HOWARD BROWN HEALTH CENTER

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Kelly Ducheny, Psy.D.

Trisha Holloway

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

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LOCAL EPIDEMIOLOGY

Men and women of color are disproportionately affected by HIV/AIDS in Chicago, with higher rates of new HIV diagnoses.[1] In Illinois, there is a 0.61 percent HIV infection prevalence among persons living in Cook County (where Chicago is located), compared to the Illinois prevalence of 0.32 percent.[2] Within the City of Chicago, the HIV prevalence rate is 868.5 per 100,000, dramatically higher than the Cook County rate. In addition, while Chicago's HIV/STI surveillance report does not capture local epidemiological information related to transgender individuals, national studies demonstrate that transgender women have HIV prevalence rates from 22 percent to 28 percent, with African American transgender women testing positive for HIV more frequently than any other demographic.[3,4]

PROGRAM DESCRIPTION

Howard Brown Health (Howard Brown) is a Chicago-based, federally qualified health center (FQHC) that specializes in providing care to gay, lesbian, bisexual, transgender and gender non-conforming (TGNC)

1 Chicago Department of Public Health, HIV/STI Surveillance Report, Chicago, December 2016

2 County Health Rankings and Road Maps, 2016

3 Baral SD, Poteat T, Strömdahl S, Wirtz AL, Guadamuz TE, Beyrer C. Worldwide burden of HIV in transgender women: a systematic review and meta-analysis. Lancet Infect Dis 2013;13(3):214-22.

4 Herbst JH, Jacobs ED, Finlayson TJ, McKleroy VS, Neumann MS, Crepaz N. Estimating HIV prevalence and risk behaviors of transgender persons in the United States: a systematic review. AIDS Behav 2008;12(1):1-17.

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

THE INTERVENTION

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

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

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

Our intervention is predicated on the value of community-tailored health intervention programs that create safe spaces for transgender women to comfortably discuss issues related to health, gender history, depression, sexual risk, and substance use (Nemoto, 2005). By building authentic community trust and

involving community members in programming and outreach, our intervention offered HIV positive TWOC and all TGNC people an opportunity to develop a relationship with Howard Brown's health care system on their terms, in their time, with their priorities validated and supported. This approach reduced the fear of discrimination in health care that many TWOC experience, especially when seeking HIV care or HIV testing (Bockting, 1998; Clements, 1993). Through improved relationships and trust with our health care system, TWOC living with HIV and all TGNC people are more effectively engaged and retained in care, and more able to re-engage in health care after being absent or out of care.

The intervention had three primary goals:

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

The intervention achieved its goals through six key components:

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

Staffing

The intervention required 0.1 FTE of a director, 0.8 FTE of a program manager, 1.5-2.0 FTE of outreach staff, and 0.5 FTE each of 2 additional program staff. All staff outside of the director are TGNC, many of whom are TWOC.

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

Key Components of the Intervention

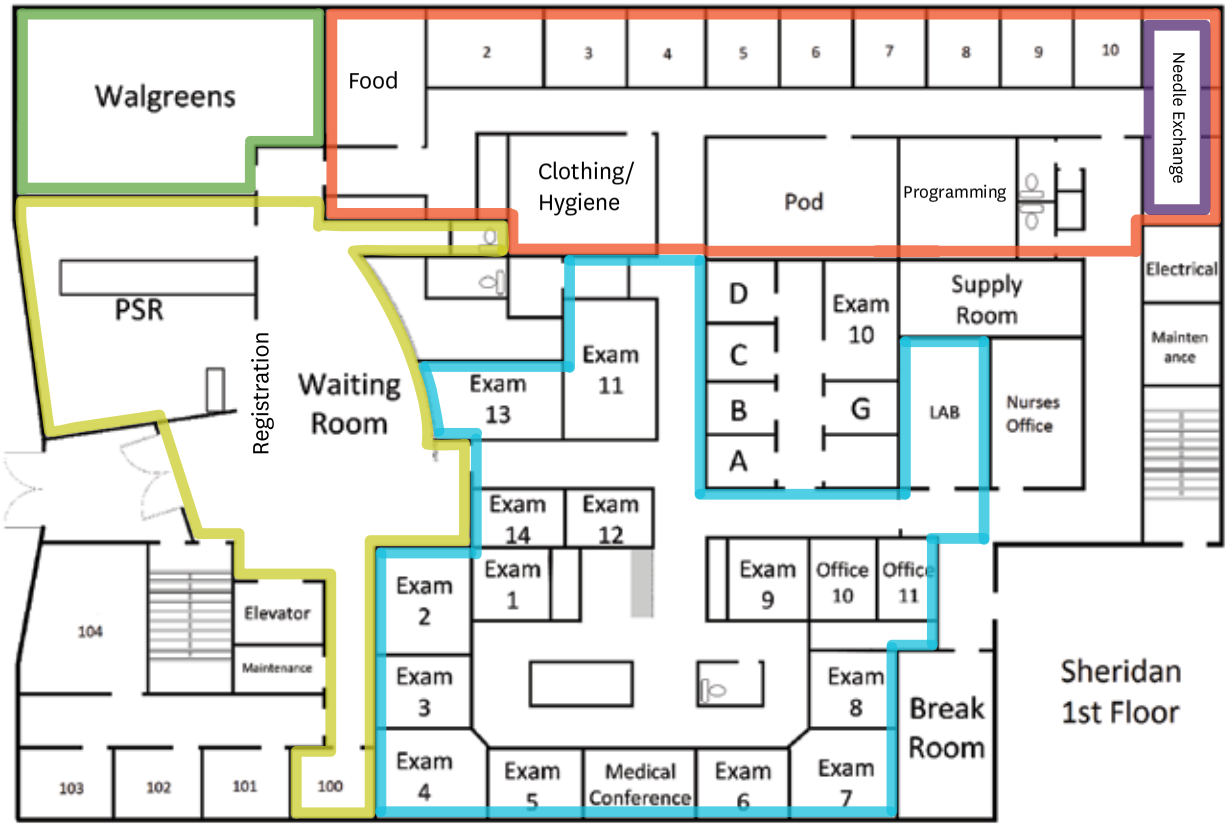
After Hours Drop-In

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

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

After Hours was designed to house a specialty medical clinic offering full primary and HIV care and wrap around services specifically tailored for TGNC people. The medical clinic and its supportive services are

After Hours Drop In



Pharmacy TGNC-only Space Needle Exchange Medical and BH Services

Registration, Insurance Counseling, Waiting Room, Shared Programming

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

Program staff responsibilities at After Hours include:

- 1 staff member helps After Hours participants fill out basic registration paperwork as they enter the lobby and assists the PSRs as they register patients for medical care or insurance enrollment counseling. This person acts as a greeter, explaining available services and ensuring participants understand that After Hours serves TGNC people only.
- 1 staff member coordinates the clothing and hygiene supplies.
- 1 staff member coordinates dinner and participants' interaction over food.
- 1 staff member and 1-2 volunteers coordinate SHINE, the trans specific needle exchange program.
- 1 staff member acts as a runner between the front desk, TGNC only programming space and the medical clinic. This person gets patients from programming space if they are running late for their medical appointment, and coordinates late requests for medical appointments, gender marker letters, or prescription refills. This allows participants to enjoy programming and other activities while waiting for their medical or insurance enrollment appointments rather than spending hours in the waiting room. This person also coordinates volunteers, presenters and programming.
- 1 staff member oversees the clinic schedule and appointment flow in the medical clinic and communicates with the pharmacy to resolve any prescription issues.

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

Youth Support Group (TYRA)

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

Adult Support Group (T-Time)

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

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

TGNC Specific Outreach

Two to three outreach staff plan and implement weekly outreach activities. Activities include 1) participation in community social events (Black Pride March, Trans Day of Remembrance, summer picnics, holiday parties), 2) attending community social events held by other organizations (bars, balls, award and celebration events, drop ins, gay family events), 3) visiting hang out locations or spaces TWOC congregate for work or community, and 4) individual and small group communication via Facebook, email and

phone. Outreach activities occur during regular business hours and from 8 p.m. until 2 a.m. Through all activities, staff discuss services offered at Howard Brown, invite participants to access services or attend programming at Howard Brown, and offer referrals to other resources should they match participant needs.

In-House Initiatives

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

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

TGNC Specific Needle Exchange

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

PROGRAM PLANNING AND DEVELOPMENT

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

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

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

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

STEP 3: Assess the readiness of the agency or organization to respectfully welcome and provide care to a larger number of TGNC people. Gather feedback from TGNC staff, cisgender staff/allies, and TGNC community members. Explore what you need to improve and/or what initiatives you need to undertake to authentically say that you offer TGNC affirmative programming and care. Most systems, even systems that consider themselves affirmative, have a fair amount of agency evolution and growth that must occur before outreach staff will be able to authentically represent your services as truly affirmative in the TGNC community.

STEP 4: Train providers and patient-facing staff in TGNC affirmative care and respectful communication. Train programming staff in drop in models, de-escalation techniques, and support group facilitation. In addition, proactively plan to provide TGNC staff with professional development that expands their skills and knowledge beyond the immediate project and prepare them to launch into other positions in the agency.

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

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

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

IMPLEMENTATION AND EVOLUTION

Staff recommend a needs assessment and preparatory training as start-up steps from experience, not because Howard Brown began its program after completing these steps. Howard Brown launched its programming and discovered areas of need as it progressed. Because Howard Brown is an LGBTQ health center and provides care that is much more TGNC affirmative than most care systems in our area, many staff assumed a higher level of agency wide TGNC competence than existed. The agency made an inaccurate assumption that because we provided care that was more TGNC affirmative than other places, the care we provided was already excellent and as TGNC affirmative as it needed to be. Staff leading support groups and conducting outreach were told by a range of community members and current/past patients about Howard Brown's errors and missteps and were challenged to improve the systems of care. TGNC program staff struggled to defend the agency in their attempts to engage community members and potential participants without knowing if the consistency of TGNC affirmative services would improve. TGNC staff reported similar struggles with their own care and with internal agency systems that failed to treat them with consistent respect. Through reflection, deep discussion and a series of meetings, the program team met with agency leadership to clarify the areas of need, articulate the high cost of maintaining the status quo, and identify the opportunity of improving the care offered to TGNC people. Agency leadership committed to improving the consistency of TGNC affirmative care in all aspects of Howard Brown, including all patient-facing and staff-facing segments of the organization. These meetings launched many of the in-house initiatives described above and, across 2-3 years, had a significant rippling impact across the agency.

Across time, staff developed work flow improvements in the After Hours Drop In clinic. After 6 months, the agency added a phlebotomist during After Hours since many patients were starting hormones and the need for bloodwork was more concentrated than in a usual clinic shift. After 18 months, to avoid delays in accessing prescriptions and to enhance the experience of taking hormones, Howard Brown began administering a patient's first hormone injection free of charge, using this as an opportunity for safer injection teaching. This process reduced the delay that occurred when a patient left the clinic to fill their prescription and then returned for injection teaching/first dose. Patients could obtain their first injection in an intimate injection teaching moment with friends and family and then shift into TGNC only programming space for special congratulations and support if they chose. Patients told staff this process dramatically improved their experience and the support they felt in their care. Howard Brown distributed hormone consents at the front desk at check-in and had sets of consents available in clinic for providers. Having a behavioral health consultant during the After Hours clinic was an important enhancement given the high levels of depression, anxiety and suicidal ideation seen in at-risk TGNC and TWOC patients. Having TGNC affirmative HIV/STI testing and counseling was a critical support at each After Hours as well.

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

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

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

The approach to outreach evolved across time. Staff tried different models of staffing and discovered that an outreach team that included someone that was trans masculine and someone that was trans feminine was most effective in reaching TWOC. In addition, having someone on the team who was Spanish speaking expanded agency ability to engage and retain Latinx participants. Across time, the focus of our outreach deepened, having the team place less emphasis on traditional social venues (bars, balls, events, dating websites) and more emphasis engaging networks that were deeply embedded in the TGNC

and TWOC community. Rather than interrupting potential participants as they enjoyed social events or activities, the team identified settings and events that offered more intimate time to talk (social media, social networks, going into gay families) and gave them opportunities to introduce resources as a peer rather than as a representative of our larger agency.

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

INTERVENTION OUTCOMES

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

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

In those same five years, the number of TWOC served in primary care increased 272 percent, from 156 patients, 105 of whom were HIV positive (2012), to 425, 147 of whom were HIV positive (2016). While the number of TWOC and TWOC living with HIV patients increased every year since 2010, the positivity rate reduced every year

(45 percent to 35 percent) and the percentage of TWOC living with HIV who received hormones increased every year (58 percent to 84 percent) even with the Delestrogen hormone shortage in 2016.

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

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

LESSONS LEARNED

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

LESSON 1: Your front line TGNC staff are the face of your organization in the TGNC community. They are absolutely critical to community building and to your successful engagement of participants. Engagement is primarily word of mouth and shared through social contact. TGNC staff are putting their reputations on the line whenever they vouch for the services your organization offers or the trustworthiness of your staff or systems. Your organization needs to work very hard to earn TGNC staff and community trust and to provide care of which your TGNC staff will be proud.

LESSON 2: Creating silo-ed TGNC expertise can result in deflection of shared responsibility for TGNC affirmative care. For the first 18 months, our program had two TGNC/TWOC patient navigators. The patient navigators were overwhelmed by the extremely high demand for their services (each worked with 500-700 people). Not only was there a high community need, but we discovered that internal systems and staff were deferring the needs of TGNC people to the patient navigators rather than providing affirmative care themselves or developing the skill or knowledge they needed to provide that care. We discontinued the patient navigation structure and instead focused on building internal systems to prepare each department and staff member to develop fundamental knowledge and skills in respectful communication and TGNC affirmative care. As confidence and internal accountability increased, staff skills and patient satisfaction increased.

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

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

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

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

LESSON 7: Conflicts and cultural competence within the TGNC community had to be regularly navigated in programming, planning, and community outreach. As TGNC people became more comfortable receiving care at Howard Brown, the racial, age, gender presentation, gender identity, and

transition experience of people receiving care in shared spaces dramatically increased. This sometimes created tension, conflict and misunderstandings between TGNC community members. For example, some participant groups with a binary gender identity would mis-gender non-binary participants or devalue their experience/identity. There was sometimes conflict between youth and older adults, Black and Latinx women, and White and people of Color groups. Staff needed to create safe space amongst participants as well as between participants and staff. We instituted safe space rules, modeled affirmative behavior and had ongoing discussions with participants and small groups to broaden awareness, understanding and support of others' experience and identity.

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

LESSON 9: Participants told us that TGNC-only programming space was of profound benefit. Some participants had never been in a TGNC devoted space and experienced a meaningful connection to community and a sense of relief. Cisgender staff and volunteers had to adapt to being restricted from entering some TGNC-only areas, and to the inability to participate in, contribute to or share in some TGNC-specific programming. ■

INTERVENTION APPENDIX

Figure 1: TransLife Care Logic Model—Enhancing Engagement & Retention in HIV Care for Transgender Women of Color (TWOC)

SITUATION: Health and social disparities impede quality of life for transgender and gender non-conforming (TGNC) people, especially transgender women of color (TWOC), including lack of culturally competent care, mistrust of health care system, lack of TWOC/TGNC-specific services and care, rigid gender roles and cultural norms within society, and pervasive transphobia in care delivery systems and society.

INPUTS

- Program Manager
- 2 Research Assistants
- Project Director/ Co-PI
- Evaluator/Co-PI
- Research Staff Member
- 2 Peer Outreach Leaders

- Outreach events and community relationships
- Space for bi-monthly Drop Ins
- Publication and marketing materials

- Partnership with pharmacy
- Medical and behavioral health care team, insurance navigation and front desk staff

- Support from Howard Brown leadership to evolve affirmative care model and agency culture

OUTPUTS

ACTIVITIES

- Meet w/ community partners
- Outreach events and social media outreach
- Marketing campaign
- Gather and incorporate community feedback
- Provide community driven programming, supplies, dinner and insurance enrollment at bi-monthly Drop Ins
- Provide medical and behavioral health care during bi-monthly Drop Ins (including PEP, PrEP, HIV/STI, HRT, HIV/primary care)
- 2 Peer support groups
- Case management, patient navigation and linkage to primary/HIV care provided by existing Ryan White Part D staff
- Meetings with agency staff/leadership to revise agency model of care and agency culture
- Staff trainings/meetings
- Dissemination of program data and evaluation outcomes

PARTICIPATION

- TGNC youth TGNC adults TWOC
- HIV+ people HIV- people
- Community agencies serving the TGNC community
- Community outreach partners
- TGNC and TWOC patients interested in affirming medical and behavioral health care
- TGNC and TWOC patients who had dropped out of care or never engaged in care
- Howard Brown leadership and staff

OUTCOMES/IMPACTS

SHORT

- Increased knowledge of community resources
- Improved community awareness of culturally competent primary medical, HIV care, and HRT services at Howard Brown
- Increased TGNC community familiarity and comfort with Howard Brown as a service provider
- Increased access to TGNC-affirmative HRT and primary/HIV care
- Improved relationships with community agencies and TGNC community leaders
- Improved knowledge of HRT risks and benefits
- Increased knowledge of safer injection methods
- Increased staff awareness of TGNC-affirmative care model

MEDIUM

- Increased number of TWOC receiving HRT, primary/HIV care
- Increased number of TGNC patients receiving HRT, primary/HIV care
- Events publicized with most effective outreach patterns/ activities identified
- Decreased needle and works sharing
- Improved medication adherence/engagement in HIV care
- Development of TGNC-affirmative clinical best practices
- Strategic TWOC and TGNC programming expansion
- Increased number of TGNC staff across multiple departments
- TGNC-affirmative health care identified as an agency priority
- Howard Brown staff trained in gender appropriate communication skills

LONG

- Increased trust of TGNC and TWOC communities
- Permanent TGNC Drop Ins
- Decrease in HIV transmission
- Reduced health disparities within TWOC communities
- Improved health outcomes, medication adherence, viral load and longevity
- Increased self-esteem/self-efficacy and strengthened social support networks
- Retention of TWOC in HIV/primary care
- Increased competence of staff and improved TGNC care provision
- Revision of internal agency procedures and deepened commitment to TGNC-affirmative care
- Development and dissemination of clinical best practices

ASSUMPTIONS: TGNC people need culturally affirming and sensitive care. Creating services open to the broad TGNC community can also effectively engage HIV+ TWOC. Peer delivered services increase engagement and retention in health care. TGNC communities need a safe space to gather and access care. TGNC-specific Drop In services improve access to and engagement in care. Internal agency culture must evolve to be TGNC-affirmative for true affirmative care to be provided to TWOC and TGNC people.

EXTERNAL FACTORS: Limited employment options for TWOC/TGNC people; discrimination in education and housing; targeted criminalization; lack of continuity of care; lack of culturally competent care for TWOC and TGNC people; transphobia; gender-based violence; absence of TGNC-affirming primary/HIV care. Significant resources necessary to undertake organizational cultural change; challenge to move all departments across an agency to prioritize TWOC/TGNC-affirmative care.