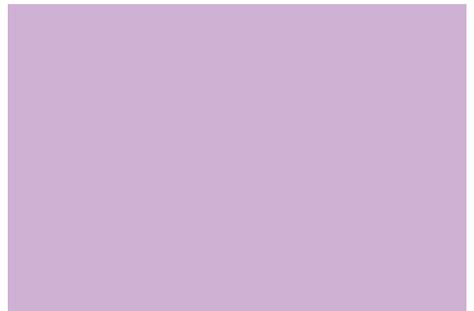
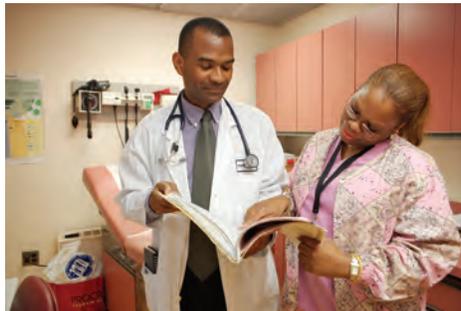
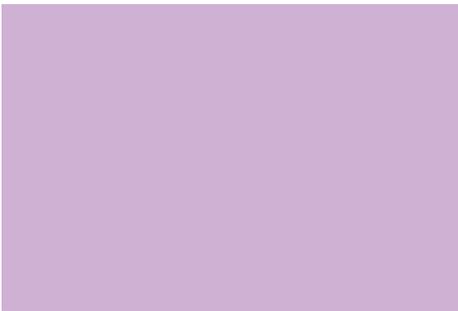


# IMPLEMENTATION GUIDE



## Enhancing Access to HIV Care for Women of Color

September 2014



U.S. Department of Health and Human Services  
Health Resources and Services Administration  
HIV/AIDS Bureau  
Special Projects of National Significance Program



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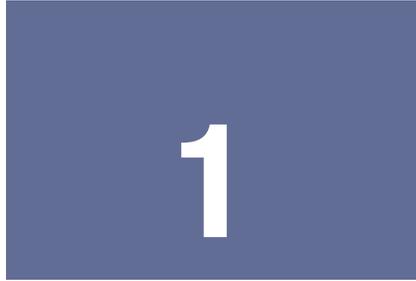
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The Health Resources and Services Administration (HRSA), HIV/AIDS Bureau (HAB) has developed the Integrating HIV Innovative Practices (IHIP) manuals, curricula, and trainings to assist health care providers and others delivering HIV care in communities heavily impacted by HIV/AIDS with the adoption of Special Projects of National Significance (SPNS) models of care. This IHIP training manual is part of that effort. Additional IHIP materials can be found at [www.careacttarget.org/ihip](http://www.careacttarget.org/ihip).



# INTRODUCTION

Across the United States, black<sup>1</sup> and Latina<sup>2</sup> women are disproportionately affected by HIV: They account for the majority of estimated new HIV infections among women; the majority of women living with HIV; and the majority of HIV-related deaths among women.<sup>3</sup> Many of these women face a daily battle to engage in and remain in HIV primary care.<sup>4</sup>

The *Enhancing Access to and Retention in Quality HIV Care for Women of Color* (WOC) Initiative, launched by the Special Projects of National Significance (SPNS) Program, was funded from 2009–2014 to meet the unique needs of these women, helping them overcome barriers that keep them from accessing and staying in care.

The mission of the SPNS Program, as administered by the Health Resources and Services Administration’s (HRSA’s) HIV/AIDS Bureau (HAB), is to test innovative and replicable models of care in response to the emerging needs of patients served by the Ryan White HIV/AIDS Program. Thus, many SPNS initiatives focus on underserved populations who are disproportionately affected by HIV, and the WOC Initiative is a prime example.

WOC Initiative grants were awarded to sites located in severely underserved areas in both urban and non-urban settings.<sup>5</sup> Participating grantees developed various service delivery interventions to help WOC overcome

common barriers across the spectrum of HIV care, specifically addressing the following:

- Linkage into quality HIV care
- Retention in quality HIV care
- Re-linkage to quality HIV care after falling out of care.

To meet those objectives, WOC initiative grantees implemented a variety of service interventions ranging from community-based outreach and patient education to intensive case management and patient navigation strategies.<sup>6</sup> Learn more about the specific interventions developed by the 10 grantee sites in Chapter 3.

## ABOUT THIS GUIDE

This implementation guide is designed to assist individuals and organizations in expanding services to meet the needs of women of color living with HIV. It is meant to inform the development of new programs, but also to assist organizations in improving existing efforts. Target audiences include all Ryan White HIV/AIDS Program grantees and other service providers, whether they are AIDS service organizations, community-based organizations, health departments, or clinical settings such as physician practices, hospitals, or health clinics.

The goal of this implementation guide is to provide practical advice and tools. The hope is that readers will feel empowered to embark on new programs or expand existing ones. The guide is part of the Integrating HIV Innovative Practices (IHIP) project that promotes dissemination and replication of successful SPNS initiatives. More information about IHIP materials — which include training manuals, curricula, implementation guides, related Webinars, monographs, and pocket guides — can be found on the IHIP landing page on the TARGET Center website at [www.careacttarget.org/ihip](http://www.careacttarget.org/ihip).

The main sections of this guide summarize activities conducted by WOC Initiative grantee sites, provide practical planning and implementation steps to follow, and capture common lessons learned from across grantee sites.

Appendix A highlights some particularly helpful curricula and Webinars from the IHIP materials on Engaging

Hard-to-Reach Populations — on topics such as motivational interviewing, inreach and outreach strategies, and more. Training materials focusing on hard-to-reach populations were created previously to provide insights and tools for working with underserved groups such as African-Americans, Hispanics/Latinos, Asians, Native Hawaiians/Pacific Islanders (NH/PIs), and American Indians/Alaska Natives (AI/ANs), as well as groups that cut across these populations such as men who have sex with men (MSM) and injection drug users (IDUs). These tools are certainly relevant for reaching women of color and can be found in full at [www.careacttarget.org/ihip/engagement](http://www.careacttarget.org/ihip/engagement).

Appendix B includes some sample tools and templates developed by a few WOC grantees. These have been made available solely as examples, however, and should be modified to meet the needs of a provider's organization or the needs of partnering organizations.



## WHY WOMEN OF COLOR?

*“When a woman is newly diagnosed, her primary concerns are what’s going to happen me and how do I adjust to this? She doesn’t care about education sessions on the basics of HIV or learning about labs [yet]; she’s still adapting to the emotional and psychological effects. You have to deal with the emotions before anything else.”*

— Janelle Job, Access and Evaluation Supervisor, Care Resource, Miami, FL

If the realization that women of color are disproportionately affected by HIV is disturbing, the actual numbers paint a shocking picture. In the United States in 2010 (the most recent data):<sup>7,8</sup>

- 60% of all women living with an HIV diagnosis were black and 19% were Latina.
- Black women accounted for 64% of the total number of estimated new HIV infections among women, while Latinas accounted for 15%.

Perhaps most distressing of all: At some point in their lifetimes, an estimated 1 in 32 black women and 1 in 106 Latinas in the United States will be diagnosed with HIV infection. This compares to 1 in 526 for white women.<sup>9</sup>

As mentioned previously, SPNS launched the *Enhancing Access to and Retention in Quality HIV Care for Women of Color* (WOC) Initiative in response to

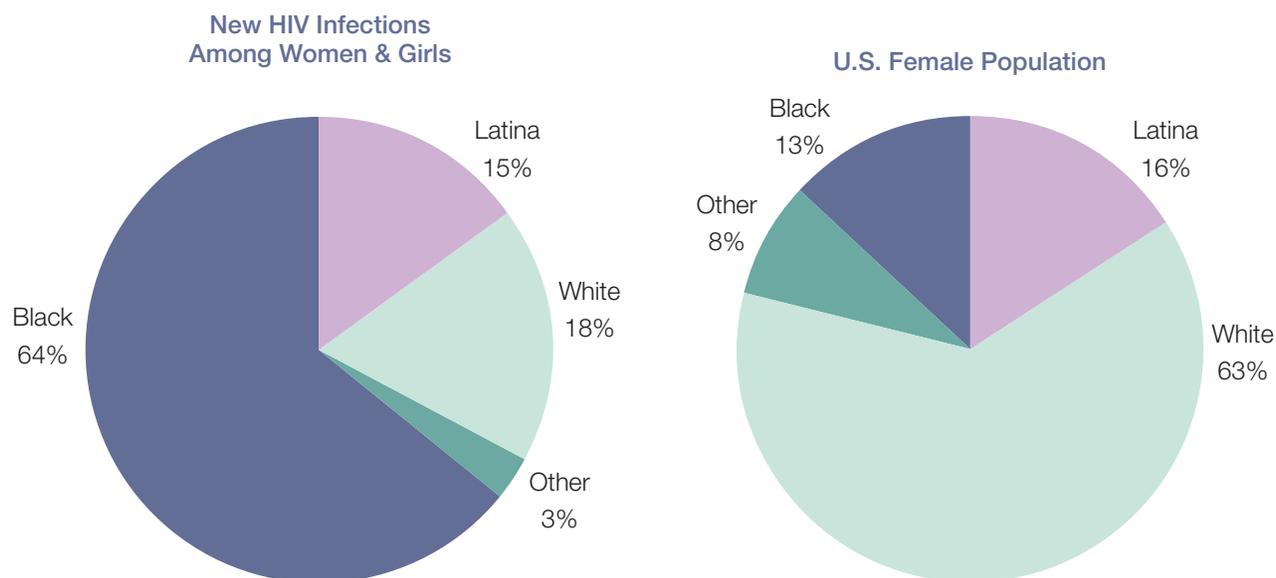
data like these. Since HIV disparities still persist among WOC, this guide serves as a useful tool for providers who are looking for evaluated and proven methodologies to better treat this population.

The purpose of the WOC Initiative was to test models of care that would help WOC overcome the common barriers that keep many of them from engaging and remaining in HIV care. In this way, the initiative plays an important role in meeting the objectives of the National HIV/AIDS Strategy (NHAS) and federal HIV Care Continuum, objectives that include reducing health disparities for vulnerable populations so that many more people achieve viral load suppression.

### RISK FACTORS AND BARRIERS TO CARE

Women, in general, face several unique risk factors for HIV infection and barriers to accessing the HIV care

**FIGURE 1**  
**New HIV Infection Among Women & Girls and U.S. Female Population, by Race/Ethnicity, 2010**



Notes: Data are estimates among those ages 13 and older and do not include U.S. dependent areas.  
 Source: CDC, HIV Surveillance Supplemental Report, Vol. 17, No. 4; December 2012. U.S. Census Bureau, 2010 Population Estimates.

they need to lead healthier lives. Women are more biologically susceptible to HIV infection; in fact, male-to-female transmission of HIV is approximately 2 to 4 times more efficient than female-to-male transmission.<sup>10</sup> This is due to women’s thin vaginal lining which makes it easier for viruses to penetrate.<sup>11</sup> What’s more, women are most often infected with HIV through heterosexual transmission and may be unaware of their partner’s HIV status and risk behaviors.<sup>12</sup> As such, women may underestimate their own risk for HIV. If women do not view themselves at risk for HIV, then they are less likely to seek out screening, and thus are more likely to present later for care.<sup>13</sup>

Even when women are aware of their HIV status, many barriers exist that prevent them from accessing care. For example, women tend to prioritize family needs ahead of their own health care.<sup>14,15</sup> Exposure to intimate partner violence (IPV) also can increase women’s risk for HIV infection (through forced sex with an infected partner, limited or compromised negotiation of safer sex practices, and increased sexual risk-taking behaviors)<sup>16,17</sup> and contribute to difficulty in remaining in care (because a fear of IPV may keep women from disclosing their status to partners, and thus limit their access to care).<sup>18</sup>

Women who have HIV are also more likely to be poor, less educated, mentally ill, or drug dependent.<sup>19</sup> All of these are factors that may limit personal autonomy when it comes to making key decisions, including decisions related to sexual behavior and health care.

#### *Additional Obstacles Faced by WOC*

The harsh reality is that women of color are more likely to die from HIV than white women; this is likely attributable to the many barriers that keep them from engaging and remaining in care.<sup>20</sup> Discrimination, poverty, low health literacy, and low access to health care all play a role, as do higher rates of mental illness and substance abuse. Communities of color often face additional obstacles too, including the following:<sup>21</sup>

- HIV stigma, particularly pervasive within some communities of color and especially among older generations and within churches and public institutions, makes it even more likely that WOC will delay or avoid care.<sup>22</sup>
- Some Hispanics/Latinas may avoid seeking testing, counseling, or treatment because of immigration status or fear of discrimination.<sup>23</sup> A lack of culturally

competent care also can present additional barriers, as some medical personnel may be unfamiliar with different cultural norms<sup>24</sup> or may not possess the linguistic skills or translation services necessary to communicate with immigrant populations.

- Black immigrant women from the Caribbean and Africa may have internalized attitudes of blame around their home countries' high rate of HIV and long histories in the global pandemic.<sup>25</sup> These feelings can keep them from disclosing their status and seeking care.
- Within some parts of the African-American community (particularly in the South), deep levels of distrust for the medical community exist. This profound level of distrust, related in part to the lingering impact of the Tuskegee experiments and other discriminatory practices,<sup>26</sup> often leads to a lack of engagement in care.<sup>27,28</sup>

#### *Barriers to Care in One Service Area*

Before beginning their interventions, several WOC Initiative grantees conducted focus groups/interviews to gain a better understanding of the needs of women of color within their geographic areas. For example, the University of North Carolina, Chapel Hill, reached out to a cross-section of WOC who had been diagnosed with HIV for more than six years. The majority of these women lacked private insurance, were unemployed, and lived below the Federal Poverty Level. In addition to poverty, the most common barriers the North Carolina women faced at *every stage of care* included:<sup>29</sup>

- Depression
- Active drug addiction
- Fear/stigma
- Lack of discretion by a local testing facility or treatment clinic.

A lack of adequate transportation to clinic visits was also cited as a barrier to engaging and remaining in care. One rurally based WOC Initiative patient described the multiple buses and long distances she has to endure to remain in care:<sup>30</sup> “With public transportation . . . I have to get on [one] bus, and then from that bus, I have to get on a different bus . . . today, since I had to get here at twelve . . . I had to leave the house at 8 a.m.” Another rural UNC patient talked about boarding a Medicaid van at 5 a.m. to get to the clinic and that appointments were all-day affairs.<sup>31</sup>

#### *An Ongoing Need for Services*

Given the complex, interconnected health care and psychosocial needs of so many PLWH, especially women of color, it is imperative to provide the kind of comprehensive care that helps these vulnerable individuals access and stay in care. Even with expanded coverage under the Affordable Care Act, there is still a need for Ryan White HIV/AIDS Program services. SPNS Initiatives develop evidence of best practice and offer scalable interventions which can be shared with the broader HIV community, so that patients can be more readily engaged and retained in care.



## ABOUT THE SPNS WOMEN OF COLOR INITIATIVE

*“These women, they’re scared . . . they have no resources. Given the high poverty, the low educational levels, the low health literacy, all these almost insurmountable kinds of issues, if they did not have a [case manager] holding their hand, I don’t think that their chances of engaging in care, much less staying in care, would be particularly high.”*

— Karen Phillips, Project Coordinator, Health Services Center Inc., Anniston, AL

In 2009, the SPNS Program launched the WOC Initiative, a five-year demonstration project evaluating HIV service delivery interventions for WOC across 10 grantee sites. This effort was in response to the steady increase of HIV infection and HIV-related deaths among WOC during the years leading up to the start of the initiative, as well as the increasing realization that WOC were falling behind other HIV-infected groups in receiving timely treatment and care.<sup>32,33</sup> Albert Einstein College of Medicine in Bronx, NY, served as the Evaluation and Technical Assistance Center for the initiative, providing technical assistance to the grantee sites and assessing the effectiveness of the selected models of care.

HRSA’s goals in selecting grantee sites were multifaceted and included the following objectives:<sup>34</sup>

- Organizations that provided quality HIV care and services in underserved urban and rural communities, especially in areas where the proportion of women of color living with HIV disease was increasing.
- Reliance on either “one-stop shop” or “network of care” (typically based on formal memoranda of understanding) models of care delivery.
- Interventions that addressed the underlying “socio-ecological” barriers preventing WOC from engaging or remaining in care.

Ultimately, a mix of urban and rural sites were selected — including several “one-stop” shops, as well as network and blended models of care. (See Table 1

**TABLE 1**  
**Summary of Grantee Sites and Interventions<sup>35</sup>**

<b>Grantee Site</b>	<b>Model of Care</b>	<b>Project Name</b>	<b>Primary Intervention(s)</b>
Care Resource Miami, FL	Clinic-based one-stop shop	I ACT for Women of Color (Intervention Assertive Community Treatment)	Coordination of medical and social care services, peer support, educational group sessions, individual adherence sessions, and multidisciplinary case review.
Ruth M. Rothstein CORE Center Chicago, IL	Clinic-based one-stop shop	Project WE CARE (Women Empowered to Connect and Remain Engaged in Care)	Peer patient navigation services and Healthy Relationships educational intervention.
JWCH Institute Inc. Los Angeles, CA	Co-located with and networked to providers	LODi (Ladies of Diversity)	Community health outreach workers and educators (primarily peer-based) performing intensive care coordination and peer support, and offering psychosocial services.
New North Citizens Council Springfield, MA	Community Development Agency facilitating access to providers within network	LEAPS (Latinas in Action Promoting Health)	Intensive, culturally based case management services.
SUNY Downstate Medical Center Brooklyn, NY	Network of clinic-based partners	POWER (Peer Outreach Worker Engagement & Retention)	Peer-based outreach, recruitment, and retention strategies and/or case management.
Health Services Center Hobson City, AL	Clinic-based providers within network	Project R-LINCS	Intensive case management services based on a strengths perspective and not limited by time or number of sessions.
Center for Human Services Bridgeton, NJ	Community organization linking to providers within network	LIFT (Latina Ladies Involved in Full Treatment)	Linkage services, linguistically and culturally based case management, translation services, and a behavior modification intervention.
Special Health Resources for Texas Longview, TX	Multifaceted institution with various clinic-based centers of care	Survival of the Fittest	Strengths-based individual case management sessions, group sessions, community education to reduce stigma, and survival stories to guide intervention/ evaluation.
University of North Carolina Chapel Hill, NC	One-stop ID clinic within university hospital setting (capacity for ancillary support)	Guide to Healing	Linkage services, structural support with gas cards, parking vouchers and cell phones, a nurse acting as a guide to care, and a women's support group.
University of Texas Health Science Center San Antonio, TX	Partnerships with providers in network	HEART (HIV Entry Access and Retention in Treatment)	Outreach, medical coordination, patient navigation, and Healthy Relationships educational intervention.

“Summary of Grantee Sites and the Interventions” for more information.)

Interventions were designed to promote access to and retention in quality HIV care. Specific strategies employed included:<sup>36</sup>

- Intensive case management services
- Linguistically and culturally based case management
- Care coordination
- Translation services
- Behavior modification interventions
- Individual adherence sessions
- Multidisciplinary case review
- Community education to reduce stigma
- Support groups (facilitated by peers or staff)
- Structural support (via gas cards, parking vouchers, cell phones)
- Navigation services (provided by peers or a nurse)
- Outreach (provided by peers or staff) and linkage to services
- Patient education (provided by peers or staff).

Two sites used an evidence-based educational intervention called Healthy Relationships that has been tested by the Centers for Disease Control and Prevention. This

curriculum focuses on reinforcing coping skills across three life areas: disclosing HIV status to family and friends, disclosing status to sexual partners, and building healthier and safer relationships. (See page 22 for more information.)

One site recorded “survival stories” for patients as a behavioral intervention based on a strengths perspective. Case managers asked participants to record or write stories from their past, focusing on stories that illustrated how they have overcome difficult situations in the past and could do so in the future. (See page 21 for more information.)

## ONGOING WOC WORK

As the WOC Initiative concludes, many grantees are working to sustain their interventions beyond the grant funding. This kind of sustainability is an important part of the SPNS mission because it extends the reach of the program. The ability of others to replicate the work is equally important, and this guide is specifically designed to help providers adapt and implement WOC interventions within their service areas. (Learn more about sustainability on page 17.)

## KEY FINDINGS FROM THE WOC INITIATIVE

While final data from a multisite evaluation of the *Enhancing Access to and Retention in Quality HIV Care for Women of Color* (WOC) Initiative have not been publically released, preliminary analysis reveals the following:

- WOC at urban sites were more likely to be Hispanic, less educated, single, living alone, unstably housed, unemployed, and to have reported lower income; urban WOC reported more barriers to care, many relating to stigma or fatalism about HIV care, than nonurban WOC did; urban WOC also reported more substance use and sexual risk behaviors.<sup>37</sup>
- Both diabetes and cardiac disease were associated with an increased risk of activity limitation among WOC, suggesting that prevention and treatment of diabetes and cardiovascular disease will need to be a standard part of HIV care to promote the long-term health of HIV-infected WOC.<sup>38</sup>
- WOC who were not engaged in care and not seeking care (“non-seekers”) were more likely to be uninsured and to report current high-risk drug use and sexual behaviors; because non-seekers represent a particularly vulnerable population of women, interventions targeting this population likely need to address drug use and be community-based given their [WOC non-seekers] limited interaction with the health care system.<sup>39</sup>
- WOC with a history of violence were less likely to be virally suppressed when compared to those without such a history; findings suggest using a variety of screening questions at entry and at follow-up care appointments may be key to identifying and supporting women survivors who may not disclose violence when first asked.<sup>40</sup>
- WOC’s experiences with navigation services provided by a nurse guide were overwhelmingly positive, suggesting that a properly trained nurse in this role can provide critical medical and psychosocial support to eliminate barriers to engagement in HIV care, and successfully facilitate patient HIV self-management.<sup>41</sup>



## GETTING STARTED

*“In our downtown area, the assumption has been that there are HIV services and women are welcome, but there was nothing specifically targeting women. In this project, we [designed everything] around the needs of the women . . . doing things that maybe other programs wouldn’t think of. . . like keeping some clean women’s underwear in a drawer or a box of sanitary napkins on hand.”*

— Tina Henderson, Project Manager, JWCH Institute Inc., Commerce, CA.

The following section of the implementation guide is designed to assist interested organizations and clinics in developing their own interventions for delivering effective HIV care to women of color.

### FACTORS TO CONSIDER

#### *Impact of Stigma and Lack of Health Literacy*

Among the grantees involved in the WOC Initiative, most agreed that stigma and lack of health literacy are still the biggest barriers to engaging and retaining WOC in HIV care. Thus, it is vitally important to consider these factors when developing an effective intervention.

“There’s still this very negative image of HIV; that you did something to bring on this illness,” says Sandra Munier, program director for New North Citizens

Council in Springfield, MA. “Our principal investigator was serving one of our women, and had to strategically schedule her visits at a particular time and make arrangements for her to enter the office through a side door so that no one would see her.”

Grantees reported that HIV-positive women of color have been rejected in church, forced to use plastic utensils, ostracized by neighbors, and accused of being prostitutes. They even feel the impact of stigma within their own families. “We have women . . . their mothers won’t hug them without gloves on,” says Allison Precht, project leader for The Ruth M. Rothstein CORE Center in Chicago, IL.

One grantee explained that stigma within their community is so high that during 20 years of working with HIV-positive people of color, she can count on one hand the number of women who have easily disclosed their

status. “The fear of disclosing is almost overwhelming,” she says.

This kind of fear can drive people underground and contribute to delayed entry into care. As such, organizations may wish to incorporate mental health care into their service offerings (if they don’t offer these services already) to assist women in addressing any internalized shame, depression, and other mental health issues. If organizations cannot offer mental health services on-site, then a partnership with a local organization where active referrals can be made should be considered.

Additional steps providers can take include:

- Developing safe spaces that avoid “HIV” branding and create a greater sense of anonymity.
- Communicating to patients that the law requires all providers to maintain patient confidentiality. Doing so may make patients feel more at ease.
- Providing public, as well as patient, education around HIV to help counter longstanding and entrenched stigma and misinformation.

Providing HIV education is critical because low health literacy both feeds and compounds problems in linking WOC to care.<sup>42</sup> There is even a perception in some communities that AIDS is terrible, but that HIV is not that big a deal, according to some WOC grantees. “We hear that all the time,” says Cathy Simpson, the project evaluator for Health Services Center Inc. in Anniston, AL.

Many grantees found that the information providers do offer needs to be very basic to be helpful. “Many of our women were convinced that saliva was a mode of transmission; they even questioned us about mosquitoes and toilets,” says Luz Amparo Pinzon, senior content associate for the Center for Human Services in Bridgeton, NJ. “After the training, one participant was saying, ‘for the first time, I know that I can hug and kiss my grandchildren.’”

Several noted that it’s also important to ensure that information is written or presented at a level that patients can understand and that is culturally sensitive. Providers also shouldn’t assume that simply translating something into Spanish, for example, is enough. Patients may still be unable to read the information because literacy levels in hard-to-reach populations may be low. As such, providers can ask patients if they would like any documents read to them or if they are comfortable reviewing the information themselves.

## *Effects of Violence and Depression*

The twin scourges of violence and depression also create significant obstacles to care, according to many grantees. They indicated that these problems are rarely discussed unless prompted by the intervention team.

“No one is talking about either of these issues,” says Pinzon, “but once you start to scratch the surface, you notice that boom, it’s there. I’ll give you an example. I randomly interviewed five of our participants, and in talking with them, all five had experienced violence and abuse. And because of these factors and HIV, they also are having problems with depression. When you feel like a victim, it’s very difficult to keep loving yourself, and by loving yourself, I mean taking care of yourself and adhering to your treatment because you want to continue living.”

The fear of IPV can inhibit women from disclosing their serostatus and compromise their treatment.<sup>43</sup> Abusers may restrict and monitor all aspects of a survivor’s life, including finances, transportation, phone use, and activities outside the house, all of which can impede medical adherence and access to medical appointments.<sup>44</sup>

Successful IPV interventions share the following components:<sup>45,46</sup>

- A written protocol and screening policies
- Documentation (in progress notes or in charts using body maps or even photographs of injuries), reporting, and referral tools
- Staff training and community education (i.e., written curricula, manuals, and continuing education)
- In-house IPV coordinators or advocates
- Availability of prevention information
- Coordination among IPV, mental health, and substance abuse providers
- Availability of support groups and services
- Signed release of information for follow-up
- Linkages to community resources.

Screening, linkage to care, and treatment are also important for dealing with depression.<sup>47</sup> One study even showed that effective treatment with antidepressants can help patients maintain their adherence to antiretroviral therapy (ART).<sup>48</sup>

## *Poverty and Addiction as Barriers to Care*

Many of the WOC grantees found that the challenges that flow from poverty — unstable housing, homelessness

and chaotic lives — often cause HIV-positive women of color to neglect or abandon their own health care. “If I’m hungry or don’t have a home, I’m probably not going to be focused on taking care of myself physically,” says Damiya Whitaker of the Center for Human Services.

Grantees that provided intensive care coordination found that it was an essential strategy for helping WOC overcome many common barriers to care, including those caused by poverty. Whether patients needed help arranging housing, applying for benefits, or some other form of assistance, a care coordinator was there to guide them through the process. While this level of service may be difficult to sustain financially, several grantees have been successful using peers in a patient navigator role and are optimistic that they can continue to provide at least some kind of continued peer support beyond the specific grant funding.

Note: Being able to provide screening and linkage to care for those individuals who were struggling with addiction was also important and was a part of grantees’ care coordination interventions.

Peer support was particularly useful for helping WOC who struggled with poverty or addiction, according to the program team at JWCH (John Wesley Community Health) Institute Inc. in Los Angeles. “It becomes an opportunity for the ladies to connect with someone who has been in their situation, but who has progressed through it and is in a more stable place,” says Tina Henderson, project manager for the JWCH team. “The peers were a good role model in terms of staying on their medication and staying in care.”

## INITIAL STEPS TO TAKE

### *Begin by Assessing the Service Area*

The socioeconomic and demographic profile of a community will provide important clues to the initial needs women of color in a service area. Examining client-level data and surveillance information can provide further clarity. When analyzing this kind of information, consider basic questions like these:

- Will patients face transportation barriers?

In rural areas, patients may have to travel long distances to find medical care, especially HIV specialty care, so transportation may become an obstacle. Even

in urban areas, however, transportation can present a barrier. For example, at more than 4,000 square miles, Los Angeles County (the location of WOC grantee JWCH Institute) is larger geographically than the combined states of Rhode Island and Delaware. And women of color in Florida’s Miami-Dade County (the location of Care Resource, another WOC grantee) often must take multiple buses to access clinic services, which can be prohibitively expensive, not to mention inconvenient.

To the extent possible, providers can offer patients assistance with transportation in the form of subway tokens, bus passes, gas cards, or parking vouchers. Another tactic is considering how feasible it is to bring care to patients.

*Example:* The Special Health Resources for Texas (SHRT) Inc. — an AIDS service organization that serves 22 counties in northeast Texas — paid for transportation for its WOC participants. With a vast service area of 15,000 square miles, however, it also was necessary for program personnel to bring care to patients. “Our social worker drove 1,500 miles a month to see these women,” says Project Director Nancy Young-Styles. “We would meet them at doctor’s visits, dental visits, anyplace we could. I had put enough transportation money in the budget so that I could pay the case managers’ mileage for them. They used their own vehicles, however. In fact, having a vehicle to drive was one of the prerequisites to apply for the job.”

Another factor to consider is that patients may be deeply rooted in their communities or they may be on the move, such as migrant workers or homeless people. In Los Angeles, drug addiction, prostitution, and homelessness on Skid Row contribute to patients’ lack of stability, even though they don’t move across huge distances, as they do in Texas. Both programs, however, focused on providing “mobile” services — taking care to patients wherever they are.

- Will patients face language or other cultural barriers?

Making faulty assumptions about a community can lead to being unprepared to provide culturally competent care with linguistic or cultural support. One grantee that served a primarily Puerto Rican population knew they wanted case managers to be bilingual and bicultural, but they also understood that not every Latina was Puerto Rican. Their service

area also included significant numbers of Mexican and Columbian women of color, and they had to account for those cultural differences.

Some examples of attitudes and values that are interrelated with culture include:<sup>49</sup>

- Accepted roles of men and women
- Value of traditional medicine versus Western medicine
- Favorite and forbidden foods
- Manner of dress
- Body language, particularly whether touching or proximity is permitted in specific situations.

### *Obtain Input from Patients and Staff*

Beyond analyzing demographic data and surveillance information, WOC Initiative grantees reported that reaching out and obtaining input from patients and staff before starting any kind of program development is a critical step — perhaps even the most important step — in creating a successful intervention. This kind of outreach is important because it provides insight into the needs of a community and helps identify any gaps in services. Several grantees held focus groups or conducted interviews with patients to ascertain unmet needs.

By doing some due diligence up front, providers can avoid making assumptions about barriers that may or may not be accurate. For example, several WOC grantees describe being surprised by these discoveries within their project sites:

- Transportation appeared not to be an obstacle for their particular sites, likely because it was addressed up front (as WOC project administrators generally provided subway tokens, bus passes, gas cards and parking vouchers).
- Child care, especially among women with large family networks, and among older HIV patients who had passed their childbearing years, also appeared to be a nonissue. That said, some patients indicated that they weren't interested in pursuing child care options through the WOC Initiative out of fear of disclosure; this seemed especially true in smaller, more tightly knit communities.
- A perceived barrier to care — inadequate phone access — turned out to be “very critical” but only for a small number of people. One grantee discovered that preprogramming phones with important phone numbers increased their use.

- Some grantees implemented support groups for WOC participants which were extremely successful in helping women remain engaged in care. Others struggled with attendance. Surveying patients to ask why they weren't participating revealed a need for increased flexibility in scheduling sessions and increased discretion (e.g., not saying it was an HIV group on the clinic calendar).

### *Identify Service Gaps*

After identifying service needs through data analysis and input, providers need to be proactive in assessing their internal capacity to provide service interventions versus exploring partnership opportunities. (See page 15 for a discussion about establishing effective partnerships).

Definitely consider existing capabilities when developing an intervention. For example, one WOC Initiative had a robust peer educator program already in place, so it made sense to explore an intervention for WOC focused around peers.

It can also help to analyze existing internal information systems to provide insight. Records about previous services offered and referrals made can be used in a decision-making capacity. *Examples:* Organizations that have offered educational sessions to women of color can evaluate attendance levels; records of referrals to dental services or housing assistance can provide proof of need. These are the kinds of areas providers can examine to prompt a rethinking of the care and services they are offering.

Pilot testing interventions on a small scale before launching is another way to test capacity.

### *Assess Staff Requirements*

Staffing needs are heavily dependent on the type of intervention implemented. Common roles in the WOC projects included:

- Program manager/coordinator
- Case manager
- Nurse case manager
- Case or patient coordinator
- Patient educator
- Peer patient educator
- Service navigator
- Peer patient navigator
- Community health outreach worker (CHOW)
- Peer outreach worker (POW)

## USING NURSES TO COORDINATE CARE

One of the interventions that the University of North Carolina (UNC), Chapel Hill, used in its Women of Color (WOC) project involved a nurse guide — which is simply another word for navigator — coordinating care. UNC adapted the idea from the role that nurses frequently play in oncology care.

As part of the intervention, a nurse guide provided intensive care coordination by keeping in regular phone contact, counseling patients from a strengths-based perspective and using motivational interviewing, and promoting support that addressed core needs. After working intensively with patients for about eight months, the nurse guide linked patients to a clinic staff nurse associated with their provider.

The principal investigator for the project, Byrd Quinlivan, M.D., originally suggested using nurses to provide this support because, as a former nurse herself, she understands their unique role. “While there are many social aspects to HIV care, getting somebody into care — getting patients to understand the medical system and getting them to take their meds and tolerate side effects long enough to where they don’t have side effects — is really a medical [process],” she says.

Nurses also can help patients navigate a complex medical system by combining multiple services into a single person. Prior to the intervention, UNC staff would make new-patient phone calls. The person making those phone calls, however, frequently was not the nurse who conducted intake and oriented new patients. “Historically, it wasn’t a coordinated approach to bringing people into care, and that’s one of the key aspects we’ve accomplished with this program,” she explains. She also points out that, in terms of funding, nursing care is considered a reimbursable service.

Perhaps the most compelling reason, however, is how others view them: “Most people have a very high opinion of nurses,” says UNC’s nurse guide Andrea Blickman. “They are one of the most trusted professions.”

Note: Case managers are distinct from medical case managers, a role that qualifies as a core service under the 2006 Ryan White HIV/AIDS Treatment Modernization Act. Under the law, medical case management must involve “providing, facilitating, and keeping a patient retained in primary medical care.”<sup>50</sup>

Several WOC grantees said that they found it helpful to address questions like these to determine staff qualifications and job descriptions:

- Is there a need for bilingual or bicultural staff?
- Will patients feel more comfortable with female program staff?
- What is an appropriate case load?

The level and type of education or experience required to fill roles also varies according to the intervention model. For example, some grantees felt that a peer could best assist patients as they navigated the health care system while one grantee site chose to use a nurse navigator (who could simultaneously answer medical-related

questions as they arose.) In either case, the navigator had to have the ability to keep care teams updated on patient progress and, over time, work with patients to develop autonomy until they are comfortable navigating the system on their own.

Those sites that choose to work with peers as outreach workers, educators, or navigators will need to take extra steps to assess peer readiness and to integrate them into the organization. (See page 17 for more information).

### *Coordinate Training Needs*

Most WOC Initiative program staff went through extensive training. One grantee who partnered with a local university to provide training in strengths-based case management techniques made sure to leverage sessions by training as many team members as possible — even those not directly involved with the WOC Initiative. The idea is that if providers are paying to bring in an expert trainer, they might as well try to get as many staff

and partners to benefit from the training as possible. “It made no difference if I had eight people or four people,” says the grantee. “They weren’t charging me by the seats.”

Beyond initial training, many program staff also engaged in additional hours of continuing education. The University of Texas Health Science Center at San Antonio estimates that its program staff spent a minimum of 12 hours per year in face-to-face or Web-based training in addition to introductory training.

All grantees that used peers found that extensive training was a prime component in establishing an effective intervention. If peer workers are properly trained, they can be the “glue” that keeps patients connected. The CORE Center in Chicago, for example, required its peers to undergo 40 hours of initial comprehensive HIV training, as well as additional training sessions almost every day for the first six months of working as navigators. CORE arranged much of this extended training through its partners, as well as through the Midwest AIDS Education and Treatment Center (AETC). In general, the AETCs can be a prime source to access training and continued education for both peers and program staff. (To find a local AETC site, visit [www.aidsetc.org](http://www.aidsetc.org).)

Whatever the source of the training, it may be helpful to cover these four categories as key components:

- Role of a peer (include training on skills such as motivational interviewing)
- HIV 101 (cover the basics of HIV disease and its management)
- Workplace skills (tackle subjects such as effective communication and boundaries)
- Evaluation implementation (review important protocols)

### *Define Intervention Protocols*

Once the interventions have been developed and approved, taking the time to record and communicate intervention procedures was a hallmark of success for many WOC grantees. In fact, publishing a guide to those protocols (defining intake procedures, intervention components, timing, communication strategies, home visits, and so on) was instrumental in helping several grantees achieve their objectives. Grantees used the guides to inform internal staff, as well as to ensure that external partners understood their roles in achieving the goals of the intervention.

## COMMON TRAINING TOPICS FOR PROGRAM STAFF

Across the board, grantees for the Women of Color (WOC) Initiative coordinated extensive training for program staff. Topics spanned everything from disease education and providing patient support to workplace effectiveness and regulatory compliance. Here are some of the kinds of training offered:

- Motivational interviewing
- Transference and counter-transference
- HIV and hepatitis C
- HIV and STDs
- Navigating the System
- Stigma
- Mental Health and HIV
- Developmental delays and disabilities
- Benefits training
- Substance use and abuse
- Nicotine addiction and HIV
- Adolescents and HIV
- HIV/AIDS and people over 50
- Working in a multidisciplinary team
- Presentation skills
- Depression and HIV
- HIV disclosure
- Cultural competency
- Abuse and neglect
- Embracing diversity in the workplace
- Drug free workplace
- Effective communication skills
- HIPAA for behavioral health providers
- Incident reporting
- The relationship between infectious diseases and drug use
- OSHA rules for blood-borne pathogens
- Proactive interventions
- Serving internal and external customers
- Safety in the field
- Sexual harassment for employees
- Universal health precautions
- Workplace ethics for employees
- Interviewing strategies and techniques
- Group facilitation
- Re-employment assistance
- Federal and state health care reform for the Medicaid population

Several organizations also developed brochures or fact sheets that they used to inform both patients and partners. These documents were not as detailed as the guides, but became a useful tool for communicating the overall goals and parameters of the program.

Ongoing communication among staff and between partners can help ensure that procedures are working as planned and being followed. Several grantees noted that procedures may need to change over time, as the needs of both patients and partners evolve or become clearer. They suggested that it's a good idea, however, to document these changes in writing to avoid any misunderstandings.

## ESTABLISHING EFFECTIVE COMMUNITY PARTNERSHIPS

Once providers have assessed the needs of women of color within their geographic areas and compared those needs to existing service offerings, they will then want to identify existing or new partners to fill any service gaps.

First, reach out to any current health care and community partners that are reliable. An organization may already have ongoing relationships with community partners; it may even have multiple memorandums of understanding (MOUs) that define the nature of those relationships. It is helpful, however, to revisit those relationships in relation to establishing a program specifically targeted to women of color. The idea is to define what is needed to serve this population in particular.

In terms of MOUs, it is important to note that providers will not be able to anticipate all challenges that might arise. Thus, it's a good idea to establish ongoing communication with partners (almost all WOC grantees suggest holding partner meetings on a monthly basis at least) to ensure smooth operations and transparency and to avoid any "turf" issues.

The University of Texas Health Science Center at San Antonio developed a statement of work (SOW) for its partners, making it clear that creating detailed, written policies and procedures would be a required part of the collaboration. The manual typically included descriptions of staff roles, responsibilities, and qualifications, required training and refresher training, and procedures for conducting the services, as well as a complete list of resources, tools, and forms partners were required to use. Note: This was requested diplomatically so as not to alienate partners.

Other tips for creating successful community partnerships with existing or new agencies include the following:

- *Work to build trust.* Help partners understand that it's not a competition for patients.
- *Make it easy to collaborate.* Whenever possible, consolidate intake forms and data collection to minimize the paperwork burden.
- *Clearly define intervention procedures.* As mentioned previously, producing a printed guide that clarifies all intervention protocols can be a useful tool for external partners.
- *Document all conversations and decisions.* Make a special note of changes to policies and procedures.
- *Consider job shadowing:* Have partners shadow each other across agencies to gain a "behind the scenes" understanding of why things are done a certain way.
- *Communicate across all levels.* Make sure that direct-care staff, as well as supervisors, are part of the conversation. Hold face-to-face meetings whenever possible.

To ensure good communication, it's helpful to realize that "the administrators are the ones who sign the MOUs," says Sandra Munier of New North Citizens Council. "They have an interest in maintaining solid relationships at the director-to-director level. But does that really mean that front-line staff understand what this MOU is about and what the referral process is about?" Thus, weekly communication between field staffers who work in different agencies is imperative.

One tip that came from several project managers was to have partners refer all patients and let internal WOC staff qualify them for the program. "They [health department staff] were accustomed to calling us about every case," says Karen Phillips, project coordinator for Health Services Center. "We just felt like it was wiser to continue with that model. If I said, 'Oh, only call us on women, and only women of color,' I was afraid if I started putting stipulations on them, they would say, 'Well, this is more trouble than it's worth.'"

Health Services also designated funds to rent space at the health department, in part so that medical staff would not view the WOC project as an imposition. Renting out its space benefited the health department, avoided sharing quarters and afforded private, confidential space for patients.

In addition, educating patients how organizations "fit" together is also helpful in terms of preventing any

## HOW FREQUENTLY SHOULD TEAMS MEET?

Grantees from the Women of Color (WOC) Initiative all stressed the importance of good communication for improving the quality of care provided, as well as for establishing and maintaining buy-in for the program. In general, they advised the following frequency and types of communication:

*Daily:* Outreach workers who are in the field should call in at least once a day; and whenever they are near the clinic or agency, they should check in with colleagues face-to-face to discuss current cases.

*Weekly:* Multidisciplinary team members — including clinicians, case managers, social workers, community and peer outreach workers or navigators, and other assistants — should meet weekly to monitor patient barriers and needs.

*Monthly:* Convene monthly meetings with key representatives of collaborating organizations to deal with issues related to program implementation.

*As-Needed:* Hold in-service presentations for all personnel involved in HIV work to keep WOC program needs and successes top-of-mind.

confusion, especially if there is any perceived overlap between the partners.

## GENERATING BUY-IN AMONG CLINICAL AND ADMINISTRATIVE STAFF

Tactics for generating buy-in among clinical and administrative staff will vary according to the needs of an organization. The following strategies, however, did help many grantees overcome some initial resistance or lack of enthusiasm.

- Engage internal clinicians and administrative staff in trainings. It's not enough to just schedule trainings; program leaders have to repeatedly encourage busy providers to attend.
- As mentioned previously, hold regular in-service presentations during the intervention to re-establish buy-in. The idea is to keep awareness about the unique needs of women of color top of mind.

- Also as mentioned previously, publishing a guide that clearly defines intervention procedures will help both internal staff and external partners better understand and engage with the program.

When communicating with administrators and external partners, make sure to cite specific information about WOC from area surveillance data and patient focus groups/surveys. At a time of dwindling funding and increased need, and amidst calls for more targeted strategic efforts, data can help make a case for why further efforts are warranted and where or what specifically can be done.

An important step in securing buy-in among staff is clearly defining roles. Several WOC Initiative grantees created specific job descriptions to clarify responsibilities or held special training sessions to discuss those boundaries. (See page 12 for more information about common roles/titles among WOC interventions.)

For example, existing case managers at nearly every grantee site expressed concerns about how WOC navigators and outreach workers would be integrated. Some worried that these program workers were being brought in to do work they had “failed at” — specifically, seeking out patients who'd been lost to care or connecting patients to care. Or they worried that outreach workers might hinder more than help them in their work, diluting their effectiveness and leading to overlapping job duties and crossed signals.

“We needed to make it clear that we were not trying to downsize the organization or change their procedures in any way,” explains Phillips. “There’s always this period of [questions]: ‘So what’s your agenda? What is your motive? Why do you want to do this? What’s in it for you versus what’s in it for me?’”

Instead, WOC demonstration project staff sought to work with them, taking responsibility for tasks that medical staff was not equipped to handle, such as providing information to patients, consoling them, and spending time with them “to work through the emotional part,” Phillips says.

Over time, non-program staff came to see that WOC Initiative case managers or outreach workers were equipped to assist them in an adjunct capacity, doing all kinds of tasks that medical case managers don't have time for, such as tracking down patients who are lost to care, providing patients with personal support, making reminder phone calls, performing clerical tasks, and

arranging for necessities such as clothing or basic health care. Or, in the words of the CORE Center's Allison Precht, peer patient navigators “are the hands, feet, eyes and ears of the case managers.”

A special note: Program staff at the Center for Human Services in New Jersey noticed early on that participants were confusing the titles “case manager” and “medical case manager,” and as a result coming to the WOC Initiative case manager with health-related issues. To solve that problem, the center changed the title for its WOC Initiative case manager to “services coordinator,” reflecting the broader nature of the work.

## HIRING AND INTEGRATING EFFECTIVE PEERS

Peers can contribute greatly to program success because they serve as role models for patients in terms of overcoming adversity and staying in care. With a truly effective peer, sometimes patients shared things they might not have detailed in such specificity with other staff.

Locating, qualifying, and keeping peers engaged, however, is not always easy. For many WOC Initiative grantees, several challenges emerged and needed to be overcome in hiring both peer navigators and outreach workers. To start with, job postings and ads can't specify “women,” “women of color,” or “HIV” because such limiting language may be construed as discriminatory. Many programs work around this issue by relying on word-of-mouth to recruit peers.

Before hiring its peer navigators — about 15 part-timers, on average — the CORE Center in Chicago put together an interview panel comprised of the WOC project leader, two health care providers, and the director of social services. Together, they developed sets of interview questions, posted the part-time (with stipends) positions, and interviewed both internal and external candidates.

“We have to do our due diligence in recruiting the right peers,” says Sergio Avina of the JWCH Institute. “By that I mean if they came from the neighborhoods we were targeting, in this instance, the downtown or surrounding areas. If a targeted area included East Los Angeles, for example, then we wanted some peer navigators who knew the east LA area and possibly were from east LA or were raised in Los Angeles. In various ways, they mirrored the target audience by their experience of previously being homeless, abusing substances, or possibly suffering depression or mental health instability.”

Street experience is just the beginning when it comes to peers. Peer education and training are vital in overcoming common problems such as limited literacy, lack of work experience, and lack of personal boundaries.<sup>51</sup>

The POWER (Peer Outreach Worker Engagement and Retention) program — implemented by the SUNY Downstate Medical Center in Brooklyn, NY — encountered an array of difficulties in employing peer outreach workers (POWs). The main hurdles, leaders reported, were the professionalism, skills, and life circumstances of the peers. POWs who were naturally able to connect to patients and who had a strong work ethic propelling them were more successful than those who were waiting to be told what to do.

And once peers were working, their safety net, including Medicaid, food stamps and housing subsidies, had to be re-evaluated. These were hard losses for the peers. Losing Medicaid was toughest; peers cited having to make co-pays when doctor visits used to be free, and often having to switch providers. Additionally, some peers weren't ready to disclose, even in the POW role, so it is important to discuss this up front during the hiring process. Some peers did not feel comfortable being “out” with their HIV status at the clinic because they felt stigmatized by fellow staff members.

To repeat, it is critical at the start for programs to stipulate workers' roles and responsibilities. “Create written job descriptions that clearly define boundaries,” one project leader advises. Peer oversight doesn't end there, however. It's important to provide ongoing supervision of peer workers, including clinical supervision, to keep patients properly informed and on the right track. See Appendix B for an example of a peer job description.

As far as recruiting peer workers, Los Angeles started seeking them through referrals from other staff, identifying them as patients in other programs who had done particularly well and had expressed an interest in volunteering, and who welcomed the \$200 monthly stipend. Brooklyn asked its final two candidates to participate in a “day of work” in the field. Whichever candidate was successful in re-engaging lost-to-care patients was hired.

## FOSTERING PROGRAM SUSTAINABILITY

The WOC Evaluation Center, which provided technical support for the grantee projects, suggests that providers who are considering implementing a WOC intervention think about sustainability from the beginning. The

## TOP TIPS FOR WORKING WITH PEERS

Chicago-based WOC Initiative grantee The Ruth M. Rothstein CORE Center compiled a succinct list of strategies for working with peers:

1. Take careful consideration of stipend vs. full-time employment for peer patient navigators, in light of possible losses in benefits from programs such as Medicaid.
2. Assign different peer navigators for inpatient and outpatient settings.
3. Include all outreach staff, including peers, as partners in clinical and field work.
4. Make sure candidates for the role of peer patient navigator feel comfortable with disclosing their HIV status.
5. Peer navigators are not case managers. They are the hands, feet, eyes and ears of the case managers.
6. When hiring peer navigators, make sure they receive training in personnel policies and professional workplace conduct. Include guidelines for maintaining healthy personal boundaries.
7. Have clearly defined roles, responsibilities, and expectations for all project staff.
8. Peer navigators must understand they are part of a multidisciplinary team and must also be comfortable working in a clinical setting.
9. Peers must be trained in the differences between medical and social issues.
10. Allow time for debriefing peer navigators on certain cases, but do not confuse this information with the work expected from case managers.

Center's Principal Investigator Arthur Blank offers some questions to consider at the outset:

- What do our patients value?
- What will have a worthy impact and make a real difference?
- Will the intervention be sustainable if grant funding dries up?

Many of the SPNS grantees involved in the WOC Initiative have been researching new funding opportunities to continue services. New North in Massachusetts, for example, has been investigating other agencies and foundations that may be able to underwrite public transportation. A drop-in center will remain to provide referrals and support groups for women of color needing HIV care. "The clinics will have case management, so that will continue," says Sandra Munier. "All of our women will be connected to a case manager. What will change is what that case manager can offer."

Under the SPNS program, "our case managers were able to provide [personal support] for multiple issues," Munier points out. "For example, one of our patients,

her identity was stolen, and so she's been having issues for years around license, around credit. Our case manager spent an entire day driving with her to Boston, going in front of the judge, and doing all of these things that she had to do to clear her name so that she could move forward with low-income housing and all these important things she wasn't able to access because, according to her record, she had a warrant out for her arrest. That's something that a [medical] case manager with the clinics can't do. They're limited to medical case managing."

Similarly, the CORE Center is researching opportunities to continue offering navigator services. "I know there is a movement to sustain the community health worker model, which definitely encompasses the patient navigator," says Allison Precht. "There is a large effort going on to make that happen, even here locally in Chicago. There's a certification program with a couple of community colleges — a certification program for a community health worker. There's been a law passed, and now they're developing the certification program. I think we definitely helped illustrate the need for that type of a role."

Often, offering sustainable services for WOC comes down to implementing low- or no-cost interventions that have proven to be effective. For example, grantees report that, in general, support groups have been extremely successful at increasing self-efficacy and creating social bonds. Many say they will continue to offer these groups for WOC or at least open them up to other patients. In some instances, the programs are moving toward using volunteer peer facilitators as the peers gain experience, education in HIV, and training in how to select topics, run a meeting and be responsive to group topics.

Other cost-effective ways grantees have pursued sustainability include:

- Dedicating staff for women; that kind of thinking ensured that one site would have feminine products and underclothing on hand.

- Offering ongoing and cross-functional training.
- Developing materials that can be adopted for all clinic patients; for example, UNC adapted its “Guide to Healing: Taking Care of Me” brochure for use across all patients.
- Creating strong referral relationships and continuing to nurture them.
- Incorporating program tasks into other positions.
- Continuing to work with peers on a volunteer basis.
- Interviewing program staff to determine effective and feasible program elements.

“A large part of the answer is current staff models,” says Blank. “For example, if you have generally worked with peers previously, then outreach or navigation to WOC by peers is likely to be sustainable. If it is a new activity, it’s much harder to do from scratch.”



## LESSONS LEARNED

*“When a woman receives a reminder call for an appointment, it’s a way of making the clinic a little less overwhelming . . . it’s a feeling that you’re coming to a place where people are expecting you . . . not just that your name is on a schedule.”*

— Byrd Quinlivan, M.D., Principal Investigator,  
University of North Carolina, Chapel Hill

The following section of the implementation guide will address several lessons learned from the WOC Initiative projects. The advice is based on preliminary reports and interviews with program staff.

### REDEFINING ENGAGEMENT IN CARE

One of the most profound lessons the Los Angeles team learned was how to define “engagement in care.” Given that their patients are WOC with tenuous housing and inconsistent or nonexistent health care, project leaders started out with the expectation that engaging them in care would be tough. The reality was even starker. Many WOC who participated in beginning focus groups shared that they did not want to be in care at all; that they just wanted to die. The diagnosis was too shameful and their families’ shunning too painful to keep living.

One focus group attendee said: “Why would I want to live? Why take medication? If I don’t take the medication, I will die and that will be that. Nobody will miss me.” Another attendee said, “When you see me on the street, you don’t know me. I don’t want to be found. Just leave me be.”

Thus, the JWCH Institute program team quickly realized that they had to reframe the way they thought about the intervention. “It was not just about linkage to care . . . giving the patient a referral to see the doctor, a long-term case manager, or a housing specialist,” says one team member. “It was about engagement in life.”

They realized that retention in care was primarily about helping patients set and achieve goals. Keeping them engaged was about making them feel accepted and providing stability. For that, peer support turned out to be vital. The WOC program staff committed to offering

support groups and “feel-good” activities like a tea or a beauty day.

“We learned that women need to see their own medical adherence as a social part of their lives,” an LA team member says. “For our ladies, when they feel appreciated and cared for, feel they have something to live for, something bigger than themselves,” they’ll take their medication. “Feeling appreciated, cared for, and useful is their reason for living.”

## FINDING SUCCESS WITH SUPPORT GROUPS

As mentioned previously, in the vast majority of cases, support groups for HIV-positive women of color were very helpful.

Although it wasn’t part of the original plan, SUNY Downstate Medical Center initiated women of color support groups in response to patient requests. The support groups have strengthened engagement and retention in care by empowering women of color and program leaders are recommending that women’s support groups be incorporated in future programming.

Stories from support groups highlight the fellowship and hope these forums can provide. For instance, Allison Precht of the CORE Center says it was common to hear during staff debriefings that a woman shared something in her support group that she’d never shared with anyone before. “The thing is,” she says, “they lifted each other up.”

Another note: Reminder calls are important to get women to come. Program staff at the University of North Carolina, Chapel Hill, found that every time the nurse guide did a round of reminder calls, there was a big upswing in attendance. If there is a particular staff member who has established rapport with the group, that person’s phone calls could be even more successful in drawing attendees.

## PROVIDING SUPPORT FOR PEERS

All WOC Initiative grantees that relied on peers to provide services found that managing peers can be challenging. “You have to recognize that supervising peers is so different. From boundary issues to daily drama, they are dealing with so much in their lives that impedes work,” says Jennifer Lee, project director for SUNY Downstate Medical Center.

## WOMEN’S ‘SURVIVAL STORIES’ CREATE HOPE

Sometimes, the most powerful interventions are the simplest. The Women of Color (WOC) Initiative project at Special Health Resources for Texas (SHRT) included intensive case management, support groups, and education. It also involved some dramatic story telling.

As part of the “Survival of the Fittest” project, case managers asked participants to record or write stories from their past, focusing on stories that illustrate how they have overcome difficult situations. The stories became powerful testaments to the women’s strengths as they face new and ongoing difficulties in life, especially those related to HIV.

Questions included:

- What was your life like prior to HIV/AIDS?
- How has HIV changed your life?
- What has helped you survive?
- What ideas do you have that we can use in your treatment?

Common themes emerged as the women realized that having an active spiritual life, a sense of belonging, and a positive attitude all influenced their ability to cope with and overcome obstacles.

Program Director Nancy Young-Styles recommends gathering the stories early so they can be used to assess and inform care. “They provided a tremendous opportunity for catharsis and hope,” she says.

Continual training is vital to program success, as peers may have limited educational attainment. Training is essential in basic literacy, medical knowledge, workplace skills and professionalism, such as how to work in a hospital or clinic setting and what behavior is appropriate at work. These are hard-earned skills. Furthermore, focused supervision and support are necessary to keep peers grounded in their work. Peers need copious amounts of support and encouragement as they learn new boundaries, such as how to avoid worrying about patients after the workday is done.

One pleasant surprise occurred when the SUNY program staff took their peer outreach workers (POWs) to

## HEALTHIER RELATIONSHIPS, HEALTHIER LIVES

“The only reason I got up this morning was because of group,” said a participant, talking about the impact that a behavioral intervention called Healthy Relationships (HR) has had on her life. She participated in HR through Women of Color (WOC) Initiative project at the Ruth M. Rothstein CORE Center in Chicago. Both the CORE Center and the University of Texas Health Science Center at San Antonio included the HR curriculum in their projects because it is an evidence-based intervention — tested by the Centers for Disease Control and Prevention — that focuses on reinforcing coping skills across three life areas: disclosing HIV status to family and friends, disclosing status to sexual partners, and building healthier and safer relationships.

The HR program calls for small, gender-based groups to meet for five weekly sessions of two hours each. Both WOC Initiative grantees embraced a unique aspect of the intervention: using popular movie clips to set up scenarios about disclosure and risk reduction (i.e., what would you do or say in this situation?); although CORE opted to update the training with two newer clips from the movies “Precious” and “For Colored Girls.”

Both the Chicago and San Antonio programs decided to modify the number and gender of the facilitators, both of them choosing to use two female facilitators instead of one male and one female as recommended and to add one to two additional facilitators to provide needed logistical support. Both programs found that small incentives (food, cosmetics, door prizes, graduation certificates, etc.) were useful for maintaining engagement, and they modified the number and length of the sessions slightly. A few additional lessons learned included:

- Allow enough time (at least three months) to arrange for and complete the required training, and inquire up front about ongoing technical assistance.
- Cross-train as many people as possible in the agency to prevent potential disruptions to curriculum delivery due to staff turnover and scheduling conflicts.

In addition, it is important to allow sufficient time to plan each session. Organizing activities — such as coordinating staff schedules, recruiting participants, finding suitable space for each session, helping with child care or transportation for attendees, arranging for refreshments or food, securing tangible incentives for participation, preparing for each session, and debriefing staff after each session — all required more time than anticipated.

Was it worth the effort? For some [participants], it was the first time they had ever experienced true female friendships. “Many of the women want to continue to get together,” says Nancy Amodei, project evaluator at University of Texas. “They expressed so much disappointment when it was over.”

Visit [www.cdc.gov/hiv/prevention/research/compendium/rr/healthierrelationships.html](http://www.cdc.gov/hiv/prevention/research/compendium/rr/healthierrelationships.html) for more information about the HR curriculum.

an HIV conference in 2011 to present about the WOC Initiative program. The POWs had the opportunity to present their experiences with the program in a respectful and validating context, while gaining professional skills by attending the conference.

Communication between peers and program staff can be tricky. Los Angeles leaders discovered that patients often shared different bits of information with peers than with they did with community health outreach workers (CHOWs). To ease communication, the LA program staff developed several forms (see Appendix B for copies of these forms):

- All team members used a “potential client form” to identify and track potential patients.
- Peers used a “peer advocacy form” to inform CHOWs about patient progress.
- Providers used an “outreach form” to request support for patients.

## SUPPORTING CASE MANAGERS, TOO

Initially, three case managers for New North Citizens Council were supposed to serve 200 women of color. It soon became apparent that estimate didn’t allow enough

time for providing the kind of intensive support that patients really needed to remain in care. The program ended up serving about 50 women, which translated into a caseload of 12 to 15 patients.

This reduced workload allowed case managers to take the time needed to perform essential functions, like helping patients obtain housing. “It was baffling to see how many women tried to access certain things, including an apartment, but were denied, and how quickly that changed when a case manager accompanied them and advocated for them,” says New North Program Director Sandra Munier.

Providing emotional support for case managers is important as well. “This is very draining work,” says Munier. “My experience prior to doing this work was clinical, and so I think I was able to be mindful of the needs of the case managers, incorporating things within the meetings that helped them feel supported and nurtured: certificates, food, and a poem, anything to recognize them along the way. They also need to time to process how they’re feeling emotionally . . . because the case managers are dealing with very overwhelming stuff, and they can’t fix it all, even though they may want to.”

## PROGRAM FLEXIBILITY IS CRITICAL

The original plan for the University of North Carolina WOC Initiative project was to have the nurse guide provide intensive case management for approximately six months — at which point the hope was that the WOC would be attending regular clinic visits, have started HIV medications, and have a suppressed viral load. It quickly became apparent that the women were not engaging quickly enough to achieve those goals within the time frame. Thus, program staff decided to extend the intervention period to 12 months.

However, after 12 months of working with a nurse guide, many women were experiencing the program termination as a loss and becoming overly dependent. So the staff decided to switch back to a shorter time frame, ultimately deciding that eight months, when women were more autonomous, was the best compromise.

In addition, the nurse guide started emphasizing the time-limited nature of the relationship more often and earlier in the relationship, even using prewritten letters to communicate with patients. The nurse guide also made a concerted effort to collaborate closely with the clinic nurse who would take over long-term care as a

woman “graduated” from the intervention, making sure to provide a progress review and a personal introduction to the patient. That gave the clinic nurse a chance to address any concerns a patient might have during the transition.

This kind of program flexibility was necessary for many grantees. Program staff at Alabama’s Health Services Center modified its intervention by not limiting the number of sessions of strength-based case management (SBCM) sessions to five or less. They realized that an average of one session per month better met the needs of patients. In fact, this patient-centered approach allowed for case manager support to be provided at times most convenient to the patients and at a frequency that best helped them resolve their crises.

The example described previously — in which New North Citizens Council reduced the total case load for its case managers from 200 to 50 — made it possible for them to immediately improve the effectiveness of the case managers. This change, however, also could contribute to long-term success of the program. If those 50 WOC become more engaged in the system and more autonomous in their care, then case managers can start to take on more patients. The overall system is functioning more effectively and achieving the goals as designed.

## ADDRESSING COMMUNICATION BARRIERS

It’s important to understand that many WOC face language and cultural barriers when communicating with health care providers. “Especially in the Latino community, people will go to a medical visit, and whatever the provider says, they’ll say ‘Yep, I agree. Okay. Yep, I’m doing this,’ says Munier. “But the reality is that they don’t understand, they’re really not sure, they have a lot of questions and they can’t put together how to say it. So instead of being embarrassed, they’d rather not ask.”

Even providing translators sometimes isn’t enough. “One of the things that we hear from our women is, ‘I don’t like when the translator is there because she doesn’t say exactly what I’m telling her.’ So . . . there is still a ‘disconnect’ because we make an assumption that [the translator] is meeting the need, but a lot of times the person who you’re translating for is sitting there frustrated.”

In terms of communicating with English speakers who may have low literacy, grantees suggested using language that readily understandable to patients. It’s not enough to tell patients to practice particular behaviors, providers

## CHECKLIST FOR IMPROVING THE USABILITY OF HEALTH INFORMATION

- ✓ Identify the intended users
- ✓ Use pre- and post-tests
- ✓ Limit the number of messages
- ✓ Use plain language
- ✓ Practice respect
- ✓ Focus on behavior
- ✓ Check for understanding
- ✓ Supplement with pictures
- ✓ Use a medically trained interpreter or translator

Source: U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion. Quick guide to health literacy. (n.d.) Available at: [www.health.gov/communication/literacy/quickguide/quickguide.pdf](http://www.health.gov/communication/literacy/quickguide/quickguide.pdf). Accessed September 12, 2014.

must also underscore why it's important. Emphasizing that there are no dumb questions can be helpful.

Above all, ensuring patients feel valued by showing a genuine interest in them as people who have lives outside of the clinic can go far in developing a solid patient-provider relationship — one in which women are more likely to open up about risk behaviors, needs, questions, and other elements compounding or affecting their care.

## ENSURING CONSISTENT OUTREACH

Consistent outreach to patients is essential to keeping WOC in care, so keeping contact information current is critical.

“Many participants, we're not going to be able to find them simply because we don't have any current [contact] information at all,” says Janelle Job, access and evaluation supervisor for the Care Resource WOC Initiative project. “For those people who are very low-income and housing is a barrier for them, they might move from place to place or shelter to shelter, and that information as they move across different places may not be updated in the medical system, or the county system that we use, or in our program log. What happens sometimes is that

## PILOTING INTERVENTIONS TO AVOID FALSE STARTS

Creating a pilot program to test interventions can help providers avoid false starts. “Sometimes you just never know what you're going to find out,” says Niko Verdecias, project director for the Women of Color Evaluation Center. “A pilot can help you see where potential gaps might be.”

For example, a number of the sites developed support groups for women involved in their programs. For some sites, the attendance rate was pretty strong and consistent. “Other sites, however, thought they would have great success with it, but [experienced] very low attendance even though many women had expressed a desire to attend,” says Verdecias. It became a “lesson learned” when the program staff found out that there were some unexpected cultural reasons for the low participation.

“I'm thinking about one site in particular,” Verdecias continues, adding that the project modified its support group and started to get better attendance after finding out why some women were staying away. In essence, the community was too close-knit.

“The women felt like, ‘I don't want my neighbors to know that I'm having problems with my husband.’ One of the patients mentioned that she didn't want to be there because one of her neighbors was there, and she didn't want her to know about a problem she was having with her husband for fear that that neighbor would start pursuing her husband,” Verdecias says.

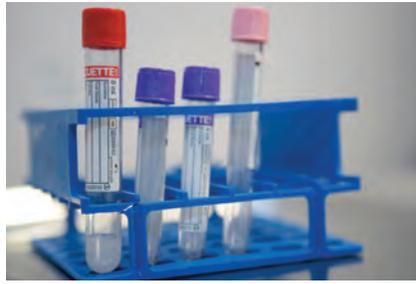
“These are the kind of things we can't think of as researchers,” she adds. “That was a really big lesson learned.”

you might have three or four different addresses for one person, but they're not there.”

Job advises checking data not only with each contact, but also through family members whom patients allow to be involved. “This needs to be almost an everyday thing with the participants. Outreach needs to be consistent.”

The program staff at the University of North Carolina discovered that reminder calls from the nurse guide helped a great deal, not only for appointments but also for checking up on whether patients are taking their medication and how it's going. "A nurse can reassure a patient that she won't become nauseated if she eats

something before taking her meds — and promise to check in with her the next day," says Byrd Quinlivan, M.D., principal investigator at UNC. "When we've been able to [connect in this way]," she adds, "we have really been able to hook women into being able to get on meds and stay on meds."



## GOING FORWARD

*“The fact that a patient may have to go down the hall, even 40 feet, for a referral to another HIV care provider . . . just that piece is an issue. We absolutely must have a well-integrated system, where when we make the handoff, the other is ready to receive them immediately.”*

— Sergio Avina, Project Investigator, JWCH Institute Inc., Commerce, CA

Reducing health disparities for HIV-positive WOC requires that HIV care providers across the country engage more women in care and offer them more and better services, all designed to move them along the HIV Care Continuum toward viral suppression. Each woman that is brought into care and retained in care moves the country one step closer to achieving the objectives of the National HIV/AIDS Strategy and the federal HIV Care Continuum Initiative.

Over the previous five years, the SPNS WOC Initiative has directly improved the health and well-being of women with HIV. The interventions were designed to help them overcome what are often very significant obstacles to linking to and remaining in care. Along the way, these providers gained new capabilities that they can use to help other patients in similar circumstances.

What’s more, through the effective dissemination of results and insights gained during the WOC Initiative projects, many more providers can apply the lessons learned and strategies within their own communities.

This IHIP implementation guide for WOC is a first step toward extending the reach of the projects in this way and can be found on the IHIP landing page on the TARGET Center website at [www.careacttarget.org/ihip](http://www.careacttarget.org/ihip). Additional IHIP training materials on Engaging Hard-to-Reach Populations are also available on the page.

It is worth noting that SPNS is currently funding two other initiatives that include women of color:

- Enhancing Engagement and Retention in Quality HIV Care for Transgender Women of Color (<http://hab.hrsa.gov/about/hab/special/transgenderwomen.html>)
- Culturally Appropriate Interventions of Outreach, Access and Retention among Latino(a) Populations (<http://hab.hrsa.gov/about/hab/special/latino.html>)

Look for additional insight and practical understanding to become available in 2016 and 2018, respectively, as those projects come to a conclusion.



# Appendix A



## TRAINING RESOURCES

### *Integrating HIV Innovative Practices (IHIP) curriculum modules for Engaging Hard-to-Reach Populations*

- **The HIV/AIDS Epidemic in the United States: The Scope of the Problem**  
<https://careacttarget.org/library/module-1-hivaids-epidemic-united-states-scope-problem>
- **The Continuum of Care: Is Your Clinic Effectively Reaching Vulnerable PLWH**  
<https://careacttarget.org/library/module-2-continuum-care-your-clinic-effectively-reaching-vulnerable-plwha>
- **Innovative Models of Care: An Overview and Traditional Street/Social Outreach**  
<https://careacttarget.org/library/module-3-innovative-models-care-overview-and-traditional-streetsocial-outreach>
- **Innovative Models of Care: Health System Navigation/Retention in Care Coordination**  
<https://careacttarget.org/library/module-4-innovative-models-care-health-system-navigation-retention-care-coordination>
- **Innovative Models of Care: Motivational Interviewing**  
<https://careacttarget.org/library/module-5-innovative-models-care-motivational-interviewing>
- **Innovative Models of Care: In-reach**  
<https://careacttarget.org/library/module-6-innovative-models-care-reach>
- **Innovative Models of Care: Outreach**  
<https://careacttarget.org/library/module-8-innovative-models-care-social-marketing-campaigns-social-networking-channels>
- **Innovative Models of Care: First Steps to Implementing a Model(s) of Care**  
<https://careacttarget.org/library/module-9-think-big-start-small-first-steps-implementing-models-care>

### *IHIP Webinars for Engaging Hard-to-Reach Populations*

- **Empowering the Patient**  
<https://careacttarget.org/library/engaging-hard-reach-populations-empowering-patient>
- **In-reach**  
<https://careacttarget.org/library/engaging-hard-reach-populations-inreach-0>
- **Outreach**  
<https://careacttarget.org/library/engaging-hard-reach-populations-outreach>

### *Other Relevant Resources*

- **HRSA's Guide to the Clinical Care of Women with HIV, 2013**  
<http://hab.hrsa.gov/deliverhivaidscafe/files/womenwithaids.pdf>
- **HRSA CAREAction newsletter, Ryan White Providers Address HIV/AIDS Among African-American Women**  
<http://hab.hrsa.gov/newspublications/careactionnewsletter/sept2012.pdf>
- **HRSA CAREAction newsletter, Intimate Partner Violence**  
<http://hab.hrsa.gov/newspublications/careactionnewsletter/sept2009.pdf>
- **HRSA's A Living History Website Video Voices Series, "Darlene: Moving Forward"**  
<http://hab.hrsa.gov/livinghistory/voices/tucker.htm>
- **The Ryan White HIV/AIDS Program, Population Fact Sheet: August 2012, Populations Served: Women**  
<http://hab.hrsa.gov/abouthab/populations/womenfacts2012.pdf>
- **HRSA's A Living History Website, Women and AIDS, Issues Essay**  
[http://hab.hrsa.gov/livinghistory/issues/women\\_1.htm](http://hab.hrsa.gov/livinghistory/issues/women_1.htm)
- **HRSA's Building Blocks to Peer Program Success: Toolkit for Developing HIV Peer Programs**  
<https://careacttarget.org/library/building-blocks-peer-program-success-toolkit-developing-hiv-peer-programs>



# Appendix B



## SAMPLE TOOLS AND TEMPLATES

The following sample tools and templates were developed by three WOC Initiative grantees — SUNY Downstate Medical Center, JWCH Institute Inc., and Care Resource — as part of their projects. These samples are included for reference only and should be modified to meet the needs of individual organizations or their partners.

- Peer Job Description
- Peer Confidentiality Agreement
- Peer Contact Form
- Outreach Contact Effort
- Peer Advocate Effort
- Potential Client Form
- Attempts to Locate
- Home Visit Protocol
- Multidisciplinary Case Staffing Protocol

## PEER JOB DESCRIPTION

Name: \_\_\_\_\_

**Title: Peer Outreach Worker**

**Job Summary:** The role of the Peer Outreach Worker is to provide a bridge between providers and clients that facilitates the medical and psychosocial care of the client. The Peer Outreach Worker works in a team setting as one component of the clients coordinated care. The Peer Outreach Worker maintains a relationship with the client that fosters trust and understanding distinct from a provider role. The Peer Outreach Worker is expected to serve as a role model who provides reliable information, appropriate referrals, and emotional support to women who are infected with HIV or AIDS. The Peer Outreach Workers help clients to access services (medical, mental health, economic, and legal) and may be called upon to accompany clients to appointments or arrange for transportation as needed. The Peer Outreach Worker must be HIV+, a woman of color, and over the age of 18.

**Responsibilities:**

- Provide one-on-one social and emotional support, education, and information to clients
  - » On phone; In clinic; In field
- Assist clients to navigate the hospital or clinic
- Accompany clients to medical appointments or other services as needed
- Assist clients to access needed services
- Provide clients with treatment education
- Coach clients in treatment adherence and provide treatment adherence support
- Use motivational interviewing to assist clients in reaching their treatment adherence goals
- On average, POWs should have weekly or bi-weekly contact with their clients.
- Document information and relay pertinent information to Program Coordinator, Case Managers, and clinic staff as necessary.
- Refer clients back to case management staff and to clinic staff when needed
- Adhere to confidentiality policies. It is a direct violation of Hospital policy to share the names or case facts concerning any client or volunteer of the Clinic with any other person with the exception of those actually involved in the care of the client.
- Maintain ethical relationships with all clients
- Provide emotional support to clients in a support group
- Follows all policies and procedures.
- Completes all appropriate paper work in a timely manner
- Participate in weekly individual supervision sessions with the Program Coordinator
- Participate in weekly group case conferences
- Participate in all on-site trainings and meetings

**Supervised by:**

Program Coordinator and onsite supervisor

Signature of Employee: \_\_\_\_\_ Date: \_\_\_\_\_

Signature of Supervisor: \_\_\_\_\_ Date: \_\_\_\_\_

## PEER OUTREACH WORKER CONFIDENTIALITY AGREEMENT

I, \_\_\_\_\_, understand in the course of my work for the Program, I may learn facts about clients/consumers, staff, and volunteers which are of a highly personal and confidential nature. Examples of such information are: HIV positive status, medical condition and treatment, finances, living arrangements, employment, sexual orientation, relations with family members and friends, and even the fact that an individual is a volunteer. I understand that all such information must be treated completely confidential. I agree not to disclose any information of a personal and confidential nature to any person not also affiliated with the Program or its partners.

Disclosure of this information without the specific consent of the individual to whom such information pertains is prohibited. The violation of confidence will cause my immediate termination as a Peer Outreach Worker and may also lead to possible legal action. In case of doubt about a situation, I will first contact the Program Coordinator or the clinic staff person with whom I am working and assisting in the clinic.

I agree to abide and uphold all of the Program guidelines.

Peer Outreach Worker (Print Name): \_\_\_\_\_

Signature: \_\_\_\_\_ Today's Date: \_\_\_\_\_

Program Coordinator Signature: \_\_\_\_\_

## PEER CONTACT FORM

Can I contact you by phone?  Yes  No

Home: \_\_\_\_\_ Cell: \_\_\_\_\_

Other: \_\_\_\_\_ Friend: \_\_\_\_\_

Friend: \_\_\_\_\_ Friend: \_\_\_\_\_

Can I leave you a voice mail?  Yes  No

What information can I NOT leave on your voice mail (does anyone else have access to your voice mail?):

\_\_\_\_\_

Can I contact you by text?  Yes  No

What information can I NOT share with you by text (does anyone else have access to your phone):

- a. Test results
- b. Name of the clinic
- c. Name of HIV related services
- d. Names of medications
- e. Referring to medications in general (“are you taking your medications” or “it is time to take your medications”)

Can I contact you by email?  Yes  No Email address: \_\_\_\_\_

What information can I NOT share with you by email? \_\_\_\_\_

\_\_\_\_\_

Can I contact you by home visit?  Yes  No Email address: \_\_\_\_\_

What should I say if someone else answers your door? \_\_\_\_\_

\_\_\_\_\_

Can I leave something under your door to let you know I came by if no one answers the door?  Yes  No

Can I send mail to your home?  Yes  No

If we happen to bump into each other somewhere how would you like to be acknowledged? Should I ignore you or come up and say “hello”? Would you feel differently if you were alone or with somebody? \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

**If you, (the Peer Outreach Worker), would prefer that clients do not disclose your HIV status, it is very important to discuss what you would like the client to do if you bump into the client when you are not alone.**

## OUTREACH CONTACT EFFORT

\*Chow (Community Health Outreach Worker)

Date/Dia: \_\_\_\_\_ \*Chow: \_\_\_\_\_

Name of CT/Nombre De Clienta: \_\_\_\_\_ Peer: \_\_\_\_\_

Address/Direcion De Clienta: \_\_\_\_\_

Telephone #/Telefono: \_\_\_\_\_

Directions/Direcciones: \_\_\_\_\_

Reason for Contact/Rason por ir a buscar: \_\_\_\_\_

Description/Como se ve: \_\_\_\_\_

Location last seen/Último lugar en el que fue visto: \_\_\_\_\_

Date of Outreach/ Fecha de Encuentro: \_\_\_\_\_ Outreach Worker/ Trabajadora: \_\_\_\_\_

Client was/La Cliente fue:  Found/Encontrada  Not found/No Encontrada

Result/Resultado:  Face to face/Cara e Cara  Appt. made/Se iso sita  
 Left Message/Deje Mensaje  Walked to Clinic/Caminamos a la clinica juntas  
 Moved/Se Mudó  Called Chow to Meet/Llame a Trabajadora para encontrar al cliente

Changes in Contact Info/Cambios en la información de Contacto: \_\_\_\_\_

### Peer and CHOW Notes/Notas de la Trabajadora y Voluntaria:

Could be:

\_\_\_\_\_ PSS (social support) \_\_\_\_\_

\_\_\_\_\_ PMS (medical support) \_\_\_\_\_

\_\_\_\_\_ PSC (peer support) \_\_\_\_\_

\_\_\_\_\_ PAS (peer advocacy) \_\_\_\_\_

## PEER ADVOCATE EFFORT

\*Chow (Community Health Outreach Worker)

Date/Fecha: \_\_\_\_\_ \*Chow/Trabajadora: \_\_\_\_\_

Name of CT/Nombre del Cliente: \_\_\_\_\_ Peer/Voluntaria: \_\_\_\_\_

CT Needs/Cliente ocupa:  Medical Appt. Escort/Asistencia para ir a la Clinica

(PMS) Address/Domicilio: \_\_\_\_\_

Services to obtain/Servicio que obtenera: \_\_\_\_\_

Special Contact/Con quien se va comunicar: \_\_\_\_\_

CT Needs/Cliente ocupa:  Social Services Escort/Asistencia con un Servicio Social

(PSS) Address/Domicilio: \_\_\_\_\_

Services to obtain/Servicio que obtenera: \_\_\_\_\_

Special Contact/Con quien se va comunicar: \_\_\_\_\_

CT Needs/Cliente ocupa:  Peer Moral Support/Apoyo Moral (PSC)

Support to Provide/Que se hizo con la cliente: \_\_\_\_\_

Directions: \_\_\_\_\_

Date of Advocacy/Fecha que se le ayudo: \_\_\_\_\_

Outreach Worker/Voluntaria: \_\_\_\_\_

Result of Effort/Resultado:  Assisted/Asistida  Not Assisted/No Asistida

Follow-up needed? If so, explain/Se ocupa seguimiento: \_\_\_\_\_

\_\_\_\_\_

Changes in CT Contact Info/Cambio de informacion: \_\_\_\_\_

\_\_\_\_\_

Peer and CHOW Notes/Notas de voluntaria (If applicable): \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

**PEER ADVOCATE EFFORT (continued)**

**Potential Clients /Clientes Potenciales**

\*Chow (Community Health Outreach Worker)

Date/Dia: \_\_\_\_\_

\*Chow Referred to/Chow Que Se Refirio:

Name of Potential CT/Nombre de Cliente Potencial: \_\_\_\_\_

Outreach Worker/Peer who referred CT/Nombre de Voluntaria: \_\_\_\_\_

Address/Domicilio: \_\_\_\_\_

Telephone #/Telefono De Clienta: \_\_\_\_\_

Where was potential CT found/Donde fue la client encontrada: \_\_\_\_\_

CHOW encounter date: \_\_\_\_\_ Screened:  Yes  No

Qualified:  Yes  No

If CT did not qualify, please provide reason: \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Baseline scheduled for: \_\_\_\_\_

Outreach Worker/Peer to receive incentive: \_\_\_\_\_

CHOW Notes: \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

## ATTEMPTS TO LOCATE

### Client Identifiers

Local Client Unique Identifier	Year of Birth	Age	Ethnicity	Race
<input type="text"/> <input type="text"/> - <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> - <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/>	<input type="checkbox"/> Hispanic/Latino <input type="checkbox"/> Not Hispanic/Latino	<input type="checkbox"/> American Indian/Alaska Native <input type="checkbox"/> Asian <input type="checkbox"/> Black/African American <input type="checkbox"/> Native Hawaiian/Pacific Islander <input type="checkbox"/> White <input type="checkbox"/> Don't Know
Date of Last Session	Date Range for 3 Month Follow-up		Date Range for 6 Month Follow-up	Data Collection Point
<input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/>	Start <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/>	Target <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/>	End <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/>	<input type="checkbox"/> f1: 3 months <input type="checkbox"/> f2: 6 months
Attempts to Locate				
<input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> @ <input type="text"/> <input type="text"/> : <input type="text"/> <input type="text"/> : <input type="text"/> <input type="text"/> M	Start <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/>	Target <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/>	End <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/>	<input type="checkbox"/> f3: 12 months <input type="checkbox"/> f4: 18 months

### Attempts to Locate

Attempt Date	Worker	Method	Outcome	Reason Unsuccessful	Notes
<input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> @ <input type="text"/> <input type="text"/> : <input type="text"/> <input type="text"/> : <input type="text"/> <input type="text"/> M	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="checkbox"/> Field <input type="checkbox"/> Agency <input type="checkbox"/> Phone <input type="checkbox"/> Internet <input type="checkbox"/> Mail <input type="checkbox"/> Other	<input type="checkbox"/> Unable to locate <input type="checkbox"/> Located	<input type="checkbox"/> Deceased <input type="checkbox"/> Out of jurisdiction <input type="checkbox"/> Other:	
<input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> @ <input type="text"/> <input type="text"/> : <input type="text"/> <input type="text"/> : <input type="text"/> <input type="text"/> M	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="checkbox"/> Field <input type="checkbox"/> Agency <input type="checkbox"/> Phone <input type="checkbox"/> Internet <input type="checkbox"/> Mail <input type="checkbox"/> Other	<input type="checkbox"/> Unable to locate <input type="checkbox"/> Located	<input type="checkbox"/> Deceased <input type="checkbox"/> Out of jurisdiction <input type="checkbox"/> Other:	



## HOME VISIT PROTOCOL

The purpose of the home visit protocol is to allow acutely or chronically ill women to participate in the longitudinal phase of the study. The preferred method is to conduct interviews at the program or partner site, and the home visit option should only be considered if getting to the hospital is not an option.

### A. Participant Criteria for Home Visit

1. History of violence — Participant has not experienced intimate partner violence in the past 12 months (Section E of screening). If the participant has experienced intimate partner violence in the past 12 months, she cannot be eligible for a home visit, EVEN if she does not currently with the perpetrator or if she is no longer in a relationship with the perpetrator.
2. Participant cannot come to the program site for an interview because
  - a. Illness
  - b. Taking care of adult family member
  - c. More than 2 young children at home
3. Participant must live either in the downtown or within a reasonable distance from the program offices (to be determined on case by case basis with Program Manager). Participants living outside the service area are considered non-eligible, even if they are eligible.

### B. Preparing Participant for Home Visit:

Before scheduling a home visit appointment with participant, interviewers should complete the Home Visit Assessment Form and review the information with supervisor. In order for a home visit to be successful, a loose contract must be agreed upon at the time of setting the time and the date. The following items from the informed consent must be reviewed with participant. Participant must verbally agree prior to fixing the time and the date:

- Time Commitment: Interviewer must clearly explain that the interview will last approximately 2 hours without interruption and that she must be able to give 2 hrs.
- Confidentiality: It is important to completely explain that the interview requires confidentiality.
  - » Intimate Partner: Intimate partner cannot be present in the house or apartment. If intimate partner is present at any time, interview will be stopped and full compensation will not be provided.
  - » Children Over 2 yrs: Children over the age of 2 years should not be present during the interview. By being present we mean within earshot of the participant and interviewer. Two Project staff should always be present at a home interview, unless the staff has already established a relationship with the client. One interviewer will conduct the interview and the other can provide childcare. If child over 2 insists on being in the room/ within earshot, the interview will be terminated and full compensation will not be provided.
  - » Space: Encourage participants to think of the place you can do the interview in their apartment. If children are going to be present, is it possible to find a place for the children to play and for the interview to be conducted out of earshot? If so, where? It is important to try to conduct the interview in a public part of the house and not a private place like a bedroom.

### C. Building Rapport

Rapport is probably the most important tool of the interviewer and is achieved through sensitivity to the participant; sensitivity to the participant's specific health and living situation, and a fundamental respect for the participant.

For the home visits, there are different challenges to building and maintaining rapport. The main challenge is to remember that you are a guest in someone's home. The fact that you are a guest also changes the culture of the visit. When conducting interviews on site, the interviewer is in complete control of the environment and it is

## HOME VISIT PROTOCOL (*continued*)

the participant who is the “guest” in the office space. When conducting home interviews, the tables change. The interviewer is now the guest in the home and may have very little control of the environment. The interviewer must understand this change in culture and accept that this may make interviewing more of a challenge and more time consuming (interruptions, introductory conversation, parting conversation etc.). The interviewer must use good rapport-building skills and interviewing skills to move the interview toward completion and leave the home with good relations and good data!

### D. Working Safely

Home Visit Assessment Form should be discussed with Program Manager. When working in what you consider a high-risk area, you should always discuss the situation with the Program Manager. Interviewers must follow the following safety rules. Exceptions to the rules must be approved by the Program Manager.

#### Participant Agreement

- Participant must agree to complete the Home Visit Assessment Form.
- Participant understands that the interview will take 2 hours at minimum. Intimate partner cannot be present in the house or apartment. Children over the age of 2 years cannot be present during the interview.
- Participant has provided clear directions to her house or apartment.

#### Interview times

- Interviews should be conducted during day light hours and finish no later than 4pm, if possible. The reason for this is two-fold: 1) in some of the rougher neighborhoods, morning and day hours mean a calmer and safer neighborhood. 2) It is difficult to get a cab back to the clinic at 4pm or later (see contact section).

#### Area

- Be aware of the area — assess the situation and observe people. Stay alert and tuned into your surroundings. Do not daydream or listen to music. Know where you are going and walk with confidence.
- Observe local businesses that are open that could offer help.
- If anyone asks who you are, briefly tell them that you are with a project for women’s health and keep moving. Do not mention the participant’s name.

#### Contact

- Project phone must be with interviewer at all times and must be turned on.
- Interviewers must let another Project staff member know the exact location of interview and start time of interview. Interviewers must let this same staff member know when they have completed the interview and have left the apartment.
- Project staff member must be available to interviewers during time of home visit by phone.
- Bring the number of a reliable car service with you to the interview. If you are returning to [location] and the car service says that they will not take you due to the time of day, tell the car service you need to go to either the program site or another hospital so you can leave the participant’s apartment and not lengthen your stay to evening hours.

## HOME VISIT PROTOCOL (*continued*)

### Dress

- Keep your dress professional yet casual. It is important to dress more conservatively than you would on a normal day.
- Do not wear jewelry.
- If possible, do not carry multiple bags. Put your keys, instrument, participant money, and tape recorder in one bag. Leave your purse at the program site or at the nearest site. If you cannot do this, then try to carry as few personal items as possible.
- Keep your program badge visible at all times.

### Multi-Unit Buildings

- Carry a flashlight — apartment building hallways can be dark even during the daytime. Often light bulbs are burned out or broken.
- Make noise, such as a low whistle, rattling keys, or conversation as you walk up the stairs or down a hallway. You don't want to startle or surprise anyone who might be hanging around or a regular in the building.
- Go right to the selected apartment and do your business — don't look interested in what folks are doing in the hallway. Do not stare. You should acknowledge them with a nod, smile, or brief eye contact, but going directly into the apartment.
- If, for some reason, you get to the apartment door and find out it isn't the right place, return to the street and place a phone call to the participant to get the correct information.
- Be aware, but do not concentrate on any other things going on in the apartment building. Your main function is to find the participant's apartment. If you look too interested, people will think, "What do you want — what are you looking at?"

### In the Home

- As much as possible, interviewers should remain in public spaces — living rooms, dens, family areas. Try not to go into rooms with closed doors (bedrooms or kitchen). If participant is bed-ridden, leave door open to bedroom and sit on side closest to the door. If worried of offending participant, tell participant that you haven't been feeling well and need fresh air or that you often feel claustrophobic.
- Try to avoid doing the interviews in the kitchen. If interviews are in the kitchen, try to sit next to the door.
- Interviewers are advised not to eat or drink anything offered. If asked to eat or drink anything, simply say "Why thank you so much, but I just ate breakfast/lunch", whatever is most appropriate given the time of day. Carry a water bottle with you and show it to the participant and say "Oh, thanks, but I just picked this up before I came over here."

### General

- Summer can be very hot in [location], particularly in apartment buildings without air conditioning. It is very important to keep yourself hydrated and well nourished! Make sure to bring water with you and if the interview time falls during lunch or breakfast, eat before you go.

### Final Note

Increasing the baseline numbers and achieving a high follow-up rate is critical to the success of Project. But ensuring the safety of the interview staff is even more important. If there is EVER a time where you feel physically unsafe or as if you are being verbally abused, leave the residence immediately and/or call 911. Talk with the Program Manager to review the incident and together you will form a plan about how — or if — the residence/participant should be approached again.

## **INTERVENTION-ASSERTIVE COMMUNITY TREATMENT FOR WOMEN OF COLOR MULTIDISCIPLINARY CASE STAFFING PROTOCOL**

### **Purpose:**

The multidisciplinary case staffing intervention component serves to staff cases with all internal providers who are directly responsible for clients enrolled in the WOC Project. Each case staffed by the multidisciplinary team functions as an exchange of information and discussion which must work to identify client barriers, client needs and focus attention to alternative and effective solutions to help clients improve in their overall engagement and retention in medical care treatment.

### **Composition:**

The case staffing meeting is composed of provider presentations represented for each department/program in which a client receives services and are listed as follows:

#### **1) Medical Staff**

- a. Primary Care Physician (PCP)
- b. Nurse Practitioner (NP)
- c. Patient Care Assistant (PCA)
- d. Nutritionist e. Dental

#### **2) Medical Case Management (MCM) Staff**

- a. MCM Supervisor (optional)
- b. Lead MCM (optional)
- c. MCM (required)

#### **3) Psychosocial Department Staff**

- a. Director of Psychosocial Department
- b. Psychosocial Department License Clinical Social Worker (LCSW)
- c. WOC Project LCSW
- d. Registered Social Work Interns e. Mental Health Interns

#### **4) Linkage & Retention**

- a. Outreach CSA

#### **5) Project Staff**

- a. Principle Investigator (PI)
- b. Project Coordinator (PC)
- c. Quality Assurance & Research Associate
- d. Lead Client Support Assistant (LCSA)
- e. Client Support Assistant (CSA)
- f. Patient Peer Navigator (PPN),
- g. Licensed Clinical Social Worker (LCSW). 1–2 Clients being staffed will be invited to attend the first 30 minutes of case staffing meeting.

#### **6) Documents used for case staffing:**

- a. *Barriers to Care and Treatment*
- b. *Case Scenario Questions for Discussion*
- c. *Multidisciplinary Staffing Note* (refer to attachments).
- d. An excel spreadsheet log must be used to electronically track client who have been staffed.

## **INTERVENTION-ASSERTIVE COMMUNITY TREATMENT FOR WOMEN OF COLOR MULTIDISCIPLINARY CASE STAFFING PROTOCOL (*continued*)**

### **Meeting Frequency:**

- Once every 4th Friday of the month for all providers involved and each client's case.
- Once every 1st, 2nd and 3rd Friday of the month for smaller case staffing with Medical Case Managers and support staff as needed.

### **Length of Staff Meeting:**

- Every 4th Friday — Meeting commences at 1:30–3:00pm or longer as needed. 4 Clients are selected to be staffed at this meeting. Emergency case staffing of additional casings are also staffed based on Physician's requests.
- Every 1st, 2nd and 3rd Friday — Meetings are staffed for 1 hour or longer as needed. 4 Clients are selected to be staffed specifically with the client's MCM and other providers as needed.

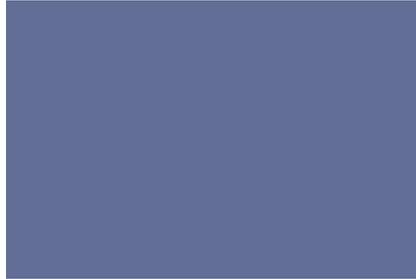
### **Eligibility Criteria:**

All actively enrolled participants of the WOC Project are eligible for case staffing with primary focus on participants who are listed across the continuum of care with a level of need score of 23 to 44 and are identified as follows:

- Newly diagnosed
- New to Care
- Sporadic Care
- Lost to Care

### **Format of Case Staff Meeting:**

- The primary case staffing meeting held on the 4th Friday of each month, is organized as a working lunch facilitated at [location]. The first 15 minutes of the meeting is designated for the invitation of one client whose case will be presented and have consented to attending the first 15 minutes of the meeting. Clients are invited to express their thoughts and provide the multidisciplinary team with feedback of their experience of all services provided. After each client has spoken, the meeting proceeds with staff only who are provided with brief overview of each client case via a PowerPoint Presentation of descriptive slides of case scenarios. Each scenario is read to the staff every 15–20 minutes, the allotted time provided to staff each case.



## NOTES

1. For the purposes of this guide, “black” includes African-American women, and usage is consistent with source material.

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