Meaningful involvement of Black Cis and Transgender Women with HIV in the Care Continuum

Improving Care & Treatment Coordination for Black Women with HIV

August 25, 2022

2022 Black Women First

NATIONAL RYAN WHITE CONFERENCE ON HIV CARE & TREATMENT

Disclosures

Venita Ray,

Meta Smith-Davis and

L’Monique King have no relevant financial interests to disclose.

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Presenters

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Learning Objectives

At the conclusion of this activity, participants will be able to:

1. Describe strategies for promoting meaningful involvement of Black women with HIV to improve care and health outcomes
2. Identify strategies for engaging women via client and community advisory boards (CAB)
3. Share impact of a leadership development program for CAB members that has empowered their engagement in the Ryan White HIV/AIDS Community.

We Will Control Our Own Destinies; We are the "Positive Women's Network-United States of America"

Posted on June 30, 2008 by pwnusa

by Waheedah Shabazz-El

The only national organization in the US led by and for women

and trans people living with HIV

Founded in 2008 by 28 diverse women living with HIV,
including women of trans experience

WOMEN DON'T

GET AIDS.

THEY JUST

DIE FROM IT.

Our mission: To *prepare and involve* women and people of trans experience living with HIV in all levels of policy and decision-making.
Our work is grounded in racial justice, gender justice and economic justice.

MIPA: History and Context

MIPA: history & context

In the beginning…

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.

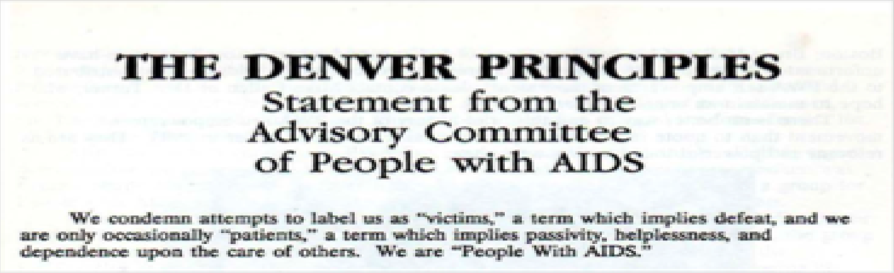
Michael Callen,
1955 –1993
AIDS Activist & Co-Author
of the Principles.

⇨WORLD AIDS DAY: **DEC. 1** **SEANSTRUB.COM**

- **12 “people with AIDS” who met for the first time at the 5th annual Gay & Lesbian Health Conference, held in Denver, CO, June 1983**

- **Manifesto outlines rights and responsibilities of “PWAs” as well as healthcare providers and care providers**

The Denver Principles



THE DENVER PRINCIPLES

Statement from the
Advisory Committee
of People with AIDS

We condemn attempts to label us as "victims," a term which implies defeat, and we are only occasionally "patients," a term which implies passivity, helplessness, and dependence upon the care of others. We are "People With AIDS."

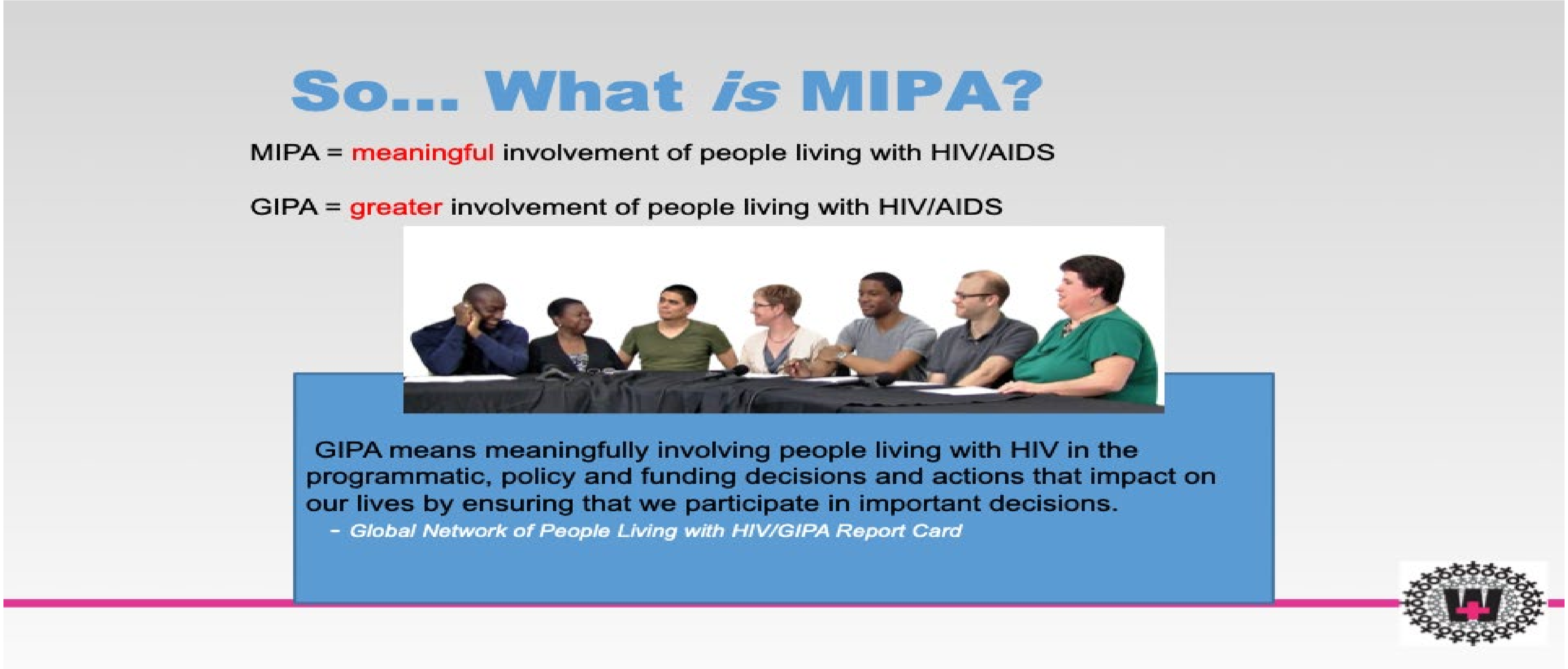
Recommendations for people with AIDS:

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 is...



So... What *is* MIPA?

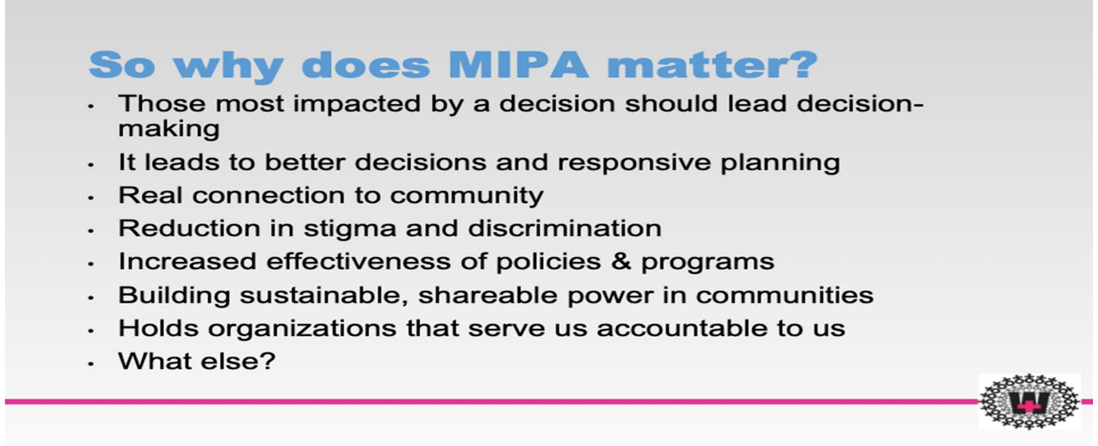
MIPA = meaningful involvement of people living with HIV/AIDS

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*

So why does MIPA matter?



So why does MIPA matter?

- Those most impacted by a decision should lead decision-making
- It leads to better decisions and responsive planning
- Real connection to community
- Reduction in stigma and discrimination
- Increased effectiveness of policies & programs
- Building sustainable, shareable power in communities
- Holds organizations that serve us accountable to us
- What else?

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Early challenges with MIPA

- Cis white gay male dominance in visibility and power
- Leadership by Black/Brown communities, women, folks of trans experience, others often not visible
- Death, poor health, burn-out, trauma
- Pressures of "professionalization" had consequences for community engagement
- As the demographics of the epidemic's visibly shifted, commitment to PLHIV leadership did the same
- Resulted in the whitening of the movement

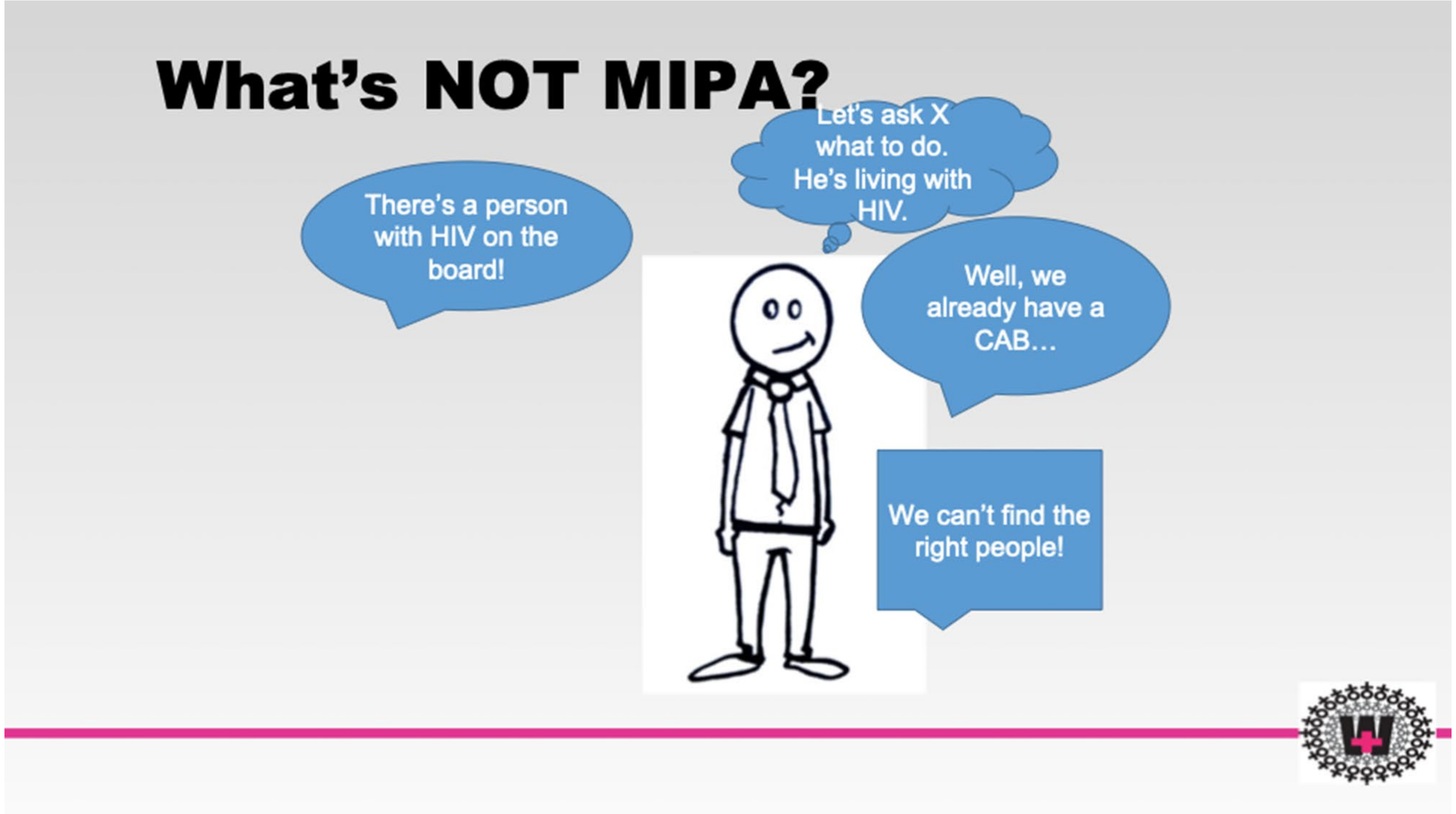
MIPA or Not?

What is meaningful involvement and what is not?

MIPA is…

- Centering PLHIV in all decision-making
- Recognizing value of lived experience and that PLHIV are subject matter experts
- Seeing important contribution PLHIV can have on program design/implementation
- Staff reflects diversity of community being served
- Ensuring PLHIV involvement is meaningful and not tokenism or "check the box"

What’s NOT MIPA



What’s NOT MIPA?

There’s a person with HIV on the board!

Let’s ask X what to do. He’s living with HIV.

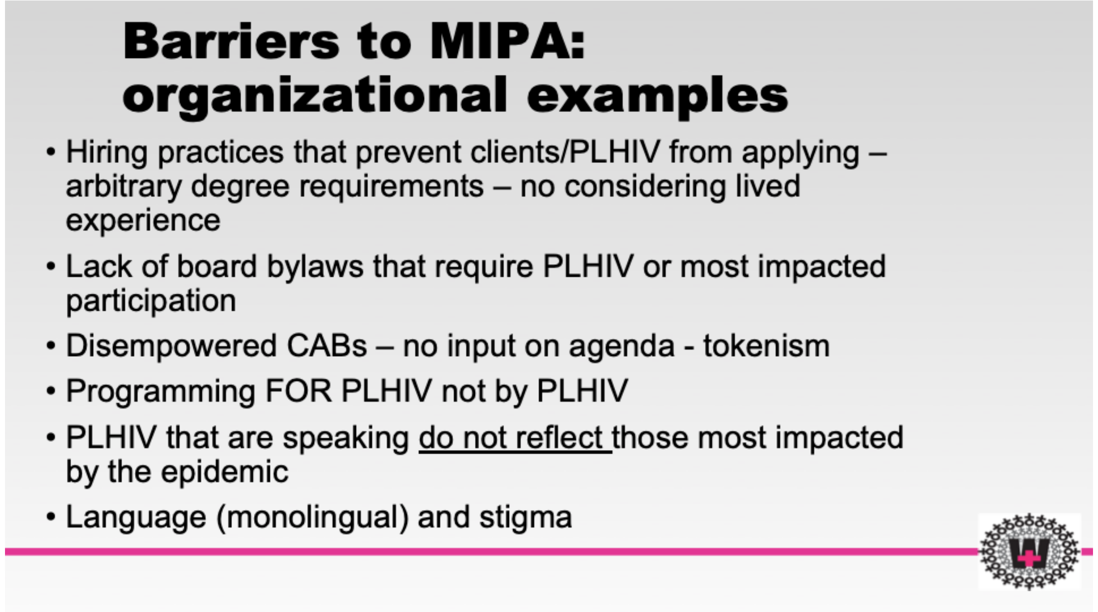
Well, we already have a CAB…

We can’t find the right people!

MIPA is not…

- Expecting PLHIV to be permanent volunteers
- Support services are not necessarily MIPA
- Meetings set for times folks can’t make unless they are employed in the field
- The “community panel” and “sand box”
- Invitations to be the “face” of a campaign… after the messaging has already been defined
- Getting information that we don’t have time to process
- Race/gender/class-neutral PLHIV representation
- Gatekeeperism: “I can represent PLHIV/POC/Black folks/women all by myself, forever!”
- Using the same “go to PLHIV” all the time

Barriers to MIPA: organizational examples



Barriers to MIPA: organizational examples

- Hiring practices that prevent clients/PLHIV from applying – arbitrary degree requirements – no considering lived experience
- Lack of board bylaws that require PLHIV or most impacted participation
- Disempowered CABs – no input on agenda - tokenism
- Programming FOR PLHIV not by PLHIV
- PLHIV that are speaking do not reflect those most impacted by the epidemic
- Language (monolingual) and stigma

- Hiring practices that prevent clients/PLHIV from applying such as:
  - arbitrary degree requirements
  - no considering lived experience
- Lack of board bylaws that require PLHIV or most impacted participation
- Disempowered CABs such as:
  - No input on agenda
  - Tokenism
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Other Barriers to MIPA

- Lack of clear commitment to address racism, classism, educational privilege, cis privilege, patriarchy etc
- Creating “safe space” does not mean that everyone has to be comfortable
- Don’t believe our voice matters
- Lack of confidence

MIPA in Practice

Commit to MIPA principles by acknowledging room for improvement - evaluate how programs are developed

Be explicit about committing to MIPA - tell the world!

Train staff and the people you serve on MIPA

Require PLHIV to serve on governance boards

Pay PLHIV for participation - it shows value; sharing our story requires emotional labor

MIPA is not race/gender neutral

MIPA in Practice continued

Involve PLHIV in the planning, design and implementation

Programs/services should be developed by and for PLHIV

Expand leadership beyond your “go to” HIV leadership

Restructure and empower CABs

Watch the use of stigmatizing language and images

Commit to building leadership and power of the people you serve by offering:

- Professional development opportunities
- Advocacy/leadership/mentorship
- Trainings and support

Katrina Haslip

WOMEN DON'T

GET AIDS.

THEY JUST

DIE FROM IT.

FB Post & Responses

Question - What do providers need to know about how to meaningfully involve Black women in developing and implementing services for them?

- *Well I think it goes back to nothing about us without us. We must be allowed at those tables so we can tell them what our issues are and how we need to be treated so first of all inclusion is a must. And it's important to finding better outcomes for Black women the voice of black women have been muted or undermined for years but if they really want better outcomes they will have to get intel from the S.M.E (Subject Matter Expert) L. Bellamy*

- *What provider are not asking is about our depression state which is a huge component*

FB Responses

Listen and let them lead!

Providers need to understand the link between trauma and stigma, which continues to be a major problem regarding Black women. How stigma can actually prevent women from speaking their truth. African American women have often been overlooked and under supported, especially dealing with HIV, substance use, toxic relationships, wages, mental health and healthcare.

Listen to understand first, then offer services with the least barriers. On site childcare and evening or weekend hours if you're serious.

Do not negate the insight they bring simply because one does not understand. And to consider them as a whole person, not just a target population.

FB Responses continued

Workshops for interaction like role play. Direct conversation. Zoom meeting. Tools that people can actually access. Panel story telling. Etc.

Many black women are head of household and work outside the home and need medical appointments outside of "normal" office hours or maybe a Saturday.
Having most if not all services in one place
Offer Uber/Lyft rides to and from appointments if patient doesn't have transportation
Set up to have 'Women's Clinic' once or twice month during evening. That way women can bring their children if needed.
Also offer dinner and maybe homework help

I'm thinking about the dangers for black women during childbirth, and when they are ignored about being in pain. Also depression and isolation. I work in the HIV clinic and a lot of black woman thinks they are alone dealing with HIV. Extremely stigmatized, and all the Healthcare messages are lgb or overly sexualized.

Why are Black women most impacted by HIV?

Understanding the context for Black women’s role in the epidemic

Historical Context - We've come a long way. Are we there yet?

JEZEBEL

Sex to satisfy insatiable desires for white men

Fulfills masters' sexual & economic desires

Mulatto/ Half Breed; Light skin, long hair, shapely bodies, with few African features

MAMMY

Asexual and Nurturing

Fulfills masters families' domestic needs

Dark skinned, large, African features; portrayed as unattractive

WELFARE MAMA

Sex with African American men to breed

Not useful to white culture's needs; "living off the system"

Physical appearance undefined and unnecessary

MATRIARCH

Sex to emasculate and control men

Not useful to white cultural needs; seen as source of African American's problems

Physical appearance undefined and unnecessary

Why are Black women most impacted?

- Historical denial of femininity/womanhood - forced to work like men
- Valued by gender and ability to reproduce
- Myth of the strong Black women denies us our humanity
- May neglect self care in order to care for others
- Hair and bodies devalued and ridiculed
- No societal desire to protect because not valued as mothers, women
- Stereotyped as angry, demanding, aggressive, mannish
- Feminist movement not always welcoming for black women
- “Aint I a Woman?”
- Live at the intersection of race and gender inequities

Intersections: Race and Gender

- Racism
- Gender
- Patriarchy
- Poverty
- Employment
- Housing
- Language/culture
- Gender based Violence
- Access to care/sexual health
- Experiencing multi forms of stigma and oppression

Lived Experiences of BWLHIV

- Physical, social, emotional and mental impacts of diagnosis
- Impacts (vulnerability and acquisition) are experienced differently across ages and life stages
- Experience implicit bias in health care and lack of culturally sensitivity; health care access is also a stressor
- Role in community - head of household, parent, leader
- Societal messages on stigma, shaming/blaming language associated with behavior/morals
- Comorbidities
- We are more than our diagnosis

Possible Strategies & Actions

1. Treat whole person and make mental health a priority - we are more than our viral load and CD4 count; pay attention to life cycle stages; Integrate sexual health care into HIV care for all life stages,
2. Design culturally relevant care/services that speak to the intergenerational and cultural practices of black women; deal with implicit bias in health care
3. Treat HIV as a symptom of structural and systemic issues that make Black women more vulnerable like housing, gender based violence, racism, poverty (SDH)
4. Counter the narrative of shaming and blaming; explain the data and not just report data; stop ignoring root causes
5. Address stigma and acknowledge it is experienced differently across ages and is multi layered; watch the language
6. Fund and prioritize our care and services in proportion to impact especially black women led organizations to do the work
7. Advocate for policies that support the unique needs of Black women

CAB Leadership Development 1

- 2 PWN facilitators
  - Women living with HIV coaching CAB leaders
  - Lived experience and expertise to support CAB leaders
  - Strengthen problem solving and accountability
  - Authentic meaningful involvement
- Curriculum
  1. Centering Black Women in HIV Response
  2. History of MIPA and Empowerment
  3. Effective Leadership
  4. Strategic Storytelling
  5. Advocacy 101
  6. Person first and non-stigmatizing Language
  7. Advancing racial and gender justice in the HIV Response
  8. Leading a Meeting: agenda planning, conflict management

Benefits of the CAB leadership development program

- Leadership roles and opportunities
- Incentives (not always money)
- Ownership
- Capacity building
- Confidence
- Social support and Community
- Employment prep
- Non-stigmatizing engagement
- Clarity in roles and responsibilities
- Long term relationships

CAB Leadership Development 2

- 16 women
- 38-64 years old
- Weekly meetings over 6 weeks
- Meals provided
- AMAZING ENGAGEMENT

Resources

- Securing The Future of Women-Centered Care: Findings from a Community-Based Research Project by Women Living with HIVhttps://pwn-usa.org/wp-content/uploads/2016/03/rwp-report-final.pdf and https://pwn-usa.org/wp-content/uploads/2016/03/rwp-teaser-final.pdf
- Positive Women's Network-USA:
- US PLHIV Caucus: https://www.hivcaucus.org/
- AIDS United MIPA Resources: https://www.aidsunited.org/resources/meaningful-involvement-of-people-with-hivaids-mipa
- GIPA Principle and Pyramid: http://aco-cso.ca/wp-content/uploads/2013/05/GIPA_EN.pdf
- Denver Principles: https://data.unaids.org/pub/externaldocument/2007/gipa1983denverprinciples_en.pdf

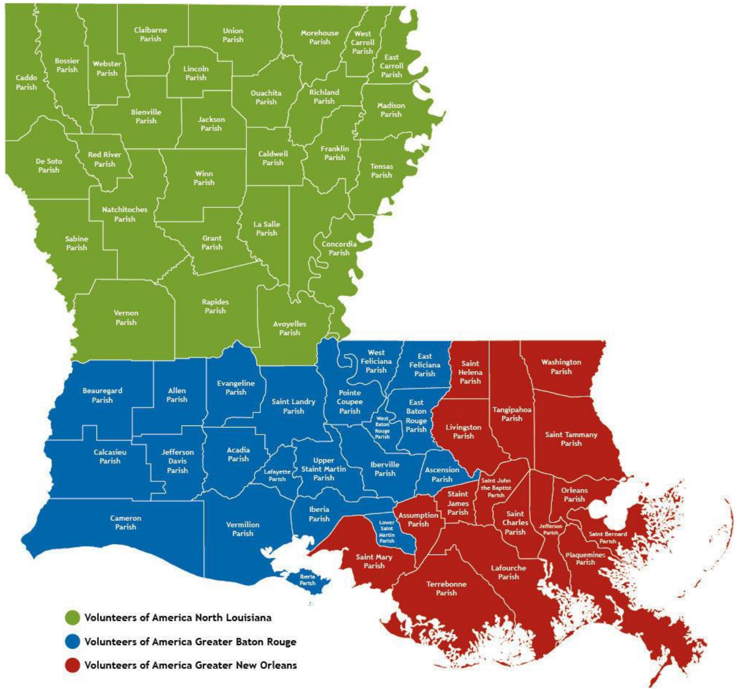
Volunteers of America, SouthEast Louisiana

Meta Smith-Davis

Volunteers of America®
SOUTHEAST LOUISIANA
Helping America's most vulnerable®

Information about VOA SELA

- Volunteers of America serves clients in 16 parishes in SE Louisiana
  - Jefferson, Orleans, St. Bernard, Plaquemines, Assumption, Lafourche, St. Charles, St. James, St. John, Terrebonne, St. Mary, St. Tammany, Washington, Tangipahoa, St. Helena and Livingston parishes.
- Project name is Stepping Stones
- Interventions that are part of the bundle
  - Enhanced Patient Navigation
  - Red Carpet Care Experience
  - Self-Efficacy
  - Trauma Informed Care
- Currently enrolled



CAB

- CAB was developed October 2021
- Called clients in the Stepping Stones program to determine interest in being a CAB member
- Clients had never heard about CABs
- 3 clients were interested in joining
- Up to 5 members
- Meet monthly
- I lead the meetings, but our goal is for them to lead

CAB continued

- Virtual monthly meetings
- Focus has been on understanding the Ryan White Parts
- Encourage members to research funding and be curious
  - Remind them that providers work for ‘us’
  - Nurses tell them ‘they’re good’
  - They need to understand their VL and CD4 results
- Positive Women’s Network Sister Circle group
- Goal to become advocates

Community Impact

- Dream for the CAB
  - Become sufficient enough to carry on this CAB
  - Co-facilitate the groups
  - Develop agenda
  - Advocate for housing funding and utility assistance
  - Identify ways services must change for Stepping Stones program and other Ryan White services
  - Member to join the CAB leadership development cohort

Quality Comprehensive Health Center

Sisters Inspiring Growth & Healing

Sigh

L’Monique King (She/Her/Hers)

- Quality – A Black owned CBO with a mission to promote wellness and health equity for those living with health disparities in the Carolinas
- Location – Located in Charlotte’s historic West End Corridor
- What services you offer – A one stop shop model offerin comprehensive services. (PowerHouse2.0, SACOT, GBHI,
- SIGH – Sisters Inspiring Growth & Healing; true to its na and designed to assist Black women living with HIV decrease barriers to care with support, referrals and resource provision

CAB (Meaningful Involvement)

- Promoting meaningful involvement of Black women isn’t very challenging when members are community stakeholders with buy in
- Peer connections that foster recruitment and retention
- Opportunities for growth and development within the realm of HIV awareness, leadership and/or advocacy
- Providing space for members to have input and voice in programmatic direction and decisions

Process for Developing and Implementing your CAB

- Frequency of meetings – CAB Members meet monthly
- Number of clients – 5
- Modality-virtual/in person – For convenience and COVID safety CAB meetings are held virtually, in-person and in combination (hybrid)
- Activities – Icebreakers, story sharing, peer support, brainstorming and leadership development
- 2 CAB members participating in the leadership development cohort

CAB's Community Impact

- Program awareness
- Stigma reduction
- Community HIV education
- Elevation of esteem
- Self advocacy & efficacy

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