



SUNNY: THE INFINI-T PROJECT

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 percent of all HIV diagnoses in NYC. Twenty-one of these diagnoses were made with concurrent diagnosis of AIDS. Of all cases, 60 percent (140/232) were among young people aged 20-29. Ninety three percent 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 percent 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 percent of these were virally suppressed as of the last data report from 2014.

¹ New York City Department of Health, January 2016. <http://www1.nyc.gov/assets/doh/downloads/pdf/dires/hiv-in-transgender-persons.pdf>

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 transgender young women of color (TYWOC) living with HIV 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 TYWOC living with HIV 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
4. (barriers to engagement and retention in care);
5. 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
6. 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 TYWOC with unmet mental health needs, regardless of HIV status;
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

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 TYWOC regardless of HIV status, 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.

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

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.”² 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.³

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

2 Singer M, Clair S. Syndemics and public health: reconceptualizing disease in bio-social context. *Med Anthropol Q.* 2003;17(4):423-441.

3 Brennan J, Kuhns L, Johnson A, et al. (2012). Syndemic Theory and HIV-Related Risk Among Young Transgender Women: The Role of Multiple, Co-Occurring Health Problems and Social Marginalization. *Amer J Public Health.* (Published online ahead of print Feb 16, 2012:e1-e7. doi:10.2105/AJPH.2011.300433.)

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 TYWOC living with HIV 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.

By utilizing a multidisciplinary approach, HEAT sought to reduce the burden of the confounding effect of these multiple psychosocial factors.

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 multidisciplinary 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 transgender women of color living with HIV. 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 young men who have sex with men living with HIV on patient navigation and escorting youth to appointments at HEAT to build upon. This experience was transferable onto working with transgender young women living with HIV. 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 transgender women of color living with HIV 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 transgender young women of color living with HIV 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 turn-over 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

The Infini-T project had a strong rapport and reputation with the transgender community it was serving.

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 RWHAP Part D as a recommended care model for youth living with HIV. 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 Infit-T baseline data is described below.

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

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

* 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 percent 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, 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 was \$256, 660 including direct costs, personnel, etc.

LESSONS LEARNED

The replication of Infini-T is based on the importance of acknowledging the unique needs of youth living with HIV 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

Focused supervision tailored to agency circumstances is necessary to keep project staff grounded in the work being done.

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 at 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

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.

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, 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 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. ■