Strength in Networks

Groups of women living with HIV expand their reach by forming coalitions.

February 12, 2018 By Alicia Green

Christie's Place has served women living with and affected by HIV in San Diego County since 1996. So when local officials revealed in 2010 that 69 percent of HIV-positive women in the county were not accessing care, the nonprofit took action.

Recognizing that significant barriers prevent women from linking to and remaining in care, Christie's Place launched Coordinated HIV Assistance and Navigation for Growth and Empowerment (CHANGE) for Women in 2011. The program aims to use peer navigators, implement trauma-informed care and create a unified system of care in partnership with local groups.

"We don't actually have a county hospital," says executive director Erin Falvey. "UC San Diego Health [one of five academic medical centers within the 10-campus University of California system] provides the majority of HIV medical care for folks in San Diego County. It's a large county. There are services available in different areas, but it's not coordinated."

When it comes to breaking down barriers across the country, supporting programs like CHANGE for Women are a vital piece of the puzzle. Thanks in part to Networks for Women grants from ViiV Healthcare, Christie's Place and four other organizations serving women living with HIV—Transgender Law Center, Positive Women's Network–USA (PWN-USA), Iris House and The Well Project—can continue expanding their networks of care.

While the local HIV epidemic is concentrated in the county center, which is where UC San Diego Health is located, Falvey says many women living with HIV in San Diego County reside in more rural areas. What's more, most of these women are living in poverty.

"Stigma, isolation and trauma are the main drivers of the epidemic for women," Falvey explains. "Because of stigma, women often don't share their status with family members, friends or support systems. Isolation is a big driver of depression, anxiety and all things that lead to poor quality of life."

In order to ensure that no women are left out of HIV care, Christie's Place has teamed up with over 80 organizations, including the UC San Diego Health Mother-Child-Adolescent HIV Program and the UC San Diego Health Owen Clinic.

“There are so many opportunities for a woman to fall out of care,” Falvey says. “We don’t want to see on a system’s level that the system is letting an individual or a family down.”

Because many women living with HIV are affected by violence and abuse, which serves as another roadblock to accessing care, Christie’s Place—through its CHANGE for Women program—has also implemented a trauma-informed care model that has been nationally recognized.

“Trauma can lead to avoidance of settings that remind someone of their trauma,” Falvey says. “It can also lead to difficulty in advocating for one’s self in a medical setting as well as retaining information provided in those places.”

CHANGE for Women has also evolved to include FAB, a program for women aging with HIV; the advocacy program Transformations; and the enhanced peer navigation intervention EmPower Women.

“In 2015, a new county statistic was released that said approximately 43 percent of women are out of care,” says Falvey. “Our efforts through CHANGE for Women have helped to reduce that estimate by 26 percent.”

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Elsewhere in California, the Transgender Law Center’s constituent-led, Oakland-based Positively Trans (T+) project is addressing the needs of trans women, a group disproportionately affected by HIV.

Longtime advocate Cecilia Chung began Positively Trans in 2014 in order to bring together trans people living with HIV (especially trans women of color) to conduct research focused specifically on the needs of trans folks and help shape the trans response to HIV on a grassroots level.

In 2016, Positively Trans, whose 18-member national advisory board consists mostly of trans women of color living with HIV, released the first national needs assessment survey for HIV-positive trans people. The survey focused on social determinants of health such as incarceration, discrimination and homelessness.

“What they do is guide our work,” says Positively Trans program coordinator Beatrix McBride. “We are not in the business of telling local communities what they need in their fight for self-determination, health care and well-being. Our job is to help them connect to and get what they need. Part of that is relying on leaders from around the country in those communities.”

In addition, during weekend-long workshops, the Positively Trans Digital Storytelling Project teaches individuals how to produce videos about their HIV journey in an effort to help educate and break down stigma.

Most recently, the project shifted its focus regionally. It worked with the Trans Sistas of Color Project in Detroit, Arianna’s Center in South Florida and Transitions Louisiana in New Orleans to

conduct a regional needs assessment, develop local storytelling workshops and build capacity.

“Our work has broadened the scope of the conversation in HIV activism and the HIV movement in that we are bringing trans people, specifically trans women of color, not just to the forefront but also to the center of our activism,” says McBride. “That is shifting how folks are thinking about the HIV movement and trans people within it.”

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One of the groups Positively Trans has been working with to highlight and center women’s voices and leadership within the HIV movement is PWN-USA, a national membership body of women living with HIV, also based in Oakland.

“We were founded to fill a gap in the national leadership and advocacy landscape,” says executive director Naina Khanna. “There was no organized collective voice advocating on behalf of women living with HIV. We wanted to prioritize building leadership and power among communities most impacted by the epidemic.”

These groups include women of color, low-income women and women of trans experience. PWN-USA helps these women develop the skills needed to be policy experts, decision makers and advocates for important issues that affect their lives.

To address the need for more support groups for women living with HIV nationwide, PWN-USA created a virtual community that allowed women to connect directly with one another, build relationships and share useful information.

The result is PWN Cares, an interactive multimedia series by and for women living with HIV, including trans women, that seeks to minimize isolation and address topics such as disclosure, intimate partner violence and the concept that undetectable equals untransmittable.

The virtual component of the interactive series includes videos that feature some of PWN’s members and address specific areas of concern. Afterward, viewers are encouraged to participate in confidential online discussions of the videos’ content. In addition, PWN’s seven regional chapters host live video screenings and in-person discussions that sometimes include panels.

“The biggest barriers to health care for people living with HIV in this country, especially for women living with HIV, are stigma, discrimination, isolation and depression,” explains Khanna. “It’s not just about access to medicine, even though poverty and access are major structural factors. Through our policy work we address those structural factors. What we really wanted to address here are these other quality-of-life issues.”

So far, says Khanna, the feedback has been powerful. Women, including those who participate as panelists, have expressed that it’s been a valuable and moving experience.

The next phase of PWN Cares, to be launched this spring, is an ongoing online community that

provides a safe and confidential space for women to continue these conversations. PWN-USA also plans to produce another round of videos for its second grant year.

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Over on the East Coast, Iris House, which provides services for women living with and affected by HIV in the New York area, is working with collaborators to form an online call-in emotional wellness group—not unlike PWN-Cares—that connects women throughout the United States.

The idea stemmed from a joint campaign with Voces Latinas, a volunteer-run organization for Latinas living with HIV in New York. Launched in March 2017, the purpose of the bilingual "Love Your Life" campaign was to educate women about HIV, to encourage them to get tested and know their status, and to talk about safer sex and in the process help break down HIV stigma.

Featuring positive messaging and vibrant images, "Love Your Life" was aimed at women of color, specifically African Americans and Latinas. Posters were made available online to be shared within communities.

"Next to young gay men, women of color have the highest HIV rate," says executive director Ingrid Floyd. "We wanted to make sure that women of color understood that they should also be tested and know their risk factors."

Started as a local project, the campaign is now being used nationally as an outreach method to link underserved women in remote areas of the country to an online support community.

"If you live in a small town where you don't have an AIDS service organization, this is another way for you to get ongoing support and be around other women who are living with HIV so that you can realize you're not alone and that there are many others who are dealing with similar issues," says Floyd.

To achieve its goal, Iris House has partnered with organizations representing the South, Southwest and West, including Women Organized to Respond to Life-threatening Diseases (WORLD) in Oakland, California; the Minority AIDS Council in Orangeburg, South Carolina; and The Afiya Center in Dallas, Texas, as well as Voces Latinas.

"It's very important for organizations like ours to make sure that we understand that women's needs are unique, that the services we need are different from the ones that our male counterparts need, that we have to keep advocating for availability of services for women and that we have to help other organizations build their capacity to offer gender-specific services," says Floyd.

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The Well Project is an online resource that was created to change the course of the epidemic through a comprehensive focus on women and girls.

It shares over 110 fact sheets related to HIV and women, gives women the opportunity to connect with one another via its A Girl Like Me blog and provides women with advocacy tools, among other resources.

“Most of our users have come to us through online searches, word of mouth, our bloggers, community advisory board members and ambassadors who share the information with their communities,” says executive director Krista Martel. “But we never really had the resources to do a very targeted outreach effort to make sure that people who are looking for this information know that we’re there.”

In 2016, The Well Project conducted its most scientifically rigorous survey to date, Martel says, to understand who was using its resources, the effect of those resources on women living with HIV and which issues were most important to them.

“What we found is that we’re having the most impact on women and their engagement in care,” explains Martel. “We also found that we had a significant impact on their overall self-care as well as overall outlook on living with HIV. We really wanted to invest some time and energy into getting the word out to more people.” And that’s where Building H.O.P.E. (Hopeful Outreach and Positive Engagement for Women Living with HIV) comes in. The awareness initiative aims to reach the most underserved communities, including women of color, transgender women, women who are newly diagnosed and those not connected to an HIV network.

A Building H.O.P.E. video and a variety of outreach materials marketed to leaders of clinics, AIDS service organizations and community-based organizations tell The Well Project’s story in the hope that these groups will drive their clients to the online resource.

In addition, The Well Project is working with outreach coordinators to target trans women and women at risk for HIV in the South as well as connecting with provider networks, such as the HIV Medicine Association, the International Association of Providers of AIDS Care and the Association of Nurses in AIDS Care, to further promote its resources.

Finally, Martel also hopes to work with providers outside of the HIV community to reach women who may not be connected to an HIV network. To that end, The Well Project has had initial discussions with Planned Parenthood and plans to reach out to family providers and general practitioners.

“You’re not alone,” says Martel. “We hear almost every day from people who are newly diagnosed and did not know that there is anyone else out there like them. There’s a whole sisterhood of women waiting to embrace you and help you through your diagnosis.”

These groups show that focusing on growing connections with like-minded organizations is key to reaching more women living with HIV who would benefit from their support.

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