MEANINGFUL INVOLVEMENT OF PEOPLE LIVING WITH HIV (MIPA)
The Cornerstone of Positive Organizing
This webinar is being recorded. The slides, handouts, and recording will be made available at aidsunited.org/webinars.

This webinar is in “listen only mode.” To ask a question, please use the Q&A box in the lower right of your screen. Audio information is provided in the right column (above the Q&A).
The United States People Living with HIV (PLHIV) Caucus is a group of organizations, coalitions, networks, client groups and individuals with HIV who advocate for PLHIV in the U.S. Formed in January 2011, the Caucus includes diverse and accountable representation by people living with HIV from throughout the United States.

www.HIVcaucus.org
Caucus partnership with AIDS United on Positive Organizing Project: Meaningful Involvement

- Support drafting of request for proposals
- Ensure voices of PLHIV are included in planning
- Participate in grantee selection
- Provide training at grantee convening
- Provide technical assistance and coaching for project grantees via
  - Webinars
  - One on one calls
  - Group calls
  - Some site visits
MIPA: history & context
In the beginning...
• 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

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.
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.
HIV as a politicized collective illness identity

• Embodied health movements literature
• PLHIV/PWA movement didn’t come from nowhere
  – Civil rights (Black, Latinx/Chicanx, Native/Indigenous Power, Asian)
  – LGBT
  – First/second/third wave feminism
  – Unions/workers movements
  – Anti-colonial, anti-apartheid
  – Popular education
  – etc...
So why does MIPA matter?

- Those most impacted by decisions 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
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
- Commitment to PLHIV leadership wavered as epidemic became Blacker and more feminized
MIPA Today

and...

- Cis privilege
- Formal education privilege
- HIV status

... etc
Ongoing Challenges to MIPA...

- Racism, transphobia, misogyny, classism in the HIV response
- Lack of funding for leadership/advocacy
- Overall lack of orientation towards building political power
- Chronic vs terminal: complacency
- AIDS Inc.
- Medicalization of response
- Perception of PLHIV as permanent service recipients (and nothing else): “consumers”
- Living with chronic illness, mental health challenges, etc.
Today

• White supremacy & misogyny structure power, access, leadership, HIV response
• Race-neutral narratives/“colorblind” ideology
• Movement leadership; representation
• Antiblackness is pervasive
• Conditions that predispose people to acquiring HIV or that lead to worse health outcomes once living with HIV are structured by race: health care access, poverty, “War on Drugs,” HIV criminalization, etc.
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*
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.
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).
Barriers to MIPA: organizational examples

• Hiring practices that prevent clients/PLHIV from applying
• Lack of board bylaws that require PLHIV participation
• Disempowered CABs with no 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
Barriers to MIPA: 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
What can MIPA look like in your grants?

• PLHIV representing the communities you are trying to reach are involved from the very beginning of the proposal development process
• Hiring from the communities you are trying to reach - PLHIV are paid or otherwise compensated for working on the project
• PLHIV are in the staffing and implementation plan; in roles with decision making authority
• PLHIV from the impacted communities are defining the priorities and messages
• Creating mechanisms to gather accountable input from PLHIV; not just going to the same one or two over and over expecting them to speak for the entire community
• A commitment to build power among PLHIV and expand their meaningful participation in your project or organization through the POP grant.
Download a free MIPA resource!
www.aidsunited.org/resources
MIPA In Action
Life Foundation Honolulu, HI
Ohana Objectives

- To initiate and develop a culturally diverse group of leaders living with HIV.
- To create an “OHANA” (family) of PLWHA where stigma and shame is a target of elimination. Where these individuals can find education, support and empowerment.

From the Hawaiian language, ‘ohana means family (in an extended sense of the term, including blood-related, adoptive or intentional). The concept emphasizes that families are bound together and members must cooperate and remember one another.
MIPA in Action
Life Foundation Honolulu, HI
Outcomes

- Three day-long meetings of Ohana
- Revitalization of Community Planning Group
- Ongoing work with the Hawaii Department of Health and input to the CHOW Project
QUESTIONS
POPs Year 4
Submitting Your Application
POP Year 4 Goals

• Increase grassroots mobilization
• Promote, increase, and strengthen leadership development for people living with HIV
• Measurably address stigma
• Improve policy, social, and community environment for effective HIV programs
• Vigorous engagement of people living with HIV
Year 4 Project Expectations

Two Tracks to apply for this year:

1. **Building a MIPA-driven organization**: projects focused on concrete activities to strengthen the organizational practices and that operationalize MIPA values at the organizational level.

2. **MIPA-driven grassroots projects**: projects focused on specific grassroots activities that involve PLWH leadership.
Year 4 Expectations

Address the following:
- Incidence and/or prevalence of HIV;
- Socioeconomic and health disparities;
- Opportunity and timeliness for policy initiatives;
- Applicant is well-positioned;
- Impact of the investment; and
- Sustainability of the effort.
Year 4 Priority Areas

• Stigma reduction and community mobilization
• Meaningful involvement of people living with HIV
• Project leadership reflective of people living with HIV
New Resource

Communities most affected by HIV must be involved in decision making, at every level of the response.

MIPA: Nothing About Us Without Us

www.aidsunited.org/resources
Eligibility & Grant Requirements

- Nonprofit status
- Organizational viability
- Current, previous or new grantee
- 8-month grant period
- Reporting cycle
- Grantee convening
- AIDSWatch 2018
Project Narrative

• Epidemiology, demographics, and organization background (10)
• Populations of interest (10)
• MIPA within your organization (20)
• Project goals and activities (25)
• Organization positioning (10)
• Impact of project on organization’s broader work (15)
• Evaluation (10)
Applying using FoundationConnect
Applying using FoundationConnect

Application Eligibility

To determine if your organization is eligible, please answer the following questions. If you meet our basic requirements, you will be invited to submit a proposal.

1. Is your organization or fiscal sponsor an IRS-registered, tax-exempt, 501(c)(3) organization; health department; or other government entity?
   - Yes
   - No

Continue
Applying using FoundationConnect

Following hints to serve you better

If you are a first time user of our online system, please click the Register button.

If you are a returning user, please enter your username and password at the right side of the page and click the Login button.

Forgotten your password? Click the Can't access your account? link next to the Login button to receive a temporary password.
FoundationConnect Tips

• Internet browser compatibility: please use Chrome or Firefox.
• You are able to save your work and complete the application in multiple phases
  - However, text has to be entered into all required fields in order to save the application or progress to the application tab.
• To monitor page limit, complete the application in a word processing program before submitting online.
• Be sure to “paste as plain text” into the system.
Attachments

• Project Budget
• Organization Operating Budget
• 2017 (or 2016-2017) Audit
• Diversity Table
• Memoranda of Agreement & Letters of Support
## Application Timeline

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<tr>
<th>Date</th>
<th>Event</th>
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<tr>
<td>July 26, 2017</td>
<td>MIPA and Application Webinar</td>
</tr>
<tr>
<td>August 14, 2017</td>
<td>Complete applications due by 5:00 pm ET</td>
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<tr>
<td>September 18, 2017</td>
<td>Approved applicants will be notified of funding decisions</td>
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<tr>
<td>September 20, 2017</td>
<td>Negotiation of final budget, grantee profiles complete, and execution of grant agreements</td>
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## Grant Year

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<tr>
<th>Date</th>
<th>Event</th>
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<tr>
<td>October 1, 2017</td>
<td>Grant period begins</td>
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<tr>
<td>January 2018</td>
<td>Two-day grantee convening</td>
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<tr>
<td>March 30, 2018</td>
<td>Interim grantee progress calls and budget expenditure reports due</td>
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<tr>
<td>June 15, 2018</td>
<td>Grant period ends</td>
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<tr>
<td>June 29, 2018</td>
<td>Final grantee progress reports due</td>
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QUESTIONS

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