest accessible to the Transgender Law Center every 4th Tuesday as a legal clinic. They provided basic information about laws that affect transgender people (e.g., employment, health care, civil rights, family law, identity document changes, etc). If needed, they provided referrals to attorneys. Since this service was provided right before our support group, it was a great incentive and attracted our participants to participate in both legal counseling and support groups.

Support Group: Our weekly support group played a critical role to implement our intervention project. We hosted the support group for transgender women every Tuesday between 6-6:30 pm at the Butterfly Nest. Facilitation rotated among the Health Educators every week, and each Health Educator planned activities for their assigned support group (e.g., organizing guest speakers, craft class, and workshop, etc.) and advertised the support group well in advance. Our Medical Consultant facilitated the discussion group on every 3rd Tuesday of the month based on the attendees’ health related questions. Approximately 5-8 transgender women attended each group, on average. Support groups were a good outreach venue. The Health Educators actively invited their clients to join the weekly support group. When they came, the Health Educators talked to them and conducted brief check-ins and reminded them of the next appointment. If time allowed, the Health Educator conducted ongoing MEI intervention sessions before the group. Moreover, clients often came to the group with their friends so the Health Educator had an opportunity to introduce the project to their friends. Our support group has been a great place to maintain a connection with participants. Moreover, we observed that our support group has established a safe place for transgender community members to talk about their concerns and network with other transgender women.
**The PRINCESS Project**

Our lives matter!

We can help you help yourself!

**The PRINCESS Project**

Pathway to Retention in Care and Promoting a Healthy Lifestyle

**The PRINCESS Project** is seeking **African American Transgender Women** for a health promotion project!

🎉 The HRSA-funded* PRINCESS Project aims to increase access to and retention in quality HIV care for African American transgender women living with HIV.

🎉 If you live, work, play, or go to school in Alameda County.

EARN UP TO $305

Sabrina: (510) 478-2771

*Health Resources and Service Administration (HRSA)*
STATE UNIVERSITY OF NEW YORK:
THE INFINI-T PROJECT

Jeffrey M. Birnbaum, MD, MPH

Elizabeth Eastwood, PhD

Jennifer Lee, MPH

Corresponding Authors:
Jeffrey M. Birnbaum, MD, MPH c/o HEAT Program
SUNY Downstate Medical Center, 760 Parkside Avenue/Room 308, Brooklyn, NY 11226
718-467-4446
Jeffrey.Birnbaum@downstate.edu
CONTENTS

Local Epidemiology ........................................................................................................................... 103

The Intervention ............................................................................................................................... 108

Program Planning and Development ............................................................................................... 110

Intervention Outcomes ..................................................................................................................... 114

Lessons Learned ................................................................................................................................. 116

LOCAL EPIDEMIOLOGY

HIV Incidence and Prevalence:

New York City Department of Health and Mental Hygiene (DOHMH) generates reports on HIV infection among self-identified transgender people. The DOHMH has been keeping records on self-identified transgender persons since 2005. The most recent data come from data 2010-2014.¹ Between 2010 and 2014 234 diagnoses of HIV were made, 232 among transgender women and 2 among transgender men. These represent 1.5% of all HIV diagnoses in NYC. Twenty-one of these diagnoses were made with concurrent diagnosis of AIDS. Of all cases, 60% (140/232) were among young people aged 20-29. Ninety three percent (94%) were Black or Latina, with slightly more Black. The highest number of new HIV diagnoses was from residents of Manhattan (N~60), followed by Queens (N~49) and Brooklyn (N~45). Overall, DOHMH reports that 49% of transgender women had documentation of at least one other risk factor for HIV compared to non-transgender HIV-diagnosed (in order, substance use, incarceration, commercial sex work, homelessness, and sexual abuse). Finally, among the known transgender population on whom data has been collected since 2005 (N~900), 61% of these were virally suppressed as of last data report from 2014.

PROGRAM DESCRIPTION

Health & Education Alternatives for Teens (HEAT) is a unique program that focuses on the special needs of teenagers living with or at risk for HIV. All of our services are confidential and comprehensive. Set in a youth-friendly atmosphere, the HEAT program operates a ‘one-stop shopping’ full service clinic and removes the barriers which youth often face while accessing health care services. The HEAT program was founded in 1991, making it the first of its kind in Brooklyn. HEAT also serves a leadership role in strengthening the network of youth-oriented providers in the metropolitan area and heightening public awareness about the impact of the HIV/AIDS epidemic on adolescents. We are committed to providing age-appropriate and culturally competent care for all youths—straight, gay, bisexual, transgendered, and from all ethnic backgrounds.

In 2012, the HEAT Program received a Health Resources and Services Administration (HRSA) Special Project of National Significance (SPNS) grant to launch the INFINI-T Project under the Enhancing Engagement and Retention in Quality HIV Care for Transgender Women of Color initiative. The purpose of the SPNS grant is to enhance engagement and retention in quality HIV Care for Transgender (TG) Women of Color. By utilizing the Health Education Alternatives for Teens Program’s (HEAT) multidisciplinary team including social work, case management, peer advocacy, mental health and medical providers to address the multiple challenges Transgender Young Women of Color (TYWOC) face, Infini-T sought to maximize HEAT’s effectiveness in identifying, engaging and retaining in care HIV+ TYWOC.

PROJECT SUMMARY

The Health & Education Alternatives for Teens (HEAT) Program of State University of New York (SUNY) Downstate Medical Center (DMC) conducted the Infini-T Project, a culturally competent, multidisciplinary care model. For Infini-T, HEAT expanded upon an existing partnership with the Hetrick-Martin Institute (HMI), NYC’s largest agency serving lesbian, gay, bisexual and transgender (LGBT) youth. HEAT provides age- and developmentally-appropriate, culturally-competent HIV care for heterosexual, LGBT, and perinatally-infected youth (ages 13-24), primarily from communities of color in Brooklyn, NY. The target population is HIV+ transgender (TG) young women of color (TYWOC) in Brooklyn, an HIV epicenter for Black and Latino youth.

NEEDS

TYWOC are at very high risk for HIV due to multiple unmet psychosocial and mental health needs and disproportionate levels of substance use, homelessness, commercial sex work, and histories of sexual abuse and incarceration.
GOALS

Utilizing HEAT’s multidisciplinary team of social work, case management, peer advocacy, mental health and medical providers, Infini-T’s goal was to identify, engage and retain HIV+ & HIV- TYWOC in care by:

1. hiring a TG Peer Youth Advocate to provide linkage to HIV testing and care at HEAT and navigation to facilitate adherence to medical, mental health and psychosocial appointments;
2. adding supplemental social work services for screening assessments, referrals, and support groups;
3. enhancing TG-focused mental health services to assess unmet mental health needs (barriers to engagement and retention in care);
4. engaging an HMI staff member as a TG Youth Services Specialist to enhance outreach, engagement, referral and linkage of HMI youth outside of the clinical setting to HEAT services; and
5. engaging a TG health consultant to develop, administer, and train other project staff in the piloting of a proposed “grass roots” group level intervention (see “Just One Of The Girls” below).

Through the use of HEAT’s multidisciplinary team, Infini-T’s overall intervention plan was to:

1. ensure early identification of new HIV cases among TYWOC;
2. ensure timely entry into co-located TG & HIV care;
3. provide early engagement in mental health services for HIV+ & HIV- TYWOC with unmet mental health needs;
4. increase the retention rates of TYWOC already receiving HIV medical care
5. re-link to care HIV+ TYWOC who were previously in care, but lost to follow-up; and
6. retain HIV- TYWOC with significant risk factors for acquiring HIV in TG care at HEAT.

Infini-T also piloted a “grass roots,” group-level psycho-educational intervention, “Just One Of The Girls” (JOG), adapted from the evidence-based intervention for African-American women, “Sisters Informing Sisters about Topics on AIDS (SISTA).” JOG was adapted to meet the unique needs and address behaviors of TYWOC (e.g., injection hormone use, injection silicone use, validation of female identity through sex) while building community among participants. While the project developed a curriculum and ran several cycles of JOG for participants, the piloting of this group level intervention was terminated mid-project due to multiple challenges with consistent participant attendance, staff scheduling, participant recruitment issues due to HIV-related stigma and other logistical issues which arose during each cycle. While JOG held much promise and many parts of the curriculum will be retained by HEAT for future use, the limited participation and subsequent data collection from the JOG participants made it impossible to conduct any statistically meaningful evaluation of the intervention.
HEAT did evaluate the success of Infini-T’s multidisciplinary strategy to maximize the effectiveness of interventions aimed at HIV+ and HIV- TYWOC, and expects the outcomes to include improved self-assessed and clinically-derived quality of care for project clients. Longitudinal measures include utilization of services relative to retention in care, decrease in adverse mental health scores, and improved HAART adherence, CD4 counts and viral load. Self-efficacy scores for JOG participants will also be assessed.

Infini-T also had a **Community Advisory Group (CAG)** which was constituted annually throughout the project. The CAG members were representatives of the TYWOC target population, as well as older transgender women who were recognized community leaders. The meetings were held at HMI.

**INTERVENTION STAFF**

The following table details project staff, their distribution among program partners, and their roles.

<table>
<thead>
<tr>
<th>TITLE</th>
<th>SERVICES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Program Director, INFINI-T</td>
<td>Adolescent HIV Specialist for treatment of HIV+ youth.</td>
</tr>
<tr>
<td>Program Coordinator, INFINI-T</td>
<td>Oversees project staff members and coordinates project.</td>
</tr>
<tr>
<td>Program Administrator/Deputy Director, INFINI-T</td>
<td>Conducts administrative functions of program (manages contracts with subcontracts and budgets).</td>
</tr>
<tr>
<td>Program Evaluator, INFINI-T</td>
<td>Manages INFINI-T Program evaluation. Develops tools for data collection and conducts evaluation.</td>
</tr>
<tr>
<td>Transgender Coordinator/ Case Manager/ Social Worker</td>
<td>Provides necessary case management and support services for HIV+ TYWOC clients.</td>
</tr>
<tr>
<td>Trans Peer Youth Advocate, HEAT</td>
<td>Provides outreach and support services to clients who are new to care or at risk of falling out of care. Identifies and recruits TYWOC.</td>
</tr>
<tr>
<td>Trans Youth Services Specialist, HMI</td>
<td>Provides outreach and support services to clients who are new to care or at risk of falling out of care. Identifies and recruits TYWOC.</td>
</tr>
<tr>
<td>LGBT/YMSM Outreach Coordinators/ Peer Outreach Staff (in-kind support staff)</td>
<td>Provides outreach, identifies, links, and recruits TYWOC into care while in the field conducting HIV/STI testing and at community-wide events.</td>
</tr>
</tbody>
</table>
COMMUNITY PARTNERS

The Hetrick Martin Institute (HMI): NYC’s largest agency serving lesbian, gay, bisexual and transgender (LGBT) youth. HEAT provides age- and developmentally-appropriate, culturally-competent HIV care for heterosexual, LGBT, and perinatally-infected youth (ages 13-24), primarily from communities of color in Brooklyn, NY.

REFERRING AGENCIES

(_JOINED MID-PROJECT TO ENHANCE ENROLLMENT_)

As explained in further detail in the Implementation and Maintenance section of this monograph, Infini-T was modified mid-project to accommodate individuals referred from other care sites as well as individuals up to age 29 years of age. These referring agencies are listed below:

STAR Health Center: The STAR Health Center, which serves HIV+ and HIV- affected adults, ages 18 and above, is HEAT’s on-campus HIV care partner at SUNY-DMC in Brooklyn. STAR has provided comprehensive care for people with HIV since 1992. STAR’s LGBT Health Initiative has specialized programming for transgender medical and psychosocial services.

Callen Lorde: Callen-Lorde is the global leader in LGBTQ healthcare. Since the days of Stonewall, Callen-Lorde has been transforming lives in LGBTQ communities through excellent comprehensive care, provided free of judgment and regardless of ability to pay. In addition, Callen-Lorde has been continuously pioneering research, advocacy and education to drive positive change around the world, because of its belief that healthcare is a human right.

Project STAY: Project STAY provides comprehensive health services for high-risk and HIV-positive adolescents and young adults between the ages of 13 and 24 in New York City.

Housing Works (HW): HW is a New York City-wide, community-based-not-for-profit organization devoted to persons living with HIV/AIDS. HW’s mission, to decrease the incidence of HIV in Brooklyn areas at high risk for infection, is realized through recruiting and training women from communities of traditionally underserved populations to educate, empower, advocate for, and provide support services to other HIV/AIDS infected and affected women and their families, and those at risk for HIV infection. HW has also referred clients to HEAT since 2006.

CK Life: The mission of CK Life is to provide the Trans community with the tools needed to achieve their personal goals while having a sense of COMMUNITY and KINSHIP. This includes providing useful information that will help people who are looking to lead the most productive life during and after transition with regards to health, employment and day to day social interactions.
THE INTERVENTION

AN EFFECTIVE INTERVENTION MODEL FOR ENGAGING TYWOC IN CARE

Singer’s Syndemic Theory (2003) describes “a set of enmeshed and mutually enhancing health problems that, working together in a context of deleterious social and physical conditions that increase vulnerability, significantly affect the overall disease status of a population.” More simply stated, the health of Infini-T’s target population of TYWOC is negatively impacted by the effects of multiple adverse conditions and epidemics resulting in numerous unmet needs layered on top of each other. These conditions and epidemics include not only HIV, but psychiatric illness, trauma, violence, homelessness, lack of access to appropriate health care and others. As further described by Brennan et al, the application of Syndemic Theory to the role of multiple, co-occurring health problems and social marginalization among TG women provides a framework for understanding the interconnectedness of factors that impact the abilities of TYWOC to access health care. This model posits that multiple psychosocial factors are additive in their relationship to sexual risk behavior and HIV risk. It also utilizes a “syndemic index” to examine the relationship between social isolation and psychosocial factors.

BARRIERS & THEIR IMPACT ON ENGAGEMENT IN CARE

While the primary focus of barriers for TYWOC to engage and remain in care exists at the individual client level, significant barriers also exist at the structural and provider levels. Individual client-level barriers include: untreated mental health problems (e.g., ongoing symptoms, psychiatric hospitalization, past negative experiences with psychiatrists, cognitive impairment), homelessness or unstable housing, intimate partner/sexual violence and victimization, incarceration, “street hormone” use (e.g., needle sharing, unsafe doses of hormones), commercial sex work (e.g., exposure to unprotected anal sex, exploitation and sexual violence) and lack of health insurance. Structural-level barriers include: lack of TG-competent or -specific care programs, lack of contiguous medical, mental health and social services, gender marker and name inconsistency on identity cards (particularly on health insurance cards), separate funding streams for co-morbid conditions (e.g., mental illness, HIV, substance abuse), absence of team approach to care, lack of coordination among local resources, lack of accessibility (e.g., location, service hours, insurance, linguistically appropriate materials, case management, specialists), inadequate transportation (e.g., inconvenience, cost), and psychosocial barriers within


the service setting (e.g., stigma, discrimination). **Provider-level barriers** include: language & communication barriers (e.g., gender pronoun sensitivity, attitude), race/ethnicity/sex/sexual orientation/gender identity (e.g., same as or different from client), and lack of experience or competency with TG &/or HIV care.

**MULTIDISCIPLINARY TEAM APPROACH AS AN INTERVENTION TO ADDRESS KEY FACTORS**

By utilizing a multidisciplinary approach including outreach and HIV C/T, social work, peer advocacy, case management, mental and medical health, HEAT sought to reduce the burden of the confounding effect of these multiple psychosocial factors. By utilizing this care model in a broader TG service program that was not solely focused on HIV-related services, HIV+ TYWOC were able to avoid the profound stigma often associated with receiving care at HIV medical clinics. By providing the same spectrum of services for HIV- TYWOC at HEAT, Infini-T was able to make HIV+ TYWOC more comfortable being engaged and retained in care and also provided a “medical home” for high-risk TYWOC who may become HIV+ after they are already engaged in care. Midway through the project, HEAT launched an integrated HIV pre-exposure prophylaxis (“PrEP”) program within its clinic that HIV- TYWOC were all offered participation in. Their existing engagement in Infini-T and retention in TG medical care facilitated their enrollment in HEAT’s PrEP services. The employment of a multi-agency collaboration (HEAT & HMI) represents an innovative intervention in which HMI will engage TYWOC, refer them to HEAT, and provide a ‘safety net’ to track, re-engage, and refer TYWOC back to HEAT when they fall out of care.

**GROUP LEVEL INTERVENTION TO ADDRESS ENTRY & RETENTION IN CARE**

As mentioned previously, HEAT sought to additionally pilot a “grass roots,” group-level psycho-educational intervention to address many of the individual client-level barriers mentioned above. While this intervention (JOG) was terminated midway through the project for the reasons previously stated, the concept of supplementing the multidisciplinarly care model employed by Infini-T with a group-level intervention with the goals of building transpride, reducing attrition from care and building community among group participants still resonates with project staff.
PROGRAM PLANNING AND DEVELOPMENT

IMPLEMENTATION AND MAINTENANCE

HEAT lost much of its core funding at the same time that Infini-T was initially funded through the HRSA SPNS initiative to enhance engagement and retention of HIV+ transgender women of color. HEAT did not anticipate the loss of Federal funding and had to quickly adapt to adverse circumstances to launch the Infini-T project. The initial phases of implementation were hampered by the loss of previously funded key staff and partners. Therefore, the PI had to reorganize HEAT’s core clinical and outreach/prevention programming with reduced funding and seek out additional funding opportunities to restore some of HEAT’s lost capacity. In spite of these overwhelming circumstances, HEAT’s long standing relationship with HMI, the commitment of its leadership and staff to seeing Infini-T implemented, and buy-in from the transgender community all enabled HEAT’s ability to implement the project. Fortunately, HEAT was able to secure a partial restoration of funds. While this was extremely helpful in stabilizing HEAT’s services to some of its former capacity, the damage to HEAT’s ability to implement the Infini-T project was already done. The additional funding will contribute to HEAT’s sustainability of its enhanced services for HIV+ transgender young women of color once the SPNS project is completed.

Staff hiring

HEAT and HMI had the responsibility of hiring respective staff within their agencies while remaining in frequent contact throughout the process. HEAT hired existing staff whose transgender expertise was essential to the project. HMI hired a Transgender Youth Services Specialist, with deep roots and connections within the transgender youth community. Synchronous with the hiring and training process, HEAT subcontracted with a TG Health Consultant to work together to develop the curriculum for implementation of JOG, Infini-T’s retreat format group-level psycho-educational intervention for transgender young women enrolled in the project.

Initial training and development

Training was ongoing throughout the entire length of the project. Infini-T staff were constantly encouraged to attend trainings on and off site, including webinars. In replicating a program like this, training is vital and must be intensive and ongoing. Topics included, Cross Gender Hormonal Treatment of Transgender Individuals, Transphobia - Reducing the Risk and Harm, Transgender People and HIV, HIV and Hepatitis C, HIV and STDs, Being Transgender and Navigating the Healthcare System, Transgender-Related Stigma, Mental Health and HIV, Depression and HIV, Benefits training, Legal Aspects of Identity Documents for Transgender People, Substance Use and Abuse, Nicotine Addiction and HIV, Opportunistic Infections, Adolescents and HIV, Working in a Multidisciplinary Team, Presentation Skills, Disclosure of HIV Status, Disclosure of Transgender Identity, Transgender Cultural Competency, and others.
Developing MOU’s and Partnerships

The relationship and partnership between HEAT and HMI was already established through a variety of other projects and maintained throughout the project. Despite the difficult time that HEAT was having due to reduced funding, the partnership between the two agencies remained strong throughout and retained effective working relationships. Monthly meetings between sites were helpful in keeping buy-in and engagement of key staff throughout the project. These strong working relationships became essential to rely on when staff issues arose later on during the project, in particular with respect to the Transgender Youth Services Specialist. Shared and coordinated responsibilities of supervision across both agencies evolved due to the strong nature of the relationship.

Developing administrative and provider support buy-in

Given the overlapping programmatic goals of HEAT and HMI, both programs had a strong level of administrative and provider buy-in for Infini-T from the outset. Administrative and provider buy-in, as well as deep understanding of Infini-T’s goals assisted in integrating the HMI-based Transgender Youth Services Specialist position as intended into the HEAT clinical and Infini-T project team. HEAT and HMI already had a successful track record in working with HIV+ young men who have sex with men on patient navigation and escorting youth to appointments at HEAT to build upon. This experience was transferable onto working with HIV+ transgender young women. After Infini-T’s launch, there were challenges for HEAT and HMI being able to jointly manage front line staff when differences of management styles between the two agencies led to delays in managing staff issues as they arose. Once it was determined that these different management styles of HEAT and HMI themselves were contributing to leaving staff issues unresolved, it was the administrative buy-in from both agencies and longstanding relationships between both which led to quickly developing effective joint strategies to address these problems. These issues and how they were dealt with are explained further in the Implementation Barriers and Facilitators section of this monograph.

Fixed monthly administrative meetings, intensive supervision and coordination between the HEAT program coordinator and the HMI on-site supervisor were all the result of administrative and provider buy-in. The level of coordination at this level throughout the project worked exceptionally well, although the project could have been much more successful if the need for a more intensive level of interagency coordination needed was understood much earlier.

Developing patient recruitment strategies

Infini-T launched with the patient recruitment strategy that was proposed in the initial SPNS application. This strategy was that HEAT would build upon its track record of accepting referrals for TG care for TYWOC from a variety of youth agencies across NYC by enhancing its collaboration with HMI. HMI would expand its on-site community-based services for TYWOC by not only providing a safe space for them for individual and group activities but also providing HIV testing on-site and referrals for both HIV and TG medical care at HEAT. All current HIV+ transgender women of color who were patients previously in care at HEAT...
were approached for enrollment in Infini-T and the multisite project evaluation. Additionally, HEAT offered participation and enrollment to any newly identified HIV+ transgender woman of color entering care throughout the full project period.

HEAT expanded its eligibility criteria to include HIV+ transgender young women of color up to age 29 and also to include participants who were in care at other sites with a multidisciplinary model. HEAT was easily able to engage participants who had age-transitioned out of care to its on-campus HIV care partner at SUNY-DMC, the STAR Health Center.

**IMPLEMENTATION BARRIERS AND FACILITATORS**

Infini-T had many barriers to successful implementation, some of which are a reflection of project staff being members of the target population of the project themselves. The boundary issues for some project staff needed to be addressed with supportive and sometimes intensive supervision for the individuals in these challenging job roles. Staff turnover at HMI also undermined HMI’s ability to meet its referral commitments to HEAT and engage the target population in care resulting in low Infini-T project enrollment into Infini-T. HEAT and HMI’s leadership worked closely together to develop an effective joint supervisory structure across both programs. This enhanced need for supervision at the level that was required was a barrier to implementation that was not anticipated.

Other barriers the Infini-T project encountered were those previously mentioned implementing the group-level intervention “Just One of the Girls”. While JOG’s initial piloting started out with some level of successful implementation, the challenges the project had with implementation continuously compounded resulting in the eventual cessation of activities on the group level intervention. Given the other challenges the project faced, this was a significant loss to the project.

JOG itself had many participant-level barriers. Many of the young women expressed not feeling comfortable participating in the group-level setting, especially one that had any mention of HIV. The participants also presented with specific life challenges that made participation in a day and a half retreat intervention group problematic. Some participants would come for one day but not the other day. This led to a shift from the weekend retreat model to a weekly model which did yield improved attendance, but staff turnover and other personnel issues resulted in discontinuing JOG, despite the fact that we still believe it would be a replicable intervention for other programs to employ.

Infini-T additionally had some strong project facilitators. HEAT and the Infini-T project had a strong rapport and reputation with the transgender community it was serving throughout the project. The project had significant
input from community members at its annual Community Advisory Group meetings and during its piloting of JOG. Although JOG had other problems cited as barriers, the community support of it was still of value. HEAT had a Peer Youth Advocate staff member who was a transgender young woman of color herself. She functioned at a high capacity throughout the project from beginning to end and helped put a representative community member on the clinic staff to make the participants feel welcome and represented their concerns from the moment they walked in the door. The one-stop shop clinic model was also a facilitator in that youth could get their transgender, HIV, and mental health care services as well as case management all in one location at the same time. Provision of MetroCards for the NYC subway system was a transportation facilitator which enabled participants to get to their appointments was an important facilitator. Finally, the project staff at HEAT itself was culturally competent to working with transgender youth and highly committed to the project. All project staff remained at HEAT throughout the duration of the project. The continuity of staff was a major facilitator in this sense for the participants enrolled in the project.

SUSTAINABILITY PLANNING

In spite of the parts of Infini-T which could not be successfully implemented, HEAT’s successful demonstration and experience in using the multidisciplinary care model will continue to be utilized. This model is an example of “Centralized HIV Services”, a model now cited by HRSA’s Ryan White Part D as a recommended care model for HIV+ youth. In Infini-T’s case, HEAT added to this model multidisciplinary elements of services specialized for transgender youth. Various elements of Infini-T will be absorbed into HEAT’s programming as funding permits.
INTERVENTION OUTCOMES

We have examined baseline data but have not yet evaluated longitudinal data on participants. We have two sources of data: a patient survey and our local group evaluation, Just One of the Girls (JOG).

SUNY Infinit-T baseline data is described below.

**TABLE 1. Sociodemographic Characteristics of Participants (N=23)**

<table>
<thead>
<tr>
<th>Age Range 19-34, Md=24</th>
<th>#Yes</th>
<th>%Yes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Education, HS or higher</td>
<td>14</td>
<td>60.9</td>
</tr>
<tr>
<td>Race/ethnicity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>African American/Caribbean</td>
<td>12</td>
<td>52.2</td>
</tr>
<tr>
<td>Afro-Latina</td>
<td>4</td>
<td>17.4</td>
</tr>
<tr>
<td>Latina</td>
<td>6</td>
<td>26.1</td>
</tr>
<tr>
<td>Other</td>
<td>1</td>
<td>4.3</td>
</tr>
<tr>
<td>Insurance</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medicaid</td>
<td>18</td>
<td>78.3</td>
</tr>
<tr>
<td>Medicaid &amp; Medicare</td>
<td>4</td>
<td>17.4</td>
</tr>
<tr>
<td>None</td>
<td>1</td>
<td>4.3</td>
</tr>
<tr>
<td>In last 6 months borrowed money to get by financially?</td>
<td>16</td>
<td>69.6</td>
</tr>
<tr>
<td>Total income in the past year ($)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 600</td>
<td>6</td>
<td>26.1</td>
</tr>
<tr>
<td>600-2,999</td>
<td>6</td>
<td>26.1</td>
</tr>
<tr>
<td>3,000-5,999</td>
<td>3</td>
<td>13.0</td>
</tr>
<tr>
<td>6,000-11,490*</td>
<td>1</td>
<td>4.3</td>
</tr>
<tr>
<td>11,491-15,282</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>15,283-35,999</td>
<td>1</td>
<td>4.2</td>
</tr>
<tr>
<td>36,000-59,999</td>
<td>2</td>
<td>8.7</td>
</tr>
<tr>
<td>NA</td>
<td>4</td>
<td>17.3</td>
</tr>
</tbody>
</table>

* Federal Poverty Level for single person in 2016 is $11,880
Although the full evaluation of the longitudinal survey and clinical data is ongoing at the time of this writing, some of the baseline findings of our cohort were quite striking. In summary, what our baseline data show is that:

1. Approximately 70% of participants are living at or below the Federal poverty level.
2. Participants had an overwhelming exposure to violence and transphobia.
3. Participants reported significant intimate partner violence, earlier childhood sexual abuse, and mental health utilization.
4. Although there were some participants that fully answered HIV related questions, for many others several sections/domains of HIV related questions were not answered at all, suggesting HIV-related stigma or not wanting to think about HIV.
5. The participants had a relatively high engagement in transgender care.

**JOG (JUST ONE OF THE GIRLS)**

Although JOG’s implementation was dropped mid-project making a meaningful evaluation of the outcomes difficult, data collected during the sessions that were held still provided some important information.

JOG was designed to be a weekend retreat for the participants. Its aims were to both inform about transgender health, empower transwomen of color to feel valued and have deeper self-worth, and to educate about HIV risks. The modules covered across the weekend retreat were Gender Identity and Gender Pride, Coming out to Family and Friends, Navigating the Health Care System, HIV/AIDS & STI Education, Gender Transitioning through Hormone Therapy and Body Transformation. In our first session, which was a pilot with 10 participants, there were no differences in HIV knowledge between pre- and post tests, but there was a trend towards taking more seriously HIV risks and ways to avoid them. It was clear to the project team that more content about HIV disease and treatment needed to be added to subsequent cycles. Most participants found the sessions useful. The findings from the instruments used to evaluate each session revealed some informative and insightful findings. The participants generally rated the group facilitators very highly. The use of facilitators who were transgender women of color themselves was a key point in the feedback that was reiterated by the participants. The subject content was also rated highly by the participants, with the HIV related content getting slightly lower ratings, a finding somewhat consistent with our baseline survey data findings cited above where participants frequently skipped answering HIV related survey questions.

In a second JOG group facilitated by the HEAT and HMI peer youth staff in 2015, the staff wrote extensive notes about the sessions, and these are paraphrased below and on the following page.

1. The older participants had a little more knowledge than those that were younger. It was also evident that those that had known that status for a while versus those whom were newly
diagnosed with HIV were more willing to participate. It did provide a space for those that were newly diagnosed to hear those who had experience navigating the health care system.

2. It would be conducive to provide a booster session, to reinforce things they learned.

3. Younger participants needed more feedback to be redirected back to the topics at hand.

4. The older participants, being more aware and knowledgeable need a modified curriculum that is geared towards them to keep them engaged.

5. The modules are excellent but repeating them without any adaptations would not add value. They need new or re-packaged material to hold their interest.

APPROXIMATE ANNUAL INTERVENTION COST

The approximate annual cost of the intervention is $300,000 in direct costs, including all costs, direct, indirect, personnel, evaluation, etc.

In trying to break this down into a per participant cost for enrollment and retention in care, we ran two analyses, one for on-site participants only and the other for all sites. The methodology for the on-site participants only was to take the cost of all on-site personnel inclusive of clinic staff, peer staff and administrative staff and dividing it by the number of participants enrolled on-site. Using this methodology, there was approximately $150,000 spent on 9 enrollees, yielding a cost of $16,667 per participant annually. While this cost seems relatively high on a per participant level, youth focused care generally is considered more labor intensive and more expensive. This would be even more true for youth-focused transgender care with the population Infini-T served. It should be noted that this per-participant cost yielded high rates of retention in both HIV care and transgender care while yielding high rates of viral load suppression.

Project wide for all Infini-T participants referred from other care sites, the methodology used was to take the on-site costs together with the costs of sustaining HMI, where the off-site participants were engaged for enrollment and dividing that by the total cumulative number of Infini-T participants enrolled. Using this methodology, there was $215,000 spent on 23 enrollees, yielding a per-participant cost of $9,348. The service intensity required for the off-site participants was significantly lower, explaining most of the difference between the two cost levels.

LESSONS LEARNED

The replication of Infini-T is based on the importance of acknowledging the unique needs of HIV+ youth and the specific elements of care required for engagement, retention and viral load suppression. The model which best matches meeting these needs is the Centralized HIV Services model. Although HEAT has effectively utilized this model since 1992, it was not formally acknowledged by this name until recently. For
younger HIV+ transgender women of color, this is the best model for programs to employ acknowledging that this model is resource intensive and requires dedicated staff with adolescent and young adult healthcare expertise. In spite of the many challenges and adverse situations that HEAT faced with its implementation of Infini-T, this program model remained a constant and was the major factor in retaining HEAT’s cohort of HIV+ transgender young women of color in care during the project.

The other major lesson learned is that of professional development, maintenance of professional boundaries and the level of staff supervision required when working with such a high need population. Focused supervision tailored to agency circumstances is necessary to keep project staff grounded in the work being done. Other professional skills should be considered as a part of training for peer project staff who may have less experience working in a hospital or clinic setting, especially when encountering larger facility staff who may be lacking in basic transgender cultural competency or workplace expectations expected from staff to be on a regular work schedule, especially when their clients may be contacting them at times independent of that work schedule. Peer staff must have endless amounts of support, praise, and encouragement along the way. Peer staff should learn boundaries, especially knowing when it is in their best interests to “turn the job off” after the work day is finished. Integrating the peer model into clinical and hospital settings can be challenging, but once the success is seen and administrators continue to demonstrate the crucial role peers can have, integration will happen with much more ease, and acceptance of transgender women as peer staff can be established. Collecting and sharing data to help them see the success more quickly can also be a facilitator in success of such a program or intervention.

**USING EVALUATION DATA TO INFORM PRACTICE**

Data were utilized to inform staff about overall progress of the project. Monthly team meetings to review enrollment and retention of participants informed the team early on what they already knew: it takes multiple efforts through multiple means to engage and retain participants in care. Participants were contacted through phone, text, Facebook, other social media web sites, through other providers, and face-to-face contacts HEAT, HMI, or other locales. The team knew each of our 23 cases well, so the needs and terms of TYWOC engagement became clear and common knowledge among the team members.

Examination of the baseline data informed the project in two important domains: 1) childhood sexual abuse (CSA) and 2) pre-occupations of young transgender women. Half the youth reported childhood sexual abuse, which is probably under-reported. For these youth, it means that they are at extremely high risk for continued sexual risk-taking and other adverse exposures. These youth need
intensive in-person, programmatic work to find self-esteem and self-worth, and it is not surprising that youth are difficult to retain, given the chaos and abuse they have been subjected to. Second, we found that many youth skipped sections of the patient survey that had to do with HIV and HIV care. But, youth did complete sections of the survey about appearance, transgender care, and the like. Youth appeared to be more interested in some of the survey questions that were age and developmentally appropriate to what youth are more typically interested in: their appearance and their presentation of self to others. Programs seeking to implement interventions similar to Infini-T should keep this in mind when working with youth. Activities which focus on body image and appearance may be useful tools to engage and retain TYWOC in care.

Contrariwise, researchers wanted to know about youth’s HIV care to keep them in good health. In the future, surveys that we develop or surveys that we utilize as part of other projects, need to consider what is important to youth. So, this might mean that for HIV-related data, that face-to-face interviewing may be the best method to get data. Issues closer to their daily lives, appearance, stigma, and other social factors may be collected by computer-administered surveys.

As an extension of how these recommendations on how to collect meaningful survey data from youth, implementation of programming and interventions also require an understanding of what is important to them. Having age and developmentally appropriate services to address the unmet needs of TYWOC, as well as youth-focused activities are all important tools in engagement and retention in care.
API WELLNESS CENTER AND THE SAN FRANCISCO DEPARTMENT OF PUBLIC HEALTH: TRANSACCESS

Janell Tryon, MPH

Royce Lin, MD

Kate Franza, LCSW

Corresponding Authors:
Janell Tryon, MPH
San Francisco Department of Public Health
472 43rd Street, Oakland CA 94609
janell.tryon@gmail.com

This intervention is dedicated to the clients of the TransAccess Clinic, and to all those who fight for equality, health, and justice for trans and gender non-conforming peoples everywhere.
CONTENTS

Evidence of Need ................................................................. 122
Program Description ............................................................ 124
Intervention Outcomes ......................................................... 134
Lessons Learned ................................................................. 137
References ................................................................. 140
Intervention Appendix ............................................................ 141

PREFACE

This intervention chapter distills the experiences and lessons learned from the TransAccess clinic, a federally-funded demonstration project intended to improve engagement and retention in care for transgender women of color living with HIV. It seeks to provide readers with the tools to implement a gender-affirming and holistic HIV primary care program for transgender women of color, while maintaining a safe and caring environment. Throughout, we will address what we consider to be the central tenets and themes of the TransAccess philosophy and the core responsibilities of the clinic and case management staff.

We will close with lessons that our team has learned and how we have adapted the intervention to incorporate these lessons as we continue to grow our program. This manual continues a tradition of sharing knowledge within the medical community, while incorporating insights from behavioral health, addiction medicine, social justice movements, and the wisdom shared with us by our client and staff community.

INTRODUCTION

TransAccess is a Special Projects of National Significance (SPNS) demonstration project initiative to design, implement and evaluate innovative interventions to improve timely entry, engagement, and retention in quality HIV care for transgender women of color (TWOC) living with HIV. The primary focus of this initiative is to identify and successfully engage and retain in care transgender women of color living with
HIV – particularly women who are not engaged in medical care, or those who are poorly engaged in care. Strikingly (but not surprisingly), our clients who are the least engaged in care, are also those who are the most profoundly affected by concurrent stressors including unstable housing, poverty, substance use, mental health problems, and recurrent gender-based traumas.

While over the course of the TransAccess project we have served a patient population of staggering medical acuity and psychosocial complexity—*22% of TransAccess clients are in the top 5% of medical utilizers in the San Francisco public health system*—it is nonetheless possible to achieve a high rate of virologic suppression in this hard-to-reach and extremely vulnerable population. A monthly assessment of TransAccess program outcomes finds that on average, 60-70% of TransAccess clients have an undetectable HIV viral load (<200 copies/mL). In our experience, what it takes to achieve these results are two essential organizing principles – or roughly speaking, the “what” and the “how” of a successful program:

1. **What:** A program model that integrates:
   a. trans-affirming medical care: medical care that integrates and prioritizes client’s gender identity, experiences, and the clinical interventions necessary to affirm gender
   b. intensive psychosocial and behavioral health support
   c. community empowerment/affirmation

   All 3 components are vital to a successful program model.

2. **How:** An approach to care that is:
   a. trauma-informed: using the standard trauma-informed model with our clients and understanding of the prevalence of trauma in a client community like TransAccess
   b. radically accepting (of client norms, priorities, and values).

**EVIDENCE OF NEED**

**NATIONAL & LOCAL EPIDEMIOLOGY**

Because public health data on transgender individuals living with HIV is inconsistent (many transwomen are still classified as men-who-have-sex-with-men, or “MSM”), we gathered evidence of need at the time of our SPNS application from urban needs assessments and risk behavioral studies. Disproportionately high rates of HIV prevalence among transgender women, and especially among transgender women of color, have been documented in studies throughout the United States. Data collected nationwide through CDC-funded HIV testing programs, for example, demonstrated that among 2.6 million HIV antibody tests conducted in 2009, new infections were identified in 2.6% of transgender people, compared to 0.9% for cisgender males and 0.3% for cisgender females (CDC 2011). Transgender women of color were by far the
group most heavily impacted with an overall positivity rate of 4.4% among African American transgender women and 2.5% among Latina transgender women (CDC 2011).

At the time the Asian & Pacific Islander Wellness Center and the San Francisco Department of Public Health applied for a SPNS grant, a body of literature had amassed regarding transgender women and HIV specifically in the San Francisco Bay Area. Studies of HIV prevalence in San Francisco yielded self-reported HIV positivity rates ranging from 22% to as high as 60% among transgender women of color, along with positivity rates based on HIV testing of between 33% and 63% among African American transgender women (Ramirez-Valles 2010). Throughout the duration of the TransAccess intervention, transwomen of color, particularly those who identify as Black/African-American, have been a demographic disproportionately at risk for HIV infection, nationally and locally.

After the TransAccess clinic opened in 2013, data continued to support a need to support transwomen living with HIV. In 2013, a meta-analysis (Baral et al. 2013) showed that the estimated HIV prevalence among transgender women was 22% in the United States and four other high-income countries. While it is uncertain exactly how many transgender folks live in San Francisco, recent studies report an estimate of 0.6% of adults in the United States, who identify as transgender (Flores et al. 2016). Although California has a higher concentration of transgender and gender non-conforming residents than national numbers, at .76% (Flores et al. 2016), transgender people are still disproportionately affected by HIV, compared to their cisgender counterparts. As recently as 2014, the
San Francisco HIV Epidemiology Annual Report found that transwomen—or “transfemales” as the report states—make up 2% of the 15,979 living cases of persons with HIV (SFDPH 2014).

Moreover, transgender folks experience significant difficulties when attempting to access all types of health care, and due to fears of discrimination, provider insensitivity, hostility and lack of knowledge about transgender health, many avoid care altogether (Sanchez et al. 2009). Transwomen of color are at the intersection of marginalized communities and are more likely to have experienced a multiplicity of stigma in healthcare and the community, at large. TransAccess, therefore, set out to address the many barriers faced by San Francisco’s transgender women of color who are living with HIV, starting with the clinical environment and working from there to advocate for transwomen of color, locally and nationally.

PROGRAM DESCRIPTION

ORGANIZATIONAL BACKGROUND

In 2012 TransAccess forged a unique public/private partnership model: the medical services of Tom Waddell Health Center, a public community health clinic that specializes in transgender medical care, were integrated into TRANS:THRIVE, a highly respected and trusted community-based transgender support program at Asian & Pacific Islander Wellness Center. This partnership has operated with the explicit goal of enhancing utilization of and retention in HIV medical care by underserved transgender women of color. The program created a unique neighborhood-based transgender medical home and a weekly clinic specifically designed to address the complex needs of this critically impacted population. API Wellness Center/TransAccess is centrally located in San Francisco’s Tenderloin district – which holds most of San Francisco’s homeless/marginally housed populations and is home to many low-income trans and gender non-conforming peoples. The TransAccess team has provided HIV primary care and psychiatric services to transgender women of color on Wednesday and Thursday afternoons since the clinic opened in 2013. TransAccess is committed to creating a safe, welcoming, and respectful environment for transgender women of color.

The Tom Waddell Health Center is one of 12 public FQHC clinics that make up San Francisco’s Community Oriented Primary Care Program. Since 1994, Tom Waddell Health Center has operated Transgender Tuesdays, a nationally respected primary medical home providing services specifically tailored to the needs of low-income transgender individuals. With over 400 active patients, the Transgender Tuesdays clinic offers care through a highly skilled, multi-disciplinary medical team, which has many decades of combined expertise in serving and supporting transgender women of color. The program utilizes a harm reduction model and a trauma-informed care approach tailored to the social, economic, and political realities of our clients. Services provided by the medical team include comprehensive HIV medical care, transgender care including medically supervised hormone therapy and other gender-affirming treatments, medical social work, and psychiatry.
Asian & Pacific Islander Wellness Center (API Wellness), Tom Waddell’s partner agency, is a non-profit, multi-service community-based agency established in 1987 to address the AIDS crisis. API Wellness operates the HIV Care Program, which provides case management, mental health counseling, and substance use counseling for persons living with HIV. Additionally, API Wellness is home to the Wellness Clinic, the city’s newest FQHC, which provides primary medical and psychiatric services to low-income and uninsured individuals. API Wellness’s TRANS:THRIVE, the agency’s flagship program for transgender clients, serves 600 unique clients annually, making it the largest program of its kind in the nation. TRANS:THRIVE offers a wrap-around transgender-specific drop-in center, which operates five days per week and offers social programs, leadership development, support groups, psycho-educational workshops, psychotherapy, and case management. This program provides the backdrop and support network for the TransAccess clinic.

**PROGRAM BASICS**

**What**

The program combines on-site primary care (MD and RNs with joint HIV and transgender health expertise, plus behavioral health services including medical social work and psychiatry) staffed by the Tom Waddell Health Center, with enriched wrap-around services provided by the API Wellness (including 5 days/week, on-demand case management and peer navigation; drop-in community support services, and weekly group sessions offered for community members to discuss risk reduction, coping skills, and shared successes). All staff within TransAccess utilize a harm reduction model.

TransAccess provides care to all eligible clients and recognizes that the model needs to adapt to the needs of the community; therefore, clients may enter into one of two variations of the model:

- **Full intervention:** at any given time about 75% of our client base is receiving the full intervention, meaning that they receive primary care (clinician and nursing), as well as psychosocial auxiliary services, such as behavioral health, psychiatry, case management, peer navigation, and drop-in services.

- **Support services only:** for those clients who are satisfied with their current primary care services, this variation provides the full scope psychosocial auxiliary services, including behavioral health, psychiatry, case management, peer navigation, and drop-in services. The remaining roughly 25% of our clients opt into support services only.

**Where**

The TransAccess program is a neighborhood-based medical home that operates out of API Wellness with the collaboration of Tom Waddell staff, in the historically underserved Tenderloin District of San Francisco.
When

Every Thursday from 1-6 pm, API Wellness hosts the TransAccess Clinic, which specifically provides HIV primary care, trans-affirming medical care, and all support services to transgender women of color in a setting that is safe, welcoming, and respectful of transgender populations and their needs. The first hour is dedicated to a support group that is run for and by transwomen of color. While this group was not part of the original framework for TransAccess, it emerged organically to provide a sense of community on clinic days.

Halfway through the TransAccess project, the team identified the need for increased mental health support and added a half-day of access to the Tom Waddell mental health team. Every Wednesday from 1-6pm, the LCSW and psychiatrist provide appointment-based and drop-in services to clients, so as to increase their access to mental health services, counseling, and psychiatry

CORE VALUES

We started TransAccess in 2012 with a general vision of the kind of care that HIV+ transgender women of color deserve, informed by the experiences of seasoned HIV care and transgender health providers. In the 5 years of our clinic’s operation, our daily work with our clients have taught all of us – clients and providers alike – what it takes to meaningfully and sustainably provide care and support for this highly-impacted, yet vibrant and resilient, population.

Through many conversations with our clients, focus groups, team retreats, and reflections from every TransAccess team member across multiple disciplines, we have distilled some of our best lessons learned into a set of core values that serve as guiding principles for every aspect of our work.

Many care models exist for the provision of HIV services to underserved populations. In our experience working with HIV+ transgender women of color, our clients consistently tell us that it is our approach to care—more than the model itself—that drives our high rate of engagement and retention.

The following values embed best practices for HIV care and treatment while imbuing each with the TransAccess philosophy:

- **Trans-affirming care:** we create a psychologically and physically safe environment that enhances trans-visibility and the voices of clients in the clinic community
- **Self-actualizing services:** we ground our provision of services in the rights, values, and preferences of the client
- **Mindful medicine:** our medical care and clinical interventions are grounded in a psycho-social and holistic understanding of the client
- **Care coordination and continuity:** we coordinate any and all types of services and assistance to meet the client’s identified needs, so that care is continuous from linkage to adherence
• **Harm reduction:** we use a non-judgmental, non-coercive, and de-stigmatizing approach in order to assist clients in minimizing risk in their environments

• **Community-centered:** we maintain that belonging (to a family, a tribe, a movement, or indeed, a community) is a central aspect of an individual’s health and wellbeing—all the more so for individuals who have historically not belonged, been actively excluded and/or othered. This is why we consider “a sense of community” to be a health outcome, on par with traditional physical health outcomes, such as blood pressure or viral load. Promoting and nurturing an individual’s journey toward belonging and inclusiveness is a healthcare responsibility.

• **Radical healthcare:** we maintain a commitment to ending transphobia and poor health outcomes in trans and gender non-conforming peoples by contributing to the body of trans-health research, exploring and integrating the boundary between medicine and social justice, disrupting conventional models of care and embracing alternate models and approaches that provide a level of care and support that is commensurate to and sufficient for the disproportionately intense medical and psychosocial needs of our clients. We have integrated a social justice lens by inviting staff and clients to participate in local and regional activism, testimonies, and movement-building.

**CASE CONFERENCE & CARE PLAN**

When interviewed about their roles and the unique philosophy of our intervention, staff consistently reported that our hour-long weekly case conference was an absolutely essential part of our program. Each Thursday, before clinic opens to clients, all team members gather for an hour to discuss client updates, changes to care plan, evaluation needs, and goals for the week. With such high-acuity clients, across medical and psychosocial domains, it is crucial to allow your program staff to coordinate client treatment plans and for all team members to provide input. Having a clear, but flexible, plan invites clients to weigh in on their treatment, ensuring their agency in determining their healthcare.

The care plan or treatment plan, as mentioned throughout the manual, reflects the shared objectives agreed upon by the client and the team. This plan includes goals for HIV primary care, transgender care, gender-affirming procedures and surgeries; living environment; benefits attainment; and all objectives within the psychosocial domain. The development of the care plan is an interactive process that encourages the client to actively participate in the decision-making process related to her/their care, support, and treatment. The purpose of the care plan is to:

• document and organize/plan for comprehensive support services and to promote continuity of care at a level that is desirable to the client;

• demonstrate a relationship between actions and the wants, needs, strengths, and limitations of the client as documented in the client assessment;

• ensure that the care plan is a realistic reflection of what the client and the case manager can accomplish together for the benefit of the client;

• provide an ongoing, living agreement for the client and the team.
THEORETICAL BASIS

ACHIEVING AND MEASURING OUTCOMES

As a means of achieving the overall goal of improved health outcomes for transwomen of color living with HIV in the San Francisco Bay Area, TransAccess has implemented a number of measurable outcome objectives. The Logic Model (see VIII. Appendix Section 1) outlines those inputs and activities that contribute to tangible outputs, products of the program, and ultimately metrics for evaluating the project’s outcomes.

The logic model inputs, activities and outputs of TransAccess result in measurable outcomes, designed to provide a means of assessing how well TransAccess utilizes resources to achieve its goal. Given the aims of this SPNS intervention, TransAccess prioritized high retention rates in care when developing the intervention. While our partners at Tom Waddell Urban Health Center had successfully paved the way for linking TWOC to care, TransAccess aimed to improve retention and continuity of care. With that said, we did not establish a target retention rate until one year into the recruitment of clients, once we were able to review client trends and coordinate realistic objectives with other demonstration sites in the Bay Area.

In 2014, HRSA released the RSR Report, which disaggregates Ryan White data into particular populations; this helped our project get a better sense of how Ryan White programs nationwide were doing in terms of retaining high-acuity populations. While at first glance, retention rates from transwomen living with HIV seem reasonably high. For instance most age groups range from 75-100% retention, with young transwomen (age 20-24), having the lowest retention rate at 69% (RSR 2014). Yet, once you filter by race and housing status, the rates shrink. Transwomen experiencing unstable housing—our target demographic—average a retention rate of just 66%; in this category, Black/African-American transwomen, who are unstably housed, have the lowest retention rate at 61% (RSR 2014). For context, the average retention rate for accessing primary care for the general population of folks living with HIV that same year was 80.4% (RSR 2014). Our desired outcome was then projected at retaining 75% of clients across the entire TransAccess client cohort.

Outcome objectives for prescribing ART were decided internally. We were committed to providing our clients with access to ART; however, for our population, many clients were not realistically ready to start ART, due to environmental, medical, and psychosocial factors. We, therefore, set our outcome at 90% for ART prescription. Rates for viral suppression, defined as <200 copies/mL in most recent viral load test, show similar outcome gaps for transwomen. Similarly, transwomen with unstable housing average a suppression rate of 53%, compared to a viral suppression rate of more than 81% for the general population (RSR 2014). Black/African-American transwomen, who are unstably housed, have the lowest viral suppression rate at 50.7% (RSR 2014). Our desired outcome was then projected at achieving viral suppression among 60% of clients, for those receiving the full intervention—meaning, they access our primary care provider onsite.
PROGRAM OPERATIONS

STAFFING TRANSACCESS

The TransAccess program is made possible by an integrated and dedicated team. The team is comprised of many key players, from both APIWC and the Tom Waddell Health Center:

<table>
<thead>
<tr>
<th>Title</th>
<th>Full-time Effort (FTE)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Peer Navigator</td>
<td>1-2 at 1.0 FTE</td>
</tr>
<tr>
<td>Senior Case Manager</td>
<td>1 at 1.0 FTE</td>
</tr>
<tr>
<td>Medical Doctor (Internal Medicine or Family Medicine with HIV/Transgender experience)</td>
<td>1 at .20 FTE</td>
</tr>
<tr>
<td>Medical Doctor (Psychiatry)</td>
<td>1 at .1 FTE</td>
</tr>
<tr>
<td>Registered Nurse</td>
<td>1-2 at .15 FTE</td>
</tr>
<tr>
<td>Medical Assistant</td>
<td>1 at .1 FTE</td>
</tr>
<tr>
<td>Licensed Clinical Social Worker</td>
<td>1 at .2 FTE</td>
</tr>
<tr>
<td>Researcher-Evaluator</td>
<td>1 at .5 FTE</td>
</tr>
<tr>
<td>Program Director/Manager</td>
<td>1 at .5 FTE</td>
</tr>
</tbody>
</table>

While the above breakdown represents the ideal staffing model for TransAccess and like programs, other models should account for staffing fluctuation. Over the course of the five year intervention, TransAccess saw significant fluctuation, particularly in staffing the role of peer navigator. For this reason, adequate and ongoing training is integral to the success of staff, especially for peer navigators, who are at risk of burn out and attrition.

Peer Navigator Training

- Health Insurance Portability and Accountability Act (HIPAA) and how to safeguard client’s personal health information (PHI)
- HIV 101: the basic principles of HIV care and treatment
- Direct mentorship senior by senior case manager to support and facilitate the implementation of client’s treatment plan
• Supervision: Weekly supervision with senior case manager, with a focus on minimizing the harmful effects of vicarious trauma and ensuring ongoing self-care

• Additional support and mentorship from the LCSW/behavioral health clinician

• Professional development goals and opportunities discussed quarterly with Program manager/director

The Clinic Flowchart (see IX. Appendix Section 2) breaks the TransAccess program down into the roles each staff person plays and which key program components their position oversees. The first step—Referral and Linkage—is anecdotally attributed to word-of-mouth recruitment during the nursing and/or primary care intake. Most often, clients are referred to Trans Access by another client, or word-of-mouth.

PEER NAVIGATION

“This job keeps us evolving. It’s not just that you are learning, professionally, from the staff and the clients, but you evolve in your personal life: medically, spiritually, holistically.”

–SG, Peer Navigator

“I see now why this program works: the combined passion—and compassion—of everyone on the team means it can’t not work.”

–TDLC, Peer Navigator

The Peer Navigators on the team provide hands-on support to the client in order to actualize the care plans made by the team as new clients enter the program. A secondary role of peer navigators is to provide general support for clients, which often comes down to listening, to help our clients manage the erosive effect of daily life stressors, micro and macro aggression due to societal racism, transphobia, and HIV stigma. Our peers are both trans-women of color and cite their similar experiences to clients as a key reason that can provide effective on-the-ground support. Unlike the medical and mental health staff, clients can access peer navigators five days a week, on a drop-in basis. The key responsibilities of this position include:

• supporting each client to actualize her care/treatment plan
  • care/treatment plan established at time of client entry
  • plans are then modified, as needed, during weekly case conference

• providing care navigation to all clients
  • assisting clients with keeping and getting to appointments, esp. primary care visits and referrals to specialists
  • supporting clients at other agencies and government organizations (e.g., accompanying clients to Social Security for enroll for benefits, signing up for insurance at MediCal office, etc.)
• conducting outreach
  • including home visits for clients who have fallen out of care, or require additional outreach and support (e.g. emotional support and encouragement) to access medical care

• maintaining daily communication with client
  • text message
  • social media
  • phone calls
  • in-person meetings

• providing community, support, and affirmation for any aspect of day-to-day life, such as: coping with stress, societal transphobia, micro and macro aggression, housing insecurity, and so on

• charting all interactions with clients in Ryan White database and in Intervention Exposure Data form

• increasing health and navigation literacy
  • goals regarding systems navigation are integrated into care/treatment plan
  • peer navigators first escort clients to appointments and model systems navigation

CASE MANAGEMENT

“You have to get in the nooks and crannies of our community to find the people who will support our clients.”

—SS, Senior Case Manager

The Case Manager on the team provides consistent support to the client in order to actualize the objectives made by the team and client. Like our peer navigators, the case manager has an open door policy, meaning the clients can access her on a drop-in basis. The key responsibilities of this position include:

• providing medical case management to all clients
• setting care/treatment plan with team for all clients, in conjunction with client and full care team
• supervising peer navigators in implementation and actualization of care plan
• maintaining open communication with clients
  • text message
  • phone calls
  • in-person meetings
• coordinating and tracking appointments for:
  • housing
  • emergency housing/ shelter
  • transition programs
• treatment/detox
• permanent residence
• specialty medical care, not provided onsite
• health insurance
  • interface with MediCal, Medicare, etc.
• benefits programs
  • food assistance programs
  • emergency AIDS funding programs
• completing all referrals to housing and other community support programs
• coordinating our Digital Storytelling workshops, wherein clients participate in a workshop that trains them to tell a part of their story with the aid of images, music, and narrative techniques
• charting all interactions with clients in Ryan White database and in Intervention Exposure Data form
• retaining high risk/high acuity clients in HIV primary care

SOCIAL WORK & PSYCHIATRY

Social Work/Behavioral Health Clinician

“The system has not served transgender women, particularly women of color, well. A huge part of our work is advocacy: help change the system so that it may better serve our clients and help our clients succeed in programs.”

–JM, Social Worker

The Social Worker on the team plays a crucial role in this intervention, by serving as a behavioral health clinician and point-person for all mental and behavioral health program as well as liaising between the San Francisco Department of Public Health systems and the onsite TransAccess initiative. The key responsibilities of this position include:

• Conducting psychosocial and mental health assessments to identify clients’ behavioral health needs
• Determining and making optimal referrals to psychiatry, psychotherapy, and/or other mental and behavioral health programs
• Triaging and managing urgent psychosocial needs, including “5150 Assessments” for clients, to determine if they are at imminent risk of harm to self or others
• Assessing clients with substance use disorders, and providing appropriate referrals based on client preferences, motivation, readiness, and other factors
• Coordinating complex care plans, esp. interface between primary care and referral services/programs, such as psychiatry, psychotherapy, substance use treatment programs, intensive case management programs, and gender-related services such as mental health assessments for gender-affirming surgeries etc.

• Providing emergency mental health support and counseling

• Coordinating mental health treatment planning between peer navigators, case manager, and medical staff

• Training staff on the affects of mental health issues on other aspects of client and treatment planning

**Psychiatry**

In a structural factors snapshot conducted in 2015, we confirmed what the team already knew: a significant proportion of our client population (36.6%), at the time of program entry, were experiencing severe mental illness, defined explicitly as bipolar disorder and/or psychosis. The majority of our clients, however, have experienced more common mental health challenges, such as major depression, anxiety disorders, and PTSD. Halfway through the program, in response to the high rate of SMI and the detrimental impact of untreated mental illness on HIV health outcomes, the team incorporated a Mental Health Clinic to the TransAccess program. The mental health clinic includes a half-day on Wednesdays, where our LCSW and Psychiatrist work onsite at API Wellness in conjunction with on-site case managers and other psychosocial support staff. The psychiatry clinic is available to clients by appointment or by drop-in. The Psychiatrist has played a huge role in supporting our team to better serve the TransAccess clients and reducing the barriers to receiving mental health services. Key responsibilities include:

• Providing accurate diagnosis of underlying mental health disorders

• Mental health treatment including pharmacotherapy and limited psychotherapy

• Diagnosis, referral, and treatment of substance use disorders

**CLINICAL TEAM**

**Primary Care**

The primary care provider offers competent and up-to-date HIV care, transgender health care, as well as general primary care toward the overall health and greater wellness of the client. The primary responsibilities of the medical doctor includes:

• **HIV care**: diagnosing HIV; monitor disease progression; provide and oversee HIV antiretroviral therapy and opportunistic infection prophylaxis; address adherence challenges.

• **Transgender health care**: providing care to transgender and gender non-conforming client populations, with special emphasis on assessing appropriateness and readiness for gender transition treatments and therapies; initiating, monitoring and supporting all gender-related treatments
Throughout a client's lifetime, including cross-sex hormone therapy and gender-affirming surgeries and procedures, such as mammoplasty, orchiectomy and vaginoplasty; and, working collaboratively with multidisciplinary approach to address gender dysphoria, trauma associated with gender identity and pervasive societal transphobia, and empowerment of gender identity.

- **Primary care**: providing primary care services including management of all general medical conditions not covered above, such as hypertension, diabetes, and other medical problems; provision of age-appropriate health screenings and preventative care; recognizing mental health and substance use challenges and provision of appropriate and timely referrals for treatment and/or support; and, working collaboratively with medical social work, case management, and other medical/mental health providers to coordinate client's overall treatment plan.

**Nursing**

The two nurses on the team provide competent and up-to-date nursing care and support for HIV, transgender health, and general primary care. Their key responsibilities include:

- **HIV care**: Work with PCP to support all aspects of HIV care, including HIV medication adherence support; dispensing HIV medications; medication reconciliation; client education regarding HIV, sexual health, etc.

- **Transgender care**: providing gender-affirming nursing care, including provision of hormone therapy, client education with respect to gender affirming surgeries and procedures; assist PCP with monitoring gender transition treatments and goals; providing general emotional support for clients affected by gender dysphoria, or traumas related to societal transphobia.

- **Primary care**: Provision nursing care in general primary care context, including clinic triage, lab draws, immunizations, STI treatments, dispensing medications, medication reconciliation, delivering clinic-based treatments.

**INTERVENTION OUTCOMES**

**SUSTAINABILITY**

As the program comes to its final year in the SPNS project, the team looks toward analysis, dissemination, and sustainability. As mentioned throughout, our clients have come to rely on the services of TransAccess and, many of them, are in the process of stabilizing their environment, HIV primary care, and are in the middle of gender-affirming surgeries. One of our outcomes, then, has been the focus of sustaining the program and engaging in conversations with the San Francisco Department of Public Health, Tom Waddell Urban Health Center, and other programming at API Wellness to ensure the continuity of HIV primary care, transgender care, and support services specifically for transwomen of color.
BASELINE OUTCOMES

Utilizing our logic model and the early goals of the program, we have been able to assess how well we have achieved our objectives for enrollment, outreach, and reducing barriers for TWOC living with HIV.

1. ENROLLMENT: We enrolled 61 clients of our eligible clients by August 2016, the close of the enrollment period for the multisite study. While this number was lower than we had expected, we were able to focus on the retention of those enrolled and improve the number of clients presenting for the follow-up surveys.

2. CLIENTS SERVED: The program has served 80 transwomen of color living with HIV in the Bay Area over the course of the intervention:
   a. 65 clients receiving the full intervention of services (primary care and auxiliary psychosocial services)
   b. 15 women accessing just support services (auxiliary psychosocial services, only)

3. ACUITY: Our caseload was affected by the incredibly high medical and psychosocial acuity of the clients we served:
   a. 22% of our clients are in the top 1-5% of high utilizers in SF (CCMS 2017)
      • high utilizers are defined as those with highest utilization of clinic, emergency department, psychiatric services, and inpatient hospital utilization
   b. According to intake data, approximately one-third of TransAccess clients were diagnosed with advanced AIDS at the time of program entry
   c. At baseline, 78% of TransAccess clients experience 1 or more structural factors. In this analysis, structural factors included: homelessness, active sex work, substance use, and severe mental illness (see figure below).

Figure 1: Structural Factors Affecting Care Outcomes
PROGRAM OUTCOMES FOR ACTIVE CLIENTS

Utilizing our logic model and the objectives we had for program outcomes, we have been able to assess how we met our goals with respect to retention, viral suppression, and improving the health and lives of TWOC living with HIV.

1. RETENTION IN CARE: prioritizing both retention in support programming and HIV primary care, we rely on our intervention exposure data—the number of encounters with peer navigators, our social worker, and our case manager—as well as, the number of medical visits within a six-month period. For active engagement in our program and due to the high acuity of our clients, we expect and see a much higher rate of visits than typical definitions for retention in HIV care.

2. VIRAL SUPPRESSION: Throughout the course of the intervention, we would conduct viral suppression (<200 copies/mL) snapshots to see how many of our clients had experienced suppression during their last set of labs.
   a. On average, 68% of active clients were virally suppressed, during the monthly snapshot of active clients, which surpassed our goal of 60% viral suppression for active clients

3. HOUSING: While most clients were unstably housed during time of enrollment, and although the San Francisco housing crisis is having deleterious effects on our already high risk populations, the TransAccess program was able to secure some form of temporary or permanent housing for many of our clients through emergency shelters, SROs, permanent residences, and treatment programs.

65% of our clients were literally homeless at baseline. Of those that were housed, most were unstably housed or had experience literal homelessness recently. This graphic below represents a 2016 snapshot of the housing status of active (not lost-to-follow-up) clients, 3 years into the TransAccess intervention. This graphic highlights successes in housing clients in single room occupancies (SROs), permanent housing, and treatment programs; while also highlighting system housing issues in terms of availability and sustainability for our clients, as evidenced by the percentage of clients who remain homeless:

Figure 2: 2016 Housing Status of Active Clients Post-Intervention
LESSONS LEARNED

As stated earlier in this manuscript, among our most important lessons learned are two essential organizing principles of a successful program. Simply put, these are the “what” and the “how” of building a successful program. We believe that there are three essential pillars that hold up a successful program for HIV+ transgender women of color. Here, we provide the “what” of TransAccess—the tangible components or skeleton of our program, as well as the “how”—the heart and soul of the program.

1. Community, empowerment of trans-identities, and belonging

As presented in our values statement, we maintain that belonging (to a family, a tribe, a movement, or indeed, the larger LGBTQI community) is a central aspect of a person’s health and wellbeing. The reason that we intentionally named “community and belonging” as the first pillar of a successful program is because our clients have shown us that it is staggeringly difficult for anyone, more so those with a history of trauma and marginalization, to achieve and sustain their medical and behavioral health goals without familial or community support.

What we’ve learned regarding community building and empowerment can be divided into two categories: structural interventions and interpersonal approaches.

Structural interventions, utilized by TransAccess:

- **Digital Storytelling Workshop:** as a requested addendum to the original TransAccess model, three rounds of storytelling workshops were added for the TransAccess cohort. Each round, 4-6 clients participated in a structure workshop where they learned how to tell their own story, frame it, and create a digital representation of their narrative. These informal workshops gave clients time and space away from the clinic environment to listen to and be heard by their peers.

- Location of primary care services within a community-based organization known for serving the trans and gender non-conforming communities

- Creation of a protected half-day clinic for transgender/gender non-conforming clients only

- A support network naturally and organically grew from clients coming to TransAccess for care. This is especially evident in the waiting room, where clients waiting to be seen socialize with one another, share information and resources, and provide mutual support.

- A support group facilitated by transwomen of color that runs concurrent with the TransAccess clinic. The group provides a safe space to build a sense of shared sisterhood.

- Supporting programs and initiatives that amplify client visibility and social justice, supporting TransAccess clients to help testify at City Hall for the life-saving impact of trans-inclusive HIV services, including more images of transgender clients in our clinic space, etc.

- Support and promote client participation in civic and LGBTQI movement activities, including organizing clients to participate in the Transgender Day of Remembrance, TransMarch, San Francisco LGBTQ Pride celebration, etc.
• An inherent asset in clinics developing partnerships with community-based organizations is being able to draw from and grow the neighborhood engagement and community trust. TransAccess and TransThrive staff have a long history of organizing clients to participate in community and civic activities that promote LGBTQ pride, equality, inclusiveness and community.

• TransAccess peer navigators promote APIWC-sponsored events, such as SF Pride and Trans Day of Remembrance, encouraging TransAccess clients to join or even volunteer. The case manager and clinical team see this community engagement as part of the care plan and, similarly, encourage clients to attend these events.

Interpersonal approaches, utilized by TransAccess:

• All TransAccess program staff share a strong belief that our work is not limited to the provision of healthcare services alone, but that together with our clients, we are all part of a larger movement toward social justice and equality. Part of effecting change beyond TransAccess is achieving empowerment within, making sure clients lay claim to their voice and their power to help effect change for the better.

• Much has been written about the concept of “medical homes”, which generally means a clinic that provides multidisciplinary services, including medical care and psychosocial services. However, most conventional models place the emphasis on the “medical” component. At TransAccess, one success we are especially proud of is the creation of a program that prioritizes the word “home”.

• Many of our clients arrive at our program feeling rejected, ostracized, or alone. Many have become estranged from their biological families, or feel betrayed or let down by their own community, friends, or intimate partners. TransAccess aims to be a place to recover from that: a place where clients feel safe and free to be exactly who they are.

• Some tips for instilling this sense of home and belonging include:
  • Radical acceptance: Accepting our clients exactly as they are, in all their varied expressions of gender, and whatever their values and priorities may be (even if health isn’t at the top of a client’s priorities).
  • Non-judgmental acceptance of a client’s choices, even around issues such as sex work, substance use, not taking meds, etc.
  • Showing vulnerability and one’s own humanity: For example, when our primary care provider meets a client for the first time, he often introduces himself by sharing why this work is so meaningful to him. For example, “When I first started working with trans clients at our clinic, I saw the lengths that people would go, and the sacrifices people make, simply for the chance to become your most authentic self. The need to be who you are, regardless of the consequences, I get that. I respect that.”
  • Human touch: warmth, laughter, food, and hand-written cards from team as the main mode of outreach for clients who have dropped off from care (“We miss you; hope to see you back in clinic soon”).
2. Intensive psychosocial and behavioral health support

Early on in TransAccess’s evolution, it became clear that psychosocial stressors and disparities, untreated mental health problems, poor coping mechanisms such as substance use, intense and recurrent traumas, and the chaos of surviving daily life as a transgender woman of color are the primary factors that drive poor outcomes in our clients. Data supporting these observations have been presented in earlier sections regarding structural factors (such as homelessness, substance use, severe mental illness and sex work) in our client population. In order to meet the extraordinarily high level of psychosocial needs of our clients, TransAccess evolved and in its second year of operation, expanded the program’s psychosocial and behavioral health staffing. Our model now includes peer navigators for day-to-day care navigation and general emotional support; senior case managers to coordinate higher level referrals and benefits (such as insurance, governmental benefits, housing, etc); medical social work/behavioral health clinician to assess, triage, and refer clients to mental health and substance use treatments, as well as coordinate complex care plans; and a psychiatrist for the management of severe mental illness, with a particular emphasis on methamphetamine-associated psychosis. Please refer to Section V for specifics on each team’s roles and responsibilities.

One additional insight comes from an analysis of intervention exposure amongst TransAccess clients, which reveals just how intensively our clients utilize and require psychosocial services such as peer navigation, case management, and medical social work. One of our behavioral health team members shared an illustrative comparison, stating: “...It feels like we are working in an intensive case management program, with primary care and psychiatry on site.” The operative word here is “intensive” – which reflects both the acuity of the urgent psychosocial and mental health challenges our clients face, as well as the experience of staff members providing that support.

Our recommendation to any emerging clinic or program is to dedicate sufficient staffing and resources toward psychosocial and behavioral health staff, and to ensure that the staff-to-client ratio reflect the intensity of our clients’ needs.

3. Co-location of HIV and trans-affirming primary care

Perhaps the single most important lesson learned regarding medical care provision for HIV+ transwomen of color, is the importance of having HIV care and transgender care co-located in the same provider or clinic.

Because gender dysphoria and gender-based trauma informs so much of our clients’ lives, the opportunity to meet a client’s gender-related needs (such as cross-sex hormone therapy) represents an incredible opportunity for client engagement and retention. For many clients, gender dysphoria and transition-related needs take precedence over concerns about HIV treatment. Many opportunities now exist for HIV providers to gain knowledge, confidence, and experience in transgender care issues. In our experience, having a provider who is versed in both HIV and transgender care issues has been a major draw for our clients.
REFERENCES


Figure 1: TransAccess Logic Model

**INPUTS**
- **Care Team**
  - MD | RN
  - Medical Social Worker
  - Peer Navigators
  - Case Manager
  - Psychiatrist
- **Partnership**
  - Public and non-profit collaboration between Tom Waddell Urban Health Center and the APIWC
- **Trans Visibility**
  - Trans staff, positive messaging about trans folks and trans issues
- **Open Access**
  - A safe and gender-affirming drop-in space for TWOC
- **Group Programs**
  - Trauma-informed workshops and events

**ACTIVITIES**
- **Care**
  - Comprehensive Primary Care: HIV, Preventative, Hormone Replacement Therapy
  - Gender-affirming procedures and surgeries
  - Client-centered Case Management
  - Mental Health Services and Psychiatric Referrals
  - Trans-Identified Peer Navigation and Advocacy
- **Support**
  - Community Advisory Board (CAB)
  - Life Skills Workshops
  - Social events and outings

**OUTPUTS**
- **Full Intervention**
  - 75 transgender women of color receive both primary care and support services
- **Support Services Only**
  - 25 of transgender women of color, already receiving primary care, receive support services
- **Other**
  - 4 CAB meetings per year
  - Weekly support groups
  - 4 social events / outings per year

**SHORT-TERM OUTCOMES**
- 75% of clients are retained in primary care
- 75% of clients are retained in support services
- 90% of clients are prescribed ART
- 60% of clients are virologically suppressed

**LONG-TERM OUTCOMES**
- 75% of clients express increased satisfaction with gender identity
- 75% of clients feel a sense of community belonging

**GOAL**
- Improve health outcomes for transwomen of color living with HIV in the San Francisco Bay Area
Figure 2: Clinic FlowChart

**STEP 1** Referral/Outreach
- Client tests positive
- Referral is made to Peer Navigator
- Linkage to Care

**STEP 2** Peer Navigator
- Pre-Screening for study inclusion
- Introduction to program
- Continued documented outreach
- Chart client encounters and progress
- Referral made to Case Manager and RN

**STEP 3** Case Manager
- Intake assessment and reassessments
- Referrals and linkage to harm reduction counseling, legal services, and psychiatric services
- Secure RN and MD appointment
- Introduce client to LCSW
- Develop client care plan
- Chart client encounters and progress

**STEP 4** RN | MD
- RN Intake and follow up assessments
- Benefit Enrollment
- Labs
- Secure follow-up appointments
- Develop RN care plan
- Chart clinical progress notes

**STEP 5** LCSW
- Intensive Psychosocial Assessment and Reassessment
- Provide psychosocial counseling and ongoing progress notes
- Collaborate with case manager on care plan
- Secure psychiatric referral and follow up

**STEP 6** Evaluator
- Discuss study enrollment and assess client’s ability to consent
- Complete account paperwork
- Enroll client into study; client completes baseline survey
- Conduct follow-up survey with client at 6, 12, 18, and 24 months
- Complete clinical chart reviews at 6, 12, 18, and 24 months
BRENDESTAR HUMAN SERVICES:
TRANSACTIVATE

Brendan O’Connell, MSW

Robert Contreras, MBA

Corresponding Authors:
Brendan O’Connell, MSW
5326 E. Beverly BLVD, Los Angeles, CA 90022
Phone: 866-590-6411 ext: 124
boconnell@bienestar.org
BIENESTAR Human Services, Inc. is a grass roots, non-profit community service organization established in 1989. BIENESTAR originated as a direct result of lacking and non-existent HIV/AIDS services for the Latino community. BIENESTAR has been committed to enhancing the health and well-being of the community through education, prevention, and the provision of direct social support services. BIENESTAR provides services out of six offices located throughout Los Angeles: Hollywood, East Los Angeles, Pomona, San Fernando Valley, Long Beach and South Los Angeles. The TransActivate intervention is provided out of each office.

Los Angeles County (LAC) is home to over nine million people, according to the 2010 U.S. Census; the 2015 estimate is 10 million. Los Angeles County covers an area of 4,058 square miles. In terms of race, approximately half the population identifies as white, 8.7% Black, and 13.7% Asian; over 30% identify as multiracial or some other race; almost half identify as Latino or Hispanic of any race.

According to the Division of HIV and STD Program’s (DHSP) most recent estimate, there are 13,788 transgender persons living in Los Angeles County; approximately 50% are transgender women (i.e., male-to-female transgender persons) and 50% are transgender men (i.e., female-to-male transgender persons).

1 Los Angeles County Commission on HIV and LAC Department of Public Health, “Los Angeles County Comprehensive HIV Plan (2017-2021),” September 2016
Los Angeles Department of Public Health estimates that approximately 0.2% of the LAC population is composed of persons of transgender experience.² The racial and ethnic disparities found in the general population are reflected in the transgender population. Among PLWHA in LAC, Latinos make up 44% of the population and 55% of the PLWHA.

By any measure, HIV prevalence among transgender individuals is high in comparison to other populations. While data on transgender individuals is not collected in many jurisdictions across the US, the Los Angeles County public agencies have been leaders in transgender HIV surveillance. Nonetheless, a dearth of precise data on transgender populations means that most of our knowledge about the population is based on estimates drawn from limited samples.

The current Los Angeles County Comprehensive HIV Plan (2017-2021) estimates that in 2013 HIV prevalence was 16.7% among transwomen (male to female) and 0.8% among transmen (female-to-male), compared to a population estimate between 0.1% and 0.2% for all transgender persons.³

Other researchers have found even higher rates: the CDC’s factsheet on HIV/AIDS among transgender individuals cites research that estimates HIV prevalence as high as 28% among transwomen in general, 56% among Black transwomen, 17% among whites, and 16% among Latinas.⁴ The LAC Department of Public Health’s (LDPH) surveillance in 2014 shows new cases varying from 20 to 40 annually, while AIDS diagnoses vary from 10 to 22. LDPH surveillance data from 2012 show that 50% of all new cases of HIV occurred among transgender persons between the ages of 20 and 29.⁵

BIENESTAR chose transgender Latinas for TransActivate’s target audience. This decision was based on the epidemiology and BIENESTAR being one of the leading community-based organizations in the Latino community. BIENESTAR has a long and successful history of working with the Latina transgender community in Los Angeles. BIENESTAR has been providing services for the transgender community for 20 years giving us unique insights into the local transgender population. Currently, 16% of BIENESTAR’s staff identify as transgender women and all are bilingual in English and Spanish.

PROGRAM DESCRIPTION

BIENESTAR Human Services, Inc. in partnership with JWCH Institute, the Los Angeles Gay and Lesbian Center (LAGLC), Los Angeles Children’s Hospital, AIDS Health Care Foundation, Rand Schrader Health & Research Center, Northeast Valley Health Corporation and AltaMed, implemented TransActívate, an 18-month

---

² Los Angeles County Department of Public Health, Division of HIV and STD Programs, Los Angeles County Transgender Populations Estimates 2012.
³ Los Angeles County Commission on HIV and LAC Department of Public Health, “Los Angeles County Comprehensive HIV Plan (2017-2021),” September 2016
⁵ Los Angeles County Commission on HIV and LAC Department of Public Health, “Los Angeles County Comprehensive HIV Plan (2017-2021),” September 2016
comprehensive, innovative and much-needed program designed to improve the timely entry, engagement and retention in quality HIV care for Latina transgender women in Los Angeles County. We have designed our program to respond to the needs of this community by utilizing the best and most innovative practices in the field and by leveraging our own organizational capacity and expertise, along with those of our clinical and clinic partners. Since Latina transgender women of color experience a multitude of patient-level, provider-level and structural-level barriers to accessing and engaging in quality HIV care, our program is robust and multi-faceted.

**LOS ANGELES COUNTY AND BIENESTAR**

BIENESTAR operates six different offices throughout Los Angeles County to meet the needs of the community across this vast area. TransActivate is offered to transgender Latinas in Los Angeles County. Due to the size of Los Angeles, BIENESTAR needed to partner with multiple Federally Qualified Health Centers in Los Angeles County to make sure the needs of all community members would be met. BIENESTAR originally only partnered with three medical clinics as part of this initiative (LA LGBT Center, Los Angeles Children’s Hospital and JWCH). Due to the size of Los Angeles and because clients were moving between neighborhoods, BIENESTAR established MOU with additional medical providers to assure geographically sensitive medical care could be provided for all those who enroll in the program.

**THE INTERVENTION**

**Theoretical Foundations**

The TransActivate program has two theoretical foundations: the [transtheoretical model](#) and a **strength-based perspective**.

The transtheoretical model, also known as the stages of change model, describes how individuals move through a series of stages of change as they progress in modifying behaviors that cause them problems. Each stage requires tasks to be completed in order to achieve the desired changes. Six particular stages are incorporated into this model: pre-contemplation, contemplation, determination, action, maintenance and relapse. From a stages of change perspective, a counselor addresses where the client currently is in the cycle of changes and assists that person to move though the stages toward successful sustained change.

A strength-based approach involves systematically examining survival skills, capacities, knowledge, resources and desires that can be used in some way to help meet a client’s goals. Furthermore, in a strengths approach, the major focus in practice is collaboration and partnership between the provider and the clients. TransActivate incorporates a strength-based service provision, meaning that we will implement all program-related activities and interventions in a manner that validates and calls upon the strengths of the clients themselves as well as the larger community. The strengths perspective first emerged as an approach to case management for people with severe mental illness, and has since gained ground within other disciplines, including HIV, as seen with its inclusion in the Antiretroviral...
Treatment and Access to Services (ARTAS). Strength-based linkage to care interventions like ARTAS, when compared to a traditional case management models, found to be more effective at linking newly-diagnosed People living with HIV persons to care.

The Linkage Coordinator/Peer Navigators (LC/PN), using direct contact with the program participants, incorporate perspectives and techniques from both of these theoretical foundations into their work with the participants. So for example, drawing upon the transtheoretical model, they assess at what stage a particular person may be in her decision of whether or not to enter the medical care system. The LC/PN will assist the client to move though the stages in order to enter medical care. Using the strengths-based approach, the LC/PN systematically examines the spectrum of a client’s resources. These resources may involve client knowledge, capacities, past survival skills and desire to enter into medical care. The LC/PN will then use this information to help a client reach the goals of entering and staying in medical care.

**Key Components of the Intervention**

- **Social Network Testing:** The primary goal of Social Network Testing (SNT) is to identify persons with undiagnosed HIV infection within various networks and link them to medical care and prevention services. SNT is a strategy that enlists People living with HIV people and High-risk HIV-negative people to recruit people from their social, sexual, and drug-use networks for HIV-testing. To identify recruiters, we approach both our People living with HIV and HIV-Negative transgender clients and explain the program to them. We share a brief description of the program’s purpose; what their participation involves; their roles as a recruiter; potential benefits the program might have for them and the network associates (NAs) they recruit for testing, and what risks might be involve in participation. After we identify Latina transgender recruiters, we coach them on how to approach associates about getting tested; about disclosing (or not disclosing) their own HIV status; how to respond to NAs’ questions about HIV transmission risks, and how and where each NA can get HIV testing at BIENESTAR.

- **Mobile Testing:** Another strategy that we utilize to identify People living with HIV Latina transgender women is mobile testing. We conduct testing via our mobile unit in the evenings, late evenings, and weekends, making it extremely convenient for our clients to get tested when they are frequenting their regular venues.

- **Social Network Engagement (SNE):** The premise of Social Network Testing, is to utilize People living with HIV and high-risk HIV-negative people to recruit from their social, sexual and drug-use networks for HIV testing. This is the same strategy to identify People living with HIV people who have fallen out of care, are accessing care infrequently, or who have never accessed care. The People living with HIV recruiters that we identify for Social Network Testing would also be enlisted for Social Network Engagement. We coach them to discuss linkage and engagement in care with their network associates (NAs) who are living with HIV.

- **Motivational interviewing based linkage and peer navigation:** In order to help our clients resolve their ambivalence about accessing care or engaging in care, our staff were trained in Motivational Interviewing (MI). MI, as defined by its founders, is a “person-centered goal-directed counseling method for helping people to change by exploring and resolving ambivalence” and draws
upon the transtheoretical stages of the change model described above. MI is meant to be applicable to a wide variety of problem areas and is able to be delivered by a broad range of helping professionals.

- **Linkage:** Once a transgender woman is diagnosed with HIV via our testing program, she immediately meets with one of two LC/PNs. The LC/PN will assess the client’s emotional state and her readiness to enter medical care, drawing from the transtheoretical stages of change model. While the LC/PN will encourage the client to enter medical care as soon as possible, if the client is ambivalent, resistant or otherwise not ready, the LC/PN will not try to coerce her to do so. Instead, the LC/PN will address whatever needs the client may prioritize at that time.

- **Peer Navigation:** Once a client is successfully linked to care, we utilize our peer navigation service to ensure she is engaged and retained in care. In addition, to those clients that we link to care, we also work with clients who may have previously accessed care but have not been engaged in care to any meaningful extent or are already enrolled in care with any of our partners and want additional support. Our peer navigation intervention is designed to guide clients through Los Angeles County’s complex medical system and facilitate their utilization of services in order to retain them in HIV care and increase their quality of life. Specific services provided by our LC/PNs include clinical appointment coordination and accompaniment; appointment coordination and accompaniment to social and other services at BIENESTAR and partner agencies; coaching clients to prepare them for their appointments; translation assistance; and the provision of HIV-related education and information. The success for our peer navigation strategy is dependent on our ability to build trusting relationship with our clients.

Below is where each key component of the program intersects with the HIV treatment cascade.

<table>
<thead>
<tr>
<th>TREATMENT CASCADE</th>
<th>INTERVENTIONS WITH PROGRAM PARTICIPANTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recruitment</td>
<td>Timely Entry/Engagement and Retention in Primary Medical Care</td>
</tr>
<tr>
<td>Social Network HIV Testing</td>
<td>Mobile HIV Testing</td>
</tr>
<tr>
<td>Diagnosed with HIV</td>
<td>x</td>
</tr>
<tr>
<td>Linked to HIV Care</td>
<td>x</td>
</tr>
<tr>
<td>Engaged or Retained to HIV Care</td>
<td>x</td>
</tr>
<tr>
<td>Prescribed Antiretroviral therapy</td>
<td></td>
</tr>
<tr>
<td>Viral Suppression</td>
<td></td>
</tr>
</tbody>
</table>
Community Partnerships

In addition to clients that we recruited, BIENESTAR also created community partnerships to recruit for TransActivate and provide medical and support services. In order to obtain referrals from other agencies, we actively promote our program, work to strengthen our established partnerships and build new partnerships in the community. One barrier we face is that providers in the community may be reluctant to support a new linkage/navigation program if they believe that it is duplicative of their work. Therefore, to promote our program, BIENESTAR clearly communicates the purpose of the program and creates MOU with our partners to define the specific roles of each agency.

Partners- We learned thought this program it was better to have multiple clinical partners because each partner has its strength and weakness. The role of the LC/PN was to find the clinic that was right for each client based off the client’s needs:

- **LA LGBT Center**  Original Partner
  **Strength**- Leading LGBT service provider in Los Angeles providing HIV Care, Hormone Replacement Therapy (HRT), legal services, mental health service and Transgender employment services and other services.
  **Weakness**- Only provides medical services in the Hollywood area, at times during the program it had long waiting periods for medical appointments.

- **Los Angeles Children’s Hospital**  Original partner
  **Strength**- Leading agency providing Transgender medical care for those under 25 years of age.
  **Weakness**- TransActivate did not enroll anyone to Los Angeles Children's Hospital due to their age restrictions (12-25 years old).

- **JWCH Institute**  Original partner
  **Strength**- Provides HIV Care, Hormone Replacement Therapy (HRT), dental services and other support services. JWCH does a great job getting people into care within 72 hours and does not have wait times experienced at other clinics.
  **Weakness**- JWCH HIV clinic is located in Skid Row. Some clients did not like attending the clinic due to the neighborhood. Skid Row has extensive drug use. In the last year, JWCH has opened new clinics in other neighborhoods that might work better for clients with past drug use.

- **AIDS Healthcare Foundation (AHF)**  Partnership established in Year 2
  **Strength**- The largest HIV provider in Los Angeles County. Has multiple locations throughout Los Angeles County. Provides HIV primary care and Hormone Replacement Therapy.
  **Weakness**- TransActivate participants stated that some front desk staff lacked transgender awareness. AHF has struggled to retain medical providers which has frustrated clients.

- **Northeast Valley Health Corporation**  Partnership established in Year 2
  **Strength**- Provides HIV primary care and Hormone Replacement Therapy. Small clinic with staff clients recognized.
Weakness- Only provided service in one area of Los Angeles. Clients faced barriers with the clinic renewing their AIDS Drug Assistance Program (ADAP) paperwork.

- **Rand Schrader Health & Research Center** Partnership established in Year 3
  **Strength-** County run HIV specialty clinic. County funded and provides medical services not covered with ADAP for those uninsured or undocumented. Offers late night hours on Tuesday and Thursdays.
  **Weakness-** Only has one location. Wait times can be long due to some clients having to access care from the county.

- **AltaMed** Partnership establish in Year 3
  **Strength-** Very easy to access linkage team and get people into HIV care quickly, provides Hormone Replacement Therapy (HRT), Spanish speaking front desk, office and medical providers.
  **Weakness-** Took very long to develop a MOU.

**Core Intervention Staffing Requirements**

The following staff have been used to implement this program:

- **Program Director (In-Kind):** The Director is responsible for intervention program fidelity, recruiting new staff and program monitoring activities, financial reporting back to the funder, and meets with linkage coordinator once a month.

- **Required trainings:** Attend a national HIV conference and all meetings required by the funder; NIH certification for Protecting Human Research Participants.

- **Program Manager (.50 FTE):** Responsible for the overall daily coordination of the program activities; prepares reports and keeps accurate up-to-date records and documentation; acts as liaison with the program’s medical providers to promote the goals of the program.

- **Training Required:** Social Network Engagement; Peer Navigation, all meetings required by the funder; NIH certification for Protecting Human Research Participants.

- **Linkage Coordinator/Peer Navigator (2.0 FTE):** The LC/PN conducts outreach, recruits participants for intervention and facilitates the intervention. The LC/PN also conducts initial assessments, creates a plan to eliminates barriers to link and maintain participant in care.

- **Trainings Required:** HIV Test Counselor Certification; Basic II: HIV Test Counselor Certification; Motivational Interviewing; Social Network Engagement; Peer Navigation, NIH certification for Protecting Human Research Participants.

- **HIV Testing Counselor (.15 FTE)** The HIV Testing Counselor provides pre and post test counseling; assures compliance with all regulations and requirements of alternative test site programs and remains current with accurate information in the area of HIV/AIDS.

- **Trainings required:** Basic I: HIV Test Counselor Certification; Basic II: HIV Test Counselor Certification, Motivational Interviewing, NIH Certification for Protecting Human Research Participants.
PROGRAM PLANNING AND DEVELOPMENT

YEAR ONE: IMPLEMENTATION

1. Hiring key program staff:
   - Two Linkage Coordinator/Peer Navigators
   - One Program Manager
   - Program Director (already in place)

2. Develop all initial local evaluation tools. Additionally, finalize all standard operation procedures (SOPs) and protocols.

3. Develop and enhance partnership with partner providers. Staff visit each clinic to notify them of the program and formalize the referral process when linking clients to medical care.

4. Develop promotional material to be given out during outreach and to medical providers.

5. Discuss TransActivate with BIENESTAR Community Advisory Boards (CAB). Get the CAB’s input on promotional material.

YEAR TWO: PROGRAM BEGINS

- TransActivate begins HIV testing.
- TransActivate LC/PN begins to recruit for SNE/SNT recruiters.
- TransActivate enrolls their first client.
- Produces monthly reports of program progress.
- Holds monthly team meeting to review program progress and strategies.
- Continues to meet with medical providers to review linkage to care process.
- Continues to develop new MOU with other medical providers that can provide primary HIV-care to transgender women.
- Posts promotional material online and in print where transgender women can access the program.

YEARS 3-5: PROGRAM CONTINUES

- Continues to provide services identified in Year 2.
- In Year 3, TransActivate holds the Transgender Women Health Conference. This conference was held based on the needs clients reported as part of TransActivate. This conference was also a recruitment tool for the program to bring new Transgender women to BIENESTAR.
- As client completes the program, they schedule a final face-to-face where all needed referrals and support services can be put in place.
INTERVENTION OUTCOMES

<table>
<thead>
<tr>
<th>Total Enrolled:</th>
<th>Total to Date</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
</tr>
<tr>
<td>Total Enrolled:</td>
<td>150</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Age: MEAN</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;18</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td>18-24</td>
<td>1</td>
<td>2%</td>
</tr>
<tr>
<td>25-29</td>
<td>3</td>
<td>6%</td>
</tr>
<tr>
<td>30-39</td>
<td>8</td>
<td>15%</td>
</tr>
<tr>
<td>40+</td>
<td>41</td>
<td>76%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Ethnic:</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Mexican, Mexican American, Chicano/a</td>
<td>105</td>
<td>70%</td>
</tr>
<tr>
<td>Another Hispanic, Latino, or Spanish origin</td>
<td>35</td>
<td>23%</td>
</tr>
<tr>
<td>Decline</td>
<td>4</td>
<td>3%</td>
</tr>
<tr>
<td>Don’t Know</td>
<td>1</td>
<td>1%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Place of Birth:</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>USA</td>
<td>9</td>
<td>6%</td>
</tr>
<tr>
<td>Mexica</td>
<td>106</td>
<td>71%</td>
</tr>
<tr>
<td>Central American Country</td>
<td>20</td>
<td>13%</td>
</tr>
<tr>
<td>Other</td>
<td>14</td>
<td>9%</td>
</tr>
<tr>
<td>Decline</td>
<td>1</td>
<td>1%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Stage of Care Continuum at Enrollment</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Newly Diagnosed</td>
<td>13</td>
<td>9%</td>
</tr>
<tr>
<td>Fallen out of care/never engaged in care</td>
<td>21</td>
<td>14%</td>
</tr>
<tr>
<td>In care but needed more support</td>
<td>117</td>
<td>78%</td>
</tr>
<tr>
<td>Client passed away</td>
<td>3</td>
<td>2%</td>
</tr>
</tbody>
</table>

INTERVENTION COSTS

BIENESTAR spent $192,109 annually implementing TransActivate. Below are tables documenting how this money was expended. Two items are missing from these estimates. First, BIENESTAR did not include its Indirect Charges that make up 22% of the total budget. Secondly, BIENESTAR did not include any of our incentives. As part of the evaluation, clients were given an incentive to come and complete a follow-up survey every six-months. The incentives increased for each follow-up survey completed. We included incentives in this description as this might have been a factor in some women enrolling.
BIENESTAR: TransActivate

LESSONS LEARNED

BIENESTAR has been working with the transgender community since 1997. During that time, we learned many lessons about how to best meet the needs of the transgender community. Here are lessons learned while implementing this linkage to care program.

<table>
<thead>
<tr>
<th>Incentive</th>
<th>Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Baseline</td>
<td>$40</td>
</tr>
<tr>
<td>6 months</td>
<td>$45</td>
</tr>
<tr>
<td>12 months</td>
<td>$50</td>
</tr>
<tr>
<td>18 months</td>
<td>$55</td>
</tr>
<tr>
<td>24 months</td>
<td>$60</td>
</tr>
<tr>
<td>30 months</td>
<td>$70</td>
</tr>
<tr>
<td>36 months</td>
<td>$80</td>
</tr>
<tr>
<td>42 months</td>
<td>$85</td>
</tr>
</tbody>
</table>
**Meeting Client’s Needs**

- TransActivate would have developed MOUs with substance abuse treatment providers. Multiple clients suffered substance abuse needs during the program. TransActivate would also have trained staff on working with clients who suffer from addiction.

- TransActivate would have worked legal assistance into its program. A majority of TransActivate clients are not born in the US and a number do not have documentation. Multiple clients wished TransActivate directly would have been able to provide them with legal counseling.

- Housing was one of the biggest barriers clients had to retaining in care. Clients had to move to different clinics because their housing changed throughout the program. If we could do it again, TransActivate would have tried to secure beds for some clients before the program started.

**Medical Providers**

- TransActivate started the program with only three medical partners. BIENESTAR would have developed additional MOUs as more clinics were needed to meet clients’ needs.

- TransActivate only got three referrals from its medical clinics. Medical clinics had clients who dropped out of care, but stated they could not notify BIENESTAR of these clients to assist with getting them back into care because of confidentiality. TransActivate would have been more effective if before the program we reached agreements with these health clinics so that at enrollment clients agreed to let BIENESTAR contact them if they dropped out of care.

- TransActivate did not enroll anyone at the Los Angeles Children’s Hospital because of their age requirement. TransActivate would not have spent so much energy on developing this relationship, but would have put it towards reaching other clinics.

**Agency Capacity**

- TransActivate had three clients pass away during the program. BIENESTAR would have done more grief training for staff so their own needs were met.

- TransActivate offered additional incentives for those enrolled through Social Network Engagement. Network associates were given $10 dollars for the enrollment and then $50 dollars after their referred client was active in the program for 6-months. This lead to a boost in program enrollments.

- BIENESTAR created other programing to recruit for TransActivate. In Year 3 of the contract, BIENESTAR held its first International Transgender Health Summit. This event was for transgender women and offered an array of speaks on transgender health issue, food and prizes. At the event TransActivate staff were able to do HIV testing, outreach and recruit for SNE and SNT. The International Transgender Health Summit is now an annual event offered at BIENESTAR.
TriCity Health Center: The Brandy Martell Project

THE BRANDY MARTELL PROJECT
TriCity Health Center: The Brandy Martell Project

Wilson, Erin C., DrPH
Arayasirikul, Sean PhD
Woods, Tiffany
Nguyen, Tam, PhD
Page III, Zettie, MD, PhD

Corresponding Authors:
Tiffany Woods, Transgender Programs Manager
Tri-City Health Center, 39500 Liberty Street, Fremont, CA 94538
Phone: (510) 252-5821
TWoods@tri-cityhealth.org
TriCity Health Center: The Brandy Martell Project

CONTENTS

Local Epidemiology ........................................................................................................................... 158
Program Planning and Development ............................................................................................... 167
Intervention Outcomes ..................................................................................................................... 169
Lessons Learned................................................................................................................................. 171
Intervention Appendix ...................................................................................................................... 173

LOCAL EPIDEMIOLOGY

DESCRIPTION OF LOCAL HIV EPIDEMIOLOGY, TARGET POPULATION AND ANY UNIQUE NEEDS OF LOCAL POPULATION

Trans women of color are highly impacted by HIV—more than any other key population in the U.S. The Alameda HIV prevention plan for 2014-2016 reported local data that at least 61 transwomen in Alameda County are known to be living with HIV. These 61 individuals make up 1.2% of the region’s total population living with HIV. Over time, trans women have made up an increasing proportion of all HIV cases. From January 2010 to December 2012, transwomen made up 1.8% of all newly identified cases of HIV (n=12). Numerous studies have identified factors such as substance use, mental health disorders, economic instability, and discrimination to be associated with HIV risk. However, none of these factors explain African American transwomen’s 30 times greater odds of being HIV+ compared to whites. Social determinants are particularly relevant for transwomen of color in Alameda County due to their multiple stigmatized identities. Stigma has long been known to impact HIV care engagement and retention. And factors such as mass incarceration, residential segregation, and socio-economic factors may create low engagement in HIV care and low medication adherence.

Scant studies specific to Alameda County transgender women of color exist; available data focus mostly on transwomen and show very high HIV risk. In 2007, TransVision staff conducted a Needs Assessment and

interviewed 104 Alameda County transwomen, 58% of whom were under 30. Of the sample, consisting of 57% African Americans, 44% did not often use condoms for anal sex; 47% were living with HIV, and 39% used drugs during sex. Over 60% reported suicidal gestures and depression. Factors linked to unprotected sex included stigma, social isolation, poverty, and sex work. Sex work was practiced by 92% of African American transwomen and 60% of transwomen of other races. Transwomen who practiced sex work reported a monthly average of 15 anal sex partners.

Other research reveals high HIV risk in areas within the same Metropolitan Statistical Area as Alameda County. A 2004 San Francisco study included 133 participants of color and found that 40% engaged in sex work, 26% were living with HIV, and 54% reported drug use with sex. During fiscal year 2012, TCHC’s TransVision program enrolled 55 transgender women into its HIV prevention program. During the mid-year assessment, TransVision reported that it had conducted 35 HIV tests, and 25 clients were identified as high risk. Overall, TCHC has 23 transgender women of color living with HIV enrolled in HIV care and management; nineteen of these clients were African American and four were Latino. Together, these transgender women of color represented 8.8% of Tri-City’s overall HIV positive patient load, which included individuals from all racial/ethnic, sexuality, and gender backgrounds. Thus, transgender women of color are highly over-represented among HIV-positive people in the area and were and continue to be in great need of services to engage and retain them in HIV care.

PROGRAM DESCRIPTION

THE ORGANIZATIONAL CONTEXT

Geographical & Organizational Context

Tri-City Health Center’s TransVision program is an award-winning service provider and resource for trans people in Alameda County that has provided trans health care, HIV prevention, testing, and care services to transgender women of color in Alameda County, California since 2002. TransVision’s program goal is to lower HIV infection among Alameda County’s transgender women by increasing knowledge of HIV risk factors, addressing factors that include HIV risk behaviors, and improving access to treatment and primary care services. Program Awards received include: Recipient of The 2007 Transgender Law Center Community Partner Award, Joint Member Resolution, California State Legislature, Nov 2008-2013, City of Oakland Mayors Proclamation 2013, Certificate of Special Congressional Recognition, 2010: Congresswoman Barbara Lee, D-9.

- TransVision provides services including:
  - Hormone therapy
  - Outreach
• One-on-one risk reduction counseling
• Agency and venue-based HIV/HCV, TB and STD screening
• One-time and multi-session groups
• Comprehensive Risk Reduction Counseling Services (CRCS)
• Comprehensive HIV care

Our clients consistently report in satisfaction surveys they like our tailored services and recommend TransVision to friends. Specifically, our hormone therapy is a big draw for clients. Every year, approximately 60% of TransVision clients come in for hormone therapy. To qualify for the treatment, they have to undergo HIV testing and mental health assessment. As a result, hormone replacement therapy (HRT) clients are enrolled into HIV prevention programs. In addition, TCHC provides confident, competent Trans health care. Our providers are trained in providing health services to transgender clients; TCHC patient intake forms and medical charts have provision for preferred names and pronouns. TCHC is currently transitioning to an Electronic Health Record (EHR) system that will continue to provide for identification and treatment of transgender clients. In addition, TCHC has a TransVision specific website that provides: enrollment forms, transgender specific resources, and protocols for safe injection. Current clients are sent appointment reminders in the form of emails and text messages. TCHC serves as a one-stop shop, providing comprehensive health services for clients. TCHC currently has served approximately 200 trans women. The Brandy Martell project is a project within the TransVision program. We were funded as a Special project of National Significance (SPNS) by the Health Resources and Services Administration branch of the federal Department of Health and Human Services to implement this project to engage and retain transwomen of color in Alameda County into their HIV care.

TCHC Transgender Advisory Board (TAB)

Our Client Advisory Board, (TAB), is a diverse group of Latina, African-American, and API trans men and women, including youth. All TAB members have crucial roles and responsibilities to provide input, feedback and advice on TransVision projects and interventions, materials, outreach, and recruitment and retention into TransVision interventions. The TCHC TAB served a central role on the Brandy Martell Project (BMP). TAB members will shared information about community needs and trends, attitudes and behaviors, and assisted in promoting The Brandy Martell interventions, projects and events.

THE INTERVENTION

Naming the Brandy Martell Project

The SPNS-funded intervention project was named The Brandy Martell Project in honor of former TransVision Peer Advocate Bandy Martell who was shot to death April 29 in downtown Oakland. By
naming the project after Brandy Martell, her legacy of helping her friends and other trans community members in the East Bay continues and brings awareness of her murder and the epidemic of violence targeted towards transgender women of color.

**Theoretical Basis**

The development of the demonstration project was based on Critical Race Theory (CRT), which provides a theoretical basis for understanding the issues of racialization, race consciousness, and social location with the intention to understand and eliminate health inequities. As identified in the Needs Assessment described above, transwomen of color face multiple barriers that are linked to their racial and socio economic status. A resonating theme from the needs assessment was that for any health interventions to work, we have to eliminate the socio economic barriers that transgender women of color encounter. Furthermore, transwomen explicitly stated their interest in disengaging from high-risk sex work and other activities but lack the opportunity and assistance to do so. TransVision’s experience with clients falling out of care to meet their basic needs underscores the significance of implementing comprehensive programs. Critical Race Theory (CRT) allows for public health research and interventions outside the standard public health paradigm to allow for study of the impact of contemporary social dynamics - race and ethnicity, transphobia, and marginalization – that directly impact and effect high of the HIV prevalence of transgender women of color. Critical Race Theory (CRT) encourages the development of solutions that bridge the gaps in health, housing, employment, and other factors that lead to health disparities and health inequities.

**Key Components of the Intervention**

Transwomen enrolled in this intervention were offered access to direct legal counsel and participation in the Living Real Workshop/Sessions series. The following were key components of the intervention:

- An Oakland-based attorney served as our project Legal Liaison. He worked individually with clients in need of assistance with legal issues such as solicitation offenses, warrants, failure to appear (FTA) offense, court fees, driving while under the influence (DUI) offenses, as well as helping to navigate the court systems/processes in Alameda County. The Legal Liaison assisted clients with overcoming existing legal structural barriers that prevent transgender women color from staying consistently in HIV care and treatment services. He conducted a monthly legal clinic as needed for BMP clients to help identify legal issues/barriers and he conducted Know Your Rights and Expungement Sessions in the Living Real Curriculum. Clients who utilized his services were offered the following:
  - One-on-one 30-60 minute counseling session with lawyer
  - Follow-up legal sessions on a case-by-case basis
  - Pro-Bono Rate: $50 per hour non-court rate, $60 per hour in court rate. All fees were paid by the project.

- Living Real Workshops (5 Tracks, 16-sessions) consists of facilitated sessions intended to tackle barriers to HIV care, as well as assist clients in moving forward in their lives. The barriers and challenges, such
as substance abuse, domestic violence, police harassment, unemployment, and safer transitioning, were included in the Living Real sessions. Session content was driven by the needs identified by the clients, advisory board members, and staff. Empowerment sessions that facilitated community and personal pride were developed to increase community involvement, job skills, healthy family and personal relationships, and personal development. Each session was designed to build off one another.

- **Track 1: What Connects Us All: Community, History and Identity**
  - Session 1: We put the “T” in LGBT history
  - Session 2: Learning from our elders and mentorship
  - Session 3: Challenges in finding community and solutions

- **Track 2: Living for Today and Tomorrow: A Healthy YOU**
  - Session 4: Trans healthcare basics
  - Session 5: Transition resources
  - Session 6: Safe transition practices
  - Session 7: HIV and Me
  - Session 8: HIV and Treatment Adherence
  - Session 9: Moving beyond condoms

- **Track 3: LIVING for It: Life, Love and Healthy Relationships**
  - Session 10: Communicating with family, friends and partners
  - Session 11: Anger management, dealing with setbacks and fostering resilience

- **Track 4: WORK! Employment**
  - Session 12: Getting started, getting a job and unable to work
  - Session 13: Career counseling and successful resumes, cover letters and interviews

- **Track 5: Express Yo’ Self, Protect Yo’ Self**
  - Session 14: Know Your Rights! Legal Advocacy
  - Session 15: Expungement/Clean Record
  - Session 16: Self-defense skills

**Intervention Logic Model**

Please see Appendix.

**Core Intervention Staff (including supervision structure)**

The Brandy Martell Project staff was comprised of a Program Manager/Project Manager supervised five full-time benefited, hourly staff, which included two African-American trans women, two Latina trans women, and one African-American MSM. All were full time, benefited employees, 1.0 FTE, although not
all were fully funded through the HRSA SPNS Initiative. All positions were Health Education Specialists with one also being a certified Medical Assistant, M.A. All hourly staff began in the Peer Advocate Program as Peer Advocates, a compensated, non-TCHC benefited employee position. TransVision utilized part and full time volunteer peer advocates, including young transgender women of color. Their primary responsibility was outreach, recruitment, and program assistance; they came with connections to their own social networks and were trained in social network-based recruiting. All Peer Advocates were promoted to Health Education Specialist over the course of four years of the project. The Program Manager/Project Manager managed all transgender services at TCHC, oversaw implementation and delivery of the project, oversaw daily supervision of program/project staff and delivery of the interventions to clients, and maintained the master schedule of activities, working directly with HIV and primary clinical team and maintains quality assurance for all program/project deliverables; this person also performed annual staff performance reviews, completed annual reports as required by the funders and agency including site visit reports as preparation, interfaced with Project Officers, and attends all relevant trainings and meetings.

**Intervention Outreach, Recruitment, and Retention Strategies**

**Social Networks**

Existing staff and client social networks were utilized in outreach and recruitment for participants into the BMP. We also elicited input from staff and clients regarding how to access their social networks and what recruitment strategies would work best.

**Street and Venue-Based Outreach**

Outreach included distribution of palm cards at clubs and street venues, and outreach took place a minimum of twice a month at five to six different venues. Street outreach was scheduled on Friday/Saturday nights from 9-1 AM with a team of three: an outreach team leader and two peer advocates. BMP Project were promoted at established outreach venues such as:

- Transgender specific and LGBT social events: Oakland Pride, Oakland Trans Pride Gala, Castro Valley Pride, Trans March
- Sex work “tracks” in Downtown Oakland
- Gay bars in Oakland, Berkeley, Hayward: Turf Club, Bench and Bar, White Horse
- Latina specific bars/clubs/shows in San Jose (Santa Clara County) and Concord (Contra Costa County)

**Internet Outreach**

TransVision has a successful track record of Internet outreach for recruitment of clients, and as a source of program and clinic information such as clinic/testing hours, trans health, TransVision services and interventions. TransVision maintained its own comprehensive program website separate from the main TCHC website as well as a Facebook page. Both served as sources of program and clinic information, resources, support, as well as immediate points of contact to TransVision staff. The TransVision program
website created its own Brandy Martell Project page to provide clients with up-to-date information on the BMP and its interventions and how to link to it. TransVision staff also contacted transgender women of color who engaged in sex work through Internet sites such as Craigslist and Backpage.com by placing advertisements for TransVision’s services on specific sites.

### Legal Assistance

- Peer advocates distributed business card/marketing materials regarding the availability of legal services.
- Peer advocates focused on recruiting sex workers and other transwomen who engaged in other high-risk activities.
- The BMP advertised its legal services on its website/Facebook page, and client social network.
- The BMP corresponded with correctional facilities to reengage hard to reach clients who have fallen out of care due to incarceration in a bid to resolve their criminal records and re-engage in care.

### Agency-Based Outreach

Internal marketing took place at TCHC’s primary/hormone and STD clinics and through HIV medical, mental health, and case management services. TCHC promoted TransVision during its existing HIV Counseling Testing and Referral (CTR), care and other prevention activities. External marketing also took place at agencies that have HIV prevention, care, and Counseling Testing and Referral (CTR) services. Referral consent forms were used to allow follow up with referred clients. Brandy Martell Project discreet business cards marketing all BMP interventions were designed for other agency staff to hand out discreetly to their HIV-positive transwomen of color clients.

### MOUs with LGBT Community Centers/Legal

TCHC/TransVision set up formal MOU (Memorandum of Understanding) agreements for referrals of transgender women of color (African American and Latina) to the Brandy Martell project. The MOUs were with the Billy DeFrank Center (BDF) in Santa Clara County, the Pacific Center for Human Growth (PCHG) in Berkley, Alameda County, and the Rainbow Community Center (RCC) in Contra Costa County. All three centers serve the LGBT community in a variety of capacities including HIV screening, peer/group support and activities, mental health counseling, and referrals. All three had African American and Latina transgender women accessing services.

Referrals of clients to the Brandy Martell Project were followed up with an email or phone call to Health Educators for a soft hand off and appropriate documentation of each referral. MOU partners referred African American and Latina transgender women to the BMP if participants were interested in participating in transgender services offered at TransVision, which include Primary Care, HIV Care/Treatment and the Brandy Martell Project for transgender women of color living with HIV or unknown status.

### Description of the Community Partners

The Pacific Center for Human Growth, (PCHG), fosters and enhances the well-being and self-respect of Lesbian, Gay, Bisexual, Transgender, and Queer youth, seniors, and adults through the delivery of LGBTQ
competent mental health and wellness services, and through the cultivation of a strong community of LGBTQ-proficient mental health care professionals in Alameda County. The Billy De Frank Center serves a large and diverse LGBT community in Santa Clara County. The Rainbow Community Center (RCC) is the only organization in Contra Costa County that is solely focused on serving the lesbian, gay, bisexual, transgender and queer/questioning (LGBTQ) community; our current priorities are to build services for LGBT youth, seniors, people living with HIV/AIDS and to develop community building efforts that will diminish the sense of isolation and promote greater acceptance of all LGBTQ people.

**Staffing Requirements and Cost Estimates**

**Year 1-2: $115,000, not including Fringe Benefits**

**Title:** Project/Program Manager – 75.00% FTE x 12 months

*Project Role:* Submission of budget and program reports on program end, supervised all Brandy Martell Project activities and daily supervision of staff/peer advocates ensuring success of interventions, assuring adherence to core elements. Leads QA activities, scheduling of interventions and Living Real facilitators, process all facilitator and legal contracts and payments, work with Project Directors directly.

**Title:** Health Educator – 80% FTE x 12 months

*Project Role:* Works specifically with Latina transgender women, including enrollment in program, intakes, scheduling appointments, counseling and case management, conducts data entry, schedules appointments, prepares client files, maintains master incentives log, works as a patient/client navigator for project clients at medical appointments, social service agencies, court, and for Living Real Intervention, including Spanish language translation services.

**Title:** Health Educator/ Medical Assistant – 100% FTE x 12 months

*Project Role:* Conducts data entry, schedules appointments, and prepares client files, works as a patient/client navigator with social service agencies, and in court. Team Lead in scheduled and administered new participant enrollments in Brandy Martell Project.

**Title:** Health Educator – 20% FTE x 12 months

*Project Role:* Works as a patient/client navigator for project clients at medical appointments, social service agencies. Outreach Team Leader, working with Peer Advocates to conduct outreach/recruitment activities for new participants/clients, assists in conducting Living Real intervention, including reminder calls and coordination of intervention activities.

**Year 3 Addition: $137,378. $115,000, not including Fringe Benefits with and additional $22,378.00 for 3 Peer Advocates**

**Title:** Peer Advocate – 50% FTE – (688 hours at $14/hour rate)

*Project Role:* Works specifically with African-American transgender women, recruitment/outreach services/activities for new participants/clients, patient/client navigation, assists in conducting Living Real intervention, including reminder calls and coordination of intervention activities.
Title: **Peer Advocate** - 50% FTE – (688 hours at $14/hour rate)

**Project Role:** Works specifically with Latina transgender women, recruitment/outreach services/activities for new participants/clients, patient/client navigation, assists in conducting Living Real intervention, including reminder calls and coordination of intervention activities.

Title: **Peer Advocate** – (688 hours at $14/hour rate)

**Project Role:** Works specifically with Latina transgender women, recruitment/outreach services/activities for new participants/clients, patient/client navigation, assists in conducting Living Real intervention, including reminder calls and coordination of intervention activities.

**Year 5: $164,822 includes salary increases, FTE adjustments, does not include Fringe Benefits**

Title: **Project/Program Manager** – 75.00% FTE x 12 months

**Project Role:** Submission of budget and program reports on program end, supervises all Brandy Martell Project activities and daily supervision of staff/peer advocates ensuring success of interventions, assuring adherence to core elements. Leads QA activities, scheduling of interventions and Living Real facilitators, process all facilitator and legal contracts and payments, work with Project Directors directly.

**Title:** **Health Educator** – 100% FTE x 12 months

**Project Role:** Works specifically with Latina transgender women, including enrollment in program, intakes, scheduling appointments, counseling and case management, conducts data entry, schedules appointments, prepares client files, maintains master incentives log, works as a patient/client navigator for project clients at medical appointments, social service agencies, court, and for Living Real Intervention, including Spanish language translation services.

**Title:** **Health Educator/ Medical Assistant** – 100% FTE x 12 months

**Project Role:** Conducts data entry, schedules appointments, and prepares client files, works as a patient/client navigator with social service agencies, and in court. Team Lead in scheduling and administering new participant enrollments in Brandy Martell Project.

**Title:** **Health Educator** – 20% FTE x 12 months

**Project Role:** Works as a patient/client navigator for project clients at medical appointments, social service agencies. Outreach Team Leader, working with Peer Advocates to conduct outreach/recruitment activities for new participants/clients, assists in conducting Living Real intervention, including reminder calls and coordination of intervention activities.

**Title:** **Health Educator** – 64% FTE

**Project Role:** Works specifically with African-American transgender women, recruitment/outreach services/activities for new participants/clients, patient/client navigation, assists in conducting Living Real intervention, including reminder calls and coordination of intervention activities.

**Title:** **Health Educator - 50% FTE**

**Project Role:** Works specifically with Latina transgender women, recruitment/outreach services/activities
for new participants/clients, patient/client navigation, assists in conducting Living Real intervention, including reminder calls and coordination of intervention activities.

PROGRAM PLANNING AND DEVELOPMENT

IMPLEMENTATION

Challenges

The legal clinic started in February of Year 2 and was easier to implement than the Living Real Sessions, as we were only working with the Attorney/Legal liaison and his schedule as opposed to the multiple facilitators, sessions, and schedules, and contracts required for Living Real intervention that took several months to finalize a sixteen session schedule for Cycle one, which finally started in June of Year 2. The legal clinic was originally planned to take place twice a month at Tri-City, either in Fremont or our then satellite site in Hayward. The Attorney/Legal liaison anticipated that most of the participants in the legal clinic would need to have more than one appointment in order for them to bring all of the necessary paperwork and documents, as well as follow up. We also realized that a barrier to having clients access the legal clinic was their past history of negative connotation with the words “legal,” “attorney,” and “court.” It took more than six months of scheduling legal clinics and attendance to the legal Living Real Sessions, facilitated by the Attorney/Legal liaison, Know Your Rights!, Expungement/Clean Record, in order to gain the trust of participants as well as our reframing the legal clinic to “legal assistance”.

The primary barriers to intervention enrollment were found with Latinas, who were clients of the clinic but were not interested in the interventions. We found that a number of clients had competing priorities with partners and jobs and do not access any other services in the agency. There were also trans women living with HIV who dropped care at TCHC who are not ready or willing to be involved in HIV care again, including being involved in BMP. Another barrier found was the lack of HIV+ Latinas identified through HIV testing or outreach activities. As far as engagement in care, the transwomen with whom we work with are incredibly hard to reach and retain. One of the biggest problems we have with our clients is housing. Despite our best efforts and dedicated staff whose primary focus is housing for clients, it is very difficult to find housing in the East Bay. Our staff are constantly working to help patients/participants to find housing, though most often it is transient and unstable, such as shelters or SRO hotels.
Recruitment

Successful intervention recruitment strategies were through word of mouth (i.e. client-client, staff-client and community outreach). Throughout implementation of the project, TCHC realized that word of mouth referrals, especially client/participant to other trans women in their social networks, combined with community outreach, were still the best and most effective ways to reach potential and recruit new participants. This approach was the most effective among African-American participants, as 14 were recruited and enrolled in the Living Real intervention in Year 3. However, this recruitment strategy was staff time intensive, as it was a bit of a challenge for participants to actually make it to our Fremont location to enroll where our clinic and interventions are located. Geographically, Oakland, where most participants live, is 30 minutes from Fremont. Travel on public transportation or by car between Oakland and Fremont can take often take an hour. As a solution, TCHC found that sequential reminder calls and scheduling same day appointments with their medical visits to be a best practice.

The project’s best strategies for retention were keeping participants connected with consistent, weekly phone /social media messaging reminders of sessions/appointments, providing transportation assistance (i.e. BART tickets), and providing psycho-education on the importance of taking care of their individual health. Providing transportation assistance (such as BART tickets and gas cards) for medical appointments in addition to intervention transportation assistance has also been a successful and necessary facilitator for recruitment and retention. Providing the $100 gift card bonus for completing all Living Real sessions has been a powerful motivator for retention. The majority of clients coming from Oakland have a harder time attending week-to-week intervention sessions.

The Brandy Martell Project staff noted many barriers to identification, recruitment, and retention, by staff and peer advocates. These barriers included: lack of communication with some BMP clients regarding changes to contact information; lack of funds for clients to maintain cell service; client no-shows; and other competing priorities and concerns experienced by clients (i.e., housing needs, substance use/abuse, mental health, sex work, stigma associated with HIV, and confidentiality concerns among clients regarding other clients enrolled and attending interventions).

Retention Strategies

Each cycle of the Living Real intervention consists of a 16 facilitated sessions delivered in five different cycles. In order to create access specifically to monolingual Latina trans women, cycle three was conducted in Spanish, with the curriculum translated in Spanish for facilitators. Despite this specific accommodation, BMP staff continued to experience difficulty engaging enrolled Latina Trans women in Living Real, as evidenced by only 4 of 11 participants engaging in the Living Real Cycle 3. One Latina client cited stigma and confidentiality concerns among other participants as reasons not to attend the Living Real Cycle 3 sessions and needed consistent patient navigation to stay linked to HIV care and services. We also saw an increase in reluctance from those with male partners to attend the intervention sessions. Partners are now attending medical appointments and answering reminder phone calls to clients resulting in much less direct staff to client/participant communication and navigation.
BMP staff continued to strategize around reengagement as opportunities presented. Staff experience over the last eight years with retaining the hardest to reach clients enabled the BMP staff to trust that the clients would reengage when their current needs were not being met or their HIV care becomes a necessity. BMP staff are continuously at work to identify, contact, and reengage all BMP participants who dropped out of the project, dropped out of care, and link them back to care and into the program. Latina participants engaged in the interventions were enlisted to help reach and engage others in their social networks who had not been responding to BMP staff. By focusing on prevention and education with these Latina participants, they were more likely to pass on the knowledge gained from their engagement in the interventions, emphasizing the importance of maintaining their HIV care and staying connected to BMP staff for patient navigation and support.

**Strategies to Address Staff Turn-Over**

TransVision had only one BMP team member, a Latina Peer Advocate, who left TCHC and the project during the life of the project. The other two Peer Advocates were promoted to Health Education Specialists/ benefited employees during year four. This unprecedented lack of staff turnover may be attributed to the economic necessity of maintaining employment and the lack of employment opportunities for trans women in the Bay Area, a history of friendships and working together, longtime trust relationships with many of the participants, and the deep friendship and respect to the BMP namesake, Brandy Martell. Promotion of two Peer Advocates to Health Education Specialists/ benefited employees during year four was the primary retention factor in keeping them.

**INTERVENTION OUTCOMES**

**TOTAL NUMBER OF PARTICIPANTS AND PARTICIPANT DEMOGRAPHICS**

Forty-six trans women of color took part in the intervention. The majority (80%) of participants were born in the United States, followed by 11% in Mexico and 9% in another country or unknown. A total of 13% of participants were incarcerated within the last six months at baseline and the majority (78%) of participants reported attaining a high school diploma or less. At baseline, 27% of participants reported a detectable viral load and 34% of participants reported ever been diagnosed with AIDS. At baseline, 11% of participants reported not ever accessing HIV primary care and 44% reported that they did not access HIV primary care in the past six months.

**LIVING REAL ATTENDANCE, CYCLES 1 AND 2**

For Cycle 1, sessions 15 (“Self-defense skills’) and 10 (“Communicating with family, friends and partners”) were the most attended sessions. For Cycle 2, sessions 6 (“Safe transition practices”), 7 (“HIV and Me”), and 8 (“HIV and Treatment Adherence”) were most attended.
PRELIMINARY PRE- AND POST-TEST DATA

The figure at right shows data from measures administered at baseline and at the conclusion of one cycle of the Living Real workshop series. This line graph is of percentages of correct responses assessing HIV knowledge (20 items) and legal knowledge (9 items). The bar chart is the average response on a 5pt Likert scale (Strongly Agree, Agree, Neutral, Disagree, Strongly Disagree) measuring feelings about having HIV and Individual Self-Care. HIV knowledge appeared to be stable and there was a decrease in legal knowledge. Feelings about having HIV remained stably neutral over time. Individual self-care was stable and positive over time despite a small drop over time.

APPROXIMATE COST OF THE INTERVENTION ANNUALLY (NOT TO INCLUDE EVALUATION COSTS)

Approximate total cost annually for interventions: $200,000.

Cost Breakdowns:

- Workshop Consultants/Facilitators = $20,000
  
  Various consultants were hired to provide mentorship, skills training, and linkages for life skills training at $400 X 2 hour session, includes prep, delivery, and any associated costs.
  
  Note: This line item dropped to $10,000 Year 3-5. We initially budgeted $200 per session, but increased to $400 due to difficulty finding/maintaining qualified Facilitators.

- Legal Liaison = $15,000
  
  The Legal Liaison was hired to provide clients with legal assistance in eliminating their criminal and solicitation records.
  
  Note: The legal Liaison budget decreased to $10,000 in year 3-4, and to $5,000 in year 5. Legal Presentations in Living Real, 2 X $400, were budgeted in Workshop Consultants/Facilitators Line Item. A core budget of $5,000-$10,000 should be maintained for projects hoping to utilize this component of the intervention.

- Marketing
  
  Educational Pamphlets/Materials/ Outsourced Printing
  
  This line item covered the cost of printing educational materials: 1,500
Marketing Campaign/Community Outreach Events: $1,540.00
This line item will cover registration fees events

- **Participant Incentives**
  
  **Client Incentives** - This line-item covered the costs of purchasing gift cards from supermarkets / drugstores for clients @ $100 per participant 40 clients x $100/participant = $4,000
  
  **Client Referral Incentives** - This line-item covered the costs of purchasing gift certificates from supermarkets and drugstores for clients who referred new clients to BMP @ $50 per referral.
  
  10 client referrals x $50/referral = $500

- **Transportation Vouchers – Participants/Client Advisory Board = $2,000**
  
  This line-item covered the costs of purchasing BART and Bus tickets for Enrolled Brandy Martell participants to attend the Legal Clinic and Living Real Session Interventions, Trans Advisory Board, and medical appointments.

- **Occupancy Cost/Space Utilization = $2,000**
  
  **Basis of Allocation:** FTE
  
  **Calculations:** This covered a portion of the cost associated with utilizing the workspace to administer the intervention activities, which included maintenance/janitorial supplies, security expenses, janitorial expenses, and building maintenance. Total Space Utilization costs for the department were $49,470. The total Space Utilization cost for the intervention was $2,473.50.

**LESSONS LEARNED**

Efforts to engage transwomen of color living with HIV into the Brandy Martell Project were time and labor intensive, requiring extreme flexibility and unique outreach, recruitment and follow-up methods. Providing access to a range of legal support services decreased institutional barriers to care. Addressing the desire for structured regular services through workshops sessions boosted retention in care and had a positive effect on social and clinical outcomes related to HIV.

1. The interventions worked best when delivered through peer patient navigation and support by dedicated transgender staff who understood the complex realities and issues in which transgender women of color live daily and must navigate such as housing, substance abuse, incarceration, stigma, sex work, targeted violence, unemployment, and family rejection.

2. Transgender women of color targeted by the intervention do not live their lives on a nine-to-five schedule, and to be a successful intervention, programs should understand this and be flexible in meeting the clients beyond nine to five programming and services. Agencies/organizations implementing the BMP Intervention should preferably have a demonstrated history of serving transgender population, with an emphasis on trans women of color.
3. As demonstrated with the Brandy Martell Project, trans women of color faced many daily, structural issues that even challenged the most experienced staff. For organizations just beginning to work with the trans community, engaging with trans peer leaders for program development and input as well as hiring trans staff from the community is highly recommended to build trust and recruitment. Consider creating a trans community advisory board to help guide organizationally.

4. Existing programming that includes transgender staff and transgender-specific programming that should include HIV Prevention and Care and Treatment access and services, access to affirming transgender primary care services that include HRT, a successful history with transgender specific interventions that incorporate gender affirmation as key components of all services.

5. Successful intervention implementation and maintenance requires top down administration support which includes supporting the staff, programming, and clients with inclusive policies, practices and mission statement supporting transgender staff and clients, a preferred demonstrated history of serving the LGBQ and transgender population in services and staffing, access to existing public transportation systems, ability to partner with trans supporting organizations for services and referrals.

RECOMMENDATIONS

Despite having access to health insurance and health care, transwomen living with HIV have competing needs far beyond those related to health that impact their HIV care engagement. Services and care sites are needed that address instrumental needs for economic opportunities, education and legal services are a great start for improving HIV care outcomes among transwomen of color. While The Brandy Martell Project addressed structural barriers of legal access and representation with empowerment, education, and employment, many other structural barriers remain preventing trans women from maintaining retention and linkage to HIV care that co-exist simultaneously such as substance use, housing, homelessness, discrimination, and incarceration and form multiple competing priorities. Interventions that can effectively help address and mitigate those issues would greatly complement the Brandy Martell Project interventions, making the interventions much more likely to have permanent, positive lasting impact and would create greater engagement with clients/patients.
INTERVENTION APPENDIX

Figure 1: Brandy Martell Project Logic Model

Effective engagement and retention in HIV prevention, care and treatment

Reduce structural barriers aka competing priorities

COMMUNITY BUILDING:
Peer referral and workshop retention via peer relationship, pride in staying in care, maintaining health

LEGAL ASSISTANCE AND SERVICES:
Assist to navigate criminal justice system, help eliminate solicitation tickets, warrants, expunge records, allowing to consistently stay in HIV care and treatment services

TAILORED MENU OF WORKSHOPS:
Know Your Rights 101
Job Skills Training
Mentorship
Communication Skills
Self Defense
Trans Healthcare Basics
Safe Transition Practices
HIV Treatment Adherence
HIV and Me
Finding Community
Job Prep

Promote services through peer advocates, social networks and Internet
Reduce existing structural barriers to accessing healthcare
Illustration 1: Brandy Martell Project Flyers

- Are You A Transwoman of Color?
  - There Are Things You Can Do To Take Care Of Yourself

- Free Monthly Legal Clinic
  - Newly diagnosed
  - HIV Status Known/Unknown
  - Recently Released From Incarceration

- Do You Have Legal Issues?
  - *Arrests
  - *Warrants
  - *Tickets
  - *Need Advocacy?
  - *Clear Your Record
  - *Navigate Legal System

For More Information
Contact TransVision:
510-456-3521 9am-5pm

TransVisions’ Brandy Martell Project
Announces a New Legal Service That Provides Advocacy and Guidance in Legal Matters.