Embodying Meaningful Involvement of People Living with HIV:
Putting the Pieces Together

HISTORY AND LESSONS LEARNED FROM THE COMMUNITY

AIDS United

US PLHIV CAUCUS

AIDS United:
www.aidsunited.org

U.S. People Living with HIV Caucus:
www.hivcaucus.org

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Introduction

While many community-based organizations (CBOs), health departments, and advocacy groups agree in theory that Meaningful Involvement of People Living with HIV (MIPA) is a beneficial practice, there remains a lack of clarity around how MIPA can be achieved and assessed. This toolkit was developed as a resource to address that need.

This resource serves as a starting point and provides an overview of MIPA, ways of thinking about MIPA, and methods of implementing and evaluating MIPA in your organization and/or community. For more extensive and tailored technical support, the organizations below are available to consult with organizations and institutions seeking to implement these practices.

Please contact us at AIDS United, Positive Women's Network-USA, and the United States People living with HIV Caucus for more information.

- AIDS United — **www.aidsunited.org**
- Positive Women's Network–USA — **www.pwn-usa.org**
- United States People living with HIV Caucus — **www.hivcaucus.org**

What Is Meaningful Involvement of People Living with HIV (MIPA)?

OVERVIEW

From the very beginning of the HIV epidemic, it has been clear that people living with HIV (PLHIV) innovate solutions that work for their communities. Yet, meaningfully involving PLHIV, requires deliberate attention and focus. The intentional engagement of people living with HIV — especially of those reflecting the communities most affected by the epidemic — in leadership, advisory, and decision-making roles, is critical to ensure that the voices of people most affected by an issue or decision are heard. In this era, when the biomedical tools needed to address the epidemic are available, having people living with HIV as leaders in all aspects of the HIV response is more important than ever as we strive to address the myriad socioeconomic and structural barriers which prevent "End the Epidemic" attempts from succeeding.

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INTRODUCTION TO MEANINGFUL INVOLVEMENT OF PEOPLE LIVING WITH HIV

MIPA means centering the voices of people living with HIV, with particular attention to those most affected, including diversity, marginalization, and lack of resources. This includes looking at who is at the table and how the decision-making process occurs.[1]

"Nothing about us, without us" is a common slogan used by people living with HIV, who have demanded representation in decisions that affect their lives since the earliest, traumatic days of the epidemic. This sentiment was encapsulated in the 1983 Denver Principles,[2] and was updated as a set of demands in the 2007 Paris Community Declaration, authored by civil society organizations to address the importance of integrating key affected populations in the global HIV response.

According to the UNAIDS Greater Involvement of People Living with HIV brief (2007), meaningful involvement of people with HIV (MIPA):

1. recognizes the important contributions and expertise of people living with HIV in evaluating and implementing policies, programs, and funding in the response to the HIV epidemic; and

2. creates a space where people living with HIV can actively participate in all aspects of the response to this epidemic.

Such involvement of people living with HIV was required in country-specific President's Emergency Plans for AIDS Relief (PEPFAR) plans and is described in the *US National HIV/AIDS Strategy: Updated for 2020,* strengthening the federal government's response to the domestic epidemic.

Involving PLHIV in decision-making translates into concrete benefits for organizations and institutions, among them:

● genuine connections and engagement with community;

● a grounded understanding of the effects of stigma and discrimination;

● increased effectiveness of policies and programs; and

● improved sustainability of projects and organizations.

> MIPA means centering the voices of people living with HIV, with particular attention to those most affected, including diversity, marginalization, and lack of resources.

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[1] Minkler, M. (Ed.) (2005). *Community organizing and community building for health*. New Brunswick, NJ: Rutgers University Press.
[2] People with AIDS Coalition (1983). The Denver Principles. Available at **http://www.actupny.org/documents/Denver.html**.

At the individual level, MIPA can translate into direct benefits for participating PLHIV, improving their sense of personal empowerment and agency, increasing engagement in health care, and more. However, PLHIV can face many barriers to involvement along the way, and systems must be constructed that support participation by PLHIV and populations affected by relevant decisions to be involved.

Meaningful involvement of people living with HIV is important, but it is not enough. Our definition of MIPA goes beyond merely accounting for HIV positive status to include representation and expertise from constituencies that are disproportionately affected by the epidemic. In the United States, this means that true MIPA must account for regional demographics as well as intentionally developing and supporting leaders living with HIV from marginalized communities, especially Black and Latinx people, youth, people who use drugs, people who are unstably housed, immigrants, queer communities, women, people of trans experience, people with incarceration experience, sex workers, and so many others.

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MIPA can take many forms. At the base level, organizations can have an advisory group or other consulting body to discuss programs, policy decisions, advocacy issues, and evaluations. In some non-profit organizations, there are specific seats reserved for people living with HIV on the Board of Directors. Others make it a priority to hire people openly living with HIV at all levels of the organization. Even at organizations that are led by people living with HIV, it's important to look at how other people living with HIV — particularly those from diverse and marginalized backgrounds — can take part in decision-making. **MIPA starts when people living with HIV know our rights, our powers, and the importance of our voice at the table.**

MIPA requires an organization to commit to ongoing attention, evaluation, and growth. Ultimately, **MIPA requires an institutional commitment to welcome and even seek out or develop leaders living with HIV at *all* levels of organizational leadership.** This is likely to require a shift in organizational culture and allocation of resources and programing.

CONTEXT: MIPA IN THE HIV MOVEMENT

Protest and civil disobedience are methods that people excluded from traditional decision-making processes have historically used to demand inclusion, representation, and access to power. The PLHIV self-empowerment movement was not born in isolation; rather, it rose as a successor to historic activism from women's health and equality movements, civil rights, unions and workers' rights, anti-colonial and anti-apartheid, community development, and anti-poverty and welfare rights movements. However, the Denver Principles, released in 1983, marked the first time a community of people with a shared health condition banded together to demand rights and representation as a group.

In June 1983, during the 5th annual Gay and Lesbian Health Conference in Denver, Colorado, twelve people affected by AIDS wrote a powerful manifesto, outlining the rights and responsibilities of people with AIDS, health care providers, and the public. It begins with language that claims power and demands recognition.

From 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.* **"**

The **Denver Principles** made specific recommendations for people with AIDS, including that PLHIV form caucuses, choose their own representation, engage with the media, set their own agenda, and plan their own strategies. They also demanded that people living with HIV be meaningfully involved in every level

of decision making and be included in forums with credibility equal to other participants, to share their experience and knowledge.

Following the release of the Denver Principles, organizations and coalitions were created to provide services for PLHIV. Many of the initial staff, volunteers, and leadership were themselves living with HIV, some very ill or dying of AIDS-related complications. In the early days of HIV advocacy, there were no medications to treat HIV. Many PLHIV were ostracized, shunned by family, fired at work, and illegally evicted from homes and apartments. Communities came together to provide care and end of life support to those dying of an illness that the United States government had yet to acknowledge. With few resources and research, there was little progress or improvement in care. Thousands died, leading to a sense of grief, despair, and rage.

In this context, groups like the AIDS Coalition to Unleash Power (ACT UP), led by people with AIDS, developed public protests and visible, vocal campaigns. In the words of one AIDS activist: "We had nothing but our anger." Through civil disobedience and deliberate engagement with politicians and medical researchers, PLHIV demanded better access to medication. The protests and activism of groups like ACT UP as well as early HIV groups like Gay Men's Health Crisis (GMHC) were clear examples of MIPA — as people living with HIV were central to all decision-making processes.[3,4]

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[3] Carroll, T. W. (2015). *Mobilizing New York: AIDS, antipoverty, and feminist activism*. Chapel Hill, NC: University of North Carolina Press.
[4] Chambre, S. M. (2006). *Fighting for our lives: New York's AIDS community and the politics of disease*. New Brunswick, NJ: Rutgers University Press.

In response to deepening need and ongoing activism by PLHIV, the Ryan White CARE Act was enacted in 1990, to provide funding intended to improve access to HIV medication and quality health care for low income, uninsured and underinsured PLHIV. Named after Ryan White, a teenager and activist living with AIDS who died in the spring of 1990, the program continues to be the largest federally funded program in the US specifically designed for PLHIV. MIPA was built into the very functions of the Ryan White program: planning councils and advisory boards for Ryan White-funded agencies are required to be comprised in part by clients.

But such involvement was never distributed equally across PLHIV communities. Many of the populations most affected by HIV, including Black and Latinx men who have sex with men, women, youth, and women of trans experience struggled to gain attention, funding, and equitable resources from the earliest days of the epidemic. Institutional racism, misogyny, and other factors contributed to a whitewashing of early AIDS organizations.

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In the 1994 Paris Declaration — a product of the Paris AIDS Summit and signed by 42 heads of government — MIPA was embedded in the text: "our determination to mobilize all of society — the public and private sectors, community-based organizations and people living with HIV/AIDS — in a spirit of true partnership."[5] Since then, the Global Network of People with HIV/AIDS (GNP+) as well as other international partners have advanced the idea of MIPA.

The advent of effective anti-retroviral therapy (ART) in 1995 contributed to the medicalization of HIV and a decline of community engagement. Because of the advocacy of HIV groups, the FDA Modernization Act of 1997 facilitated expedited review of drugs which treat serious or life-threatening conditions such as HIV. Many PLHIV were able to return to work, and even dream of a regular life. It appeared that the crisis of HIV was over but the socioeconomic,

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[5] Paris AIDS Meeting. (1994). The Paris Declaration. Available at **http://data.unaids.org/pub/externaldocument/2007/theparisdeclaration_en.pdf**

psychosocial, and structural barriers to care; political power; and resources remained. Grassroots PLHIV-led organizations were defunded in the mistaken belief that medical interventions were sufficient to end the HIV epidemic, ignoring the underlying stigma, discrimination, and the social implications that left communities vulnerable to HIV and less able to access services in the first place. While HIV is now perceived as a chronic rather than terminal disease, this over-reliance on medication as a "silver bullet" eroded PLHIV involvement over time.

At the time of this writing, meaningful involvement of people living with HIV and networks led by and for people living with HIV in advocacy and politics is on the rise. In Iowa, Colorado, and California, groups led by PLHIV worked with state legislators to pass revisions to laws criminalizing people with HIV. Efforts in at least ten other states are currently being led by PLHIV. Repeated attempts to repeal the Affordable Care Act have revitalized the HIV community's advocacy and brought many "retired" advocates and activists to political advocacy. Other community-led campaigns have amplified the voices of people living with HIV. "Language Matters" returns to the "people first" language of the Denver Principles while demanding changes to the use of stigmatizing words. The U=U or Undetectable equals Untransmittable campaign, launched and led by PLHIV, demands access to information and resources to eliminate HIV-related stigma. The *US National HIV/AIDS Strategy: Updated to 2020* calls for meaningful involvement listing "persistent advocacy from people living with HIV" and "the engagement of affected communities" as cornerstones to success.

PLHIV involvement has thus ensured that programs and policies meet the needs of those most affected by the HIV epidemic. To realize the full potential of biomedical approaches to the epidemic, cultural and structural shifts must occur as well. Purposeful partnerships between organizations, government and people living with HIV have led to groundbreaking innovation. As we move to the future, these alliances are imperative for success.

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RESOURCES:

1994 Paris Declaration at United Nations

1999 UNAIDS From Principle to Practice

2006 US President's Emergency Plan for AIDS Relief

2007 UNAIDS Brief on the Greater Involvement of People Living with HIV (GIPA)

2015 US National HIV/AIDS Strategy

The Benefits of MIPA: Health Outcomes

I n addition to improving the health of organizations and institutions, MIPA has elements of personal empowerment and community-building that can improve the health of people living with HIV. In this section, we focus on how MIPA improves social support, immune function, health literacy, and ultimately the health of people living with HIV. This includes countering the negative impacts of structural violence and poverty, two of the major barriers faced by people living with HIV trying to actively engage health care and community institutions.[6]

'LOCUS OF CONTROL' AND HEALTH

Locus of control refers to an individual's belief about who controls their circumstances and conditions — whether internal (e.g. "I can do this") or external (e.g. "something/someone else is doing this to me"). In this context, locus of control refers to the ability of a person living with HIV to control their own circumstances and conditions. In HIV, locus of control has been connected to treatment adherence, comfort with a medical provider,

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[6] Axelrod, J. E., Mimiaga, M. J., Grasso, C. and Mayer, K. M. (2013). Trends in the spectrum of engagement in HIV care and subsequent clinical outcomes among men who have sex with men (MSM) at a Boston community health center. *AIDS Patient Care and STDs, 27*(5), 287–296.

remaining in care, and capacity to manage stigma[7]. By meaningfully engaging people living with HIV in decision making about their health care and the HIV response in their community, MIPA can directly increase a person's locus of control.

The higher a person's perception of internal locus of control, the more likely they are to feel as if they are making decisions in health care, and stick to the choices they make.[8] As a result of this increased feeling of control, PLHIV report feeling that they are in partnership with health care providers, and are more likely to adhere to treatment plans, lab work, and care appointments. In addition, people living with HIV who feel a stronger internal locus of control report feeling increased ability to manage stigmatizing situations.

SOCIAL SUPPORT AND HEALTH

Meaningful involvement of people living with HIV in coalitions, organizations, and decision making also increases social support of people living with HIV. Social support has a direct connection to improved health of people living with HIV including improved immune function, enhanced health literacy, and lowered stress.

Social support and organizational contact can increase the likelihood of people living with HIV to be engaged in care faster and reduce opportunistic infections at time of diagnosis.[9] Social support can also improve immune function in both psychological and physiological terms. Psychologically, social support generally produces praise and encouragement of healthy behaviors in a range of areas such as exercise, tobacco cessation, personal hygiene and appearance, and employment.[10] This positive reinforcement of healthy behaviors supports immune function. Physiologically, there is evidence that older people with more social support have evidence of higher immune function — which has particular dimensions for

> Meaningful involvement of people living with HIV in coalitions, organizations, and decision making also increases social support of people living with HIV.

[7] Uchino, B. N. (2006). Social support and health: A review of physiological processes potentially underlying links to disease outcomes. *Journal of Behavioral Medicine, 29*(4), 377–387.

[8] Beach, M. C., Keruly, J. & Moore, R. D. (2006). Is the quality of the patient-provider relationship associated with better adherence and health outcomes for patients with HIV? *Journal of General Internal Medicine, 21*(6), 661–665.

[9] Axelrod et al., 2013.

[10] Persson, L., Gullberg, B., Hanson, B. S., Moestrup, T. and Osttergren, P. O. (1994). HIV infection: Social network, social support, and CD4 lymphcyte values in infected homosexual men in Malmo, Sweden. *Journal of Epidemiology and Community Health, 48*, 580–585.

people living with HIV in the 50+ age range.[11] Other research has mixed findings on the direct physiological impact of social support for younger people living with HIV, but it is clear that social support has a moderating effect.[12]

Social support can also lower stress levels. Social support from organizations, community members, and social networks can bolster quality of life, as well as provide resources to manage stressful situations. Support from community members and social networks can also reduce stress, as individuals are more likely to have resources to manage stressful situations.[13] Consistent contact with a supportive organization has been tied to lower suicidal ideation, lower depressive events, and reduced perceptions of stigma.[14]

Health literacy — the ability to obtain, share, and understand health information to make health-related decisions — is also increased by social support. Several authors and historians have written about the impact of people living with HIV support groups as well as ACT UP and GMHC on health literacy: people shared knowledge about treatments, prophylaxis, side effects, and drug trials.[15] People discussed social and personal issues including sex, available housing, feelings of stigma, and experiences with discrimination. In these groups, people living with HIV built community, including organizations to respond to the HIV epidemic.[16,17] Public health research also ties social support to increased health literacy. Individuals already connected to organizations were more likely to know how to get treatment on a range of

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[11] Theorell, T., Blomkvist,V., Jonsson, H., Schulman, S., Berntorp, E. and Stigendal, L. (1995). Social support and the development of immune function in human immunodeficiency virus infection. *Psychosomatic Medicine, 57,* 32–6.

[12] Uchino, B. N. (2006). Social support and health: A review of physiological processes potentially underlying links to disease outcomes. *Journal of Behavioral Medicine, 29*(4), 377–387.

[13] (Persson et al., 1994).

[14] Sherr, L., Yakubovich, A. R., Skeen, S., Cluver, L. D., Hensels, I. S., Macedo, A. and Tomlinson, M. (2016). How effective is help on the doorstep? A longitudinal evaluation of community-based organization support. *PLoS ONE, 11*(3): doi: 10.1371/journal.pone.0151305.

[15] Esptein, S. (2007). *Inclusion: The politics of difference in medical research.* Chicago, IL: University of Chicago Press.

[16] Kayal, P. M. (1993). *Bearing witness: Gay Men's Health Crisis and the politics of AIDS*. Boulder, CO: Westview Press.

[17] Trapence et al., 2012).

health issues, as well as the capacity to find those resources faster.[18] In addition, individuals in contact with other people living with HIV demonstrated more treatment knowledge and resources to manage side effects.[19]

POVERTY AND HEALTH

While structural determinants like racism, sexism, and homophobia impact HIV health outcomes, poverty has been examined in multiple global contexts and has particular bearing on MIPA.[20] We do not prioritize poverty over other kinds of structural violence. We use poverty as an example of how larger structures impact the health outcomes of people living with HIV. In the case of MIPA, poverty has a detrimental impact on the capacity of people living with HIV to engage and be present in decision-making processes.

Poverty reduces an individual and community's capacity to respond effectively to HIV. A lack of resources will result in people prioritizing things such as housing and food over health care. In addition, poverty greatly reduces the overall health infrastructure, leading to reduced efficacy of health care.[21]

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To adequately address MIPA, organizations must also address how structural violence disempowers people living with HIV locally.[22] Examples of advocacy goals that organizations can take up could include universal health care access, disability benefits, housing discrimination, and employment discrimination and opportunities. In fact, interventions that involve housing support, nutrition support, and income support achieve more robust health outcomes than those interventions that featured just care coordination and community outreach.[23]

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[18] (Axelrod et al., 2013).

[19] (Persson et al., 1994).

[20] Taylor, L. A., Tan, A. X., Coyle, C. E., Ndumele, C., Rogan, E., Canavan, M., Curry, L. A. and Bradley, E. H. (2016). Leveraging the social determinants of health: What works? *PLoS ONE, 11*(8): doi:10.1371/journal.pone.0160217.

[21] Thielman, N., Ostermann, J., Whetten, K., Whetten, R., O'Donnell, K., and the Positive Outcomes for Orphans (POFO) Research Team. (2012) Correlates of poor health among orphans and abandoned children in less wealthy countries: The importance of caregiver health. *PLOS ONE, 7*(6), e38109. **https://doi.org/10.1371/journal. pone.0038109**

[22] Trapence, G., Collins, C., Avrett, S., Carr, R., Sanchez, H., Ayala, G., Diouf, D., Beyrer, C. and Baral, S. D. (2012). From personal survival to public health: Community leadership by men who have sex with men in the response to HIV. *Lancet, 380,* 400–410.

[23] (Taylor et al., 2016).

Person-First and Empowering Language

Harnessing the power of language to empower ourselves and our communities.

The stigma attached to HIV is a significant barrier to living well with HIV. Stigma fuels isolation and decreases empowerment and advocacy by people living with HIV. Language is a critical tool to address stigma and discrimination. Language influences thought and action; it can generate strength or take it away.

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As we seek to meaningfully involve people living with HIV, we have a responsibility to stop using language that labels and "others" people with HIV and communities affected by and vulnerable to HIV.[24]

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[24] PWN-USA, Five Things Media Makers Can Do NOW to Stand Up to HIV Stigma: **http://www.pwn-usa.org/media/five-things-stand-up-to-hiv-stigma/**

The overall goals of empowering language are to:

- Use appropriate terminology

- Use empowering terminology

- Use non-stigmatizing language & images

- Portray people with HIV living positively

- Empower yourself and others

Below are five strategies for using person-first and empowering language.

RELEVANCE TEST

☐ Is a person's HIV status, health condition, or other status relevant to the story or conversation? *If not, don't use it.*

ELIMINATE BIASED PHRASES AND SLANG WORDS

☐ Slang words like *clean and dirty* and phrases like *victim of* and *suffers from* have negative connotations. Use scientifically accurate, clear terminology.

PERSON-FIRST LANGUAGE

☐ Person-first language puts a person before their illness or condition. It describes what they have, not who they are (people living with HIV, people who inject drugs, people of low income, etc*.)*

CLAIM POWER THROUGH SPEECH

☐ Speaking patterns can be infused with gender, race, educational privilege, and other power-based dynamics. Here are some tips for you to claim your power.

Goal	Don't	Do
Drop the "just"	I just want to add...	I want to add...
Don't apologize for your opinion	I may be wrong, but... I'm not an expert, but...	I'm my experience... I believe that...
Erase the self-doubt	Does that make sense? Am I making sense?	Any questions? Do you need additional information?
Take out the filler words	We work to ensure that people are able to access HIV care	We connect people to HIV care. We help people access medical services.

? As you explore meaningful involvement of PLHIV within your organization ask yourself:

➥ What language or visuals does my organization use on its website, emails, and social media?

➥ How do staff, volunteers, clients, and participants talk about HIV and people living with HIV?

➥ How does your larger community talk about HIV?

➥ In what areas would you like to increase your use of empowering language?

Identifying where there is room for improvement will help you plan how to operationalize empowering language within your agency. It's important that you have buy-in from your agency to make this a sustainable change. Consider establishing an organizational taskforce to review your website and social media content, plan organization-wide and community trainings on empowering language, and hold community meetings with people living with HIV to review your language (and compensate them for their time).

See **appendix** for more resources on empowering language.

WATCH YOUR LANGUAGE!25

We can raise awareness and help improve the lives of those living with HIV by being mindful of language. Language can be a tool to empower or to further stigmatize.

Replace these terms . . .	. . . with these preferred terms
HIV positive, positives or HIVers AIDS or HIV carrier HIV patient, AIDS patient	Person/people living with HIV
Infected with HIV	Diagnosed with HIV; acquired HIV
Catch AIDS, Contract AIDS	Received an AIDS diagnosis, develop AIDS
Full-blown AIDS	AIDS; an AIDS diagnosis
Clean or dirty (re: STD/HIV status, syringes, etc.)	*Do not use*
Victim	*Do not use* when referring to a person living with HIV, or the partner of a person living with HIV
Prostitute or prostitution	Sex worker, sale of sexual services
Promiscuous	Having multiple partners
Drug user	Person/people who use drugs

25 PWN-USA, Five Things Media Makers Can Do NOW to Stand Up to HIV Stigma: **http://www.pwn-usa.org/media/five-things-stand-up-to-hiv-stigma/**

Employment and People Living with HIV

Maximize meaningful involvement of people living with HIV across the workplaces of HIV service delivery and policy programs

HIV service organizations and policy departments represent an important arena of employment opportunity for people living with HIV. Additionally, they are workplaces where our expertise and insights are essential to the design and implementation of effective HIV care and prevention services, policymaking, and advocacy. Administrators, managers, and supervisors can and should take steps to maximize the ability of people living with HIV to contribute at their highest level and be well-supported for success in employment, career development, and strengthened economic security and wellbeing.

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Most people diagnosed and living with HIV are working age adults. Many who are working at the time of their diagnosis become separated from the workforce due to their physical and mental health needs, housing changes, stigma, their ability to access services in their area, and other challenges. Thousands of PLHIV have economic poverty reinforced or develop as one of the impacts of their HIV diagnosis. Communities disproportionately affected by HIV have long histories of discrimination and stigma in employment and disparities in economic and employment outcomes. Racism, homophobia, and transphobia fuel the HIV epidemic with parallel obstruction of parity in economic and employment opportunity.

Despite increased awareness of the relationships between poverty, unemployment and underemployment, and health disparities associated with HIV, the national systems of HIV clinical and supportive services, such as Ryan White, do not currently have the capacity to prepare PLHIV for, and link them to, employment opportunities. Additionally, in the national policy efforts to end the epidemic, the employment needs of PLHIV are not prioritized.

HIV organizations — including direct-service and policy organizations, as well as public and private entities — must recognize the necessity of meaningfully involving people living with HIV at all levels of their work. This includes leadership, hiring, and decision-making roles at national, state, local, and community levels. This is critical to reducing the rampant unemployment, underemployment, and poverty experienced by communities most affected by HIV. It also brings in the expertise, experience, and talents of people living with HIV to inform and improve the services and policies designed to benefit them and their communities.

BEST PRACTICES ON RECRUITING, HIRING, AND SUPPORTING PLHIV:

1 EVALUATE YOUR ORGANIZATION'S IMPLEMENTATION OF MIPA:

Ongoing evaluation and assessment are critical parts of implementing MIPA in hiring and staff support. Evaluate policies and procedures for opportunities to achieve greater inclusivity and representation of people living with HIV. Here are examples of ways to get started (see the Evaluation MIPA section for more information).

☐ Create anonymous surveys to ask staff and clients about MIPA at the agency

☐ Consider organizational challenges, opportunities, things your organization does well, and how you can continue to improve

☐ Consider engaging an outside facilitator living with HIV to guide the process. Compensate them for their work.

2 CREATE ACCESSIBLE JOB OPPORTUNITIES FOR PLHIV:

☐ Develop a recruitment strategy to identify areas for improvement and set goals to increase employment of affected communities across the HIV workforce.

☐ Reprioritize hiring decisions and position descriptions to value the lived experience, expertise, and often unpaid work histories of PLHIV as job qualifications and indicators of strengths and abilities. Recognize that this may be more important than traditional credentials and measures of qualification.

☐ Remove unnecessary educational or professional requirements as they discourage PLHIV who are otherwise capable from applying. When creating job descriptions, consider if they can be made optional, or if they can be removed entirely.

☐ Include language in job postings that encourages people with lived experience to apply.

☐ Advertise where PLHIV will see your posting. This will be different for each community.

☐ Create opportunities for volunteers to transition to funded positions to prevent permanent volunteerism

☐ Include a clear list of benefits in job listings.

3 SUPPORT PLHIV ON STAFF:

☐ Provide comprehensive new hire training and consistent ongoing supervision.

☐ PLHIV entering employment for the first time or after a significant time out of the workforce may need additional, personalized support to succeed. Supervisors should understand challenges that arise from work transitions or histories of trauma.

☐ Create an environment where people are comfortable sharing their needs with supervisors and HR.

☐ HR must be prepared to provide accurate, individualized information and assistance to help PLHIV navigate how changes in income may affect their enrollment in and eligibility for health and economic stability programs, including those supporting access to income replacement (i.e., SSI, SSDI, HASA), health coverage (i.e., Medicaid, Medicare, ADAP), housing (i.e., HOPWA, Section 8, HASA), and food/nutrition (i.e., SNAP, HASA).

☐ Remove and prevent career dead-ends and second-class status of peer work positions. Ensure that "peer" workers and all PLHIV staff have equal status with all staff.

☐ Develop colleague mentoring and offer ongoing access to technical, professional development, and career advancement training and supports throughout employment.

For more information:
National Working Positive Coalition http://www.workingpositive.net/

MIPA Assessment and Evaluation

In this part of the MIPA toolkit, we explore assessment and evaluation.

ASSESSING MIPA

To be effective, MIPA must be regularly assessed, monitored, and evaluated throughout the life of the organization. Take for example, an organization that develops MIPA initiatives that result in the hiring of people living with HIV, but these were all part-time and entry-level positions. While this produces some economic viability for the people living with HIV involved, it also reduces the independence of their voice — leading the people living with HIV to be the lowest paid staff in the organization.[26] Assessment can help prevent, identify, and remedy such situations.

> To be effective, MIPA must be regularly assessed, monitored, and evaluated throughout the life of the organization.

MIPA can be assessed in a variety of ways. Organizations exist as systems including physical space; digital presences; people such as employees,

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[26] Dlamini-Simelane, T. (2017). The GIPA concept 'lost in transition': The case of expert clients in Swaziland. *Anthropology in Action, 24*(3), 1–10.

volunteers, constituents; resources and funders; protocols and procedures; partner organizations and governmental agencies; and program design and evaluation. Each system can be looked at in terms of MIPA.

Assessments should be done at regular intervals and be resourced adequately (in terms of personnel and time). Assessments should be culturally and linguistically appropriate — use language that's accessible to and understood by your community.

Some assessment questions could include:

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:

☐ When was the last time people living with HIV took part in defining meaningful engagement of the organization?

☐ 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" or object without repercussions to their services?

  – Are their recommendations implemented?

  – Is there a mechanism for them to sign off on policies?

See the **appendix** for additional resources.

EVALUATING MIPA

Evaluation is a key part of organizational and programmatic growth. This is when you can see how well you're doing in reaching your MIPA goals.

Evaluation is not disciplinary or punishment. If you don't know organizational successes or challenges, how will you know what to repair or enhance? Evaluation works best when there is enough time and people power to develop data points, collect and analyze the data, and review protocols and policies.

Before you get started, ask yourself: Does the organization already have a culture where evaluation is important? How frequently are these evaluations done?

Regardless of the process, evaluation has to be embedded in the organizational culture and made part of everyday processes. Building an evaluation culture does require stakeholder involvement, as every level of the organization has to believe in its worth.[27]

Sample evaluations can be found in the **appendix** and the GNP+ GIPA REPORT CARD, which describes a process for developing MIPA evaluation items, is accessible here: **https://www.gnpplus.net/our-solutions/gipa-report-card/**

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[27] Preskill, H. and Russ-Eft, D. (2016). *Building evaluation capacity: Activities for teaching and training*. Thousand Oaks, CA: SAGE Publishing.

Conclusion

From the very beginning of the HIV epidemic, it has been clear that people living with HIV create solutions that work for their communities. Yet, meaningfully involving people living with HIV, especially from those communities most affected by the epidemic, requires deliberate attention and focus. Intentional collaboration and participation with people living with HIV helps develop more responsive systems and services, creates a trusting environment, and supports empowerment of communities to lead toward a solution. When done well, the investment in meaningful involvement of people living with HIV improves the health and wellness of your staff, clients, organization, and community.

Case Studies:
MIPA In Action

How one woman built a family of people living with HIV — who now sit on the health department planning committee

In 2016, Keiva-Lei Cadena, a Community Engagement Coordinator at Hawai'i Health & Harm Reduction Center, set out to create a culturally diverse group of leaders living with HIV spanning all the islands of Hawai'i. As a transgender woman living with HIV, Ms. Cadena wanted to create an ohana* of people living with HIV where people could find support, education, and empowerment, all while working to eliminate shame and stigma. With support from AIDS United, Ms. Cadena built her Ohana by organizing trainings covering MIPA, leadership development, and more. She invited people from across the islands and supported their attendance by providing transportation assistance.

In late 2017, Ms. Cadena learned that the Hawaii Department of Health's Harm Reduction Services Branch — which manages the state's HIV programs — was looking to include more community voices on their community planning group (CPG), the body that determines how CDC prevention funding is dispersed. Ms. Cadena saw this as a critical opportunity to maximize the impact of Ohana and put the principles of

*From the Hawai'ian language, *ohana* means family, including blood-related, adoptive, and intentional family. The concept emphasizes that family are bound together, members must cooperate and remember one another.

MIPA to work on a larger scale. She spoke with a member of the CPG and requested that they save two seats for members of Ohana. They agreed.

With the goal of getting Ohana members ready to serve on the CPG, Ms. Cadena kicked Ohana trainings into high gear. She invited presenters from the health department to help people understand the intricacies of HIV-specific funding streams and how they are spent. She encouraged members to think about the services that are currently offered and what people actually want and need. Initially she worried this content might be too dry, but people were very interested because it had a direct impact of their lives. In 2018, the CPG had their first meeting with four Ohana members sitting at the table, fully prepared to participate in a sustainable way. The Ohana, along with the CPG, is currently preparing *Hawaii 2 Zero,* the Department of Health's new strategy to address HIV in the state.

The Ohana is still going strong with over 55 members from across Hawai'i. Empowered by the principles of MIPA, Ohana members got fired up to create the programs they wanted without waiting for permission. Now, they are a vibrant family running their own support groups, presenting at conferences about MIPA, and are more engaged in their own health care. As Ms. Cadena puts it, Ohana members are motivated "to not wait for someone to do things for us — we can do it for ourselves with little or no money."

How this coalition built community across a rural state

Pat Kelly, of Orangeburg, South Carolina, is a founding member of Positive Women's Network — USA (PWN). Shortly after the launch of the PWN-USA, Ms. Kelly recognized the need for a chapter in her home state to motivate and empower women living with HIV like herself. The first PWN-SC chapter meeting was held in 2010. Twelve women came, with many driving over two hours to be there. With the support of PWN-USA, the group began providing regular member trainings in leadership development, HIV basics, and whatever topics were of interest to their members. They started going to community events to raise awareness about HIV, reduce stigma, and reach other women living with HIV.

The chapter developed an advocacy focus as well, with the goal of reforming the harmful, stigmatizing, and outdated HIV criminal laws in their state. In their advocacy, they engage allied groups like Women's Rights Empowerment Network, the ACLU, and others. To lay a framework for successful partnerships, they make sure that each group clearly understands the other's mission as well the importance of MIPA.

As the group has grown — now they have over 50 members — to make sure that chapter members have a voice in chapter activities, they connect with each other

through regular meetings, phone calls, and in-person events. Since SC is a largely rural state, they use web-conferencing for their regular meetings, but are exploring holding in-person chapter meetings throughout the state. As Ms. Kelly puts it, "Sometimes it's necessary to reach out and touch somebody, rather than only meet over the phone."

The chapter has proven to be an important social connection for women living with HIV in the mostly rural, southern state. Through their participation in PWN-SC, members have become empowered to start support groups at their clinics, join clinic Community Advisory Boards, present at conferences, and more. "Women are not waiting for someone to try and save us. We're trying to do it ourselves because it ain't happening," reflects Ms. Kelly.

This organization built by and for people living with HIV stays true to the mission

THRIVE SS began as a small, in-person support group by and for young black gay men living with HIV in Atlanta, GA. When they started, they had about five to seven people regularly attending their support group each month. They wanted to expand their audience and have the ability for people to access support around the clock. They took THRIVE SS online and within one month, they had 100 members. Now they have over 900 members in the Atlanta area and 3,300 members nationwide.

Now, THRIVEE SS couples their online support with an in-person location in Atlanta. They've expanded their services based on what their membership wants — this includes support for people over the age of 50, laundry services for people who are unstably housed, a wellness space, and more. They are constantly listening to their membership. They hold monthly members meetings, have online polls, and touch base with people individually to check in about what they want and what's working. And they make sure to follow up on every request, since it is important that each person sees themselves reflected in THRIVE. Larry Scott-Walker, Executive Director at THRIVE SS, explains, "MIPA means recognizing that black gay men living with HIV are not a uniform group — we are all unique and deserve to be uplifted."

THRIVE SS attributes part of their success to their differences from traditional support groups. Theirs is a group of people living with HIV who come together as friends to support each other. "Our goal is to run interference in the death and despair that is related to being a black gay man living with HIV," explains Mr. Scott-Walker. And every member can take ownership in that mission.

With the support of the THRIVE community, 86% of members are undetectable — significantly higher than the state average — and they regularly check in with each other about taking their meds. Members have formed their own groups within THRIVE, like the Undetectable Cars Group, a group of guys who like cars but also are there for each other around HIV too, or the Silver Lining group of black gay men living with HIV over 50. Members who were never involved in organizing work previously have started their own organizations including Atlanta's first black and queer-owned foodbank.

As Mr. Scott-Walker puts it, "When people living with HIV are given the tools to galvanize their communities, regardless of education or degrees, we end up doing something magical."

How one woman turned a part-time passion project into her career

In 2014, Venita Ray got a part-time position at Legacy Community Health managing a pilot grant from AIDS United to mobilize grassroots leadership among people living with HIV. Through People Organizing Positively (POP), Venita trained 14 people living with HIV to become engaged advocates and mentors. As the program gained momentum, Ms. Ray began working full-time in leadership development for people living with HIV.

POP graduates built what Ms. Ray endearingly refers to as her POP family, which has over 50 members who meet regularly to support each other, share ideas, and coordinate on projects. Many state-wide coalitions grew out of the POP family, including the Positive Women's Network Texas chapter (PWN-TX) and the Texas Network of People Living with HIV, POP family members are also serving on the Ryan White Planning Council and Community Advisory Councils, registering people to vote, running their own support groups, and more. In fact, due in large part to their advocacy, the Houston area Ryan White Planning Council adopted person-first, non-stigmatizing language in materials that discuss HIV.

Ms. Ray is a strong advocate for compensating people for their time and takes issues with CBOs that value degrees over lived experience. The POP family works together to help members improve their resumes, network, and has even applied for its own funding (which it received). When possible, she prioritizes providing stipends for people to present at trainings, since their time and knowledge is valuable.

Ms. Ray stresses that you can't just train people, graduate them, and leave them. Conscious, long-term community building and support is critical to the close-knit POP family. "Even though we have successes, we're dealing with the sting and reality of living with HIV, which makes the community support that much more important," Ms. Ray reflects. "Within our POP family we've experienced four deaths, including two in the last two months."

Now Ms. Ray is the Deputy Director for the Positive Women's Network–USA. Looking back, she reflects that this is not a career path she would have planned for herself, but through her advocacy and community organizing work she has grown her confidence, learned to use her voice, and is thrilled to be able to empower women living with HIV on a national scale.

Appendix

MIPA FACT SHEET

Meaningful Involvement of People with HIV/AIDS (MIPA)

"Nothing About Us Without Us"

MIPA ENGAGEMENT IS: Meaningful, Valued, Ongoing, Intentional, Authentic, Inclusive, Equitable, Purposeful, Significant, Integrated

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

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[1] International 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.

AIDS United: www.aidsunited.org

U.S. People Living with HIV Caucus: www.hivcaucus.org

MIPA FACT SHEET *continued*

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

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 LGTBQ-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.

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

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:

AIDS United:
www.aidsunited.org

U.S. People Living with HIV Caucus:
www.hivcaucus.org

HIV LANGUAGE MATTERS: USING PREFERRED LANGUAGE TO ADDRESS STIGMA

HIV #LanguageMatters:
Using preferred language to address stigma

Created for & by People Living with HIV

Acknowledgements: thewellproject | C2N COMMUNITY HEALTH | IrisHouse | RUTGERS Francis Xavier Regional Center | SERO | Francis House

Stigmatizing	Preferred
HIV infected person	Person living with HIV, PLHIV. Do not use "infected" when referring to a person. Use *People First Language,* which emphasizes the person, not their diagnosis
HIV or AIDS patient, AIDS or HIV carrier	
Positives or HIVers	
Died of AIDS, to die of AIDS	Died of AIDS-related illness, Died of AIDS-related complications or end stage HIV
AIDS virus	HIV (AIDS is a diagnosis not a virus - it cannot be transmitted)
Full-blown AIDS	There is no medical definition for this phrase - simply use the term AIDS, or Stage 3 HIV.
HIV virus	This is redundant; use HIV.
Zero new infections	Zero new HIV acquisitions/transmissions
HIV infections	HIV transmissions, diagnosed with HIV, PLHIV
HIV infected	living with/diagnosed with HIV, contracted/acquired HIV
Number of infections	Number diagnosed with HIV/number of HIV acquisitions
Became infected	Contracted, acquired, diagnosed with
HIV-exposed infant	Infant exposed to HIV
Serodiscordant couple	Serodifferent, magnetic, or mixed status couple
Mother to child transmission	Vertical transmission/perinatal transmission
Victim, Innocent Victim, Sufferer, contaminated, infected	Person living with HIV, survivor, warrior (Do not use "infected" when referring to a person)
AIDS orphans	Children orphaned by loss of parents/guardians who died of AIDS related complications
AIDS test	HIV test (AIDS is a diagnosis, there is not an AIDS test)
To catch AIDS, To contract AIDS, Transmit AIDS, To catch HIV	An AIDS diagnosis, developed AIDS, to contract HIV (AIDS is a diagnosis, which cannot be passed from one person to the next)
Compliant	Adherent
Prostitute or prostitution	Sex worker, sale of sexual services, transactional sex
Promiscuous	This is a value judgment and should be avoided instead use "having multiple partners"
Unprotected sex	Condomless sex with PrEP, Condomless sex without PrEP, sex not protected by condoms, sex not protected by antiretroviral prevention methods
Death Sentence, Fatal condition or life-threatening condition	A serious health issue, chronic health condition or manageable health for people who have access to care and treatment
"Tainted" blood; "dirty" needles	Blood containing HIV; shared needles, shared syringes
Clean, as in "I am clean are you?"	Referring to yourself or others as being "clean" suggests that those living with HIV are dirty. Avoid!
"a drug that prevents HIV infection"	a drug that prevents the transmission of HIV
End HIV, End AIDS	End HIV transmission, Be specific: are we ending HIV or AIDS?

SAMPLE MIPA ENVIRONMENTAL SCAN

US PLHIV Caucus MIPA/GIPA Environmental Assessment

This tool is meant to be used to examine MIPA/GIPA in an environmental way for an organization. It is not a report card: there are no right or wrong answers. It is an attempt to gain a sense of where barriers might be for the Meaningful Involvement of People living with HIV in your organization.

Please have at least 3-5 people respond in order to have a range of opinions, at least one should be a person living with HIV.

In order to analyze responses, find the average of each response set and that would indicate the closest response of the responses available.

Thank you for your honest responses.

SAMPLE MIPA ENVIRONMENTAL SCAN *continued*

Q1 Organizational Name

_____

Q2 Staff Completing Assessment

_____

Q3 Position at agency

_____

Q4 Your e-mail

_____

Q5 I identify as a person living with HIV

○ Yes (1)

○ No (2)

○ Prefer not to disclose (3)

SAMPLE MIPA ENVIRONMENTAL SCAN   *continued*

Q6 Do you know what the Meaningful Involvement of People living with HIV means?

◯ Yes (1)

◯ No (2)

Q7 When completing the following table, consider <u>your staffing</u> in your organization:

Staffing	Number living with HIV	Total Number	Proportion (# living with HIV/Total #)
Volunteers			
Administrative Support			
Direct Service			
Management			
Executive			
Board			

Q8 For the following table, consider <u>the physical space</u> of your organization:

How accessible are the staff to the clients/community?	1 Schedule in advance only	2 Waiting room, locked door away from staff	3 Client/ Community space where people can chill	4 Open access to staff during work hours	5 Total access, including social media and phone
Client/Community space	1 Separate office space, uncomfortable seating	2 Available to anyone, with restrictions about substance use and other behavioral disruptions	3 Comfortable seating, separate office space	4 Open, available to anyone	5 Open, available to anyone, services and technologies to support activities
HIV posters	1 None	2 Fear-based, "hard hitting"	3 No PLHIV visible	4 PLHIV clearly identified	5 PLHIV seen as thriving
Average score: (add up the scores and then divide by 3)					

Q9 For the following table, consider your <u>local community</u>:

How are PLHIV spaces visible in the local community?	1 No visible spaces	2 Gay bars, LGBT centers and women's center, no HIV	3 Gay bars, LGBT centers or women's center with	4 PLHIV support groups	5 PLHIV center

SAMPLE MIPA ENVIRONMENTAL SCAN *continued*

		materials	HIV materials		
PLHIV Networks	1 None	2 PLHIV are consumers of HIV services only	3 Support group	4 PLHIV Advisory Board	5 PLHIV Network exists
	1 None	2 Fear-based, "hard hitting"	3 No PLHIV visible	4 PLHIV clearly identified	5 PLHIV seen as thriving
Average score: (add up the scores and then divide by 3)					

Q10 For the following table, consider your <u>local media</u>:

How accessible are the media to the HIV community?	1 HIV community has no access to media	2 HIV community has little access to media	3 HIV community has access to key media	4 Open access for HIV community during work hours	5 Total access, including social media and phone
HIV-specific discussions in local media	1 None	2 Fear-based, stigmatizing	3 No HIV-specific discussion, but some on LGBT, women's health, substance users, sex workers	4 HIV is discussed occasionally, like at World AIDS Day	5 HIV is consistently part of local politics
Billboards and media campaigns	1 None	2 Fear-based, "hard hitting"	3 No PLHIV visible	4 PLHIV clearly identified	5 PLHIV seen as thriving
Average score: (add up the scores and then divide by 3)					

Q11 For the following table, consider your <u>local politics</u>:

How accessible are politicians to the HIV community?	1 HIV community has no access to politicians	2 HIV community has little access to politicians	3 HIV community has access to key politicians	4 Open access for HIV community during work hours	5 Total access, including social media and phone
HIV-specific criminalization laws	1 HIV criminalization laws exist and are used commonly	2 HIV criminalization laws exist and only used on one community	3 No HIV-specific laws exist, but PLHIV are scared of prosecution	4 HIV-specific laws exist but are not enforced	5 HIV-criminalization laws do not exist
HIV-specific discussions in local	1 None	2 Fear-based,	3 No HIV-	4 HIV is	5 HIV is

SAMPLE MIPA ENVIRONMENTAL SCAN   *continued*

politics		stigmatizing	specific discussion, but some on LGBT, women's health, substance users, sex workers	discussed occasionally, like at World AIDS Day	consistently part of local politics
Average score: (these are reverse-coded – so much invert scores – 1 becomes 5, 2 becomes 4, etc., add up the scores and then divide by 3)					

RESULTS FROM EACH SECTION SHOULD INFORM FUTURE WORK TO BUILD MIPA/GIPA IN YOUR COMMUNITY

MIPA/GIPA IN ORGANIZATIONS and COMMUNITIES

Start of Block: Default Question Block

This tool is designed to prompt your thinking about the ways that people living with HIV and people of color are involved in your organization and community. It is not a report card: there are no right or wrong answers. It is an attempt to gain a sense of where you and your project is in terms of the Meaningful Involvement of People living with HIV.

Please have at least 3-5 people respond in order to have a range of opinions, at least one should be a person living with HIV.

In order to analyze responses, find the average of each response set and that would indicate the closest response of the responses available.

Thank you for your honest responses.

Page Break

SAMPLE MIPA ASSESSMENT   *continued*

Q2 Organizational Name

_____

Q3 Staff Completing Assessment

_____

Q4 Position at agency

_____

Q5 Your e-mail

_____

Q29 I identify as a person living with HIV

○ Yes (1)

○ No (2)

○ Prefer not to disclose (3)

Page Break

SAMPLE MIPA ASSESSMENT   *continued*

Q27 Do you know what the Meaningful Involvement of People living with HIV means?

○ Yes (1)

○ No (2)

- -

Q28 Is it "meaningful" if ...

	Yes (1)	Maybe (2)	No (3)
people living with HIV are invited to the decision-making table? (1)	○	○	○
decision-making bodies reserve one seat for a person living with HIV? (2)	○	○	○
the person living with HIV does not show up to the meeting? (3)	○	○	○
the advisory group has food? (4)	○	○	○
the advisory group votes on policies and initiatives without the time to review them? (5)	○	○	○
people living with HIV select their own representation for leadership? (6)	○	○	○
people living with HIV at the table are reflective of the local epidemic? (7)	○	○	○
people living with HIV get along with health department representatives? (8)	○	○	○

SAMPLE MIPA ASSESSMENT   *continued*

Q6 For the items considered below, indicate how people living with HIV are involved in the following, from 1-4, with 1 being "not considered" to 4 being "mandatory." Use your own judgement about the involvement of people living with HIV. Think of concrete evidence of your assessment.

	Don't know (1)	1) Not Considered - I do not recall any consultation with people living with HIV (2)	2) Somewhat Important - people living with HIV have been consulted once or twice (3)	3) Very Important - people living with HIV are regular advisers - monthly meetings (4)	4) Mandatory - nothing happens with people living with HIV (5)
People living with HIV are key partners to elected officials in my state (1)	○	○	○	○	○
People living with HIV are featured in local media regularly (2)	○	○	○	○	○
People living with HIV are key partners in local health department decisions (3)	○	○	○	○	○
People living with HIV are part of my organization's management decisions (4)	○	○	○	○	○
People living with HIV are solicited and included in the decision making process at the program level at my	○	○	○	○	○

SAMPLE MIPA ASSESSMENT *continued*

organization (5)					
People living with HIV are involved in the recruitment and hiring at my organization (6)	○	○	○	○	○

SAMPLE MIPA ASSESSMENT   *continued*

Q7 Please indicate whether you feel that your organization does the following from 1-4, with 1 being "none of the time" and 4 being "all of the time". Use your own judgement in each situation - think of concrete evidence of your assessment.

	1) none of the time (1)	2) some of the time (2)	3) most of the time (3)	4) All of the time (4)
My organization provides resources to attend advisory meetings to people living with HIV (1)	○	○	○	○
My organization provides resources for people living with HIV to attend conferences (2)	○	○	○	○
My organization provides leadership opportunities to people living with HIV internally (3)	○	○	○	○
My organization provides employment opportunities to people living with HIV (4)	○	○	○	○
My organization has people living with HIV represent them at community events (5)	○	○	○	○

Page Break

SAMPLE MIPA ASSESSMENT   *continued*

Q8 Choose the top 3 ways that people living with HIV were involved in the development of your organizational initiatives

☐ Consulted on the grant (1)

☐ Developed the project (2)

☐ Wrote the grant (3)

☐ Identified the problem (4)

☐ Approved the grant (5)

☐ Grant supports people living with HIV financially (6)

- -

Q9 Are there people living with HIV organizations, groups or networks in your area, organizations that are specific to a membership of people living with HIV?

○ No (1)

○ Yes (2)

- -

Q10 Please name them

_____

_____

_____

_____

_____

- -

SAMPLE MIPA ASSESSMENT   *continued*

Q11 How frequently do you partner with them?

○ Never (1)

○ Once per year (2)

○ Bi-Monthly (3)

○ Monthly (4)

○ Weekly (5)

○ We are the group of people living with HIV (6)

Q12 What is the formal advisory process in place at your organization for people living with HIV? Choose the best answer

○ An advisory board or committee (1)

○ A senior manager is openly living with HIV (2)

○ There are board members openly living with HIV (3)

○ Key staff positions are openly living with HIV (4)

○ All of the above (5)

○ None of the above (6)

○ Other (7) _____

Q13 Do people living with HIV play any role in choosing their representatives in the above process?

○ Yes (1)

○ No (2)

SAMPLE MIPA ASSESSMENT   *continued*

Q14 What impact has this formal process had with your organization? Think of concrete examples of what changes or directions the organization has followed based on people living with HIV advising.

_____

_____

_____

_____

_____

Q15 Is people living with HIV participation encouraged at Board and/or staff meetings?

○ Yes (1)

○ No (2)

Page Break

SAMPLE MIPA ASSESSMENT   *continued*

Q16 For the following questions, consider your local HIV epidemic.

- -

Q17 Do you feel that the people living with HIV involved in your organization reflect the larger local HIV epidemic?

○ Yes (1)

○ No (2)

Skip To: Q18 If Do you feel that the people living with HIV involved in your organization reflect the larger loca... = Yes

- -

SAMPLE MIPA ASSESSMENT   *continued*

SAMPLE MIPA ASSESSMENT *continued*

Q30 If not, what do you think is the biggest reason for that? Use your best judgement

○ Resources to get people at the table (1)

○ Meetings occur during work hours only (2)

○ People living with HIV do not show up (3)

○ Levels of HIV stigma in organization (4)

○ Levels of sexism in organization (5)

○ Levels of racism in organization (6)

○ Levels of transphobia in organization (7)

○ Levels of ageism in organization (8)

○ Levels of homophobia in organization (9)

○ Discomfort with substance users in organization (10)

○ Discomfort with people who are homeless in organization (11)

○ Discomfort with people who are mentally ill in organization (12)

○ Other (13) _____

SAMPLE MIPA ASSESSMENT *continued*

Q18 What communities are represented well in your organization? (Please click all that apply)

- ☐ gay and bisexual men (1)

- ☐ youth (2)

- ☐ women (3)

- ☐ seniors (4)

- ☐ transgender women (5)

- ☐ transgender men (6)

- ☐ Latinos (7)

- ☐ African Americans (8)

- ☐ Asian Pacific Isanders (9)

- ☐ Native Americans (10)

- ☐ Homeless (11)

- ☐ Substance users (12)

- ☐ sex workers (13)

- ☐ OTHER (14) _____

- -

SAMPLE MIPA ASSESSMENT *continued*

Q20 What communities are NOT represented well in your organization? (Please click all that apply)

☐ gay and bisexual men (1)

☐ youth (2)

☐ women (3)

☐ seniors (4)

☐ transgender women (5)

☐ transgender men (6)

☐ Latinos (7)

☐ African Americans (8)

☐ Asian Pacific Islanders (9)

☐ Native Americans (10)

☐ Homeless (11)

☐ Substance users (12)

☐ sex workers (13)

☐ OTHER (14) _____

SAMPLE MIPA ASSESSMENT *continued*

Q21 In what ways are traditionally marginalized groups (e.g. sex workers, trans* people, injection drug users, youth, etc.) involved? (Click all that apply)

○ Explicitly part of mission statement (1)

○ Advisory group (2)

○ Board members (3)

○ Board membership required in by-laws (4)

○ General focus of services (5)

○ Employed as senior managers (6)

○ Employed as middle managers (7)

○ Employed as line staff (8)

○ None (9)

○ Other (10) _____

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Page Break ———————————————————————————————————

SAMPLE MIPA ASSESSMENT *continued*

SAMPLE MIPA ASSESSMENT   *continued*

Q22 Look at the following issues. Consider how serious they are for people living with HIV in your local area? (1-5, with 1 being "Not an issue" and 5 being "Serious issue for the entire HIV community")

	1) not an issue (1)	2) somewhat serious for a small part of the HIV community (2)	3) serious for about half of the HIV community (3)	4) serious for most of the HIV community (4)	5) serious for the entire HIV community (5)
Treatment access (1)	○	○	○	○	○
Quality healthcare (2)	○	○	○	○	○
Stigma (3)	○	○	○	○	○
Poverty (4)	○	○	○	○	○
Racism (5)	○	○	○	○	○
Sexism (6)	○	○	○	○	○
Homophobia (7)	○	○	○	○	○
Lack of community (8)	○	○	○	○	○
Substance abuse (9)	○	○	○	○	○
Erratic housing (10)	○	○	○	○	○
Erratic food provision (11)	○	○	○	○	○
Unemployment (12)	○	○	○	○	○
Places to socialize (13)	○	○	○	○	○

SAMPLE MIPA ASSESSMENT *continued*

Finding sex partners (14)	○	○	○	○	○
HIV criminalization laws (15)	○	○	○	○	○
Lack of political voice (16)	○	○	○	○	○
Under-resourcing HIV cure research (17)	○	○	○	○	○
Viral suppression (18)	○	○	○	○	○
Policies that reflect the science of HIV viral suppression (19)	○	○	○	○	○
Other (20)	○	○	○	○	○

SAMPLE MIPA ASSESSMENT *continued*

Q24 Please rate the following in terms of what would lead you to believe that people living with HIV are meaningfully involved in your organization from 1-5, with 1 being "Not meaningfully involved at all" to 5 being "absolutely meaningfully involved."

	1) Not meaningfully involved at all (1)	2) Somewhat involved (2)	3) Kind of involved (3)	4) We definitely have people living with HIV involved (4)	5) People living with HIV are absolutely meaningfully involved (5)
We got more funding for HIV services (1)	○	○	○	○	○
Senior management are people living with HIV (2)	○	○	○	○	○
Staff are out as people living with HIV (3)	○	○	○	○	○
Board members are people living with HIV (4)	○	○	○	○	○
We were featured in local media as an HIV service provider (5)	○	○	○	○	○
People living with HIV determine organizational communication content (6)	○	○	○	○	○
We increased HIV Pre-Exposure Prophylaxis efforts (7)	○	○	○	○	○
People living with HIV are featured in all organizational	○	○	○	○	○

SAMPLE MIPA ASSESSMENT   *continued*

website and printed materials (8)					
We enhanced our HIV testing services (9)	○	○	○	○	○
People living with HIV choose policy priorities (10)	○	○	○	○	○
We serviced more people living with HIV (11)	○	○	○	○	○
People living with HIV develop programs and initiatives (12)	○	○	○	○	○
Our point person to the HIV Planning Council is a person living with HIV (13)	○	○	○	○	○
The most marginalized people living with HIV are part of our advisory group (14)	○	○	○	○	○
Other (15)	○	○	○	○	○

SAMPLE MIPA ASSESSMENT *continued*

Q26 At the end of your project, what would be evidence that you had succeeded in involving MIPA/GIPA? (Please click all that apply)

○ Local Community Based Organizations commit to people living with HIV issues through statements (1)

○ People living with HIV are part of Board (2)

○ Local Community Based Organizations commit to people living with HIV issues through programs (3)

○ More people of color living with HIV will be able to tell their stories (4)

○ A social marketing campaign on people living with HIV will emerge (5)

○ There will be more focus on HIV criminalization reform locally or at state level (6)

○ People living with HIV are employed as staff (7)

○ There are more stories about people living with HIV in the media (8)

○ More politicians identify HIV as a key issue (9)

○ More politicians identify health care as a key issue (10)

○ More politicians identify sexual and reproductive rights as an issue (11)

○ Other (12) _____

Page Break

SAMPLE MIPA ASSESSMENT   *continued*

Q26 What do you think your biggest challenges will be to successfully implement MIPA/GIPA? (Select as many as apply)

☐ Fundraising (1)

☐ Recruiting people living with HIV (2)

☐ Developing curricula (3)

☐ Evaluation (4)

☐ Getting the right staffing on the project (5)

☐ Getting access to local politicians (6)

☐ Developing educational materials (7)

☐ Getting access to media (8)

☐ Other (9) _____

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Q25 Please let us know if there is anything you'd like us to know that we haven't asked

_____

_____

_____

_____

_____

End of Block: Default Question Block