# POP Year 6 Session #2

## MIPA for and with Organizations

February 11th, 2021

RECORDING IN PROGRESS

# Opening

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# Welcome

- Purpose of Convening
  - Learning
  - Connection (individually and organizationally)
- Chance for new folks to introduce themselves
- Community Conversations
  - Conversation by us and with us- open to all PLHIV
  - Language Friday March 5th
- Evaluations – anonymous and helpful

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# AIDSWatch



AIDSWatch
REGISTRATION
NOW OPEN
MARCH 22-24, 2021
AIDSUNITED.ORG/AIDSWATCH

https://mm.swoogo.com/aw2021

# Recap of Convening Session #1

- AIDS United and US PLHIV Caucus Introductions
- Introduction to People Organizing Positively Project
- Panel of past POP participants and impact of MIPA on their leadership and lives
- Organizational Introductions
- And what stands out to you?

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# Group Agreements

- Support everyone participates
- Respect each others' opinions even if you don't agree with them
- Minimize distractions
- Confidentiality-some things shouldn't be repeated outside of this convening
- This is a learning space, share what your experiences are without ramifications for your organization.

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# Workshop Outline

- Welcome
- Opening for Session 2
  - Presenter introduction,  learning objectives, agreements, and session outline
- Valuing and Appreciating the Lived Experience
- Centering MIPA in Organizations
- Breakout Session #2 - MIPA & Organizational Decision-Making
- Enhancing Organizational Power
- Breakout Session #3 - MIPA & Organizational Dynamics
- Close Out: Summary and Evaluation

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# Learning Objectives

**By the end of our training, participants will be able to:**

1. Recognize and honor contribution of PLHIV both organizationally and movement wide
2. Identify steps and facilitate increased MIPA organizationally
3. Promote the importance of PLHIV involvement for good decision making
4. Identify barriers within their organization to PLHIV leadership
5. Excited and empowered to drive greater involvement of PLHIV within their organization

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# Valuing & Appreciating the Lived Experience

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# MIPA is about Leadership

Leaders are individuals who are called to use their skills, knowledge, & experience to lift communities up and bring forward their voices.
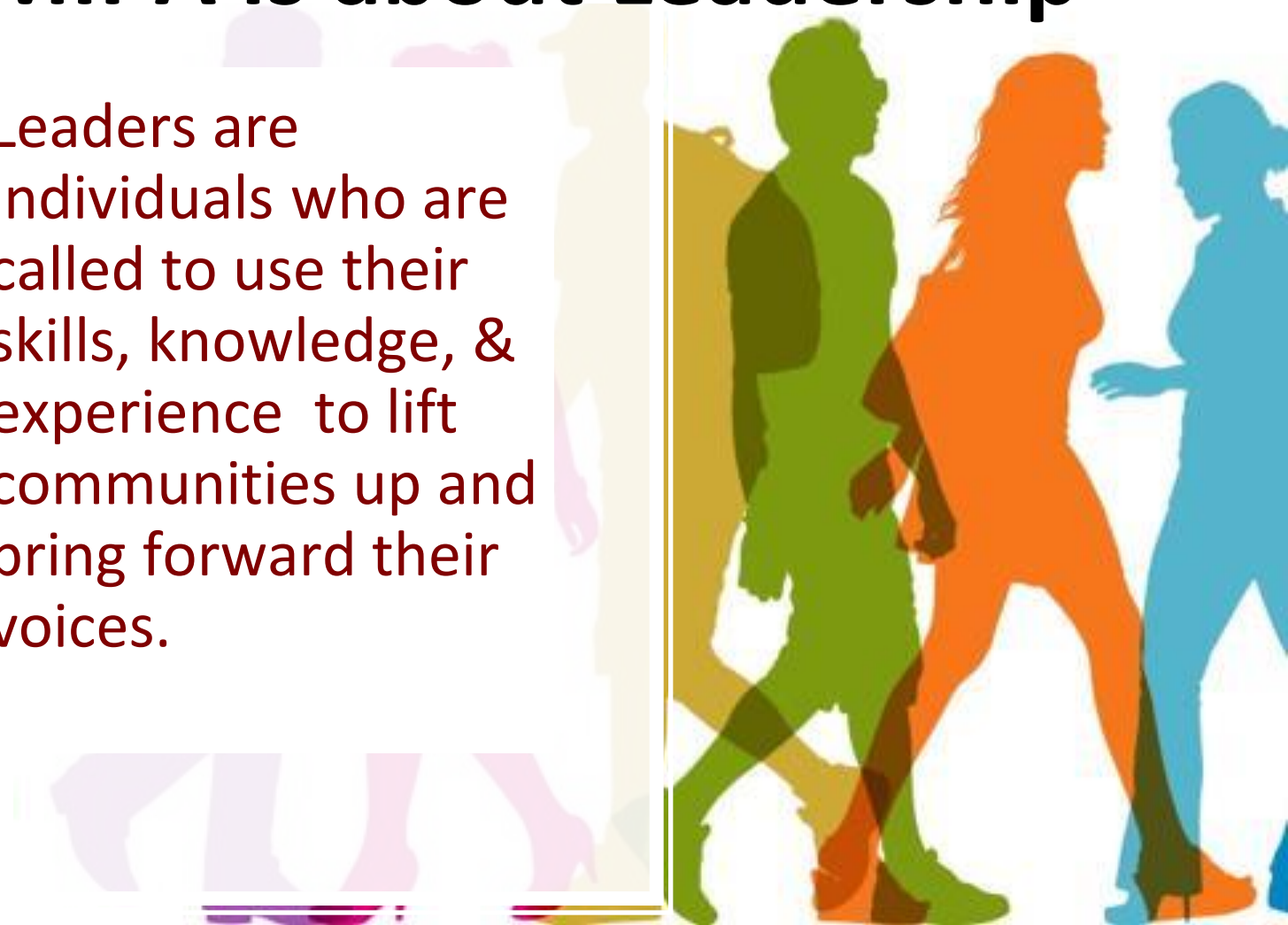
# An Approach for Supporting PLHIV Leadership

Lived Experience

Experience

Expertise
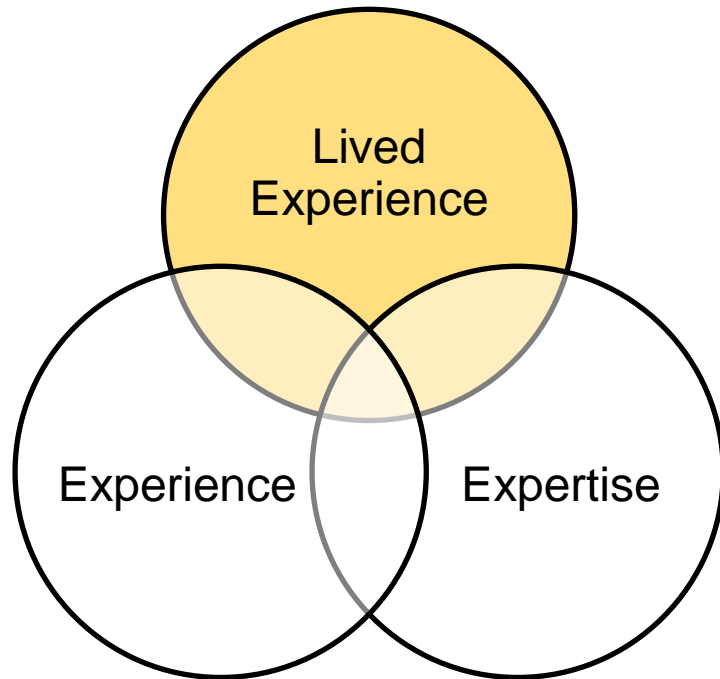
**This model will enable organizations to:**

1. Recognize the important contribution people living or affected by HIV/AIDS can make in the response to the epidemic

2. Create space within organizations for PLHIV involvement and active participation in all aspects of the HIV response.

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# The Lived Experience Defined

- **Lived experience responds not only to people's experiences, but also to how people live through and respond to those experiences.** The body of work on lived experience focuses on everyday life occurrences and self-awareness. The term also represents common experiences that are life changing and life affirming.

- **Lived experience may be defined as people's perspective on the social, political and economic situation within their areas and the way that they interact with them.** There are a number of factors that influence the extent to which people's lived experience of places and engagement with them varies, such as age, length of residency, deprivation and ethnicity.

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# The Lived Experience Defined (cont.)

- **Lived experience refers to a representation of the experiences and choices of a given person, and the knowledge that they gain from these experiences and choices.** Human experiences, choices, and options and how those factors influence one's perception of knowledge

- **Personal knowledge about the world gained through direct, first-hand involvement in everyday events rather than through study.** Unlike research, the lived experience is about reflecting on an experience while living through it AND is recollective, where experience is reflected on after it has passed or lived through

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# Lived Experiences can be Motivating

- Engaged and more active because there is desire for change and a better life.
- Develop connections with others who are similarly situated, to gain a greater understanding of a situation, i.e., formation of PLHIV coalitions, partnerships, and networks

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# The History of Involvement

The history of involvement of persons living with HIV demonstrates how communities can take many paths to shared goals.

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# The Denver Principles

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

- This manifesto outlines rights and responsibilities of "PWAs" as well as healthcare providers and care providers

# GIPA

Self-determination or the belief that individuals and communities should have the right to participate in the decision-making processes, is a value held by People Living with HIV globally.

This value is enshrined in the GIPA (ge-pa) Principle. GIPA stands for the "Greater Involvement of Persons with AIDS"

# So... What is MIPA?
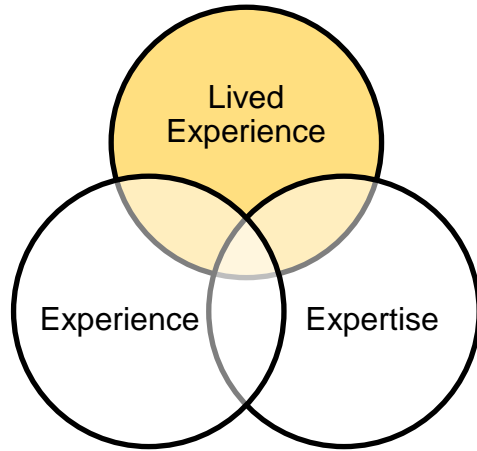


**MIPA** = meaningful involvement of people living with HIV/AIDS

**GIPA** = greater involvement of people living with HIV/AIDS

**MIPA, also known as 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*

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# How MIPA can be Actualized

**Operational**

- Board of Directors
- Staff in decision-making positions
  - Executive Directors or senior director
  - Investigator
- Staff in work positions that involve community engagement
  - Community Health Worker
  - Intervention Facilitator
  - Outreach Worker
  - Patient Navigator
  - Trainer & Educator
  - Faculty and Lecturing
  - Community Collaboratory Research

**Planning**

- Planning Councils (RWP-Part A)
- HIV Planning Groups (RWP-Part B)
- Consumer Advisory Groups
- Quality Management Teams
- Indicators/Measurement Development Teams
- Research Advisory Boards
- Technical Expert Panels and Consultations
- Statewide Advisory Boards

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# How MIPA is NOT Actualized

- Being present but not having a vote or voice
- Getting information that we don't have time to process
- Being asked to participate in meetings but not to set the agenda.
- Expectations that we will always volunteer our time rather than being compensated
- Being asked to be the face or voice of a project or campaign but not to define the goals, audience or message?
- Expectations that one PLHIV represents "the community"
- **What are some other examples?**

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# Interactive Activity

## Polling Question

- Does your organization support people living with HIV in participating in activities outside the organizations?
  - Yes
  - Yes, but we can do more
  - No
  - Not sure

## Brainstorming Chat

- Share ways that your organization has created space for the involvement of people living with HIV in local, regional, or national community decision-making bodies.

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# MIPA Defined

- The principle of **Meaningful Involvement of People Living with HIV/AIDS (MIPA)** is another important set of values put forward, demanding that people living with HIV be substantively engaged in policy and programmatic decision-making activities that impact our lives, and fairly compensated for our participation.

- Together, the Denver Principles and MIPA make demands of our allies, our institutions, our government and our communities. They articulate our responsibilities as people living with HIV to engage each other and our representative institutions. They recognize the power of language to affirm or destroy and the potential to change social and cultural norms while reaching political goals.

- We believe that, more than ever, the meaningful involvement of people living with HIV must guide policy and practice on ending the domestic epidemic.

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# MIPA is anchored in …

**ADVOCACY**
- Footprints - The Denver Principles, GIPA, and MIPA

**POLICIES**

Blueprints - National HIV Plans (EHE and NHAS)

**PLANNING**
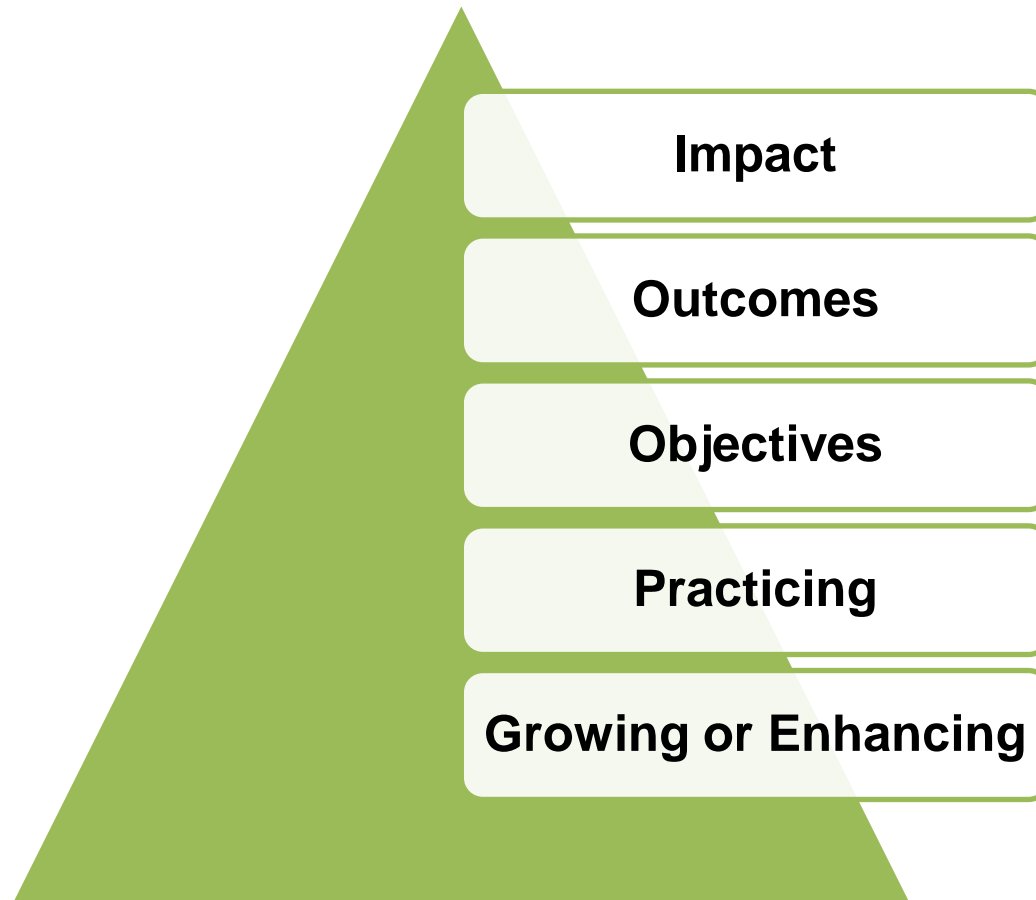- Action Planning - Community HIV Integrated Planning Process

**IMPLEMENTATION**
- Organizations - Governance, programs, staffing, consultants & volunteers

**MONITORING**
- Betterment - Quality Improvement Plans and Advocates

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# MIPA Logic Model Diagram

Impact

Outcomes

Objectives

Practicing
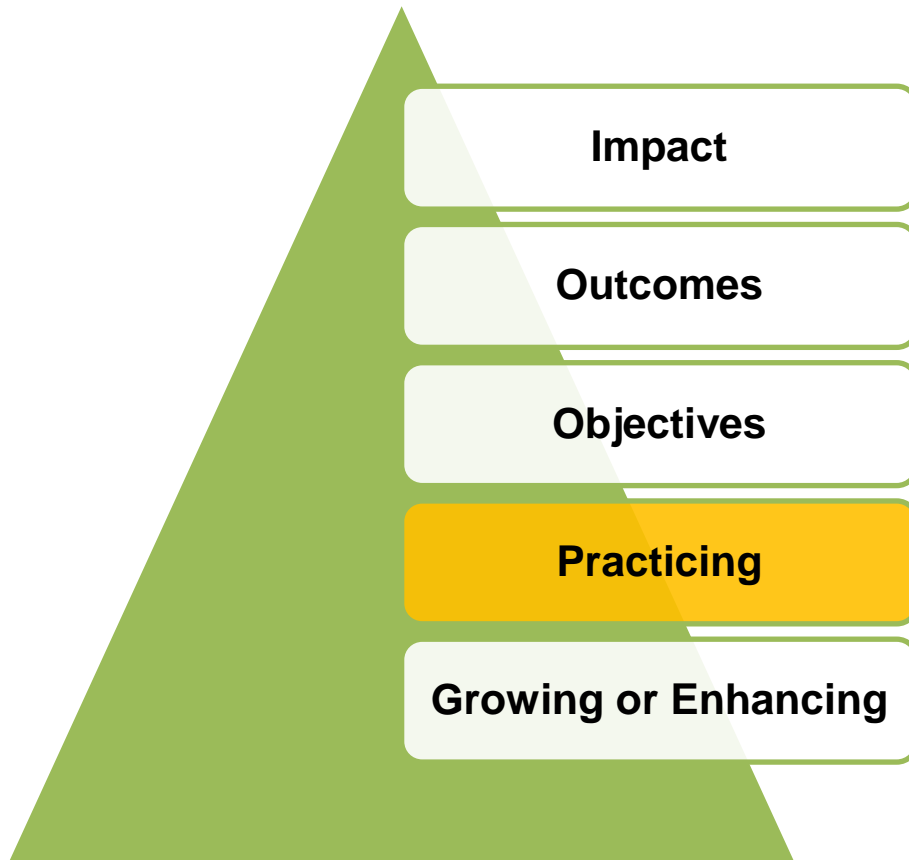
Growing or Enhancing

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# MIPA Logic Model Diagram - Inputs

## Conduct organizational assessment to determine

- Level of organizational commitment, i.e., supportive HIV workplace policies are in place, employ a rights-based approach, strive for shared decision-making
- The number of PLHIV in your organization, their role and responsibilities as well as pay
- Develop mechanisms promoting participation, i.e., capacity building assistance, training, twinning
- Address barriers to participation
- Engagement of PLHIV should include dedicated resources, psychosocial support, and peer support

**Impact**

**Outcomes**

**Objectives**

**Practicing**

**Growing or Enhancing**

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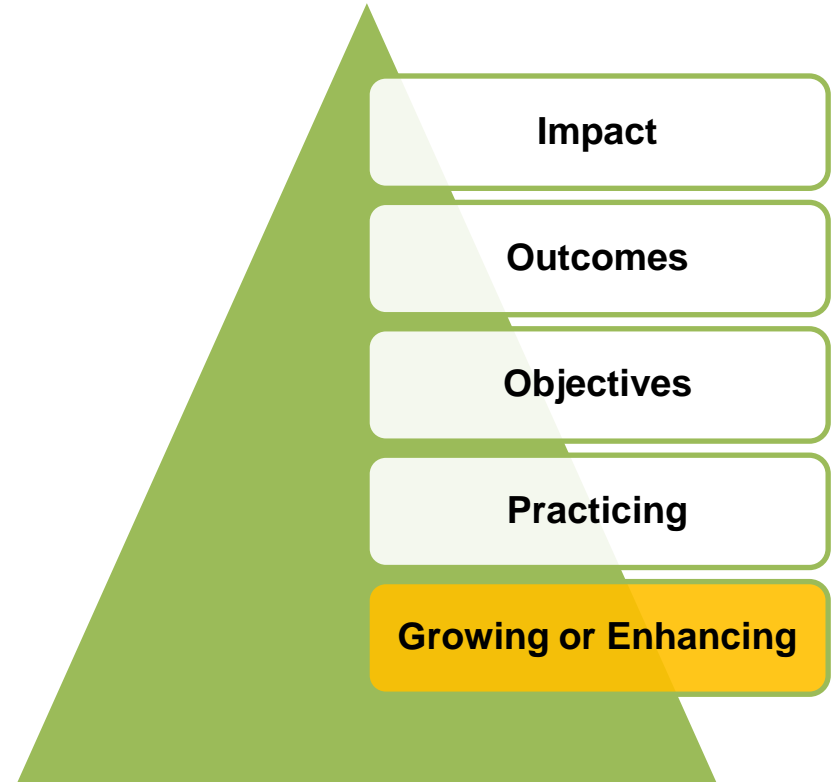
# MIPA Logic Model Diagram - Activities



**Impact**

**Outcomes**

**Objectives**

**Practicing**

**Growing or Enhancing**

**Representative decision-making**

- Governance, i.e., board of directors
- Staff (paid or unpaid)
- Consultants or advisors
- Researchers
- Evaluators
- Partners
- Support of PLHIV networks or organizations

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# MIPA Logic Model Diagram - Objectives

Impact

Outcomes

**Objectives**

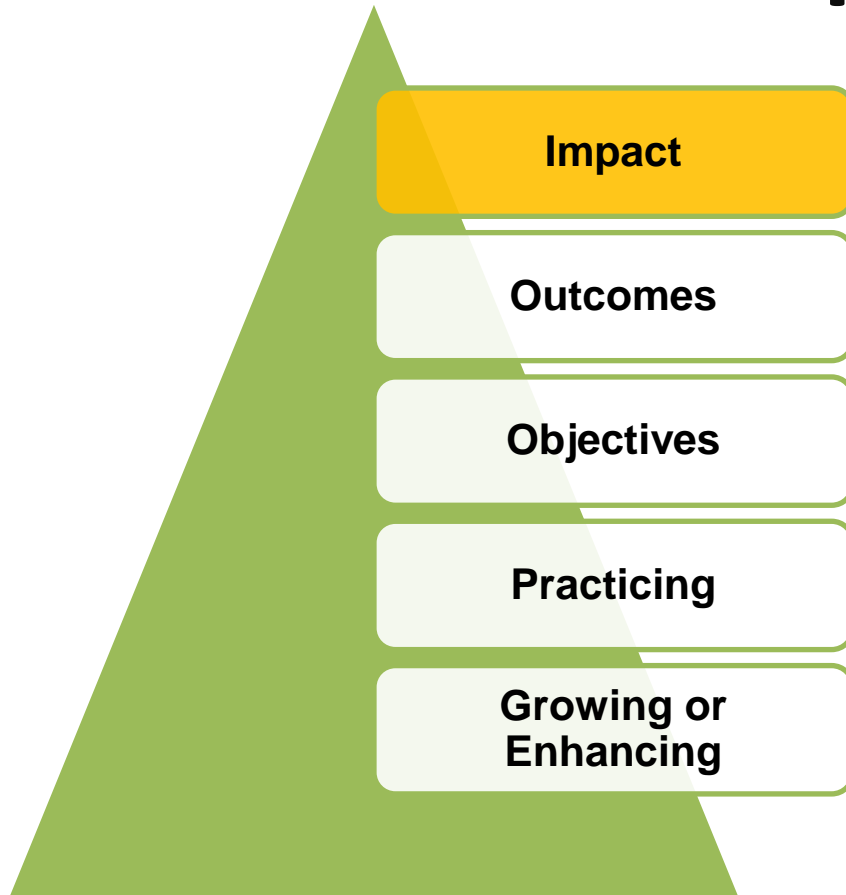Practicing

Growing or Enhancing
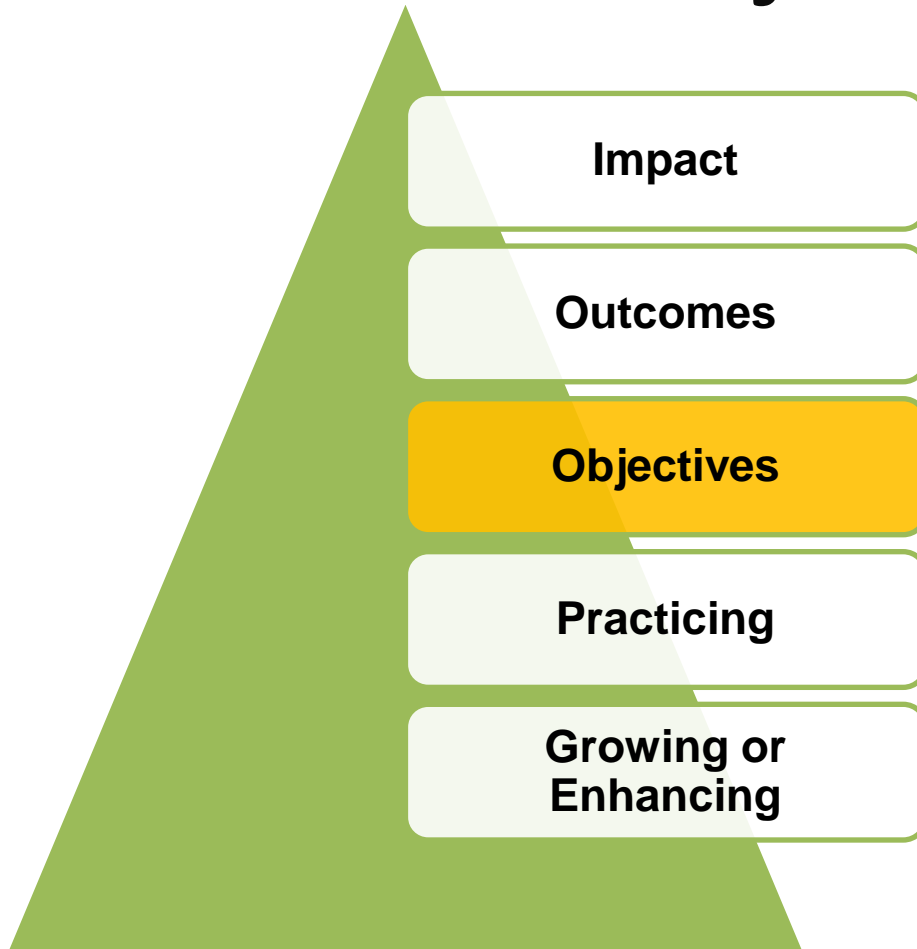
1. Better local responses to HIV

2. Programs and policies are tailored and responsive

3. Increased self-determination and personal development for people living with HIV

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# MIPA Logic Model Diagram - Outcomes

- **Better responses**
  - Key populations are engaged
  - Inequalities are addresses
  - Stigma is reduced
  - Accessible services
- **Tailored and responsive**
  - Non-stigmatizing messages or act
  - Needs are met
  - Organizations are credible
  - Partnerships increase
- **Increased resiliency**
  - Increased self-esteem
  - Improved adherence
  - Increased employability
  - Stronger PLHIV networks and organizations

**Impact**

**Outcomes**

**Objectives**

**Practicing**

**Growing or Enhancing**

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# MIPA Logic Model Diagram - Impact



Pyramid diagram from top to bottom: **Impact** (highlighted), Outcomes, Objectives, Practicing, Growing or Enhancing

- Strong healthy and empowered communities

- Universal access to HIV treatment, prevention, and support

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# MIPA Preparation

- What does MIPA or shared decision-making with people living with HIV look like at your organization?

- What personal and professional opportunities are provided specifically for people living with HIV in decision-making roles ?

- What tools or support is your organizations utilizing to support people living with HIV in decision-making roles?

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# MIPA in Action
# Positive and Negative Examples

# Boston Clinic for Women Living with HIV

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# Denver Planning Council

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# National HIV/AIDS Strategy

# BREAKOUT SESSION

How are decisions made in your organization and who makes these decisions?

How you're organizational decision-making reflect your population?

# Culturally Responsive Leadership

Culturally responsive leadership for organizations supports inclusive environments and improved service delivery for people living with HIV with culturally and linguistically diverse backgrounds.
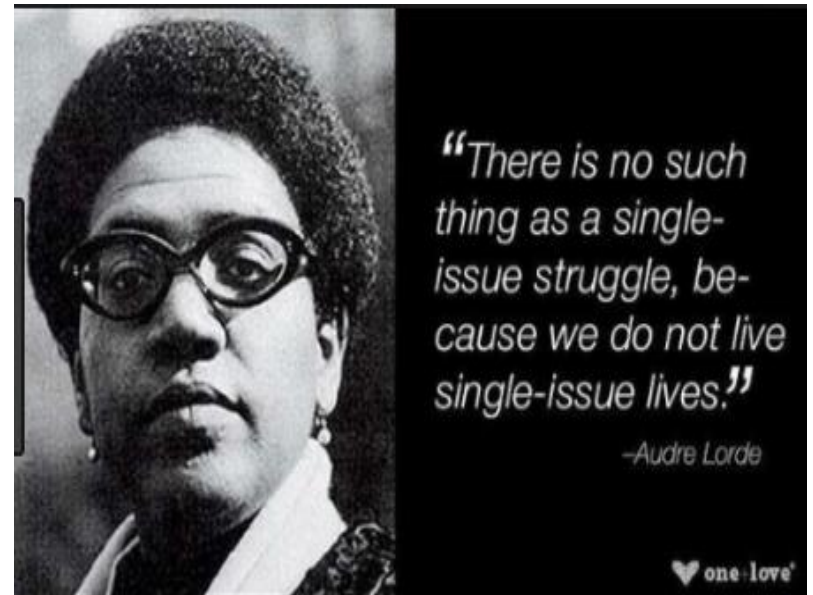
# Disclosure and Leadership

- **Disclosure is a continuum**
- Disclosure can mean different things to different people
- We must create opportunities for PLHIV to participate along disclosure spectrum
- Disclosure of our status is our choice
- Stigma and discrimination is real
- There should be freedom to speak our truth
- Violence against PLHIV happens, so there should be a focus on creating safe spaces for disclosure

# Intersectionality and Leadership

- **Identity is complex and changing**
- HIV is only one part of our identity, but other parts become more pronounced based on the circumstances
- We must demand that all our identities and the challenges they bring be a part of HIV advocacy
- Our lives aren't simple, our advocacy shouldn't be either



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

–Audre Lorde

one·love

# Public Policies at the Federal Level



**NATIONAL HIV/AIDS STRATEGY** for the **UNITED STATES:**

UPDATED TO 2020

JULY 2015

THE WHITE HOUSE WASHINGTON

"Activities that contributed to successful coordination include… Persistent advocacy from people living with HIV and their allies, pressing all sectors to do more, better, and faster… Engagement of affected communities and mobilization of broad sectors of society to take action…"
- Pg. 43

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# MIPA in Action
# Organizational structural Dynamics

# Organizational Structural Dynamics:
## Where is the Power?



- Who are the decision-makers or decision-making bodies in your organization

- Who has access to the decision-makers?

- Who holds decision makers accountable?

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# How are Decisions Made?

**Formal Process**

- Scheduled meetings
  - -Open
  - -Closed
- Defined decision-making procedures
  - -Voting
  - -Consensus

**Informal Processes**

- One-on-one conversations
- Ad-hoc meetings
- Casual conversations
- Off-site gatherings or meetings

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# Organizational Power Dynamics that Serve as Barriers to MIPA

- **Racism, homophobia, transphobia and misogyny in the HIV response**
- Lack of funding for leadership/advocacy
- Chronic vs terminal: complacency
- AIDS Incorporated
- Medicalization of response
- Living with chronic illness, mental health challenges, etc.

# Barriers to MIPA:
## Organizational Culture

- Are Roberts Rules of Order really necessary?

- Do you really need the input in writing?

- Does it need to be an attachment?

- Sense of urgency in decision-making

- *"What just happened?"* Lack of transparency in decision-making

- Is there a fear of open conflict in your organization?

# Barriers to MIPA:
# Organizational Examples

- Hiring practices that prevent PLHIV from applying

- Lack of board bylaws that require PLHIV participation

- Disempowered CABs

- Lack of organized input from PLHIV

- Programming for PLHIV not by PLHIV

- Involved PLHIV <u>do not reflect</u> those most impacted by the epidemic

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# Barriers to MIPA:
# More Organizational Examples

- 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



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# Barriers to MIPA:
# Organizational Examples

- X is "high functioning"
- "You're so well-spoken"
- "This might be over their heads"
- Wouldn't a service be a better use of our resources than investing in leadership?
- We *do* have people with HIV on our board/staff – they're just not out about it
- Personal responsibility narratives/slut-shaming/"We will help them reduce risky behavior"

# Strategies and Tools to Increase MIPA in your organization

**Assessment Questions**

- What percentage of your organizational leadership (board, management/director level staff) are people living with HIV?
  - **Ask same question for any constituency you primarily serve (Black, Latinx, MSM, trans, low-income, etc.)**

- Conduct an Assessment
- Consider ways to integrate MIPA

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# More Assessment Questions

- Looking at your staff chart: Does your organization become progressively whiter, more male, less reflective of constituency served as you go up the decision-making ladder?

- Look at your "go-to" HIV leadership. To what extent do they reflect the constituency you primarily serve? Do you keep involving the same PLHIV all the time?

- Do folks most reflective of the constituency served tend to "get stuck" in front line service provision?

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# More Assessment Questions

- Are your meetings at times & places the impacted community can attend?

- How are you addressing accessibility needs in planning?

- Are input gathering or decision-making processes unnecessarily bureaucratic?

- Does the job really require a formal degree?

- Are your hiring practices designed to exclude clients? How might that be addressed?

- How might HIV stigma, racism, sexism, classism be operating in organizational practices?

- What practices are in place to support trans and gender non conforming folks on staff, including during transition process?

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# Organizational Strategies
## Integrate MIPA - Examples

- Establish a minimum percentage of seats on governance board for PLHIV, POC, queer-identified folks
- Consider ways to structure representation so that it is *accountable*
- Commit to involve PLHIV reflective of constituency served in development/design of new programs – *not just implementation*
- Create protocols to take input from clients safely
- Budget for financial support for participation

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# Organizational Strategies
## Integrate MIPA - Examples (cont'd)

- Assist in developing indicators to monitor and evaluate the quality and impact of PLHIV engagement
- Operationalize MIPA. Build it into new program development, design, seeking of resources
- 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)
    - Mentorship; facilitate networking

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**BREAKOUT SESSION #2**

**Breakout Question #2 How do the power dynamics in your organization serve as barriers or facilitators to MIPA?**

CLOSING: Summary & Evaluation

# MIPA Matters because …

- Those most impacted by a decision should lead decision-making
- Better decisions; responsive planning
- Real connection to community
- Reduction in stigma and discrimination
- Increased effectiveness of policies & programs
- Building sustainable, shareable power in communities

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# QUESTIONS

# References

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2. GNP-Plus (GNP+). Greater Involvement of People Living with HIV (GIPA) - Good Practice Guide.pdf
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4. USPLHIV Caucus. MIPA - Building Sustainable Leadership-final (1.12.18).pptx
5. Health Policy Plus. 2017. Positive Health, Dignity, and Prevention: Training Modules for Promoting Leadership among Persons Living with HIV in Jamaica, Second Edition. Washington, DC: Palladium, Health Policy Plus.

THANK YOU!

Evaluation