

Meaningful Involvement of People with HIV/AIDS (MIPA)

“Nothing About Us Without Us”



The principle of meaningful involvement of people with HIV/AIDS (MIPA) was first articulated in the Denver Principles in 1983, and has also been endorsed by UNAIDS, the body that coordinates global action on the HIV/AIDS epidemic. *The National HIV/AIDS Strategy: Updated to 2020* supports MIPA as well, acknowledging the “persistent advocacy from people living with HIV” and “the engagement of affected communities.”

Partnering with people living with HIV to make informed decisions about their own health care and treatment, research agendas that affect them, and creation and review of policies and programs that directly impact them are important cornerstones of the global response to HIV.

As UNAIDS explains, at its most basic level, MIPA does two important things:

- 1 recognizes the important contribution that people living with and affected by HIV/AIDS can have in the response to the epidemic as equal partners and
- 2 creates a space within society for involvement and active participation of people living with HIV in all aspects of that response.

WHY MIPA MATTERS

People living with HIV are likely to be intimately familiar with factors that place individuals and communities at risk for acquiring HIV in the first place; barriers to accessing care and treatment; and challenges to living a full and healthy life with dignity.

When people living with HIV are involved in program development and implementation, it can improve relevance and effectiveness of strategies. Moreover, raising visibility of people living with HIV and elevating their voices and experiences can help decrease HIV-related stigma and discrimination. Studies show that when individuals and communities are proactively engaged in ensuring their own wellbeing, improved health outcomes are more likely.¹

MIPA IS ABOUT MORE THAN JUST HIV STATUS

Historically, there have been many barriers to meaningful inclusion of people living with HIV in decision-making roles



within organizations and service delivery settings. Many of these ultimately lead back to a need to address systems of privilege that structure who has access to power — such as racism, misogyny, transphobia, formal education requirements, and decision-making processes that are unnecessarily bureaucratic.

MIPA today is about ensuring that the communities most affected by HIV are involved in decision-making, at every level of the response. Specifically, many organizations may need to re-envision their systems to involve young people, folks of trans experience, and Black and Latinx communities in decision-making.

“Our PLHIV partner organization supported us in identifying meaningful ways to include patient voices at each stage of our transformation towards becoming a trauma-informed primary care clinic. We now have our patients at the table for every major programmatic decision. The result is a feeling and reality that our program is grounded in the actual needs and visions of our patients.”

—Edward Machtinger, MD
Director, Women’s HIV Program, University of California, San Francisco

¹International HIV/AIDS Alliance and Horizons (2003). *The Involvement of People Living with HIV/AIDS in Community-based Prevention, Care and Support Programs in Developing Countries.*

People living with HIV commit to treatment and prevention fully only when there is a commitment to involving and engaging them authentically.

Benefits of MIPA are vast:



Individual level. Involvement can build self-esteem, counter depression, increase HIV and health care knowledge, improve engagement in care, develop stronger connections to the community, increase empowerment, autonomy and self-advocacy, and improve health outcomes.



Organizational level. Involvement can improve: program processes and outcomes; cultural competency; responsiveness to client needs; client satisfaction; quality of care and services; organizational trust; and prevention, treatment, care, and support services for people living with and affected by HIV. Importantly, people feel more valued and invested in an organization when they are involved in decision-making.



Community level. MIPA can decrease HIV stigma, discrimination, and myths; develop safe spaces for marginalized populations; increase opportunities for collaboration; improve services available; decrease community viral load; and improve community pride.

MECHANISMS FOR INVOLVEMENT

People living with and affected by HIV can be engaged on a range of levels including executive leadership and governance; policymaking; program development and implementation; leadership development; peer support; policy and advocacy; designing campaigns; public speaking; and evaluation.

MIPA does not happen in a vacuum. Rather, it requires buy-in and dedication from organizational decision makers and intentional actions to ensure that people living with HIV, especially those from marginalized communities, are, in

AIDS United and the United States People Living with HIV Caucus are here to help.

fact, meaningfully involved and set up for success.

This also includes investing in *capacity building* and technical assistance for people living with HIV, *enlisting these individuals on decision-making bodies*, ensuring those enlisted are *reflective of the epidemic* and marginalized communities, *hiring people living with HIV*, establishing a clear and objective *feedback loop*, educating staff and establishing policies to *counter stigma*, and *monitoring implementation* of recommendations. For government agencies and other funders, requirements and associated reporting on MIPA-centric policies and activities are important measures in ensuring their uptake and adherence.

Examples of organizational practices that can be put in place:

- minimum percentage of seats on the governance board for people living with HIV and in organizational leadership;
- minimum percentage of people living with HIV, people of color, and LGBTQ-identified folks in management roles;
- commitment to involve people living with HIV in development and design of new programs;
- protocols to take and act on input from clients or patients on an ongoing basis; and
- financial support for participation in meetings, such as travel stipends, honoraria, and per diems.

MIPA requires dedication, planning and assessment, organizational buy-in, and a champion to help usher its development and continued assessment. Decades of HIV work have shown MIPA's unique—and critical—role in addressing the HIV epidemic and advancing the lives and health of people living with and affected by it. This work takes time but this investment is critical, doable, and well worth the effort.

THE MIPA "LITMUS TEST"

ASK YOURSELF:

LEADERSHIP AND REPRESENTATION:

- What positions do people living with HIV and people of color hold in your organization?
 - To what extent are they represented in management and decision-making positions?

INTERSECTIONALITY:

- Have you considered how HIV stigma, racism, sexism, classism, and other forms of oppression may be operating in organizational practices? How might these be addressed?
- What practices and policies do you have in place to support trans and gender non-conforming staff and clients, including those who are in a transition process?

INPUT AND ENGAGEMENT:

- How do people living with HIV provide input into service delivery?
- How are client concerns about services resolved?
- Do you have formal mechanisms for input by clients?
 - Are people living with HIV represented and are they reflective of the constituency you serve?
 - Can they safely say, "no"?
 - Are their recommendations implemented?
 - Is there a mechanism for them to sign off on policies?

Learn more about technical assistance opportunities for you to advance MIPA in your own organization or community: