

A group of diverse healthcare professionals, including doctors and nurses, are sitting in a circle in a meeting room. They are holding notebooks and pens, suggesting a collaborative discussion or training session. The setting is a bright, modern office or clinical environment.

Supporting Intersections of Care for Women Living with HIV Along the Care Continuum

Presenter



Naina Khanna

**Executive Director, Positive Women's
Network – USA**



Training Objectives

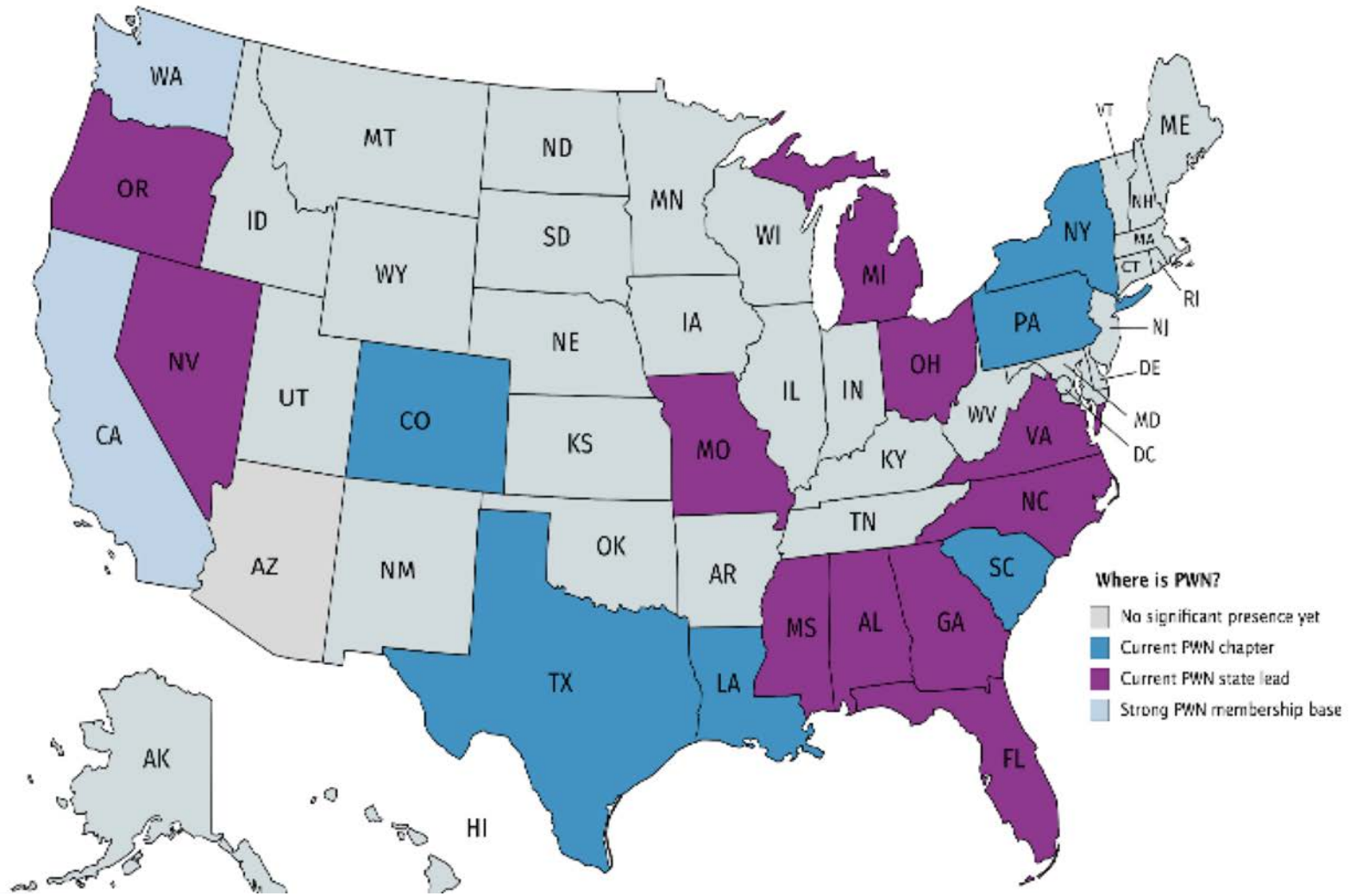
1. Participants will learn to identify factors influencing access to and quality of care along the HIV care continuum for women with HIV in the U.S.
2. Participants will be able to recognize barriers to meaningful involvement of women living with HIV in their care
3. Participants will understand strategies and tools for providers and clinicians to improve care for their clients.



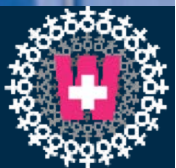
About Positive Women's Network-USA

- The only national organization in the US led by and for women and trans people living with HIV
- Mission: To *prepare and involve* women living with HIV, in all our diversity, in all levels of policy and decision-making.

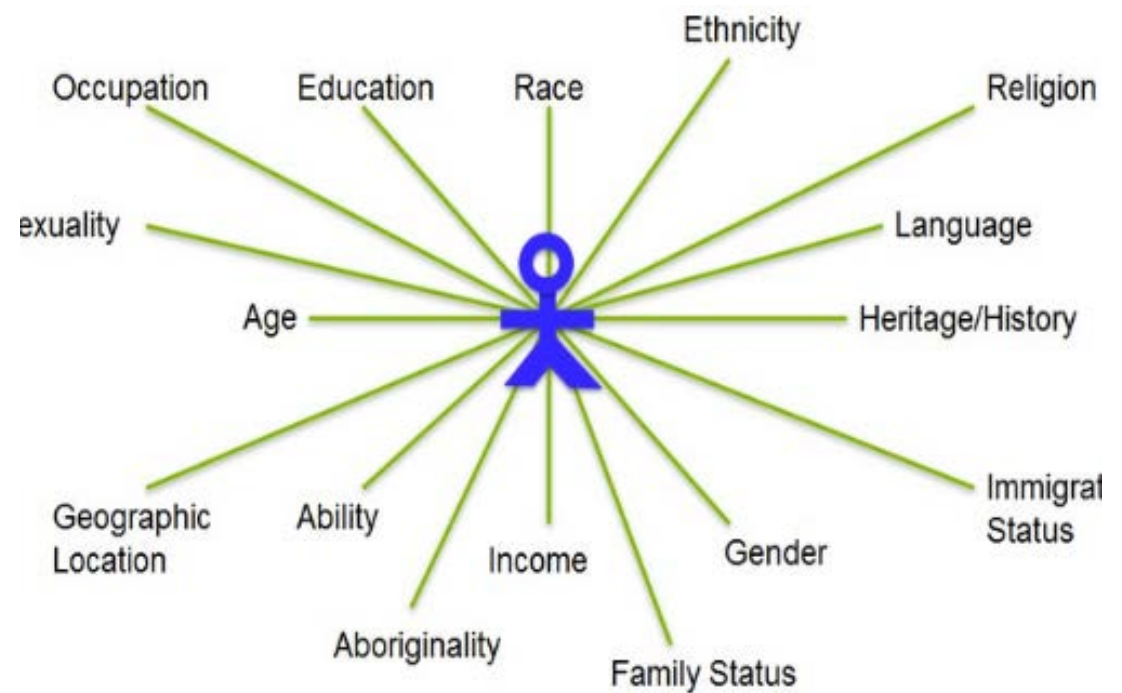




What's actually going on in the lives of women with HIV?



Multiple Factors Influence Women's Experiences with HIV Post-diagnosis

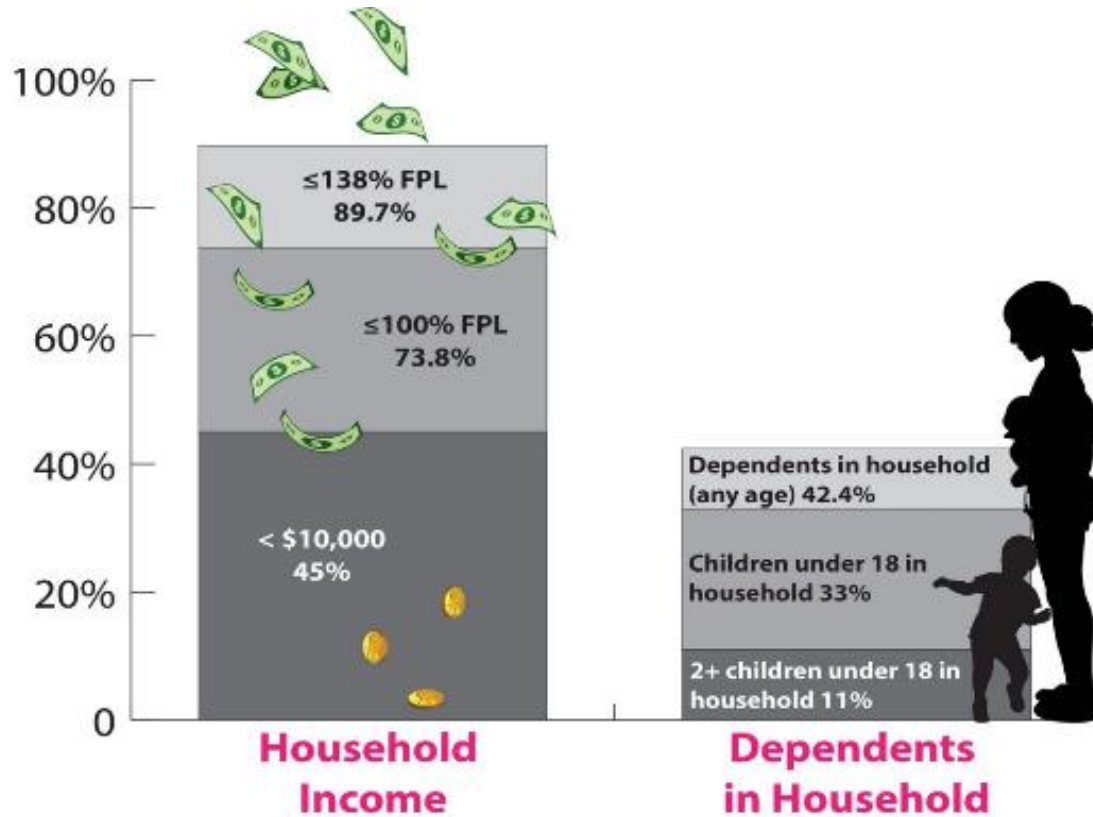


Understanding Structural Violence

- Action built into the structures of society which show up as unequal power and unequal life chances; the unequal distribution of resources and the unequal distribution of power to decide over the distribution of resources
- Depersonalized – no clear perpetrator
- Ongoing and pervasive – beyond independent events
- Invisible - violence has been converted into structures of power that are normalized and routinized; it's part of everyday life



Income & Family Responsibilities



- N=180
- Securing the Future of Women-Centered Care: Findings from a Community-Based Participatory Research Project, 2016
- By Positive Women's Network-USA
- Full report available at <https://pwn-usa.org/wpcontent/uploads/2016/03/rwp-report-final.pdf>

HIV Diagnosis Can Push Women Into Poverty

“But I also know that this woman actually has control over what ultimately is a life or death decision with the stroke of her pen. And clearly she is in a bad mood... What I have is a very expensive medical condition and no way to pay for it... it is that simple. I need help. We as women living with HIV are driven into poverty and held there, and we are drowning.”

Under Surveillance by Medicaid

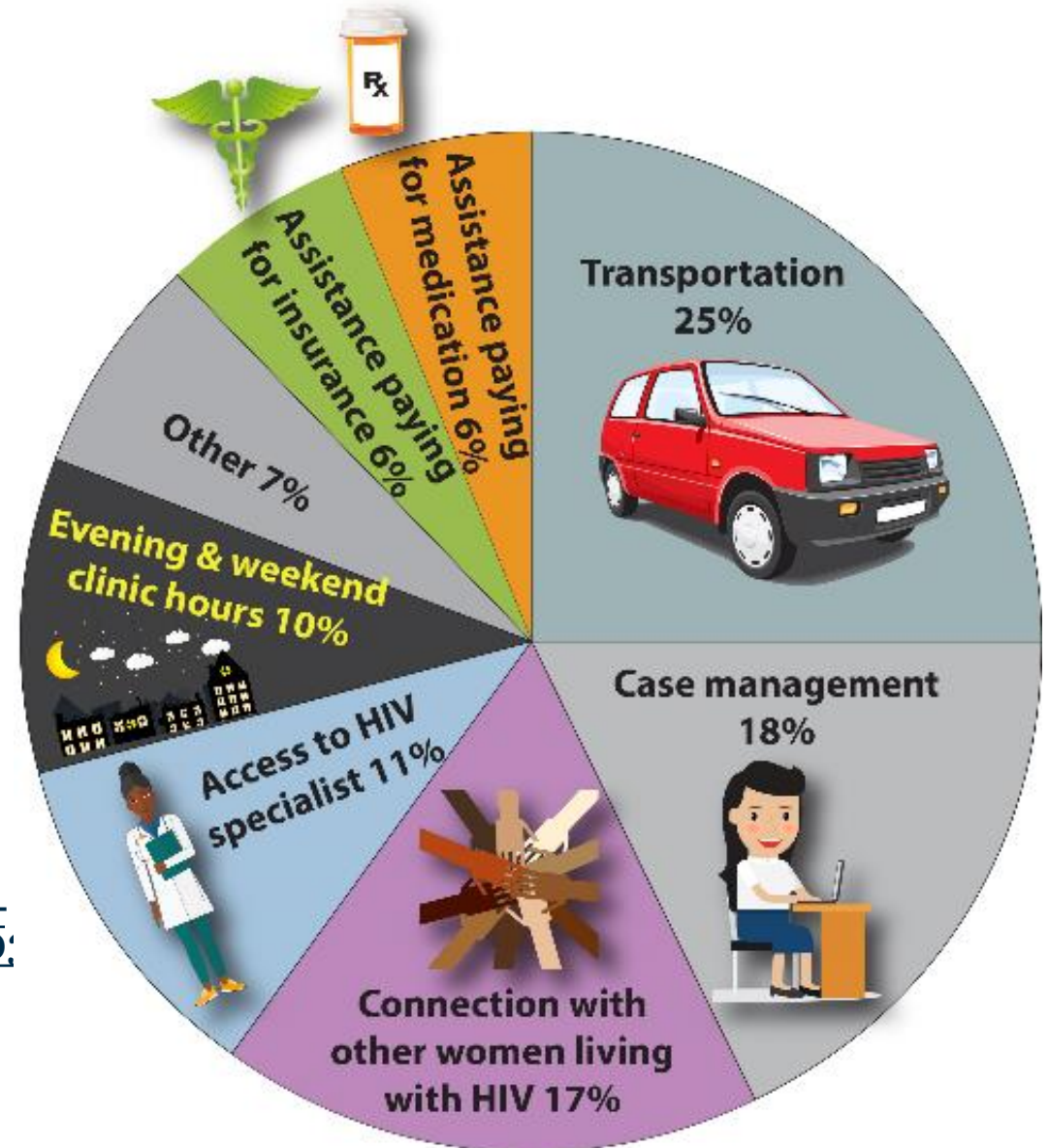
by [ADMIN](#) on APRIL 19, 2012 · [LEAVE A COMMENT](#)



By [Kat Griffith](#) in Peoria, IL

Barriers to Care

- Q. What ONE thing would improve your ability to stay in care?
- N=180
- Securing the Future of Women-Centered Care: Findings from a Community-Based Participatory Research Project, 2016
- By Positive Women's Network-USA
- Full report available at <https://pwn-usa.org/wpcontent/uploads/2016/01/rwp-report-final.pdf>



What are some of the things you really want Ryan White providers to know about providing high quality and accessible care for women living with HIV?



“Poverty is a full-time job”

“Poverty is a full-time job. Doing what’s required to certify for all these **TOTALLY NECESSARY** programs for food stamps, medical care, unemployment, etc... I’ve easily spent 20-30% of my time the last 2 weeks doing this. Ryan White/ADAP programs aren’t any different really. Synching cert periods up would help. Standardized requirements And centralized filing of documents for access ...would be amazing. Like - oh hey, got a new lease! Let me upload to “The poor bastard’s document hub,” so all the pertinent organizations can access my updated info. Bang bang address change.” –
M, Alabama



Yes, Family-centered Services are STILL Necessary for WLHIV to Effectively Participate in Care

“We need childcare in our clinics. Most visits are only 15-30 minutes. What are we supposed to do with our kids/grandkids? Providing childcare also creates jobs.”
- T, Philadelphia

“I’m a family unit not just a single person, although I need self care, I am well when my kids are well. When they don’t have what they need, it’s hard for me to focus on my care. Kids living with a parent living with HIV have higher incidence of mental health challenges. Take good care of my family then I can take care of me!!” – N, Chicago



Ensure Quality of Sexual and Reproductive Healthcare

“...not one clinician offers advice or talks about reproductive health. Having sex after HIV or even contemplating having children is like an elephant in the room and these conversations are like taboo.” – L, Birmingham, AL

“I get asked if I use a condom but nothing else about my sex life or whether I want to get pregnant.”
-C, Orangeburg, SC

“I was really upset when I learned that I could have been advised to freeze sperm before my transition.” – B, Detroit, MI

Recertification is a Huge Barrier!

“They need to provide online application after a one-time in person visit across the board. PLHIV should never be forced to walk or take 6 buses or more in some cases round trip to ensure our care, when our case managers usually have cars but don't provide home visits in every city. It's unnecessary in 2020.” C, Reno, NV

“ I am no longer in care with Ryan White... when calling in to make a recertification appointment and a voice mail is left, the appointment setters need to make the time to call the client back. Some of us do work and have to request the time off, hence I fell through the cracks....
Now during COVID, no virtual recertification option has been offered”
– R, South Florida

“Recertification is a bummer and a half...my day has to come to a grinding halt for an hour +/- so that I can wait, sign the same old stuff, answer the same questions I answer EVERY SINGLE TIME IM THERE, and leave. I realize it's necessary to do, but talk about a meeting that could've been an email...” – M, Alabama

Lack of Coordination Among Providers Creates Challenges for Clients

“ My Endocrinologist and my HIV doctor needed to speak with each concerning medications being used to treat my diabetes. They did not and my viral load which started going up while I did not have a resistance profile... All my care providers must be in communication.” – M, NYC, NY

“A lot of times the left hand does not know what the right one is doing. I think it would help if Dr's had one number they could give to patients to access a case manager especially for newly diagnosed patients.” - D, Portland OR



Cultural Relevance and Life Experience Matter

“Have physicians that look like us, understand us... also some medical care & providers and their institutions must be aware the harmful practices that are in place... Some form of Implicit Bias trainings. Cultural Humility trainings.” – C, Chicago, IL

“it’s hard not seeing us when we go to providers... I would like to see more women in the positions especially women of color. Also I would like for the provider to consider experience base instead of just degrees” – L, Detroit, MI



Other Barriers Mentioned by Several Respondents

- Not knowing or understanding what services are available
- Fear of retribution/Actual retribution when expressing concern about services, providers, staff



In the era of COVID-19...



PWN Members are Expressing...



Virtual support groups are great!
However, not everyone has the
equipment, data, or technology
familiarity to participate



Trouble filling 3-month
prescriptions for shelter in place



Difficulty maintaining
recovery/sobriety

- Crisis due to services closing
- Food insecurity
- Housing instability/eviction concerns
- Household income loss
- Intimate partner violence
- Increased anxiety and depression
- Grief & loss



Meaningfully Involving Women with HIV



HIV < Empowerment

Know the Denver Principles.

When a group of people with AIDS met at a hotel room in Denver in 1983 and wrote a manifesto outlining the rights and responsibilities of people with AIDS,

the Denver Principles,

it was the first time in the history of humanity that people who shared a disease organized to **assert a collective political voice.**

Michael Callen,
1955 -1993
AIDS Activist & Co-Author
of the Principles.



⇒ WORLD AIDS DAY: **DEC. 1** 

SEANSTRUB.COM 

Recommendations for people with AIDS:

1. Form caucuses to choose their own representatives, to deal with the media, to choose their own agenda and to plan their own strategies.
2. Be involved at every level of decision-making and specifically serve on the boards of directors of provider organizations.
3. Be included in all AIDS forums with equal credibility as other participants, to share their own experiences and knowledge.



MIPA = meaningful involvement of people living with HIV/AIDS

GIPA = greater involvement of people living with HIV/AIDS



GIPA means meaningfully involving people living with HIV in the programmatic, policy and funding decisions and actions that impact on our lives by ensuring that we participate in important decisions.

- Global Network of People Living with HIV/GIPA Report Card

From UNAIDS, 1999, MIPA Means...

1. Recognizing the important contribution people living or affected by HIV/AIDS can make in the response to the epidemic
2. Creating space within society for PLHIV involvement and active participation in all aspects of the HIV response.



UNAIDS Policy Brief 2009



The Greater Involvement of People Living with HIV (GIPA)

POLICY BRIEF

GIPA seeks to ensure that people living with HIV are **equal partners** and breaks down simplistic (and false) assumptions of “service providers” (as those living without HIV) and “service receivers” (as those living with HIV).

Context

Nearly 40 million people in the world are living with HIV.¹ In countries such as Botswana and Swaziland, people living with HIV make up a quarter or more of the population.

People living with HIV are entitled to the same human rights as everyone else, including the right to access appropriate services, gender equality,² self-determination and participation in decisions affecting their quality of life, and freedom from discrimination³.

All national governments and leading development institutions have committed to meeting the eight Millennium Development Goals, which include halving extreme poverty, halting and beginning to reverse HIV⁴ and providing universal primary education by 2015. GIPA or the Greater Involvement of People Living with HIV is critical to halting and reversing the epidemic; in many countries reversing the epidemic is also critical to reducing poverty.

at the 2006 High Level Meeting on AIDS also advocated the greater involvement of people living with HIV.

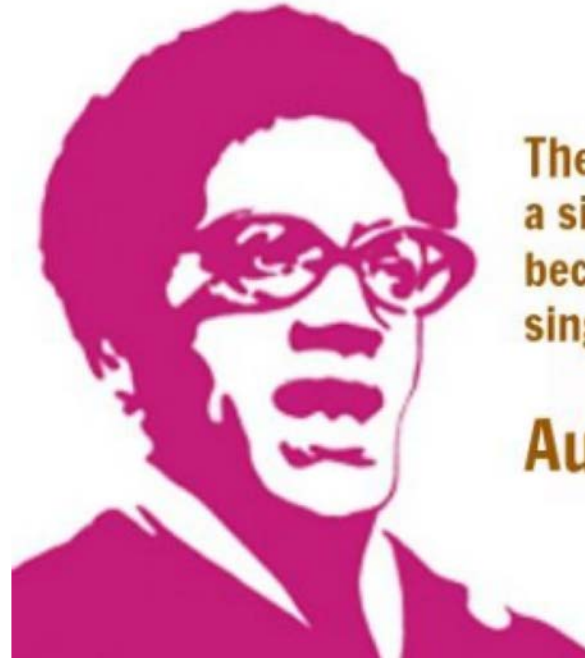
Why GIPA?

People living with HIV have directly experienced the factors that make individuals and communities vulnerable to HIV infection—and once infected, the HIV-related illnesses and strategies for managing them. Their involvement in programme development and implementation and policy-making will improve the relevance, acceptability and effectiveness of programmes. Measuring involvement of people living with HIV in policy is not an easy or exact science. However, experiences⁷ have shown that when communities are proactively involved in ensuring their own well-being, success is more likely. GIPA seeks to ensure that people living with HIV are equal partners and breaks down simplistic (and false) assumptions of “service providers” (as those living without HIV) and “service receivers” (as those living with HIV).



Ongoing Challenges to MIPA in Care Settings...

- Perception of PLHIV as permanent service recipients (and nothing else): “consumers”
- Racism, transphobia, misogyny, classism in the HIV response
- Lack of support for leadership/advocacy
- Overall lack of orientation towards building political power
- Chronic vs terminal: complacency
- Medicalization of response; loss of peer-based services
- Discrimination against people living with mental illness, substance use, etc



There is no such thing as a single-issue struggle because we do not live single-issue lives.

Audre Lorde

Barriers to MIPA: Organizational/Clinic Examples

- Hiring practices that prevent clients/PLHIV from applying
- Lack of board bylaws that require PLHIV participation
- Disempowered CABs with no real impact on decision making process
- Lack of organized input from PLHIV
- Programming FOR PLHIV not by PLHIV
- PLHIV that are speaking do not reflect those most impacted by the epidemic
- Creating “safe space” does not mean that everyone must be comfortable



What can you do?

- Reduce power differentials between providers and clients
- Hire from the communities you are trying to reach
- Provide clear ways for clients to share feedback anonymously, without fear of retribution
- Minimum percentage of seats on governance board for PLHIV, POC, queer-identified folks, women, trans folks (whoever you serve)
- Budget for financial support for participation in client advisory boards
- Commit, affirmatively, to build leadership and power of the constituency you serve: professional development opportunities, advocacy or leadership training, technical skills training and support (computers, MS Office, resume writing), etc.



In Memory of Deloris Dockrey



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Questions?



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Sustainable Strategies TargetHIV Link:
<https://targethiv.org/ta-org/sustainable-strategies-rwhap-community-organizations>



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THANK YOU