

Ontario Organizational

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Think of the moment that inspired you to get involved in the movement.

What year was that?



For those of you who may be new to the sector, or those who may not be familiar with our organization...

- Established 1995
- Government response to ASO requests for long term organizational development (OD) support

Mission:

- To strengthen the capacity of ASOs and HIV-funded programs in Ontario to determine direction with awareness
- To foster a culture of taking responsibility for their own organizational development



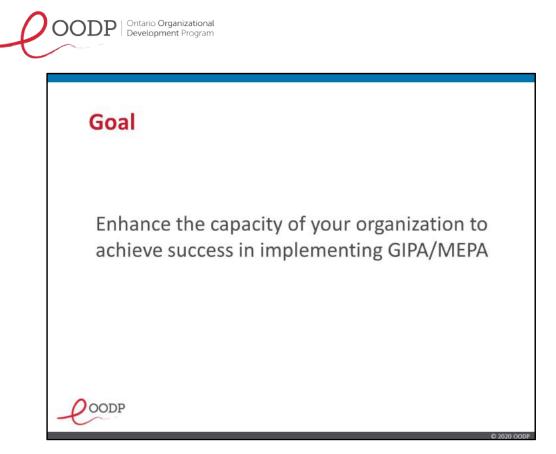
For complete description – visit our website at <u>www.oodp.ca</u>

Snapshot:

- Workshops (Governance, Boundaries, ARAO, GIPA/MIPA)
- Planning (Strategic Planning, Operational Planning, Annual Work Plans Staff and Board, Organizational Self-Assessment Tool, Board Self-Assessment Tool, Mergers/Partnerships)
- Coaching (Executive Directors, Board Chairs, Leading and Managing Change)
- Individualized Consult Requests



What we need for today...



Audience:

•AIDS Bureau funded agencies and programs

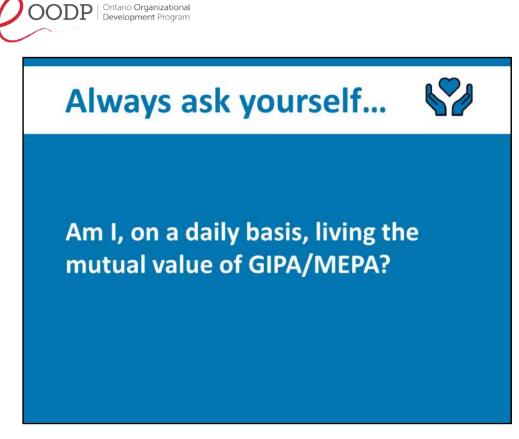
Focus:

The organizational development and operationalizing of GIPA/MEPA
Assumes that a commitment and basic understanding exists
Complements workshops that deepen personal understanding

Learning Objectives:

After completing this learning session, you will

1. Have an enhanced understanding of the importance of the greater involvement and meaningful engagement of people living with HIV/AIDS (GIPA/MEPA) in the organizations that represent them.



- While there exists strong commitment to the principles of GIPA/MEPA and powerful history as a sector, we still find organizations struggle with how to implement GIPA/MEPA in day-to-day activities and practices.
- Doing so successfully requires intentionality, commitment and planning.
- 'Living' the mutual value of GIPA/MEPA refers to the importance of building organizational culture of GIPA/MEPA - 'living' GIPA/MEPA rather than simply 'doing' or checking the box
- Another key factor in successful implementation of GIPA/MEPA is understanding that the implementation approach needs to be based on the understanding that GIPA/MEPA benefits the organization (and community) but also the individual PHA. Self-determined meaningful engagement is most often a part of an individual's selfcare and wellness.

Presentation Overview	
Definitions	
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Resources	
Reflection & Wrap-up	
OODP	



Does "greater" = "meaningful"?

• Provide examples of "meaningful" roles that compliment the assumptions often made that all PHAs want to move towards full time employment and any other engagement is not meaningful. What is meaningful to an individual is self-identified.

Other acronyms that have been suggested: MIPA, MIEPA, GIEPA, MEPA

- MIPA= Meaningful Involvement of People with AIDS (PWAs)
- MIEPA= Meaningful Involvement and Empowerment of PWAs
- GIEPA= Greater Involvement and Empowerment of PWAs
- MEPA= Meaningful Engagement of PHAs

At its most basic, GIPA means:

Recognizing the important contribution people living with HIV/AIDS (PHAs) can make in the response to the epidemic.

Creating space within organizations and society for their meaningful involvement and active participation in all aspects of that response.



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People Living with HIV?

PHAs are individuals who:

- Are HIV positive
- May be positive but don't know for certain
- Fully or partially disclose their HIV status
- Do not disclose their HIV status

Diversities of Persons living with HIV and AIDS includes persons based on:

1. Lived experience

- Prisoners
- People who use drugs

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- Injection drug users
- Sex workers
- Rural or urban dwellers
- Married, single, or divorced parents
- Living in poverty
- Living co-infected (HIV/HCV)
- Under-housed or homeless

2.Sexual orientation

- Gay or lesbian
- Bisexual
- Heterosexual

3. Racial/cultural background

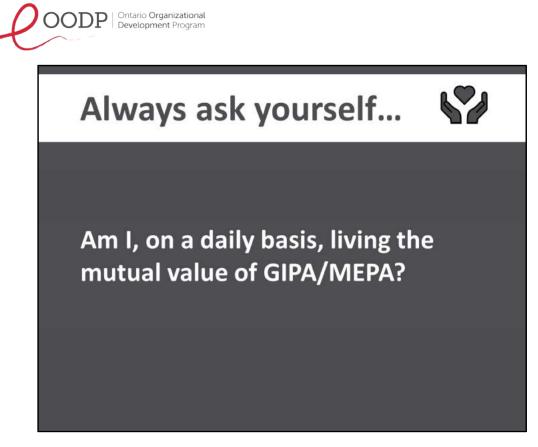
- Aboriginal, i.e., Métis, Inuit, First Nations
- Black/African/Caribbean
- Middle Eastern/Arab
- South Asian
- South East Asian
- White/European
- Bi-racial/multi-racial

4. Gender identity:

- Male
- Female
- Transgendered

In short, HIV/AIDS does not discriminate based on age, sex, race, sexuality, or roles we have in our life.

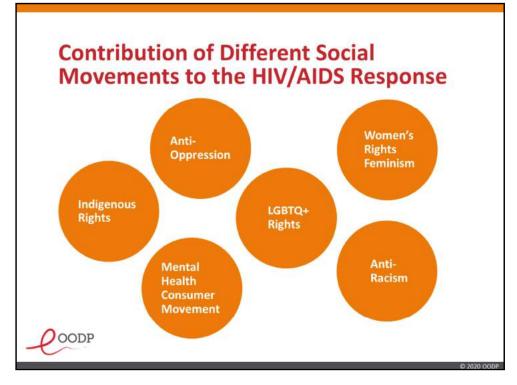
Some definitions of GIPA/MEPA reference 'people living with and affected by' HIV. There are complex discussions and emotions around this inclusion of affected individuals. One particular rationale for including this is to ensure that those who are not disclosed can be included.



Consider examples of how you could demonstrate living the mutual value of GIPA/MEPA within your organization.

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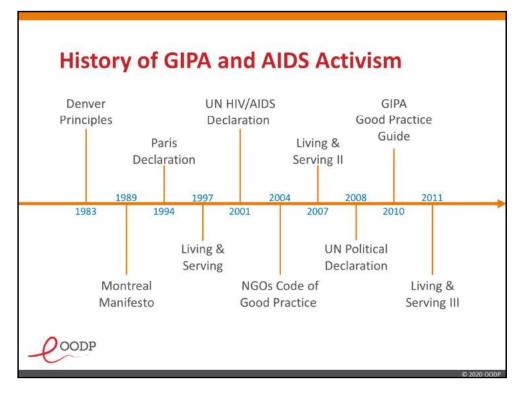
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In understanding the development of GIPA, it is useful to remember the other social movements that preceded and contributed to our community and global AIDS Responses. The Gay, Lesbian, Bisexual and Transgender rights movement was key in empowering gay men in North America and Europe who were among the first people recognized with HIV. At the same time, feminism had given birth to a women's health movement (manifest in such books as "Our Bodies, Ourselves") which declared that women had the right to control their own bodies in maintaining their health. As well, there was a consumer health movement, especially seen in psychiatry and mental health, that empowered people to reject the label of "patient" and demand to be recognized as consumers of health services; plus there was a growing movement around anti-racism, anti-oppression (ARAO) that refused to accept the inherent racism and classicism of a white dominated health and social service system.

These movements coalesced into a community HIV/AIDS Movement empowered by a growing awareness that health was not just determined by physical and medical factors like viruses and genetics, but critical social determinants of health like poverty and housing. The Community AIDS response developed their own key movements including GIPA and Treatment Activism around access and literacy which, as HIV became increasingly a global issue, joined with the movements for Global Economic Development and a Global Health Agenda to create a Global HIV/AIDS Response which is the current HIV/AIDS response.

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The Denver Principles (1983)

"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 historic statement articulated by the advisory committee of PLWHA in Denver 1983 remains equally relevant and powerful today when it continues to define the basic principles and goals of PLWHA activism. In fact, it was this group which coined the acronym "PWA'. (Ontario PWAs preferred the term PHA: Person with HIV or AIDS) The terms "patient", "sufferer" or "victim" were rejected in favour of a term which is both neutral and hopeful.

This example of individuals networking to share their experiences took place 2 years after HIV/AIDS appeared in North America, mainly among gay men. At that time, plans were being made to attend the 2nd National AIDS Forum, sponsored by the Lesbian and Gay Health Education Forum. A few people with AIDS began urging local AIDS organizations to sponsor other PWAs and to pay their expenses so they could attend. According to Michael Callen, one of the founders of the movement, "the idea struck like a bolt of lightening", that infected people could be more than simply passive



recipients of the very genuine care and concern of the uninfected - whether they be their friends or their doctors. The idea caught on like "wildfire". Before anyone really understood how HIV was being transmitted, the visionary Michael Callen proposed the first safer sex guidelines. This is an early example of how a courageous group of PHAs created a network of local groups that would eventually form a national association of PHAs ("from tiny acorns grow mighty oaks").

Montreal Manifesto (1989)

Tim McCaskell, a local PHA, leads a group of Canadian and international activists into the building and onto the stage where **the 5**th **International AIDS Conference** is taking place (June 1989) and demands that the conference make room for PLWHAs. The Montreal Manifesto calls for an international code of rights that is based on acknowledging and preserving the humanity of people with HIV disease. Community becomes an integral part of the international conferences in the years that follow.

Declaration of the Paris AIDS Summit – December 1, 1994

This meeting brought together the heads of government or their representatives from 42 countries (or "States") to come to consensus on the best way forward to slow the spread of HIV and to ensure treatments, support and care are made accessible to all who need them, declaring:

- The principle of Greater Involvement of People Living with HIV/AIDS (GIPA) is critical to effective and ethical national, regional and global responses to the epidemic.
- Further, that all persons living with HIV/AIDS are able to realize the full and equal enjoyment of their fundamental rights and freedoms.

In an emotional address to the summit, Yolanda Simon, a member of GNP+ from the Caribbean who is HIV-positive, challenged the delegates to follow through on their promises, especially the declaration's vow to "fully involve" organizations of people with AIDS in public policy decisions.

"Your policies for the last 10 years have driven most people living with HIV and AIDS underground," she said. "Many of them are dying in isolation. We are tired of the lip service that you have been paying to us. Now what are you going to do when the ink on your signatures has dried?"



At Opening of International AIDS Conference

"Access for All" & "Greed = Death" are Rallying Cries

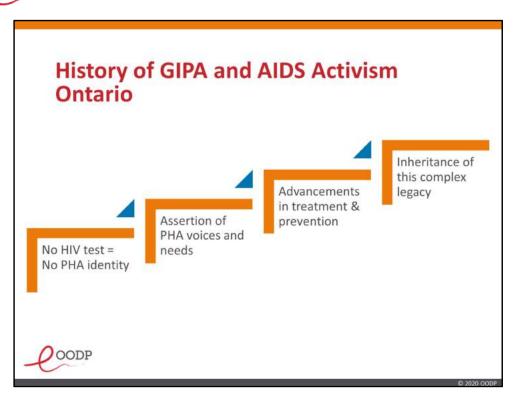
(Vancouver, July 7) -- Hundreds of AIDS activists from around the world demonstrated during the opening session of the IX International AIDS Conference. Members of the activist group ACT UP (the AIDS Coalition to Unleash Power) unfurled banners during the ceremony proclaiming "Roche, Merck, and Abbott: Greed = Death", and "Demand Access for All", threw bundles of "AIDS Profiteer" money into the air, distributed leaflets to conference attendees, and brought the ceremony to a halt with their chants, whistles, and sirens. Among their chants targeting drug companies were "greed kills! Access for all!."

"Silence = Death" became a popular slogan and rallying cry for many Act Up chapters in the 1980s

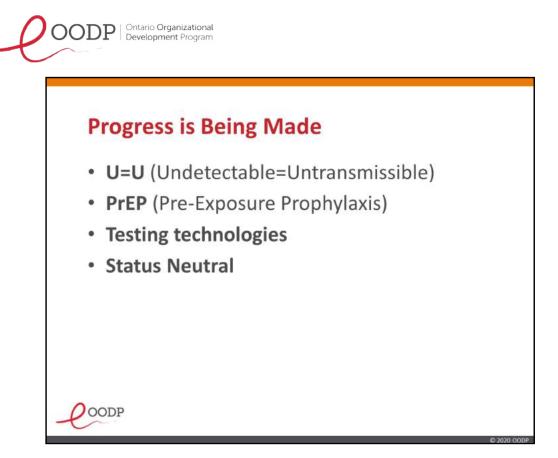
"Greed = Death" refers specifically to the perceived greed of the drug companies charging high prices for their medicines

"Access for all" has become a popular slogan that describes access to treatment (and prevention technologies and information) as a human rights issue

"Nothing about us without us" refers to the idea that no policy should be decided by any representative without the full and direct participation of members the group(s) affected by that policy. It has been used as a rallying cry by people who use drugs. ODP Ontario Organizational Development Program



- AIDS "committees" were formed by PHAs, friends and allies, many of them gay and lesbian.
- No HIV test meant no PHA identity. Once available, HIV testing was discouraged in the beginning no anonymity, no treatments, no human rights protection.
- People got sick and died very quickly sometimes within weeks. This greatly impacted staff and volunteers of ASOs (AIDS Service Organizations).
- Many ASOs became de facto lesbian and gay rights organizations.
- As more got tested, and later, HAART (highly active anti-retroviral therapy) was rolled out, people came out publicly as living with the virus: the PHA identity was born. We were no longer "all in this together". PHAs asserted their unique voices and needs. *How did they do this in your region?*
- With HAART, many PHAs experienced improved health and went back to work, left ASOs, gave themselves permission to step back from years of involvement to live lives less focused on AIDS.
- ASOs' client base also transformed to include more complex needs including poverty, housing, drug use, immigration, street-involvement, mental health.
- Further treatment and prevention advancements, such as U=U, transformed the lives and needs of those living with and affected by HIV
- ASO staff and volunteers inherit this complex legacy



All of these exciting and transformative treatment and conceptual advances for people living with HIV, have impacted GIPA/MEPA by challenging stigma and shifting personal priorities of what is meaningful.

U=U (Undetectable=Untransmissable) arose from a global community of people living with HIV, researchers, clinicians and community-based organizations through the Prevention Access Campaign. It arose to raise awareness around new science of HIV transmission. U=U has been transformative in the understanding of people with HIV, their friends and families, and those who work with them, that they can live long, healthy lives, have HIV-negative children, and never have to worry about passing on HIV to people they have sex with. This has opened up social, sexual and reproductive choices never before dreamt of. Equally or perhaps even more important, U=U has created an impetus for people living with HIV to see themselves differently by addressing sense of self-worth, public and self-stigma.

Pre-exposure prophylaxis (PrEP) is an HIV prevention approach where HIV-negative individuals use anti-HIV medications to reduce their risk of becoming infected if they are exposed to the virus. It is an additional tool for people to consider in the HIV prevention toolbox. Medication for PrEP was approved in Canada in 2016 and introduced new opportunities for prevention efforts beyond condom use. It also began to shift the onus of prevention from solely that of the PHA.



Testing technologies have advanced significantly with Point of Care testing and now home testing options. These advances along with the evolving evidence of optimal testing guidelines are reducing the wait time for test results and other barriers. It is giving more choice and placing more control with those needing to get tested.

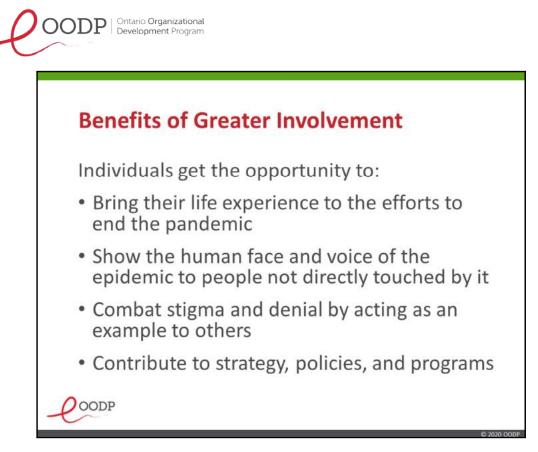
Status Neutral is an approach that emphasizes the value of all individuals, regardless of HIV status, are treated in the same way. At the point of testing and following test results, any result, positive or negative, kicks off further engagement with the healthcare system, leading to a common final goal, where HIV is neither acquired nor passed. This model was pioneered in New York City and not only improves overall care but further breaks down the distinction between HIV positive and HIV negative.



Always ask yourself...

Am I, on a daily basis, living the mutual value of GIPA/MEPA?

Benefits		

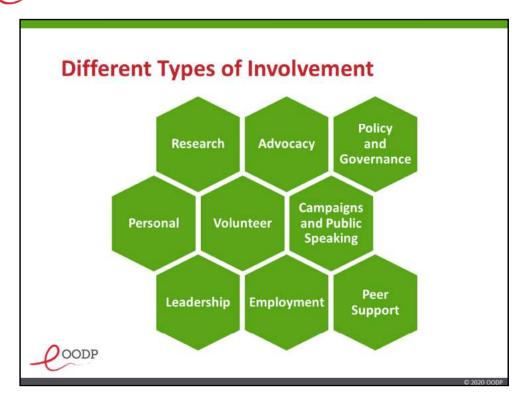


Our understanding of GIPA has shifted from a limited "greater involvement" to an expansive vision aimed at investing in people living with HIV, investing in the capacity building/advocacy role of PHA groups/networks, and investing in PHA leadership.

Individuals get the opportunity to:

- Use their experience of living with or being affected by HIV/AIDS in the greater response to the epidemic
- Give a human face and voice to the epidemic in the minds of people not directly touched by it
- Act as examples to others to combat stigma and denial
- Work as paid staff
- Contribute to policies and programs
- Help set strategic direction in governance

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Policy & Governance. Involved in policy development, on boards of directors, and advisory committees.

Advocacy. Involved in different forms of treatment, legal or human rights advocacy.

Research. Providing advice to researchers, being a peer research assistants or conducting community-based research.

Volunteer. Provide service in the agency and community.

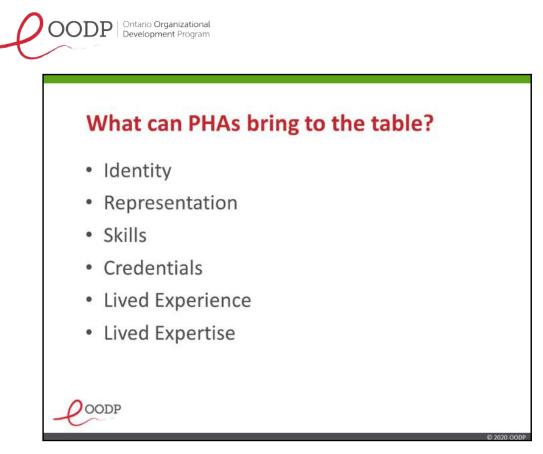
Peer Support. Providing support to other PHAs.

Campaigns and Public Speaking. Acting as spokespersons and doing public education.

Leadership. Taking a leadership role in support groups, networks and agencies.

Personal. Actively involved in one's own health and well-being.

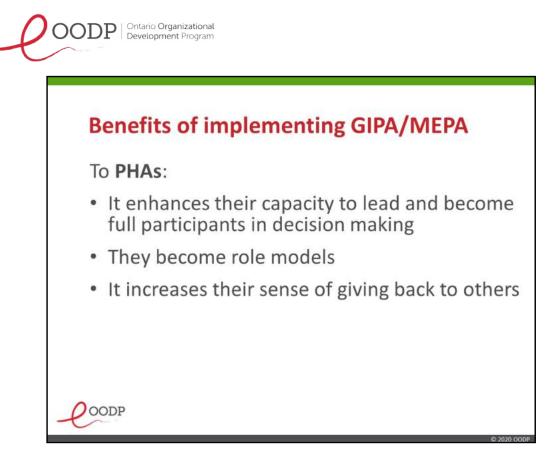
Employment. Paid work in the HIV sector.



In working at an agency, serving on a committee or a Board, PHAs can bring different things to the table.

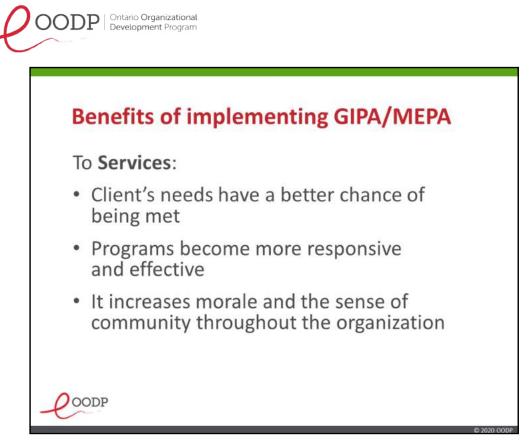
HIV status is an identity that draws on lived experience but also on other things individuals identify with (ethno-cultural background, gender, etc). Representation is how much PHAs choose to represent other people who share that identity. Lived experience is the sum total of experiences whereas skills are the specific competencies PHAs hold and credentials, the reflection of formal training. Lived expertise is a newer distinction and reflects intentional training and capacity building efforts towards a PHA applying their lived experience strategically at an organizational or system level.

Questions this raises include: Is GIPA/MEPA a skills set? Can one person represent all PLHIV (or all women, or all drug users)? As the HIV response is facing increased accountability, how do agencies balance skills, credentials, lived experience, and lived expertise?



Benefits for PHAs:

- PHAs become full participants in decisions affecting their care and support
- PHA capacity to participate and lead is enhanced; this can contribute to improved mental health, increased self-esteem and reduced sense of social isolation
- Increased knowledge creates a sense of empowerment
- Provides role models
- Increased sense of giving back to others
- Ensures that PHAs have the same protection of their human rights as other people



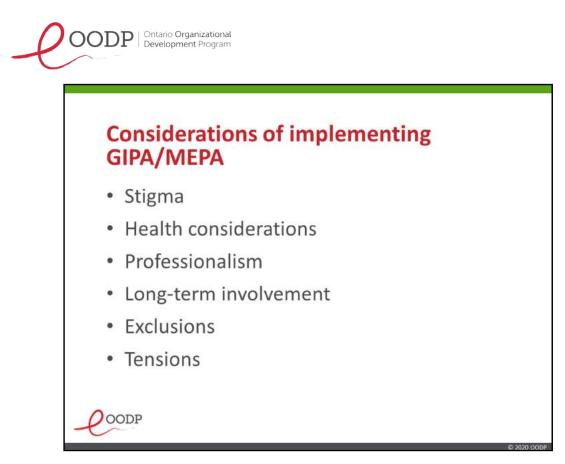
Benefit to services:

- Expertise and lived experience of PHAs improves services and their delivery; real needs have a better chance of being met
- Programs become more flexible, responsive and effective
- Staff and decision makers share power with PHAs; this can lead to an enhanced sense of community and higher morale throughout the organization
- Peer support offered by another HIV positive person
- Breaks down "service giver" vs. "service receiver" roles (PHAs provide a unique perspective of lived experience to the work place)
- Leads to more effective programs and policies when GIPA/MEPA principles are in place
- Improved communication, less stigmatizing, responsive to PHA needs
- Increased organizational credibility and accountability in the community



Community benefits:

- Involvement, knowledge, cultural connection of race, gender, socio-economic status
- Public acknowledgement helps to eliminate stigma and discrimination at all levels
- Involvement is a tool for breaking down internal barriers
- PHAs reinforce and validate prevention efforts
- HIV association is with a person and not a virus or a statistic
- Meaningful PHA involvement leads to increased community "buy in"
- GIPA/MEPA increases capacity-building and knowledge exchange for <u>all</u> stakeholders, e.g. researchers, healthcare providers



Considerations of implementing GIPA/MEPA

Stigma:

Particularly acute in smaller settings and smaller communities within larger cities

Concerns about confidentiality

Concerns about disclosure of HIV status and the increasing complexity of full or partial disclosure

Health considerations for PHAs as volunteers or staff:

Poor Health

Some PHAs may lose disability benefits if they work

Episodic nature of HIV may require them to have disability benefits as a fallback

PHAs who become staff may be reluctant to use services

Good health

Many PHAs are well enough to work in other fields

Some PHAs don't want to work in HIV and have to think about it all the time



Increasing 'professionalism' of AIDS organizations and services:

Increasing requirement for formal skills and education ("creeping credentialism") over lived experience and/or track record

Lack of support and training within organizations

Paying adequate compensation and benefits may be a challenge for an ASO with limited resources

ASOs viewed as less compassionate and more bureaucratic

Commitment to long term involvement:

Risk and fear of burn-out, exhaustion

Need to take a break from HIV-related work

Exclusion:

Some groups made to feel unwelcome at existing ASOs, e.g. women, Aboriginals

The increased diversity of PHAs is not well recognized

Ongoing issues of racism, homophobia and discrimination

Fear of loss of services if a service user is critical of existing practices

Tensions that may arise:

Power imbalances between and among staff and service users, HIV positive and negative people; this may require new approaches and ways to dialogue with PHAs

Resistance to change

PHAs feeling like tokens

PHAs who are volunteers experiencing tensions with PHAs who are staff

PHAs may feel undervalued because they are not paid or because they see little possibility of future paid employment with the ASO

Organization's lack of preparedness or willingness to involve PHAs – need for additional resources

Some PHAs believe that to work in HIV means that they are then excluded from dating or having sex with other PHAs who may be clients of the agency

Working with people whose lives may be chaotic or unstable, for example dealing with active drug use, being homeless or under-housed, facing mental health issues



Adapted from:

Living and Serving II: The Involvement of People Living with HIV/AIDS in the Community Based AIDS Movement in Ontario (2007)

Living and Serving 3: GIPA engagement guide and framework for Ontario ASOs (October 2011)



Always ask yourself...

Am I, on a daily basis, living the mutual value of GIPA/MEPA?

Resources		



OAN PLDI (PHA Leadership Development Institute)

1.Objective: Support individuals in connecting with their personal power. **2.Audience**: PHAs

2.Audience: PHAS

3.Focus: Animating GIPA at a personal level

4.Mission: PLDI exists with the purpose of supporting people who are living with HIV/AIDS to realize their leadership potential and increase their capacity to participate meaningfully in community life by challenging HIV stigma.

THN (Toronto HIV/AIDS Network)

1.Objective: Increase understanding and commitment of GIPA/MIPA among volunteers and staff who support volunteers in HIV-related work.

2.Audience: Volunteers & staff of Toronto ASOs (pos, neg, non-disclosed) **3.Focus**: GIPA/MIPA as it relates to volunteer roles

4.Mission: THN facilitated HIV/AIDS planning, collaboration, engagement and innovation to improve access to programs and services for people from diverse communities living with and most affected by HIV/AIDS.



Living and Serving was a 1996 study conducted and written by Dr. Charles Roy (who later became ED of AIDS Committee of Toronto) and funded by the Canadian AIDS Society. It examined the involvement of PHA's in the community AIDS movement in Canada. It is considered one of the first systematic studies of GIPA.

In 2006, the OHTN supported Evan Collins, Roy Cain and team of researchers to do a ten year follow up of Living and Serving among PHAs in Ontario. A link to Living and Serving II is in your resource list http://www.ohtn.on.ca/Documents/Publications/living_serving_report_April07.pdf

A third installment in the series of Living and Serving which offers concrete suggestions for implementing GIPA/MIPA at the agency level. This guide also contains the Ontario Accord, a statement of solidarity with GIPA/MIPA

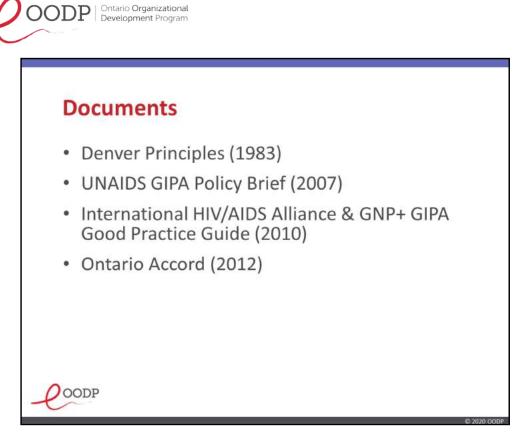
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PHA Capacity Building

- Ontario AIDS Network (OAN) Positive Leadership Development Institute
- AIDS Bereavement and Resiliency Program of Ontario (ABRPO) Turning to One Another
- Committee for Accessible AIDS Treatment (CAAT): Ethno-Racial Treatment Support Network
- OAN Living and Serving 3: GIPA engagement guide and framework

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- 1. <u>Ontario AIDS Network (OAN) Positive Leadership Development Institute (PLDI)</u> <u>https://oan.red/pldi/</u>
- 2. <u>AIDS Bereavement and Resiliency Program of Ontario (ABRPO) Turning to One</u> <u>Another</u> — <u>https://abrpo.org</u>
- 3. <u>Committee for Accessible AIDS Treatment (CAAT): Ethno-Racial Treatment Support</u> <u>Network</u> — <u>http://www.hivimmigration.ca/index.php/programs/pha-capacity-</u> <u>building/etsn-ethno-racial-treatment-support-network-learning-and-helping-out-</u> <u>peer-treatment-counselor-training/</u>
- <u>Committee for Accessible AIDS Treatment (CAAT): Legacy Project PHA Capacity</u> <u>Building Mentorship Program</u> — <u>http://www.hivimmigration.ca/index.php/programs/pha-capacity-building/legacy-pha-capacity-building/</u>
- 5. <u>Canadian AIDS Society (CAS): One Foot Forward: A GIPA Training Toolkit</u> <u>https://www.cdnaids.ca/?s=one+foot+forward</u>
- 6. <u>OAN Living and Serving 3: GIPA engagement guide and framework</u> <u>https://oan.red/living-serving/</u>
- 7. <u>HIV Code: NGO Code of Good Practice: Self-Assessment Checklist & Action Plan:</u> <u>Meaningful Involvement of PLHIV and Affected Communities (MIPA)</u> – <u>https://issuu.com/ippfresources/docs/meaningful_involvement_of_plhiv_self_asse</u> <u>ssment</u>



- 1. <u>Denver Principles (1983)</u> <u>https://www.seroproject.com/wp-content/uploads/2016/11/denver_principles-FINAL.pdf</u>
- <u>UNAIDS GIPA Policy Brief (2007)</u> <u>https://www.unaids.org/en/resources/documents/2007/20070410_jc1299-</u> policybrief-gipa_en.pdf
- 3. <u>International HIV/AIDS Alliance & GNP+ GIPA Good Practice Guide (2010)</u> <u>https://issuu.com/aids_alliance/docs/gpg-gipa-english</u>
- 4. Ontario Accord (2012) https://oan.red/ontario-accord/
- 5. <u>OAN U=U Position Statement (2018)</u> <u>https://oan.red/u-equals-u/</u>
- 6. <u>When PHAs First Sat at the Table (1989 ACT UP article)</u> <u>https://actupny.org/documents/montreal.html</u>
- 7. <u>Paris Declaration (1994)</u> <u>https://data.unaids.org/pub/externaldocument/2007/theparisdeclaration_en.pdf</u>
- From Principle to Practice: Greater Involvement of People Living with or Affected by HIV/AIDS (1999) — https://data.unaids.org/publications/irc-pub01/jc252-gipai_en.pdf
- 9. <u>ICW Bearing Fruit http://oodp.ca/media/ICW-Bearing-Fruit.docx</u>



- 10. <u>Living and Serving II (2007)</u> <u>http://www.ohtn.on.ca/Documents/Publications/living_serving_report_April07.pdf</u>
- 11. <u>Global Network of PLHIV (GNP+) GIPA Report Card</u> <u>https://www.gnpplus.net/our-solutions/gipa-report-card/#:~:text=GIPA%20Report%20Card%20%2D%20GNP%2BGNP%2B&text=The%20GIPA%20Report%20Card%20is,and%20the%20Declaration%20of%20Commitment.</u>
- 12. <u>An "HIV status neutral" paradigm shift (2019)</u> <u>http://blog.catie.ca/2019/11/04/an-hiv-status-neutral-paradigm-shift/</u>
- 13. <u>Practice Guidelines in Peer Health Navigation for People Living with HIV (2018)</u> <u>https://www.catie.ca/en/peernavigation-guidelines#practice</u>



Always ask yourself...

Am I, on a daily basis, living the mutual value of GIPA/MEPA?

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Being **connected** is fundamental to health and well-being. This is particularly important for people living with and affected by HIV who can be more isolated and often have less access to traditional support networks.

Meaningful engagement is self-directed and fluid. What is meaningful for one person at a given time is completely different than what might be meaningful for someone else.

Organizational capacity to provide the best possible services relies on GIPA/MEPA. Note that this is only one important aspect of effectively implementing GIPA/MEPA.

For many, meaningful engagement and **giving back and helping others** is part of their wellness and self-care.

We've all experienced times in our lives when we were re-energized to **pursue personal goals.** Imagine how incredibly powerful this feels for individuals whose HIV diagnosis put personal goals on the sidelines, sometimes for years.

Progress in the response to HIV has moved us from a no-PHA identity in the early days to a strong and critical PHA voice, and further evolving to the nuanced status neutral framework. Now, as much as ever, supporting organizations in successfully implementing GIPA/MEPA is fundamental.

The work of ASOs literally changes lives. Understanding GIPA/MEPA, its powerful history and how you can contribute to it in your roles on a daily basis, helps you to be an effective part of this incredible work.



Now that you know more about GIPA/MEPA, what can you do to contribute to it in your roles on a daily basis?



