

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

CONTENTS

Local Epidemiology	63
Program Description	64
Dun annua Diagrafia a sand Dunai annuart	70
Program Planning and Development	/0
ntervention Outcomes	72
Lessons Learned	73
ntervention Appendix	75

LOCAL EPIDEMIOLOGY

In Los Angeles County (LAC), the HIV seroprevalence rate among trans women is estimated to be 21 percent,¹ a rate comparable to that among trans women across the United States and other high-income countries,² and 40 percent 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 percent 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 percent 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 womens' 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

¹ Office of AIDS Programs and Policies. (2008). Prevention plan 2009-2013. Los Angeles, CA: Los Angeles County Department of Public Health. Retrieved from http://publichealth.lacounty.gov/aids/PreventionPlan.htm. Accessed on April 8, 2012.

² Baral, S. D., Poteat, T., Strömdahl, S., Wirtz, A. L., Guadamuz, T. E., & Beyrer, C. (2013). Worldwide burden of HIV in transgender women: a systematic review and meta-analysis. *Lancet Infectious Diseases*, 13, 214-222.

³ Centers for Disease Control and Prevention. (2016). HIV Infection Risk, Prevention, and Testing Behaviors among Men Who Have Sex With Men—National HIV Behavioral Surveillance, 20 U.S. Cities, 2014. HIV Surveillance Special Report 15.

⁴ Office of AIDS Programs and Policies. (2008). Prevention plan 2009-2013. Los Angeles, CA: Los Angeles County Department of Public Health. Retrieved from http://publichealth.lacounty.gov/aids/PreventionPlan.htm. Accessed on April 8, 2012.

⁵ Perez, M. (2011). New directions: A briefing to stakeholders. Los Angeles, CA: Los Angeles County Department of Public Health, Division of HIV and STD Prevention. Retrieved from http://ph.lacounty.gov/aids/PresentationsReportsArchive.htm. Accessed on March 23, 2012.

⁶ Office of AIDS Programs and Policies. (2008). Prevention plan 2009-2013. Los Angeles, CA: Los Angeles County Department of Public Health. Retrieved from http://publichealth.lacounty.gov/aids/PreventionPlan.htm. Accessed on April 8, 2012.

PROGRAM DESCRIPTION

THE ORGANIZATIONAL CONTEXT

LAC is an urban, metropolitan city, is both geographically large and populous, and covers over 4,700 square miles (including land and water) 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 percent 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 multileveled 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. Closed network status is especially salient among trans women, as viral loads are commonly high.8

⁷ Boyce, S., Barrington, C., Bolaños, H., Galindo Arandi, C., & Paz-Bailey, G. (2011). Facilitating access to sexual health services for men who have sex with men and male-to-female transgender persons in Guatemala City. Culture, Health, & Sexuality, 14, 313-327. doi: 10.1080/13691058.2011.639393.

⁸ Perez, M. (2011). New directions: A briefing to stakeholders. Los Angeles, CA: Los Angeles County Department of Public Health, Division of HIV and STD Prevention. Retrieved from http://ph.lacounty.gov/aids/PresentationsReportsArchive.htm. Accessed on March 23, 2012.

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 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

⁹ Bandura, A. (1994). Social cognitive theory and exercise of control over HIV infection. In R.J. DiClemente & J.L. Peterson (Eds.), *Preventing AIDS: Theories and methods of behavioral interventions* (pp. 25-29). New York, NY: Plenum Press.

¹⁰ Bandura, A. (2001). Social cognitive theory: An agentic perspective. *Annual Review of Psychology*, 52, 1-26. doi: 10.1145/annurev.psych.52.1.1

¹¹ Safren, S.A., Traeger, L., Skeer, M., O'Cleirigh, C., Meade, C.S., Covahey, C., & Mayer, K.H. (2010). Testing a social-cognitive model of HIV transmission risk behaviors in HIV-infected MSM with and without depression. *Health Psychology*, 29, 215-221. doi: 10.1037/a0017859

¹² Sugano, E., Nemoto, T., & Operario, D. (2006). The impact of exposure to transphobia on HIV risk behavior in a sample of transgendered women of color in San Francisco. *AIDS and Behavior*, 10, 217-225. doi: 10.1007/s10461-005-9040-z

¹³ Baird, S.J., Garfein, R.S., McIntosh, C.T., & Özler B. (2012). Effect of a cash transfer programme for schooling on prevalence of HIV and herpes simplex type 2 in Malawi: A cluster randomised trial. *The Lancet*, 379, 1320-1329. doi:10.1016/s0140-6736(11)61709-1

¹⁴de Walque, D., Dow, W.H., Nathan, R., Abdul, R., Abilahi, F., Gong, E., ... Medlin, C.A. (2012). Incentivising safe sex: A randomised trial of conditional cash transfers for HIV and sexually transmitted infection prevention in rural Tanzania. BMJ Open. 2, e000747. doi: 10.1136/bmjopen-2011-000747

participant in obtaining health-promoting behaviors, focusing particularly on the multiple and complex cofactors 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-naïve 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.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

¹⁵ Ribaudo, H., Lennox, J., Currier, J., Kuritzkes, D., Gulick, R., Haubrich, R., ... Hughes, M. (2009, Feb). Virologic failure endpoint definition in clinical trials: Is using HIV-1 RNA threshold <200 copies/mL better than <50 copies/mL? An analysis of ACTG studies. Paper presented at the 16th Conference on Retroviruses and Opportunistic Infections, Montreal, Canada. Abstract retrieved from http://www.retroconference.org/2009/Abstracts/33925.htm.

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 Logic Model diagram on page 75.

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 Metal 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 selfidentified 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 percent 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 percent. At baseline, 26 percent (33/128) of the participants had never been in HIV care and, among those who had previously been in HIV care, 41.9 percent (n=36/86) had dropped out. Furthermore, at baseline, 48.2 percent (n=67/139) of participants were in need of an ART medication prescription, and 51.1 percent (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 percent (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 percent 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).

APPROXIMATE COSTS OF THE INTERVENTION ANNUALLY

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 percent achieve all HIV health-promoting goals the annual cost for CM rewards would be $$500 \times 50 \times .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 percent effort, and two Peer Health Navigators both at 100 percent 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.



INTERVENTION APPENDIX

The Alexis Project Logic Model

People/ communities you work with and what characteristics they have The resources required for this program to operate

What this program does in day-to-day operations

The "stats" that result from regular program operation

Desired changes for target population as a result of program activities

Trans Women of color

Ages 18-65

Living in Los Angeles County, CA

African American, Latina, Asian, Pacific Islander, Native American, multi-ethnic, and other races/ ethnicities

HIV-positive

Service collaborations with medical providers for HIV care (AIDS Healthcare Foundation (AHF), LA LGBT Center

Service collaborations for other agencies

Volunteer social network recruiters

2 Full-time Peer Health Navigators (PHN)

1 Part-time Project Director

1 Part-time PI

1 Part-time Process Evaluator

1 Part-time Data Manager

Consultant, Medical Consultant Conduct social network recruitment for HIV testing and social network engagement with those who are aware of their HIV status

Provide HIV counseling and testing as part of social network testing (SNT)

Provide HIV prevention through existing programs for trans women

Provide additional support services including mental health, primary care, hormone therapy, support groups, housing, and youthspecific at partner agencies

Link those who test HIVpositive to a PHN

Link HIV-positive trans women of color to HIV care

Implement combined Peer Health Navigation and Contingency Management intervention

Provide Contingency
Management rewards
for attending HIV care
appointments and achieving
HIV milestones, i.e., reduced
or suppressed viral load (VL)

10 trans women will become volunteer recruiters for the SNT program

60 trans women of color will receive HIV counseling and testing

139 HIV-positive trans women of color will be linked to a Peer Health Navigator (PHN)

85% of those linked to a PHN will be linked to HIV medical care

70% of those linked to HIV medical care will be retained, i.e., at least two completed HIV-related medical visits 3 months apart

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

70% of HIV-positive trans women linked to HIV medical care will report >95% adherence to ART, and an undetectable VL or VL<200

85% of HIV-positive trans women will complete quarterly follow-ups to monitor engagement in care and HIV outcomes 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

Increase in percentage of newly diagnosed trans women of color linked to, re-engaged in or retained in care

Increase in percentage of already diagnosed who were never or not in care trans women of color linked to, reengaged in or retained in care

Decrease in viral load among trans women of color engaged in care

Increased viral load suppression

Figure 1: The Alexis Project Study Design

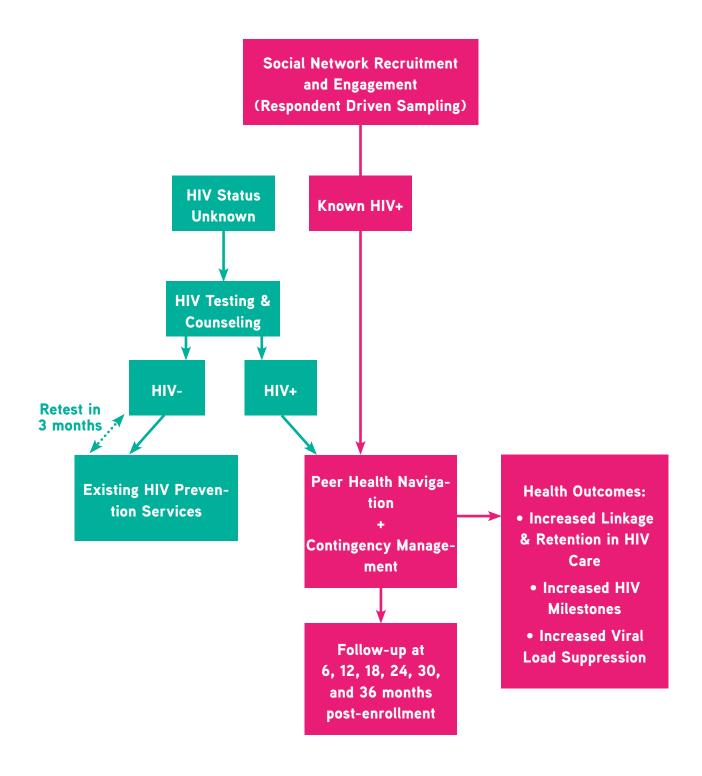


Figure 2: Combined Peer Navigation and Contingency Management Intervention

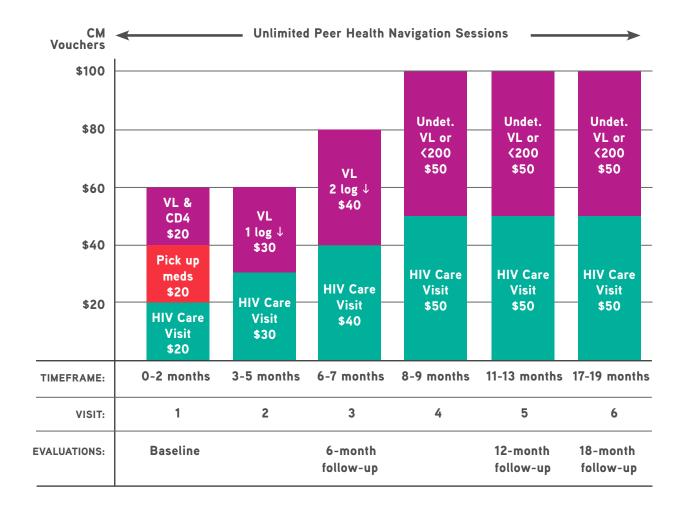


Illustration 1: Recruitment Flyer



HIV+ Trans Women of Color Will Be Immediately Linked to a Peer Health Navigator

We provide HIV testing for those who don't know their status or haven't had an HIV test in the last 3 months.

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 34, 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 Research Institute. 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

