

# Engagement and Retention Strategies for Populations with Unique Needs: Women, African-born and Caribbean- born Communities

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*Women Organized to Respond to Life-threatening Diseases  
(WORLD), Oakland, CA*

# WORLD

## WOMEN ORGANIZED TO RESPOND TO LIFE-THREATENING DISEASES

### Starting with a newsletter in a living room...

- Formed in 1991 by and for all self-identified HIV+ women
  - Emotional & practical support
  - Mental Health services
  - Outreach and Linkage to Care
  - Wraparound services
  - HIV-related treatment adherence
- Services have expanded to include:
  - Linkage and Retention Specialists for women out of care and tenuously in care
  - HIV testing
  - **Women's HIV Specialty Care Clinic** Services provide at **WORLD's house** and in local clinics
- WORLD's Motto: "You are not alone."





# WORLD



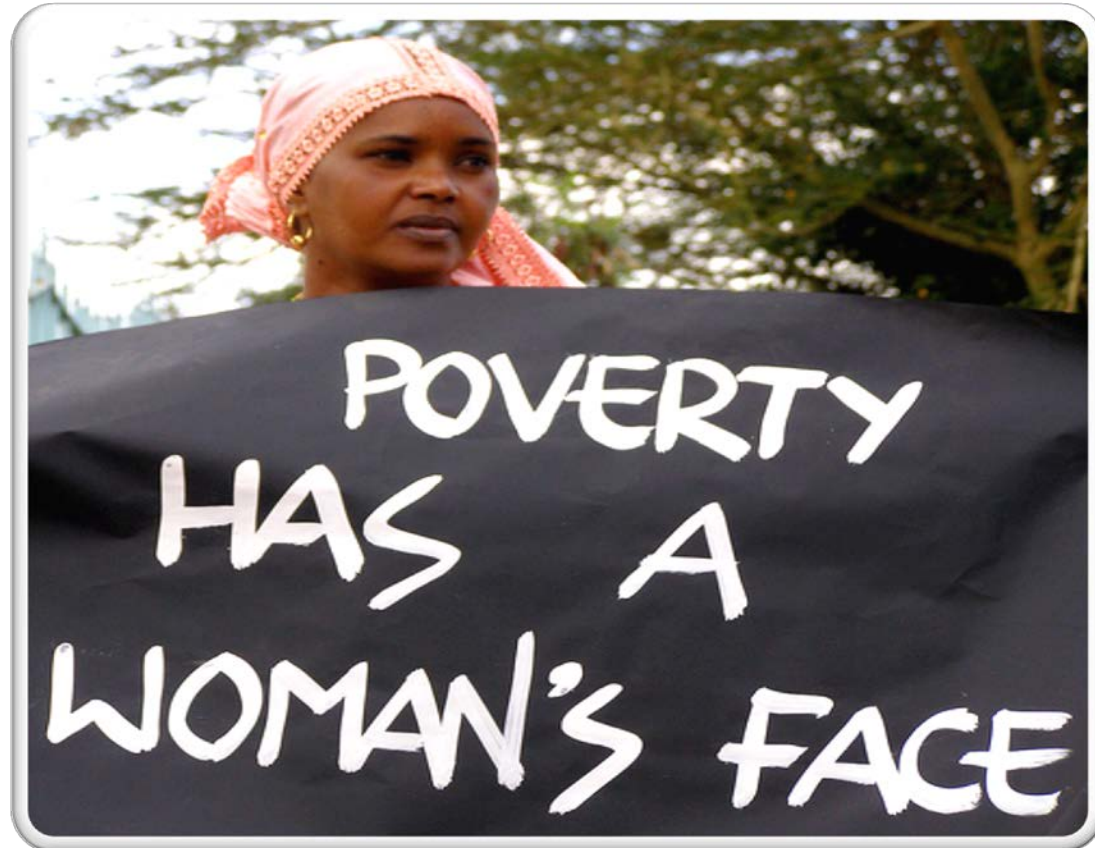
## WOMEN ORGANIZED TO RESPOND TO LIFE-THREATENING DISEASES

### Family Care Network (FCN) **Peer Advocacy** Program:

- Providing high-quality, accessible, and culturally competent social support and treatment adherence services that enhance the quality and length of life of Ryan White-eligible WICY living with HIV in Alameda and Contra Costa Counties.
- Paid staff living with HIV
- In both English and Spanish
- Coordinate care access to FCN clients
- Identify and address barriers to care, Advocate for access to needed services
- Support overall retention in care & adherence to medications
- Clinic-based hours weekly
- Individual and group work, outreach, linkage to care, psychosocial support

# Identify unique barriers to care for women and how to address them

- Poverty
- Language Barriers
- Transportation
- Stigma
- Childcare



# The Connection Between Peers Advocacy and the Client

Peers are specially trained individuals from the community who are living with HIV/AIDS. As members of the community, peers help promote treatment adherence and foster trust in the health care system. They help clients navigate the sometimes intimidating world of HIV treatment and services by providing a range of support activities that include :

- Explaining the basis of HIV/AIDS and self-care to the newly diagnosed
- Connecting people with the needed services
- Assisting with appointment reminders and transportation
- Accompanying clients to appointments
- Acting as a liaison between clients and their care providers



# Who Understands Chronic Care?

No one understands the reality of HIV better than someone who lives with it every day. Peers—**specially trained members of the community who are living with HIV/AIDS**—have the power to serve as important role model to others who are learning to cope with the daily challenges living with HIV.

# Starting the Relationship

Having patience in beginning the client/peer relationship is critical.

“It’s hard to be scared in front of a stranger. So, you can’t be a stranger. You have to give it time until you aren’t a stranger anymore. That’s when they’ll let you in and when you’ll finally really be able to make a difference. “

-WORLD staff member



# Goals of Linkage and Retention Efforts

Once the client formally agrees to participate in linkage and retention services at WORLD, the next step is an assessment of barriers to care. This is an assessment of the needs that the client feels are most important, for them to link to and be retained in care – not an assessment of what the OLS believes the major barriers to be . Once support needs have been identified by the client, the client and OLS work together to determine next steps and overall plans to address barriers and ultimately connect the client to care. This plan is revisited and needs are reassessed at each subsequent interaction.

Helping a client be regularly in high- quality medical care improves health and wellness.



# Building Trust

Spending time with the clients outside of medical visits is crucial to building trust.

- Demonstrates to a client that they are important to the Peer as a whole person.
- Helps the client believe that the Peer understands the complexities of their lives, all of which may impact their interest or ability to be regularly engaged in medical care.
- “We see more parts of our women’s lives, so they trust us more. If we’re doing it right, we get to weave in why seeing the doctor and adhering to medications are so important.”

-WORLD Staff Member



# Support with Appointments

WORLD Peer Advocates not only transport clients to medical appointments, they accompany clients during appointments if they wish, helping to advocate on their behalf and providing additional education.

“Sometimes it’s 10 ,20, 30 missed appointments before it pans out. And some of those clients are very communicative and very apologetic – not what you’d think. But you have to stick with it, and eventually, they’ll get there.”

-WORLD Staff Member

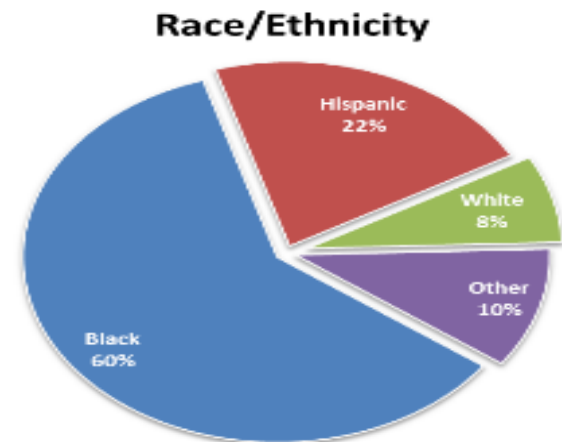
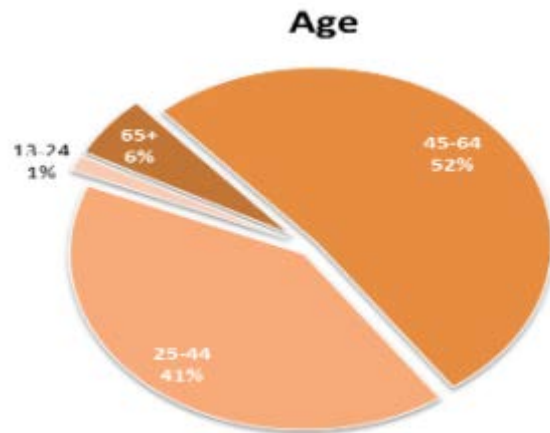
# WORLD Clients

In 2014, WORLD provided Peer Advocacy to 209 unduplicated clients.

- 98% identified as women, 2% identified as transgender
- 83% of them were living below the federal poverty level ( an annual income of \$ 11,670 per year for a single adult, and \$23,850 for a family of 4- shockingly low figures given the cost of living in the San Francisco Bay Area).
- 76% of WORLD clients that year were stably housed ( they owned or rented their home)
- 12% were homeless either on the streets or in an emergency shelter. The remaining either had a temporary situation or their housing status was unknown.

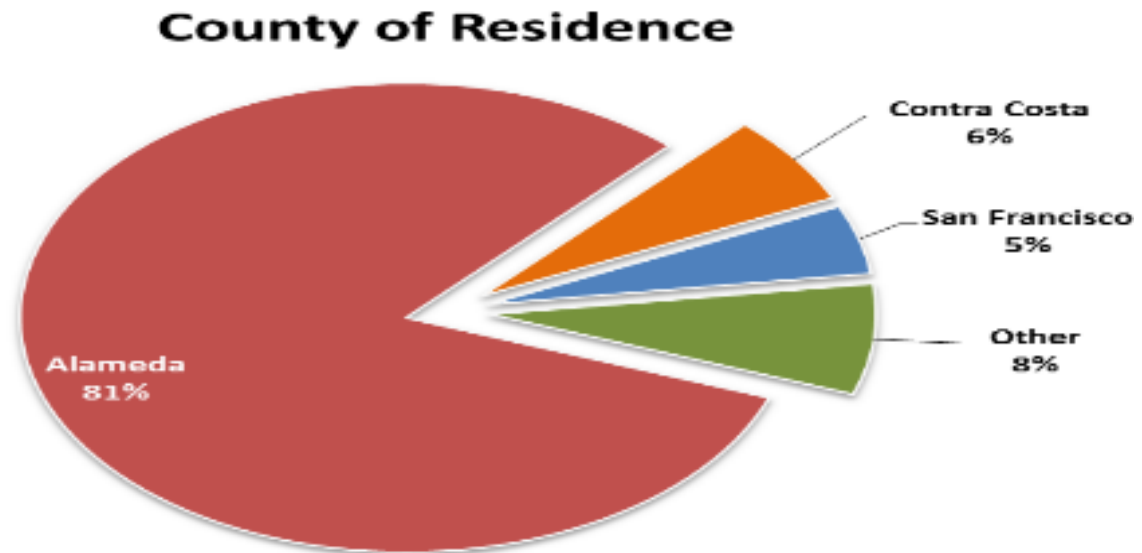
# WORLD Clients

- ❖ The majority of WORLD clients are ages 25-64, unsurprising given the demographics of HIV in the Bay Area. However, almost 1 in 10 clients were younger than age 25 or older than 65.
- ❖ Nearly 2/3 of clients in 2014 were Black, with another 1/4 Latina.



# WORLD Clients

Four out five WORLD clients live in Alameda County, which includes Oakland, where WORLD is located. However, it is important to note that 1 out every 5 clients travels to WORLD for services despite living as far away as Contra Costa County or across the Bay.



# Program Model

At WORLD, there are two types of linkage and retention support:

- Intensive model conducted by Outreach and Linkage Specialists (OLSs)
- Peer Advocacy model conducted by the peer advocates.

The bottom line of both models is simple: client-focused care. Ultimately, it is a matter of creating an organizational culture that puts the needs of the client in the center and builds everything else around them.

# Client-Centered Approach





# Thank you!

To find out more about WORLD, please visit  
[www.womenhiv.org](http://www.womenhiv.org)

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