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Recruiting, Linking, and Retaining High-risk Transgender Women into HIV Prevention and Care Services: An Overview of Barriers, Strategies, and Lessons Learned

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Abstract

Despite disproportionately high HIV prevalence rates and high risk for HIV acquisition and transmission, trans women in the United States are less likely than other high-risk populations to be aware of their HIV status or to perceive HIV infection as a serious health threat. Furthermore, concurrently high rates of unstable housing, few legal employment opportunities, lack of social support, and distrust of social service providers limit trans women's interest or ability to be recruited by, retained within, or linked into HIV prevention and care services. This article provides an overview of the barriers that prevent many high-risk trans women from being recruited, linked, and retained within HIV prevention and care services as well as accessing HIV testing services, and discusses several strategies for overcoming these barriers. Best practices in working with high-risk trans women include hiring trans women indigenous to the local trans communities, designing culturally specific recruitment and retention strategies including the creation of living “community maps” to ensure successful community outreach, the construction of a trans women-specific CAB to create dialogue with community stakeholders including consumers, and extensive cultural sensitivity training for staff and community collaborators to sensitize them to the specific needs of high-risk trans women participants.

Keywords

transgender women; HIV; recruitment; linkage; retention

INTRODUCTION

The United Nations recognizes that all human beings are endowed with an inalienable right to pursue personal dignity and good health, and transgender persons are no exception (United Nations Development Program 2013). Unfortunately, transgender women (hereafter

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"trans women") in the United States are estimated to be 34.2 times more likely to be infected with HIV than other adult populations (Baral et al., 2013). Even in the face of this disproportionate disease burden, trans women are less likely to receive HIV testing (Schulden et al., 2008), to perceive HIV infection as a serious health threat (Herbst et al., 2008), or to be aware of their HIV-positive status than other high-risk populations (Bauer, Travers, Scalon, & Coleman, 2012; Herbst et al., 2008; Reisner, Lloyd, & Baral, 2013; Schulden et al., 2008). Furthermore, among those who are aware of their HIV-positive serostatus, studies have demonstrated that trans women in the United States are less likely to be linked into and retained in HIV medical care than any other adult risk population (Melendez et al., 2006), and examination of the HIV treatment cascade (Gardner, McLees, Steiner, del Rio, and Burman, 2011) for trans women reveals associations between economic factors (e.g., housing instability) and adherence to HIV primary care (Santos et al., 2014). Due to such elevated rates of HIV prevalence, perceived lack of HIV as a health threat, unknown HIV infection, demographic disparities, and limited linkage/retention/adherence to HIV medical care services, the Institute of Medicine recently identified transgender-specific health needs as a priority area of research (Institute of Medicine, 2011), noting that effective HIV prevention and care services for high-risk trans women are of utmost importance. However, recruiting, linking, and retaining trans women into HIV prevention and care services can present unique challenges, even for service providers who employ trans women staff, and who have a history of working with marginalized, vulnerable, hidden, and/or hard-to-reach populations. This overview examines the barriers facing recruitment, linkage, and retention of high-risk trans women into HIV prevention and care services and, based on lessons learned from the experience of over 20 years of working with high-risk trans women in Los Angeles County, California, offers effective strategies for overcoming such barriers.

RECRUITMENT AND HIV TESTING FOR HIGH-RISK TRANS WOMEN

Recruitment Barriers

Many high-risk trans women experience homelessness (Mottet & Ohle, 2006; Spicer, 2010; Fletcher, Kisler, & Reback, 2014), substance use including addiction (Benotsch et al., 2013; Herbst et al., 2008; Hoffman, 2014; Santos et al., 2014; Wolf & Dewa., 2012), mental health comorbidities (Bockting, Miner, Swinburne Romine, Hamilton, & Coleman, 2013; Fredriksen-Goldsen et al., 2013; Gijs, van der Putten-Bierman, & De Cuypere, 2014; Gleason, Costanzo, Oost, Livingston, & Cochran, 2014; Horvath, Iantaffi, Swinburne-Romine, & Bockting, 2013), and engagement in sex work (Bowers, Branson, Fletcher, & Reback, 2012; Hoffman, 2014; Nadal, Davidoff, & Fujii-Doe, 2013; Operario, Soma, & Underhill, 2008; Reback & Fletcher, 2014), each of which can reduce the time, inclination, and/or ability to enter into HIV services (Rapues, Wilson, Packer, Colfax, & Raymond, 2013). Simply meeting basic needs such as locating food, clothing, and/or shelter may be more pressing than the perceived need for services (Center for Disease Control and Prevention [CDC], 2007). It is not uncommon for staff working with trans women to encounter and attempt to recruit a potential participant into services or care only to find the potential participant to be disinterested, suspicious, or (often repeatedly) unable to follow through with an appointment.

Effective Recruitment Strategies

Building trust and rapport—Due in part to pervasive reports of personal dissatisfaction and/or mistreatment when seeking services (Bauer et al., 2009; Dewey, 2008; Kenagy & Bostwick, 2005; Lombardi, 2008; Nemoto, Sausa, Operario, & Keatley, 2006), trans women routinely report low levels of trust or interest in receiving health-related care (De Santis, 2009; Nuttbrock, 2012; Shipherd, Green, & Abramovitz, 2010). Building trust and rapport with a potential participant is paramount to successful recruitment into services. A primary and integral method of establishing trust is the hiring of indigenous trans women (i.e., trans women who come from the community they will serve) for the recruitment and provision of services to trans women participants. For example, when implementing a motivational interviewing intervention with out-of-treatment, substance-using trans women, a trans woman who identifies as a former substance user would be an ideal candidate for employment; or, when working to link and retain HIV-infected trans women into HIV care, a HIV-infected trans woman who is in care and medication adherent would be an ideal candidate for employment. The shared experience of being a trans woman can facilitate the ability to establish trust and rapport swiftly; this experience, which must be phenomenologically experienced to appreciate and understand, cannot be fully realized through any amount of staff sensitivity training. Employing trans women from the local communities is a proven successful method for recruitment (Barrington, Wejnert, Guardado, Nieto, & Bailey, 2012; Reback & Fletcher, 2014), and is one of the most impactful and important factors in reducing the trepidation that high-risk trans women feel in speaking to staff about important HIV prevention and care services (Thornhill & Klein, 2010).

However, as critical as it is to employ indigenous trans women to work with high-risk trans women, it is also critical to carefully recruit, screen, and train appropriate staff. Previous studies have found a high prevalence of trauma, depression, and social anxiety among trans women (Bockting et al., 2013; Kussin-Shoptaw, Fletcher, & Reback, 2014). Thus, for some trans women working with others who are currently experiencing similar circumstances can be re-traumatizing or may trigger a depressive episode or anxiety. Additionally, staff burnout can be high if staff are not properly supervised and supported in their work environment.

Indigenous trans women staff can provide useful insights on how to recruit, retain, and link local participants, serve as invaluable role models and, additionally, serve as a bridge between participants, service providers, and other community agencies and institutions (i.e., faith-based, law enforcement) to build trust and rapport among a population that has historically been suspicious of outsiders. Given that many trans women have few legal employment opportunities and (in most states) have no legal protection against employment discrimination due to their gender identity and/or gender presentation, employing trans women staff can be one of the most empowering methods of recruiting and retaining participants in programs. Furthermore, access to legal employment can reduce engagement in the street economy, reduce homelessness, and improve the personal health of the individual and the public health of the community. Hiring indigenous trans women staff usually requires extensive training prior to program implementation and service delivery as well as ongoing supervision and support, but such oversight, input, and mentoring can prove to be indispensable to the quality and integrity of the program.

Physical and digital social networks—It is important to understand the nuances of the ever-shifting social and geographic landscape of the many and varied local trans women communities. For example, learning and continually updating the actual physical locations where high-risk trans women congregate is a necessary tool for implementing a successful recruitment campaign. Ensuring that staff are familiar with the specific parks, street corners, bars, clubs, hotels, and food lines utilized by high-risk trans women is a necessary step in any effective recruitment effort. As these physical locations shift, so must the outreach efforts. Maintaining an up-to-date "community map" is an ongoing process. High-risk trans women are often not active or do not congregate during regular business hours, implying that staff must not only be willing to remain cognizant of their shifting migration patterns but must also be willing and available to work late nights, early mornings, and weekends.

Of equal and perhaps increasing importance is knowledge of the digital locations that trans women access, as trans women were some of the earliest and most avid adopters of social media sites (Shapiro, 2004; Singh, 2012). Though reduced educational attainment and elevated rates of poverty are common problems in trans women communities (Grant et al., 2011) and known barriers to Internet use (Rainie, 2010), the trans community has nonetheless embraced the Internet for the expression of their gender identities and the promotion of transgender-related issues (Shapiro, 2004; Rosser, Oakes, Bockting, and Miner, 2007; Hines & Sanger, 2010). Evidence increasingly suggests that trans women routinely share information about trans women-specific resources, information, and opportunities through social media sites and other digital communication venues (Green-Hamann & Sherblom, 2013; Magee, Bigelow, DeHaan, & Mustanski, 2012; Rosser et al., 2007). Established and/or influential trans women leaders or gatekeepers (often called "mothers;" Reisner et al., 2009) from the local community as well as consumers (i.e., trans women receiving services) can provide important insight into the physical and digital locations most used by local high-risk trans women, and may provide the necessary sensitivity to changes in site popularity and/or migrations of trans women's social networks to new social milieus.

Outreach and field strategies—Given the insular nature of many trans women networks (Barrington et al., 2012; Reisner et al., 2009) and the mistrust many trans women have for service providers (De Santis, 2009; Nuttbrock, 2012; Shipherd, et al., 2010), it is crucial that staff meet a potential participant "where she is at," in an environment of her choosing, and at a day and time that is convenient for her. Such *in situ* meetings are especially important when meeting a potential participant for the first time, when suspicion or mistrust may be at its most intense. Additionally, the provision of a small trans woman-specific gift (e.g., make-up, jewelry, perfume, nail polish), or a generic gift such as a transit pass, hygiene kit, or gift cards to local eateries or stores, are effective ways to thank a potential participant for her time and to demonstrate respect for her needs. Gifts, unlike condom and lube kits, which are identified with HIV prevention programs, can serve to capture a potential participant's interest which can then develop into an outreach encounter.

As critical as it is to approach a trans woman "where she is at," it is equally important to note that safety is of utmost importance whenever staff encounter potential participants in high-risk settings. Staff should receive extensive training on appropriate engagement

strategies and safety standards, particularly when approaching potential participants in the streets and venues where drug and sexual transactions occur. This will work to protect staff and increase their professionalism, facility with the population, and improve the services they administer. Staff should always work in teams of twos and threes, but never more than three, as not to overwhelm the potential participant.

Patience from staff can be underestimated but is essential for the effective recruitment of high-risk trans women. Building trust and rapport takes time and cannot be abrogated by using shortcuts. Mistreatment at the hands of service providers has established a baseline of mistrust and suspicion among many high-risk trans women, and it is only through careful and patient hard work that this mistrust can begin to be overcome. It is not uncommon for staff to encounter a potential participant multiple times before she will agree to receive services.

Extensive training on outreach strategies, establishing trust and rapport, and how to empower but not enable participants, will provide a foundation for staff (Broadhead & Fox, 1990; Reback, 1995). A suggested training strategy is to have new staff observe senior staff in the field; observations can then be accompanied by didactic trainings involving basic information on HIV/STDs, street drugs, and the development of a “community map.” Once these preliminary stages of outreach training are complete, but before new staff enters the field, a series of mock outreach encounters can be very helpful to practice how to handle difficult situations in the field. The final stage of training may include senior staff observing new staff as they conduct an actual outreach encounter. The senior staff can provide immediate feedback to ensure that the new staff fully understands how to convey the correct risk reduction information and culturally appropriate referrals, and that these activities are done in a manner that is acceptable to local high-risk trans women. When each of the aforementioned stages has been completed and new staff have demonstrated proficiency, new staff may then conduct outreach encounters with a partner. The entire training process can take approximately six to eight weeks.

Trans woman-specific community advisory board—Given the unique importance of the social networks of trans women (Pinto, Melendez, & Spector, 2008), it is crucial for agencies working with high-risk trans women to establish strong ties and lines of open communication with trans women leaders, gatekeepers, “mothers,” and consumers. A useful strategy for accomplishing this goal is the establishment and maintenance of a trans women-specific Community Advisory Board (CAB), through which open lines of dialogue with influential community members can be fostered. If resources permit, provide a meal and incentive at the CAB meeting to thank the attendees for their time and for providing valuable feedback. Such a CAB should ideally be comprised of stakeholders from various settings, including law enforcement, faith-based institutions, community-based organizations, consumers, and, perhaps most importantly “mothers” from the local trans women communities. Evidence from prior studies clearly demonstrates the special importance of elders and opinion leaders; such individuals yield disproportionate influence upon the actions and opinions of other trans women, due to their central position in the traditionally insular social networks of trans women (Reisner et al., 2009). Leaders, gatekeepers, and “mothers,” not only serve as important contact points between the agency and the broader

trans communities, but can also offer invaluable insights into the needs, interests, and concerns of high-risk trans women, including providing advice on potentially underutilized recruitment strategies.

When barriers to recruitment, retention and/or linkage are recognized by staff, a first step would be to consult forums (such as a trans woman-specific CAB) to solicit insight from leaders, gatekeepers, “mothers,” and consumers. These individuals can share their lived experience to help construct solutions that are both feasible and acceptable to high-risk trans women. Successful program planning and implementation should also include such avenues for feedback from both community members and participants throughout the formative, implementation, and process evaluation phases to ensure effective and culturally competent provision of services. This will inevitably require flexibility in programming as modification may be required following CAB feedback.

Testing Barriers

In spite of disproportionately high rates of HIV infection, available evidence strongly suggests that trans women on average do not receive adequate access to HIV testing services (Schulden et al., 2008). As a result, meta-analytic and epidemiological research have revealed that significant proportions of HIV-infected trans women are unaware of their HIV positive status (Herbst et al., 2008), increasing the risk for unintended transmission of HIV to sexual and/or injection partners as well as compromising their personal health. Low rates of HIV testing in this population are affected by the same structural and individual barriers that influence poor recruitment success into other services (e.g., homelessness, substance use including addiction, mental health comorbidities, engagement in sex work), but are further exacerbated by the stigma attached to being both a trans woman and HIV positive (Nemoto, Operario, Keatley, Nguyen, and Sugano, 2005). Furthermore, high-risk trans women who engage in sex work may be resistant to receive HIV testing services and learn their HIV status because, if they are known to be HIV positive and are arrested for prostitution, the charge can be elevated to a felony. Moreover, when competition for exchange partners between trans women is high, the stigma of being labeled as HIV positive may limit available sex work, a consequence which may serve to avert testing or even the presence at a HIV testing or care facility (Poteat, German, & Kerrigan, 2013).

Effective Testing Strategies

Utilizing social networks—Once again, community leaders and “mothers” are invaluable resources to not only encourage other trans women to get tested, but also to encourage trans women to recruit others from their social, sexual, and/or drug-using networks to be tested. The use of social network testing methods (e.g., respondent driven sampling, snowball sampling) will further expand the ability of the service agency to identify (and link) newly diagnosed HIV-infected trans women as well as to engage or re-engage known HIV-infected trans women into HIV care. Such reliance on social network testing methods is particularly effective among high-risk trans women, who greatly rely on their social networks for support due to an often lack of social support from family, employment, and other traditional network connections.

Evidence also suggests that support from social network peers is particularly effective in promoting personal resilience among trans women, an important factor in overcoming perceived stigma. The minority stress model (Kelleher, 2009) suggests that social support, self-acceptance, and ongoing contact with a community of peers can ameliorate the stress and sundry health consequences of a stigmatized social identity, and such support has been associated with reductions in the psychological and physical health sequelae common to communities of trans women (Bockting et al., 2013). Thus, sociological factors (e.g., social network recruiting, social support, identity integration) are particularly effective at increasing testing rates among trans women.

There are several other effective strategies that are useful in encouraging trans women to get tested such as the provision of monetary incentives, setting up testing sites at large community events (e.g., Trans Pride), and the application of motivational interviewing techniques through individual counseling sessions. Additionally, HIV self-test kits are being used among members of stigmatized populations, though the cost of these kits may prevent many no- or low-income trans women from utilizing them. Different agencies may choose to research and apply these general testing methods on their own, given the specific limits of their funding, staff, and scope of mission.

Linkage Barriers

In spite of the high HIV burden evident in this population, prior evidence has demonstrated that high-risk trans women have poor linkage rates into HIV primary care (Melendez et al., 2006). Mistrust and suspicion due to widespread reports of abuse at the hands of healthcare providers has made trans women hesitant and resistant to link into HIV primary care (Kosenko, Rintamaki, Raney, & Maness, 2013). Even when a HIV-infected trans woman is identified through testing, and the HIV care services are through the same agency, linkage can be difficult. For a variety of reasons, even HIV-infected trans women who are not experiencing homelessness, substance use, mental health comorbidities, and do not engage in sex work may still be resistant to HIV care.

Some medical facilities use forms that only list two gender options: male or female. This exclusionary binary option can re-traumatize a trans woman who has had past stigmatizing and hostile experiences with health care providers. Health care providers may refer to the trans woman patient by her legal (i.e., male) name and assigned sex and, thus, accessing medical care can be humiliating and even embarrassing. As the patient, the trans woman may not wish to be put in the position of educating her health care providers, as she has come to the provider for their expertise. Also, it is important to note that undocumented HIV-infected trans women may fear accessing medical services as many require a social security number or a form of state- or federally issued documentation. As a result, service providers working with trans women must realize that simply referring a trans woman to HIV care or setting an initial appointment will often fail to effectively link her into HIV care. Finally, staff should be sensitive to the fact that some HIV-infected trans women may not be ready to access HIV care, particularly those who are newly diagnosed. The minority stress model suggests that there may be a period of identity integration before the individual can be prepared to face the stigma associated with their new identity (Kelleher, 2009;

Bockting et al., 2013). In such situations, the consistent support and contact that is so critical to overcoming recruitment barriers can also serve as instrumental for linking those newly diagnosed trans women who are initially resistant to HIV care.

Effective Linkage Strategies

Empowering the decision-making process—Presenting linkage to HIV primary care as an opportunity and not a mandate provides a narrative of empowerment, which moves the focus of control from the health care provider to the participant. In this way the HIV-infected, high-risk trans woman is empowered to "make her own choices" and to "take charge of her health." This shift to a client-centered narrative may increase linkage and reengagement in HIV care among high-risk trans women.

Peer support—Employing HIV-infected trans women who have overcome their personal barriers to receiving HIV care, who are medication adherent, and have achieved virological suppression can serve as role models and provide invaluable social support (Thornhill & Klein, 2010). Furthermore, a structured Peer Health Navigation program can work with HIV-infected trans women to remove as many barriers as possible. A Peer Health Navigator can make and attend appointments, interface with service providers, provide transportation, send appointment reminders and, if funding is available, provide a monetary incentive for attending medical appointments. Over time, Peer Health Navigation has been demonstrated to increase self-efficacy that results in long-term positive health outcomes (Bradford, Coleman, & Cunningham, 2007), and peer support may reduce the stigma that prevents some HIV-infected trans women from linking to care (Bockting et al., 2013).

Coupling hormone therapy with HIV primary care—Certainly, HIV care facilities that also offer legal and monitored hormone therapy can increase enthusiasm for HIV care among trans women who are seeking low- or no-cost hormone therapy to enhance their gender presentation (Williamson, 2010; Reback, 2014). In addition to improving the likelihood of linkage to and retention in HIV primary care, such a practice can simultaneously work to reduce the use of illegal hormones and, thereby, reduce the potential harmful consequences of "street" hormones and the attendant risks of needle usage. Staff should proactively learn which HIV care providers also offer low- or no-cost hormone therapy and provide this information to HIV-infected trans women as a combined opportunity to improve their overall health outcomes.

RETAINING HIGH-RISK TRANS WOMEN

Retention Barriers

The fundamental barriers to recruiting and linking high-risk trans women into HIV prevention and care services (e.g., homelessness, substance abuse including addiction, mental health comorbidities, engagement in sex work) are the same barriers to retaining participants in these services, with the added barrier of cycles of short- and/or long-term incarceration. An examination of the HIV care continuum among trans women (Santos et al., 2014) reveals many trans women who are successfully linked into HIV care are not retained, leading to elevated rates of unsuppressed viral load. Urgent and emergency needs often

compete for the attention and emotional energy of high-risk trans women and reduce her availability and commitment to ongoing services. Attendance to basic survival needs, such as the acquisition of food, clothing, and/or shelter may present a serious challenge for many high-risk trans women, and often lead participants to forego program attendance and medical appointments in favor of basic subsistence needs. This is revealed through the observed association between basic subsistence indicators (e.g., housing instability) and failure to progress through the HIV care continuum among trans women (Santos et al., 2014). Therefore, retention of high-risk trans women can be especially challenging for both individual and group-level interventions that requires participants to attend multiple sessions. Furthermore, many high-risk trans women experience unstable housing and they may not have access to a permanent address, cell phone, or the Internet, which makes locating participants for follow-up appointments or required program activities particularly challenging. Without ongoing contact to maintain the trust and rapport established during recruitment, many high-risk trans women will miss appointments or fully drop out of HIV prevention services and/or care.

Effective Retention Strategies

Continuity—Consistent and continuous contact with high-risk trans women participants is essential to effective retention. Consistency demonstrates commitment to the participant, which can translate into a reason to talk about risk behavior, sexual health, and other personal topics such as stigma, discrimination, and gender transition. Continuity, or simply showing up each week, signifies to the participant that staff are committed to her needs. Beyond continuing to build or maintain a trusting relationship, a consistent presence also serves to assist in locating individuals for appointment reminders and follow-up activities. Though a stable address may be lacking, contact can often be readily maintained if staff remain informed of the ever-shifting sites where high-risk trans women congregate. Staff must also anticipate missed appointments and be willing to reschedule multiple times to ensure ongoing engagement in the program activities, and to avoid losing contact with the participant. For homeless trans women and/or those experiencing mental health comorbidities, it becomes particularly difficult to maintain appointments that are scheduled months, weeks, or even days in advance. Therefore, reminders (delivered whenever and however possible, through phone calls/voicemails, social media messaging services, text messages, street outreach, etc.) the day of, and days leading up to, an appointment or program activity can markedly improve retention and, again, demonstrate commitment to and care for the participant.

Continuity in the field will also allow staff to maintain an up-to-date community map. The popularity of venues and streets change, sometimes as the seasons change, or sometimes as police sweeps remap drug-using and stroll districts. As high-risk venues and streets change so must outreach efforts and, at times, programming. Community mapping should be ongoing and staff should be prepared to modify program activities as a result of ongoing mapping as well as process evaluation (e.g., updating street outreach locations and times or changing group times to better coincide with the lifestyle and needs of the participants).

Continuity and consistency can also work in reverse, i.e., rather than staff going into the field, mechanisms can be established for participants to come to the agency, even when services are not provided. For example, providing an incentive such as a gift card, or a meal, or a snack, or a soda to the participant just for coming into the agency to say hello. Or, if a drop-in facility is not feasible due to funding and/or space restrictions, providing a private computer station with Internet access can attract participants to return to the agency. These strategies are particularly useful for staying connected with the very hard-to-reach participants such as those who are homeless and/or have mental health comorbidities.

Trans woman-specific incentives—As with recruiting high-risk trans women into services, the offer of culturally appropriate incentives such as wigs, purses, perfume, lipstick, body lotion, make-up, jewelry, nail polish, or gift cards to local stores where trans women prefer to shop, as well as food, bus tokens, hygiene kits, and other generic gifts can also retain trans women in HIV prevention and care services. For example, the ability to provide a razor to shave off facial hair can be an empowering mechanism to retain a trans woman participant. As previously noted, the provision of a small trans woman-specific gift is a very effective way to show appreciation to program participants. Gifts are coded as fun, as opposed to risk reduction supplies, which should also be given but are coded as a necessary risk reduction strategy. Therefore, gifts serve to contribute to the retention and maintenance of a trusting relationship between staff and participants.

A continuum of services—Providing a continuum of services, ranging from low to high intensity can improve an agency's ability to retain high-risk trans women. If a participant begins to use other ancillary site-based services (e.g., health education and risk reduction programs, counseling, mental health counseling and therapy, legal services, HIV care, HIV and/or sexually transmitted infection testing, housing placement, substance abuse treatment, employment development), additional opportunities exist that allow staff to continuously interact with participants. As high-risk trans women are in need of additional resources, the availability to offer wraparound programming provides an additional “safety net” and increased opportunities for staff and participants to maintain ongoing contact.

Over time, staff may become confidants, counselors, and mentors to participants; these social ties strengthen the bond between the participant and the agency; thus, aiding in successful retention. In some cases, staff may be the only social support a participant has. If so, these participants might seek out staff in times of need, and without advance notice, for emotional support. Staff can enhance retention by allowing walk-in appointments and providing (often unscheduled) services when a participant needs it most.

Working with law enforcement—Cycles of incarceration may serve as an especially difficult barrier to the retention of high-risk trans women in services (Sevelius, Keatley, and Gutierrez-Mock, 2011), particularly for trans women of color (Sevelius, Patouhas, Keatley, and Johnson, 2014). In some urban areas, a common misperception by law enforcement is that all trans women engage in sex work; thus, many homeless and street-based trans women experience additional scrutiny by law enforcement. Therefore, even if a trans woman is not participating in illegal activity, law enforcement may target her to check criminal backgrounds and search for outstanding warrants. Due to actual or perceived participation in

the underground street economy (e.g., sex work, selling or possession of illicit drugs) for survival, or minor homeless infractions, high-risk trans women frequently experience repeated short- and/or long-term cycles of incarceration. As a result, it can be difficult to successfully move these participants through an intervention that requires multiple sessions or follow-up appointments.

Due to the potentially contentious relationship between street-based trans women and law enforcement, successful retention relies on the establishment of ongoing communication and increased understanding between an agency and the local police department. This can often be accomplished through informational presentations by agency staff and consumers to law enforcement as well as by law enforcement to agency staff and consumers. Informational presentations that highlight the struggles of street-based trans women can increase sensitivity to these communities and offer law enforcement the tools to communicate with trans women in a culturally appropriate manner. Conversely, informational presentations by law enforcement can also explain their duties and include tips on how to avoid arrest. Although some local law enforcement academies might be resistant, others will be willing to attend or host a presentation; such dialogue may serve to overcome biases and can increase trust between these two divergent groups. Strengthening interrelationships in this way will benefit participants as they may then experience less arbitrary discrimination and learn more about their rights when interacting with law enforcement. In turn, law enforcement can improve communication skills when interacting with this population. Additionally, the agency can better help their participants by reducing police sweeps through communities which will then serve to improve retention.

Networking with law enforcement can sensitize this group to the needs and health risks faced by high-risk trans women. Law enforcement personnel may benefit from cultural sensitivity and competency training to enhance their ability to interact in a manner that affirms a transgender identity. The ability to offer such training can further enhance community partnerships and increase the delivery of local culturally competent services.

Follow-up appointments—Retention can also be increased through the development and maintenance of a detailed trans women-specific locator form. This locator form should gather information on phone number(s), email address(es), personal webpage(s), social network sites, emergency contact(s), family member(s) and trans and non-trans friend(s), and typical “hang-outs.” The locator form should clearly ask the participant what name she would prefer the agency to use when family and friends are contacted. As previously noted, a useful strategy for maintaining an up-to-date locator form is to provide a trans woman-specific gift to participants to come to the agency and update their locator information on a monthly basis.

CONCLUSIONS AND LESSONS LEARNED

The overview of strategies presented here reflects insights and lessons learned from over 20 years of working with and providing culturally competent services and research projects to high-risk trans women in Los Angeles County, California. It is important to note that many of the same barriers of recruitment and retention experienced when working with high-risk

trans women are also common to other marginalized, vulnerable, hidden and/or hard-to-reach populations (e.g., the homeless, those with mental health concerns, substance users, youth, the elderly: Areán, Alvidrez, Nery, Estes, and Linkins, 2003; Hough, Tarke, Renker, Shields, & Glatstein, 1996; Pollio, Thompson, & North, 2000; Yancey, Ortega, & Kumanyika, 2006). In this sense, many of the barriers faced when working with trans women are not entirely exceptional. However, although many of the barriers may be similar, the strategies and solutions to overcome these barriers can and should be customized to the specialized needs and concerns of trans women, so as to maximize the benefit of the services provided and the research conducted, and to afford trans women the dignified health care and social services they are entitled to. Over the last 20 years our group has encountered each of the aforementioned barriers. To address these barriers, our group crafted and refined the strategies discussed and has, thus, accumulated many lessons learned. Perhaps the greatest lessons learned are that non-trans women staff must be open and willing to learn from trans women staff, community leaders, gatekeepers, “mothers,” and consumers, and may we always remember to thank our participants.

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REFERENCES

Areán PA, Alvidrez J, Nery R, Estes C, Linkins K. Recruitment and Retention of Older Minorities in Mental Health Services Research. The Gerontologist. 2003; 43(1):36–44. doi: 10.1093/geront/43.1.36. [PubMed: 12604744]

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 Diseases. 2013; 13(3): 214–22. doi:10.1016/S1473-3099(12)70315-8. [PubMed: 23260128]

Barrington C, Wejnert C, Guardado M, Nieto A, Bailey G. Social network characteristics and HIV vulnerability among transgender persons in San Salvador: Identifying opportunities for HIV prevention strategies. AIDS and Behavior. 2012; 16(1):214–224. doi:10.1007/s10461-011-9959-1. [PubMed: 21538082]

Bauer GR, Hammond R, Travers R, Kaay M, Hohenadel KM, Boyce M. “I don't think this is theoretical; this is our lives”: How erasure impacts health care for transgender people. Journal of the Association of Nurses in AIDS Care. 2009; 20(5):348–361. doi:http://dx.doi.org/10.1016/j.jana.2009.07.004. [PubMed: 19732694]

Bauer GR, Travers R, Scanlon K, Coleman TA. High heterogeneity of HIV-related sexual risk among transgender people in Ontario, Canada: a province-wide respondent-driven sampling survey. BMC Public Health. 2012; 12(1):292. doi:10.1186/1471-2458-12-292. [PubMed: 22520027]

Benotsch EG, Zimmerman R, Cathers L, McNulty S, Pierce J, Heck T, Snipes D. Non-medical use of prescription drugs, polysubstance use, and mental health in transgender adults. Drug and Alcohol Dependence. 2013; 132(1–2):391–394. http://dx.doi.org/10.1016/j.drugalcdep.2013.02.027. [PubMed: 23510637]

Bockting WO, Miner MH, Swinburne Romine RE, Hamilton A, Coleman E. Stigma, mental health, and resilience in an online sample of the US transgender population. American Journal of Public Health. 2013; 103(5):943–951. doi:10.2105/ajph.2013.301241. [PubMed: 23488522]

Bowers JR, Branson CM, Fletcher JB, Reback CJ. Predictors of HIV Sexual Risk behavior among men who have sex with men, men who have sex with men and women, and transgender women.

International Journal of Sexual Health. 2012; 24(4):290–302. doi:10.1080/19317611.2012.715120. [PubMed: 24660042]

Bradford JB, Coleman S, Cunningham W. HIV System Navigation: An emerging model to improve HIV care access. AIDS Patient Care and STDs. 2007; 21(1):S–49-S-58. doi:10.1089/apc.2007.9987.

Broadhead RS, Fox KJ. Takin' it to the Streets: AIDS outreach as ethnography. Journal of Contemporary Ethnography. 1990; 19(3):322–348. doi:10.1177/089124190019003004.

Centers for Disease Control and Prevention [CDC]. US Department of Health and Human Services (Ed.). Washington, D.C.: 2007. HIV/AIDS and transgender persons.. http://www.cdc.gov/lgbthealth/pdf/fs-transgender-06192007.pdf

De Santis JP. HIV infection risk factors among male-to-female transgender persons: A review of the literature. Journal of the Association of Nurses in AIDS care. 2009; 20(5):362–372. doi:10.1016/j.jana.2009.06.005. [PubMed: 19732695]

Dewey JM. Knowledge legitimacy: How trans-patient behavior supports and challenges current medical knowledge. Qualitative Health Research. 2008; 18(10):1345–1355. doi:10.1177/1049732308324247. [PubMed: 18832767]

Fletcher JB, Kisler KA, Reback CJ. Housing Status and HIV Risk Behaviors among Transgender Women in Los Angeles. Archives of Sexual Behavior. 2014 doi: 10.1007/s10508-014-0368-1.

Fredriksen-Goldsen KI, Cook-Daniels L, Kim H-J, Erosheva EA, Emlet CA, Hoy-Ellis CP, Muraco A. Physical and mental health of transgender older adults: An at-risk and underserved population. The Gerontologist. 2013; 54(3):488–500. doi:10.1093/geront/gnt021. [PubMed: 23535500]

Gardner EM, McLees MP, Steiner JF, del Rio C, Burman WJ. The Spectrum of Engagement in HIV Care and its Relevance to Test-and-Treat Strategies for Prevention of HIV Infection. Clinical Infectious Diseases. 2011; 52(6):793–800. doi: 10.1093/cid/ciq243. [PubMed: 21367734]

Gijs, L.; van der Putten-Bierman, E.; De Cuypere, G. Psychiatric comorbidity in adults with gender identity problems.. In: Kreukels, BPC.; Steensma, TD.; de Vries, ALC., editors. Gender Dysphoria and Disorders of Sex Development. Springer; New York, NY: 2014. p. 255-276.

Gleason, H.; Costanzo, M.; Oost, K.; Livingston, N.; Cochran, B. A systematic review of mental illness in the transgender community.. Paper presented at the 142nd American Public Health Association (APHA) Annual Meeting and Exposition; New Orleans, LA. 2014. Retrieved from https://apha.confex.com/apha/142am/webprogram/Paper309675.html

Grant, JM.; Mottet, LA.; Tanis, J.; Harrison, J.; Herman, JL.; Keisling, M. Injustice at Every Turn: A Report of the National Transgender Discrimination Survey. National Center for Transgender Equality, and the National Gay and Lesbian Task Force; Washington, D.C.: 2011.

Green-Hamann, S.; Sherblom, JC. Developing a transgender identity in a virtual community.. In: Cunningham, C., editor. Social Networking and Impression Management. Lexington Books; Plymouth, UK: 2013. p. 185-205.

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 Behavior. 2008; 12(1):1–17. doi:10.1007/s10461-007-9299-3. [PubMed: 17694429]

Hines, S.; Sanger, T., editors. Transgender Identities: Towards a Social Analysis of Gender Diversity. Routledge; NY: New York: 2010.

Hoffman BR. The interaction of drug use, sex work, and HIV among transgender women. Substance Use and Misuse. 2014; 49(8):1049–1053. doi:10.3109/10826084.2013.855787. [PubMed: 24779504]

Hough RL, Tarke H, Renker V, Shields P, Glatstein J. Recruitment and retention of homeless mentally ill participants in research. Journal of Consulting and Clinical Psychology. 1996; 64(5):881–891. doi: 10.1037/0022-006X.64.5.881. [PubMed: 8916615]

Horvath KJ, Iantaffi A, Swinburne-Romine R, Bockting W. A comparison of mental health, substance use, and sexual risk behaviors between rural and non-rural transgender persons. Journal of Homosexuality. 2013; 61(8):1117–1130. doi:10.1080/00918369.2014.872502. [PubMed: 24380580]

Institute of Medicine. The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding. National Institutes of Health/National Academy of Sciences; Washington, D.C.: 2011.

Kenagy GP, Bostwick WB. Health and social service needs of transgender people in Chicago. International Journal of Transgenderism. 2005; 8(2-3):57–66. doi:10.1300/J485v08n02_06.

Kosenko K, Rintamaki L, Raney S, Maness K. Transgender Patient Perceptions of Stigma in Health Care Contexts. Medical Care. 2013; 51(9):819–822. doi: 810.1097/MLR.1090b1013e31829fa31890d. [PubMed: 23929399]

Kussin-Shoptaw, A.; Fletcher, JB.; Reback, CJ. Physical and/or Sexual Abuse is Associated with Increased Distress among Transgender Women.. Paper presented at the Annual Conference of the American Psychological Association; Washington, D.C.. 2014.

Lombardi E. Substance Use Treatment Experiences of Transgender/Transsexual Men and Women. Journal of LGBT Health Research. 2008; 3(2):37–47. doi:10.1300/J463v03n02_05. [PubMed: 19835040]

Magee JC, Bigelow L, DeHaan S, Mustanski BS. Sexual health information seeking online: A mixed-methods study among lesbian, gay, bisexual, and transgender young people. Health Education & Behavior. 2012; 39(3):276–289. doi:10.1177/1090198111401384. [PubMed: 21490310]

Melendez R, Exner T, Ehrhardt A, Dodge B, Remien R, Rotheram-Borus M-J. The National Institute of Mental Healthy Living Project Team (2006). Health and health care among male-to-female transgender persons who are HIV positive. American Journal of Public Health. 96(6):1034–1037. doi:10.2105/AJPH.2004.042010. [PubMed: 16131645]

Mottet L, Ohle J. Transitioning our shelters: Making homeless shelters safe for transgender people. Journal of Poverty. 2006; 10(2):77–101. doi:10.1300/J134v10n02_05.

Nadal KL, Davidoff KC, Fujii-Doe W. Transgender women and the sex work industry: Roots in systemic, institutional, and interpersonal discrimination. Journal of Trauma & Dissociation. 2013; 15(2):169–183. doi:10.1080/15299732.2014.867572. [PubMed: 24313294]

Nemoto T, Operario D, Keatley J, Nguyen H, Sugano E. Promoting health for transgender women: Transgender resources and neighborhood space (TRANS) program in San Francisco. American Journal of Public Health. 2005; 95(3):382–384. doi:10.2105/AJPH.2004.040501. [PubMed: 15727962]

Nemoto T, Sausa LA, Operario D, Keatley J. Need for HIV/AIDS education and intervention for MTF transgenders. Journal of Homosexuality. 2006; 51(1):183–201. doi:10.1300/J082v51n01_09. [PubMed: 16893831]

Nuttbrock LA. Culturally competent substance abuse treatment with transgender persons. Journal of Addictive Diseases. 2012; 31(3):236–241. doi:10.1080/10550887.2012.694600. [PubMed: 22873185]

Operario D, Soma T, Underhill K. Sex work and HIV status among transgender women: Systematic review and meta-analysis. J Acquir Immune Defic Syndr. 2008; 48(1):97–103. doi:10.1097/QAI.0b013e31816e3971. [PubMed: 18344875]

Pinto RM, Melendez RM, Spector AY. Male-to-female transgender individuals building social support and capital from within a gender-focused network. Journal of Gay & Lesbian Social Services. 2008; 20(3):203–220. doi:10.1080/10538720802235179. [PubMed: 20418965]

Pollio D, Thompson S, North C. Agency-Based Tracking of Difficult-to-Follow Populations: Runaway and Homeless Youth Programs in St. Louis, Missouri. Community Mental Health Journal. 2000; 36(3):247–258. doi: 10.1023/a:1001905114143. [PubMed: 10933242]

Poteat T, German D, Kerrigan D. Managing uncertainty: A grounded theory of stigma in transgender health care encounters. Social Science & Medicine. 2013; 84(0):22–29. doi: http://dx.doi.org/10.1016/j.socscimed.2013.02.019. [PubMed: 23517700]

Rainie, L. Internet, Broadband, and Cell Phone Statistics. Pew Internet & American Life Project. Pew Research Center; Washington, D.C.: 2010.

Rapues J, Wilson EC, Packer T, Colfax GN, Raymond HF. Correlates of HIV infection among transfemales, San Francisco, 2010: Results From a Respondent-Driven Sampling Study. American Journal of Public Health. 2013; 103(8):1485–1492. doi:10.2105/ajph.2012.301109. [PubMed: 23763398]

Reback, CJ. Constructing the outreach moment: Street interventions to women at risk.. In: Schneider, B.; Stoller, N., editors. Women Resisting AIDS: Feminist Strategies of Empowerment. Temple University Press; Philadelphia, PA: 1995. p. 170-191.

Reback, CJ. Disparities in research and clinical treatment: Transgender women.. Paper presented at the Social and Behavioral Sciences Research Network Conference; Los Angeles, CA.. 2014.

Reback CJ, Fletcher JB. HIV prevalence, substance use, and sexual risk behaviors among transgender women recruited through outreach. AIDS & Behavior. 2014; 18(7):1359–1367. doi: 10.1007/s10461-013-0657-z. [PubMed: 24287786]

Reisner SL, Mimiaga MJ, Bland S, Mayer KH, Perkovich B, Safren SA. HIV risk and social networks among male-to-female transgender sex workers in Boston, Massachusetts. J Assoc Nurses AIDS Care. 2009; 20(5):373–386. doi:S1055-3290(09)00102-2 [pii], 10.1016/j.jana.2009.06.003. [PubMed: 19732696]

Reisner, S.; Lloyd, J.; Baral, S. [June 25, 014] Technical report: The global health needs of transgender populations.. USAID, AIDS Support and Technical Assistance Resources, AIDSTAR-Two. 2013. Retrieved from http://www.aidstar-two.org/upload/AIDSTAR-Two-Transgender-Technical-Report_FINAL_09-30-13.pdf.

Rosser BRS, Oakes JM, Bockting WO, Miner M. Capturing the social demographics of hidden sexual minorities: An internet study of the transgender population in the United States. Sexuality Research and Social Policy. 2007; 4(2):50–64. doi:10.1525/srsp.2007.4.2.50.

Santos GM, Rapues J, Wilson EC, Macias O, Packer T, Colfax G, Raymond HF. Alcohol and substance use among transgender women in San Francisco: Prevalence and association with human immunodeficiency virus infection. Drug and Alcohol Review. 2014; 33(3):287–295. doi: 10.1111/dar.12116. [PubMed: 24628655]

Schulden JD, Song B, Barros A, Mares-DelGrasso A, Martin CW, Ramon R, Heffelfinger JD. Rapid HIV testing in transgender communities by community-based organizations in three cities. Public Health Reports. 2008; 123(s.3):101–114. doi:10.2307/25682060. [PubMed: 19166094]

Sevelius JM, Keatley J, Gutierrez-Mock L. HIV/AIDS programming in the United States: Considerations affecting transgender women and girls. Women's Health Issues. 2011; 21(6):S278–S282. doi:10.1016/j.whi.2011.08.001. [PubMed: 22055679]

Sevelius J, Patouhas E, Keatley J, Johnson M. Barriers and Facilitators to Engagement and Retention in Care among Transgender Women Living with Human Immunodeficiency Virus. Annals of Behavioral Medicine. 2014; 47(1):5–16. doi: 10.1007/s12160-013-9565-8. [PubMed: 24317955]

Shapiro E. 'Trans'cending barriers: transgender organizing on the internet. Journal of Gay and Lesbian Social Services. 2004; 16(3-4):165–179. doi:10.1300/J041v16n03_11.

Shipherd JC, Green KE, Abramovitz S. Transgender clients: Identifying and minimizing barriers to mental health treatment. Journal of Gay & Lesbian Mental Health. 2010; 14(2):94–108. doi: 10.1080/19359701003622875.

Singh AA. Transgender youth of color and resilience: Negotiating oppression and finding support. Sex Roles. 2012; 66(1/2) doi: 10.1007/s11199-012-0149-z.

Spicer SS. Healthcare needs of the transgender homeless population. Journal of Gay & Lesbian Mental Health. 2010; 14(4):320–339. doi:10.1080/19359705.2010.505844.

Thornhill L, Klein P. Creating environments of care with transgender communities. Journal of the Association of Nurses in AIDS care. 2010; 21(3):230–239. doi:org/10.1016/j.jana.2009.11.007. [PubMed: 20207173]

United Nations Development Program. Transgender Health and Human Rights. United Nations; New York: 2013.

Williamson C. Providing care to transgender persons: a clinical approach to primary care, hormones, and HIV management. Journal of the Association of Nurses in AIDS care. 2010; 21(3):221–229. doi:10.1016/j.jana.2010.02.004. [PubMed: 20363651]

Wolf ECM, Dewa BJ. Understanding risk factors contributing to substance use among MTF transgender persons. Journal of LGBT Issues in Counseling. 2012; 6(4):237–256. doi: 10.1080/15538605.2012.727743.

Yancey AK, Ortega AN, Kumanyika SK. Effective Recruitment And Retention Of Minority Research Participants. Annual Review of Public Health. 2006; 27(1):1–28. doi: doi:10.1146/annurev.publhealth.27.021405.102113.