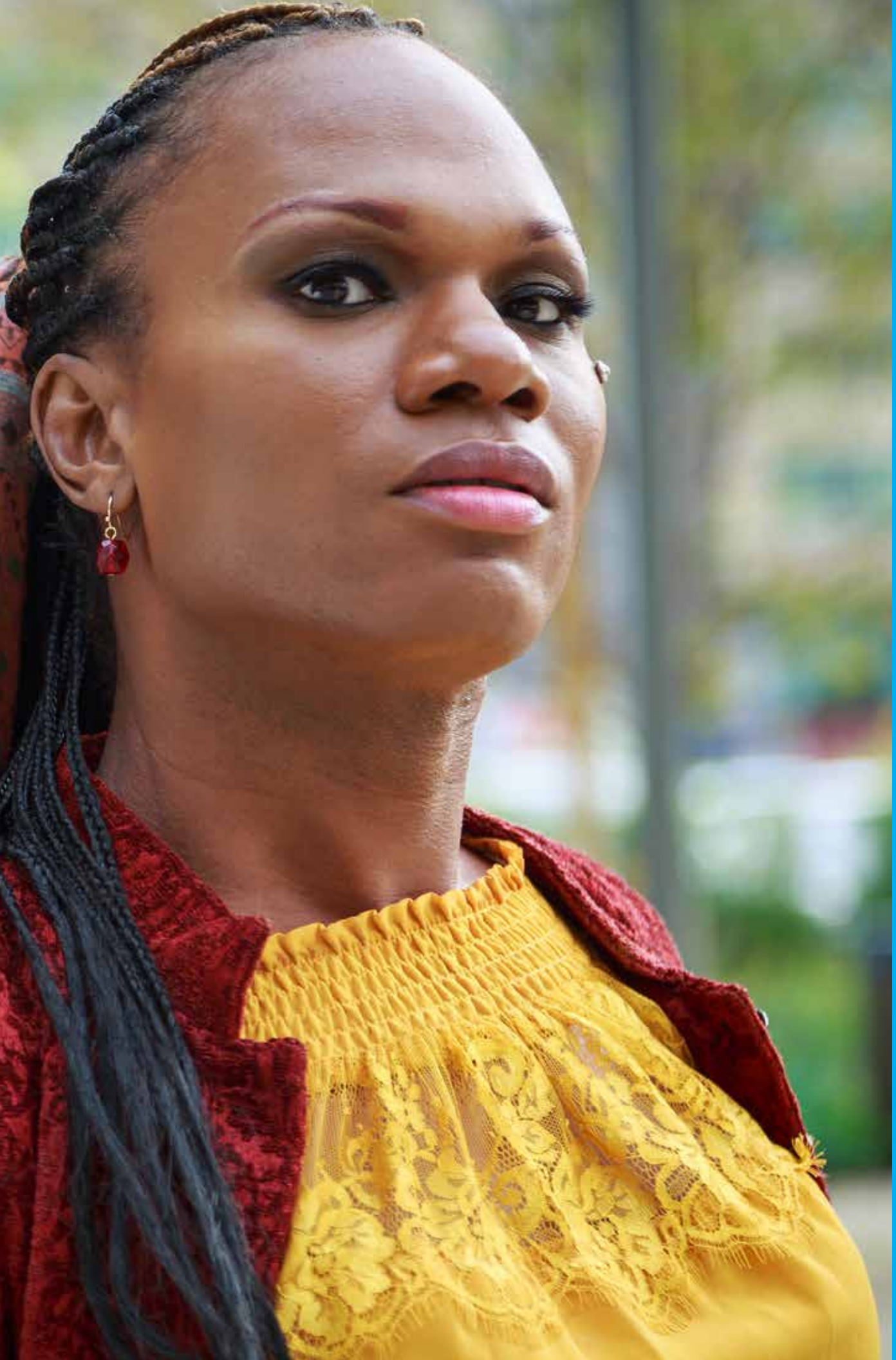

CHN FAMILY HEALTH CENTER: T.W.E.E.T. CARE

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

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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.

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 show that the Jamaica neighborhood has the third highest number of new HIV

1 Source: U.S. Census Bureau, 2011-2015 American Community Survey 5-Year Estimates

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 transwomen engage in sex work as a means of employment.[6]

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2 Source: NYC/DOH 2015 data

3 Ibid. And Poteat, T., Reisner, S. L., & Radix, A. (2014). HIV epidemics among transgender women. Current Opinion in HIV and AIDS, 9(2), 168-173.

4 Reback, C. J., & Fletcher, J. B. (2014). HIV prevalence, substance use, and sexual risk behaviors among transgender women recruited through outreach. AIDS and Behavior, 18(7), 1359-1367.

5 James, S. E., Herman, J. L., Rankin, S., Keisling, M., Mottet, L., & Anafi, M. (2016). The Report of the 2015 U.S. Transgender Survey. Washington, DC: National Center for Transgender Equality.

6 James, S. E., Herman, J. L., Rankin, S., Keisling, M., Mottet, L., & Anafi, M. (2016). The Report of the 2015 U.S. Transgender Survey. Washington, DC: National Center for Transgender Equality.

Homelessness is another critical issue for transgender people: one in five transgender individuals have experienced homelessness at some point in their lives. Family rejection, 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 percent 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 percent 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 Transgender Women Engagement and Entry To Care Project (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

Community Health Network (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

7 National Center for Transgender Equality http://www.transequality.org/issues/housing-homelessness

than 95 percent of CHN's patients are people of color, approximately 35 percent are uninsured, and 77 percent 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

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:

- 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 Transgender Leaders 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

THE INTERVENTION

The two interventions that serve as the foundation for the T.W.E.E.T. Care Project are the **Popular Opinion Leader**[8] and the **Teach Back**[9] 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.

8 Popular Opinion Leader Intervention. https://www.cdc.gov/hiv/research/interventionresearch/rep/packages/pol.html

9 Teach Back Intervention. Agency for Healthcare Research and Quality. https://www.ahrq.gov/professionals/quality-patient-safety/patient-family-engagement/pfeprimarycare/interventions/teach-back.html

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 HIV /AIDS and other 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

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

AREA B:SEXUAL HEALTH

Core focus	Optional focus	Example of additional information
• Oral, vaginal and anal sex • Sexual harm reduction • Anal health • Condom use	• Sex work • "Partying and playing" • Sexual risk continuum • Sexual health myths • Serosorting	• BDSM • Role-playing • Eroticizing safer sex

AREA C: TRANSITIONING

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

AREA D: WELLNESS

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

AREA E: MENTAL HEALTH

Core focus	Optional focus	Example of additional information
• Depression and anxiety • Abuse • Substance use • Gender Identity Disorder contradiction	• Relationship with sexual partners • Anger management • PTSD • Discrimination • Domestic violence • Harm reduction	• Eating disorders • Holiday blues • Overview of drugs • Dealing with stigma and discrimination

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

Healthcare discussion at an intervention session

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 other 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 Supplemental Security Income

(SSI), cash, and food vouchersAccompanying 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. We conducted community mapping to scout 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, and 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; and 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; and 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; tracking all referrals and services provided; and 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 turn-over 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

PROCESS MEASURES AND INTERVENTION OUTCOMES

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 percent (135/163)** of participants were either in active care or had pending appointments
- **17 percent (28/163)** were either non-compliant or lost to follow-up due to substance abuse, depression and/or other social factors.
- **79.2 percent (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 percent**

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

INTERVENTION COST

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
- 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.■

TWEETCare graduation

INTERVENTION APPENDIX

Figure 1: TWEETCare Logic Model