2011

Living and Serving 3:

GIPA engagement guide and framework for Ontario ASOs

Ontario AIDS Network

October 2011

Dedicated to the memory of the late Dr. Charles Roy and the more than 27,000 people who are HIV positive in Ontario

This disease will be the end of many of us, but not nearly all. And the dead will be commemorated, and we'll struggle on with the living, and we are not going away. We won't die secret deaths anymore. The world only spins forward. We will be citizens. The time has come.

Tony Kushner, *Angels in America*

Living and Serving 3 is a GIPA project hosted by the Ontario AIDS Network

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A statement of solidarity with GIPA/MIPA

We, people living with HIV/AIDS and allies in the community:

- Commit to the greater involvement and meaningful engagement of people living with HIV/AIDS (GIPA/MIPA); GIPA/MIPA puts PHAs at the centre and is grounded in human rights and the dignity of the full human being
- Aim to transform all who live with, work in, and are affected by, HIV/AIDS in Ontario
- Commit to personal and social transformation
- Value community expertise in embracing the challenge for the betterment of society
- Value inclusion over exclusion, a quest for integrity at all times and the embodiment of self-determination
- Promote the evolution of thought, action and collaboration among us and with our allies

Because GIPA/MIPA is about human struggles and aspirations, ethics, empowerment and accountability are its foundation.

This Accord was created by representatives of Ontario organizations at a Living and Serving 3 consultation meeting in July 2011

1.0 Foreword

Welcome to *Living and Serving 3,* a GIPA wise practices guide and engagement framework for AIDS service organizations. It has been 17 years since the Paris Declaration stated the fundamental rights of people with HIV to self-determination and their centrality in the decision-making processes that affect their lives. Today, in 2011, GIPA, the greater involvement of people with HIV/AIDS, remains a core principle and challenge for AIDS service organizations (ASOs) and other organizations serving people with HIV/AIDS. GIPA is always a work in progress -- a continual process of renewing our commitment and ensuring that our practices at all levels of our organizations ensure the engagement, investment and participation of people with HIV/AIDS.

This document builds on the work done by the Ontario AIDS Network (OAN) and the Ontario HIV Treatment Network in supporting *Living and Serving II*, a ten-year progress report on GIPA in Ontario ASOs published in 2007. *Living and Serving II* was the outcome of research conducted by the Ontario HIV Treatment Network and led by Dr. Roy Cain and Dr. Evan Collins. It built on the pioneering work of Dr. Charles Roy, the author of *Living and Serving* (1995).

This guide and framework document also builds on OAN's commitment to GIPA through the Positive Leadership Development Institute. Although this document focuses on AIDS service organizations in Ontario, we acknowledge that this is only part of the picture of the reality of persons with HIV/AIDS today and that much additional work needs to be done.

We hope that you will find this guide and engagement framework helpful in reaffirming your commitment to GIPA in principle and in practice.

Stacey Mayhall
Co-Chair
Ontario AIDS Network

Jay Koornstra
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Ontario AIDS Network

Rick Kennedy
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Executive Director
Ontario AIDS Network

1.1 Foundations

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".

...[to People with AIDS]: Be involved at every level of decision-making and specifically serve on the boards of directors of provider organizations.

Montreal Manifesto (1989): ... An international code of rights must acknowledge and preserve the humanity of people with HIV disease. This code must include: ... active involvement of the affected communities of people with HIV disease in decision-making that may affect them.

Paris Declaration (1994): ...Support a greater involvement of people with HIV/AIDS through an initiative to strengthen the capacity and coordination of networks of people with HIV/AIDS and community-based organizations. By ensuring their full involvement in our common response to the pandemic at all – national, regional and global – levels, this initiative will, in particular, stimulate the creation of supportive political, legal and social environments. [This is usually considered to be the fundamental GIPA declaration.]

United Nations General Assembly Special Session on HIV/AIDS (UNGASS) 2001: Resolution reaffirming GIPA as expressed in the Paris Declaration.

United Nations High-Level Meeting on HIV/AIDS (2006): Reaffirmed support for the greater involvement of people with HIV.

NGO Code of Good Practice – Global Network of People Living with HIV/AIDS and Asia Pacific Network of People Living with HIV/AIDS: We advocate for the meaningful involvement of people with HIV/AIDS and affected communities in all aspects of the HIV response; We foster active and meaningful involvement of people with HIV/AIDS and affected communities in our work.

The Ontario Accord - **A statement of solidarity with GIPA/MIPA (2011)**: This statement was created by representatives of Ontario organizations during a meeting in Toronto in 2011.

We, people living with HIV/AIDS and allies in the community:

- Commit to the greater involvement and meaningful engagement of people living with HIV/AIDS (GIPA/MIPA); GIPA/MIPA puts PHAs at the centre and is grounded in human rights and the dignity of the full human being
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1.2 Acronyms

APHA: Aboriginal person with HIV/AIDS

ASO: AIDS service organization

CATIE: Canadian Treatment Information Exchange

GIPA/MIPA: Greater involvement of people with HIV/AIDS/ Meaningful involvement of people with HIV/AIDS

HIV/AIDS: Human immunodeficiency virus/Acquired immune deficiency syndrome

HR: Human resources

OAN: Ontario AIDS Network

OCHART: Ontario HIV/AIDS Reporting Tool

OHTN: Ontario HIV Treatment Network

PHA: Person with HIV/AIDS. Persons with HIV/AIDS are also known as PWAs and PLWHAs

UNAIDS: United Nations Joint Programme on HIV/AIDS

UNGASS: United Nations General Assembly Special Session on HIV/AIDS (2001 and subsequent meetings in 2006 and 2011)

2.0 Acknowledgements

The Ontario AIDS Network acknowledges with thanks the work of all those who have championed GIPA and have practised it in their work. In particular, we wish to acknowledge the contributions of:

- Dr. Charles Roy, who pioneered this work with his 1995 study *Living & Serving, Persons with HIV in the Canadian AIDS Movement*
- Drs. Roy Cain and Evan Collins, authors of *Living & Serving II: Ten Years Later – The Involvement of People Living with HIV/AIDS in the Community AIDS Movement in Ontario* and the members of their research team
- Members of the three Working Groups who have furthered the work in Ontario of *Living & Serving II*
- Thousands of people with HIV/AIDS and their associates around the world who have championed and actualized GIPA through their research, publications and work
- The Canadian AIDS Society for its development of *One Foot Forward*, a GIPA training toolkit and facilitator's guide
- All those who have contributed to the development of this guide and framework through consultations in 2010-2011
- Rick Kennedy who guided the entire project, David Hoe who facilitated the process and developed the Framework, and Janet Dunbrack who wrote the Guide

OAN acknowledges with gratitude the financial and material support of the Ontario AIDS Bureau. The views presented in this document do not necessarily reflect the views held by the Ontario AIDS Bureau and the Government of the Province of Ontario.

3.0 Introduction

GIPA, the greater involvement of people with HIV/AIDS, has been a guiding principle of the HIV/AIDS movement for almost three decades. GIPA is never achieved once and for all; it is a goal and commitment that must be continually renewed. GIPA is a practice, not a project, and is similar to all other accountabilities of healthy HIV organizing and service delivery. Our practices in AIDS service organizations (ASOs) must be continually re-evaluated in light of the changing realities of HIV/AIDS and of those living with it.

GIPA principles often refer just to persons living with HIV/AIDS. The Ontario individuals and organizations that participated in the consultations for Living and Serving 3 affirm that GIPA concerns all who live with, work in, and are affected by, HIV/AIDS. Another way of stating this is that GIPA engages PHAs and their allies in a culture of inclusivity. Although this document focuses on more strongly on the PHA component of GIPA, it is intended to foster an expanding and inclusive approach that embraces PHAs in all their diversity and circumstances and includes those affected by HIV/AIDS and all allies. The principles and concrete actions discussed in this document can be applied to diverse and expanding communities.

Engaging in GIPA can be challenging. Barriers such as stigma, the tendency to see people who are HIV positive as clients in need of support, and competing demands on time and resources in organizations stretched to the limit, can result in the under-involvement of PHAs in all aspects of the organization.

Engaging in GIPA requires conscious attention, without which the daily operational demands of an ASO can seem to be the most important. This conscious attention requires intentionality and accountability that are meaningful and demonstrate that the agency sees beyond service alone.

This *Living and Serving 3* document, containing a wise practices guide and engagement framework, is intended to help Ontario ASOs put GIPA principles into practice.

The guide and framework are one outcome of a process of consultation and identification of needs. Following the publication of *Living and Serving II* in 2007, three working groups were set up to reflect on the recommendations in that report. The Working Groups are: Values and Code of Practice; Capacity Building, Enhancement and Accreditation; and Implementation and Monitoring. Among the many recommendations made by the working groups was the dissemination of best practices and profiles of success in acting on GIPA. The working groups thought that this would help determine more consistent standards in skills and capacity building by ASOs.

In early 2011, a process of consultation began to explore how PHAs and ASOs are experiencing GIPA and what needs to be done next. Meetings were held with focus groups in London and Toronto, composed of ASO members and HIV-positive individuals, which resulted in wide-ranging discussions about the realities of PHAs and their ability and desire to be involved. The desire for standards, accountability, a strength-based GIPA model and capacity building were among the ideas that surfaced. The decision was made to create this wise practices guide and framework for GIPA engagement.

The guide (Sections 1-7) describes the evolution of GIPA and the models used to visualize it, the meaning of GIPA for ASOs today, and suggested ways of engaging with GIPA more fully in your ASO. Various types of PHA involvement are described, each with its benefits and challenges. In each case, a real-life example from an ASO in Ontario or elsewhere is included. Ways of investing in PHA capacity for involvement and leadership are suggested. A section on monitoring and accountability of ASO success in GIPA engagement includes a GIPA report card and various evaluation checklists for organizations adapted from international examples.

The engagement framework (Section 8) aims to provide a set of structures for ASOs to:

- Assess current relationships and practices of GIPA/MIPA
- Develop an organizational mind-set about GIPA/MIPA
- Determine a progressive, sustainable and measurable plan to honour GIPA/MIPA
- Monitor and set up accountability practices to deepen the progression and sustainability of GIPA/MIPA

The final section of this document provides links to resources.

4.0 GIPA to MIPA: a foundation for the HIV/AIDS movement

4.1 Evolution of GIPA to MIPA

Living and Serving 3 is a link in a process going back at least three decades, beginning with the Denver Principles of 1983. You'll find the key foundation statements at the beginning of this document. The following words are not included in the formal declarations of GIPA, but they sum up what people with HIV/AIDS have been affirming for three decades: *Nothing about us without us*.

GIPA is grounded in human rights. The United Nations Universal Declaration of Human Rights (1948) and the Canadian Charter of Rights and Freedoms (1982) recognize the inherent dignity and freedom of every person and the right to freedom from discrimination. This grounding in human rights includes the right to self-determination and participation in decisions that affect a person's life.

Since the Paris Declaration of GIPA in 1994, our experience with living out GIPA has caused many people with HIV/AIDS and several international organizations to prefer the term MIPA: Meaningful Involvement of People with HIV/AIDS. This change resulted from the experience of some PHAs of being involved as tokens by organizations that were demonstrating their practice of GIPA, rather than involving PHAs in meaningful ways where they have a real voice in decision making and leadership and where their expertise and lived experience are both sought and valued. MIPA also can mean that a significant percentage of leadership or representation positions in organizations are occupied by PHAs, rather having only one or two PHAs without true decision-making power, which can be tokenism.

4.2 Foundation work

Living & Serving I and II

There have been many important documents written about GIPA. Some of these are listed in the resource section at the end of this document if you wish to learn more. Pioneering GIPA work has been done by Canadians.

Dr. Charles Roy was a Canadian HIV/AIDS activist and a PHA. He was the Executive Director of the AIDS Committee of Toronto (ACT) until shortly before his death in 2002. His 1995 doctoral thesis, *Living & Serving*, described the advantages and barriers associated with GIPA, and made a series of recommendations for increasing PHA involvement. His research showed that among Canadian AIDS Society member organizations across Canada, more than 80% had at least one PHA board member, but that the total number of PHA board members was low. In terms of staff, nearly 63% had no PHA staff members. Close to 64% of organizations that had PHA staff had fewer than 30% PHAs.

Ten years later, *Living & Serving II* reported that things in Ontario had improved but that much remained to be done. 33% of the 30 organizations reporting had no self-declared PHAs on staff but more than 75% of organizations reported having hiring policies to encourage PHA applications. 90% of the organizations had at least one self-declared PHA on the board of directors, but the largest group had fewer than 25% PHA board members. Most organizations had PHAs involved as volunteers. The study found that, since Charles Roy's work, things had improved regarding PHA representation on staff, but that board representation had stayed at similar levels or had slipped. Among the recommendations of *Living & Serving II* was a yearly internal review of PHA involvement by organizations and the use of existing templates (or the development of new ones in their absence) that promote best practices in PHA involvement.

The three working groups established to work on the *Living & Serving II* recommendations called for: improved hiring and workplace practices, including work on stigma and discrimination; a variety of capacity and skills building approaches for PHA leadership development; and the development of annual reviews to promote greater compliance with GIPA by organizations.

UNAIDS documents: pyramids to circles

The Joint United Nations Programme on HIV/AIDS (UNAIDS) has published several documents promoting GIPA. Two of the most significant are *From Principle to Practice: Greater Involvement of People Living with or Affected by HIV/AIDS (GIPA)* (1999) and a Policy Brief on GIPA (2007).

The 1999 UNAIDS paper contained the GIPA pyramid of involvement which has been reproduced in many documents. It appears in Figure 1 below.

Figure 1. A pyramid of involvement by PWHAS

This pyramid models the increasing levels of involvement advocated by GIPA, with the highest level representing complete application of the GIPA principle. Ideally, GIPA is applied at all levels of organization.

DECISION MAKERS: PWHAs participate in decision-making or policy-making bodies, and their inputs are valued equally with all the other members of these bodies.

EXPERTS: PWHAs are recognized as important sources of information, knowledge and skills who participate – on the same level as professionals – in design, adaptation and evaluation of interventions.

IMPLEMENTERS: PWHAs carry out real but instrumental roles in interventions, e.g. as carers, peer educators or outreach workers. However, PWHAs do not design the intervention or have little say in how it is run.

SPEAKERS: PWHAs are used as spokespersons in campaigns to change behaviours, or are brought into conferences or meetings to “share their views” but otherwise do not participate. (This is often perceived as "token" participation, where the organizers are conscious of the need to be seen as involving PWHAs, but do not give them any real power or responsibility.)

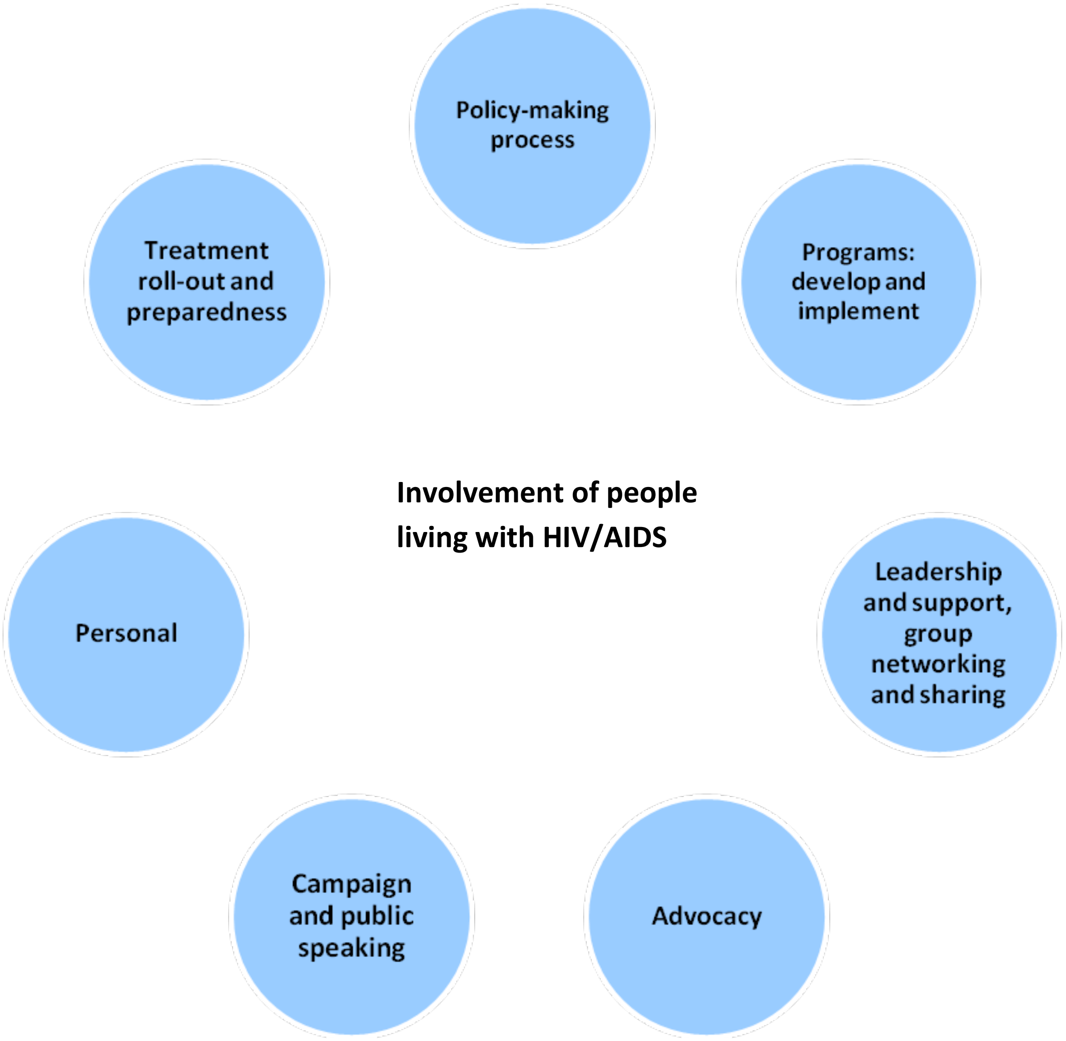
CONTRIBUTORS: activities involve PWHAs only marginally, generally when the PWHA is already well-known. For example, using an HIV-positive pop star on a poster, or having relatives of someone who has recently died of AIDS speak about that person at public occasions.

TARGET AUDIENCES: activities are aimed at or conducted for PWHAs, or address them en masse rather than as individuals. However, PWHAs should be recognized as more than (a) anonymous images on leaflets, posters, or in information, education and communication (IEC) campaigns, (b) people who only receive services, or (c) as "patients" at this level. They can provide important feedback which in turn can influence or inform the sources of the information.

In a 2007 policy paper on GIPA, UNAIDS reaffirmed the grounding of GIPA in human rights: *People living with HIV are entitled to the same human rights as everyone else, including the right to access appropriate services, gender equality, self-determination and participation in decisions affecting their quality of life, and freedom from discrimination*.

Interestingly, the GIPA pyramid used in the 1999 UNAIDS paper (Figure 1) was replaced in the 2007 paper by a less hierarchical, more fluid representation – a set of circles. See Figure 2 below.

Figure 2. A GIPA circle of involvement



This representation of GIPA involvement is less hierarchical than the earlier pyramid and conveys the message that all types of involvement have value, but that leadership and meaningful power-sharing are still important. Most of the activities in the circles are self-explanatory. Personal involvement is defined in the UNAIDS policy brief as: *People living with HIV are actively involved in their own health and welfare. They take an active role in decisions about treatment, self education and adherence, and positive prevention.* This new GIPA model reflects the reality that GIPA is moving in the direction of including greater involvement by PHAs in their personal concerns, including care and support.

UNAIDS continues to incorporate GIPA into all its work. The UNAIDS Strategy for 2011-2015 reaffirms commitment to GIPA and recognizes GIPA's contribution to "exceptional global solidarity".

Other recent resources

Canadian AIDS Society

The Canadian AIDS Society published a GIPA training toolkit in 2009: *One Foot Forward*. This resource is a collection of seven educational modules designed by and for PHAs to assist them in building capacity and acquiring leadership skills that promote their greater and more meaningful involvement in communities. The modules can be worked on by individuals on their own or in groups. The toolkit can be used by people in areas where no training sessions are available or where an ASO may lack the funds to bring in trainers. Topics include: understanding GIPA; leadership; identity, diversity and disclosure; ASOs; boards and governance; and working effectively in groups. Additional modules are planned for youth and for treatment options. This series is a useful resource for ASOs seeking to invest in building capacity with PHAs. A step-by-step facilitator's guide is available for the toolkit, which can be used by ASOs to support PHAs and others to work through the modules. Many ASOs are focusing on Module 4, *Boards and Governance*, to build capacity for both PHA and non-PHA board involvement.

Positive Leadership Development Institute

The Positive Leadership Development Institute™ (PLDI™) exists to support people with HIV/AIDS to realize their leadership potential and increase their capacity to participate meaningfully in community life. A partnership between the Ontario AIDS Network and the Pacific AIDS Network, the PLDI honours the leadership of the past, values the leadership of today and inspires leadership for the future. Those who have completed Level 1 represent 3,167 years of lived HIV experience.

The following curriculum objectives of the leadership training provide participants with the opportunity to:

- Understand the 5 principles and 10 commitments of leadership
- Realize individual leadership potential
- Participate in building a network of leaders within the PHA community
- Realize the potential and strengths that each individual brings to the network
- Learn about and practise leadership skills in a safe environment
- Inspire others to become leaders
- Encourage participants to take on facilitator and mentoring roles in the community
- Expand participants' awareness of our community

The PLDI™ training includes three levels:

- Level I: Who am I as a Leader?
- Level 2: Bored? Get on Board!
- Level 3: Communications

The main objectives of Level I- *Who am I as a Leader?* are to:

- Identify personal values and philosophy
- Develop leadership skills and practices
- Gain community knowledge and awareness

The primary focus of Level 2 - *Bored**?** Get on Board**!*** is board governance and will include presentations and discussions on:

- The voluntary sector in Canada
- Board governance models
- Board accountability/ responsibilities
- Bylaws/policies/procedures
- Understanding committee structures and purpose
- Other topics related to serving on a Board of Directors

Level 3 - *Communications* skills training will explore the following topics through presentations, group work and discussions:

- Conducting effective meetings

- Active listening
- Dealing with difficult situations
- Effective feedback
- Decision making strategies
- Public speaking – the basics
- Developing effective presentations

International HIV/AIDS Alliance and GNP+

A valuable GIPA guide was published in 2010 by the International HIV/AIDS Alliance and the Global Network of People Living with HIV (GNP+): *Greater Involvement of people living with HIV (GIPA): Good Practice Guide.* This guide is intended mainly for organizations in the global South but is useful for ASOs in all regions. The image chosen to represent GIPA involvement in this guide is a tree rooted in GIPA principles and nourished by good organizational practices. The three main branches of the tree are: Better local responses to HIV; Programs and policies are tailored and responsive; and Increased self-determination and personal development for PHAs. The guide includes examples of good practice and checklists for organizations to measure their progress in implementing GIPA. Some of these evaluation checklists are adapted in section 7 of this document.

4.3 Another way of visualizing GIPA

GIPA can be visualized in many other ways. A way that emerged from discussions about this document is to see GIPA as a fan-shaped dynamic which puts the individual PHA at the source and fans out as the person becomes increasingly involved with others through community and organizations. All places on the fan can be occupied at the same time. Personal development can be ongoing while one is involved in many relationships and activities with others. The levels of involvement are coherent and pivot around the PHA. This is represented in Figure 3 below.

Figure 3: A GIPA fan of living and breathing

4.4 Changes in PHA populations require innovative responses

Since the 1994 Paris Declaration of GIPA, the dynamics of HIV/AIDS have changed, as have PHA populations and needs. In Canada and many other global North countries, the advent of anti-retroviral treatments in 1996 and subsequent treatments have radically altered the experience and management of living with HIV.

Persons with HIV/AIDS in many cases now enjoy good health. Many have returned to work in non-HIV/AIDS environments that offer better benefits and higher pay scales without the need to be “the workplace PHA”. Many have less time and may have reduced connection and interest in ASO work. Some have expressed this change as wanting their lives to be centered on things other than an identity that is virus-based. For some ASO employers, this situation is a shift from *PHAs are too sick to work here* to *PHAs are too well to be here*.

The addition of a personal dimension of GIPA in the 2007 UNAIDS policy brief (Figure 2 above) reflects the growing movement toward grounding GIPA in the personal development of the individual PHA. Building a foundation of dignity, self-worth and rights and responsibilities toward the self and the community can provide the point of origin for GIPA. Each PHA can craft what GIPA means to her or him and can connect to the ASO to create together a meaning that is resonant for both.

Affected populations appear to be more diverse than they were in 1994. Gay men still comprise the largest group of PHAs and newly-infected persons in Canada,[1] but women, Aboriginal peoples, ethnocultural communities, people who use injection and other drugs, prisoners, sex workers, youth, and poor and marginalized people are now recognized among the populations affected by HIV/AIDS. This diversity presents a challenge to AIDS service organizations serving a variety of people with widely differing needs. In larger centres, specialized ASOs have been created to serve specific populations.

Reaching the unaffiliated

The Public Health Agency of Canada estimates that between 19% and 35% of PHAs do not know that they are positive, depending on which population they are identified with.[2] If we assume

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[1] The population at highest risk of new infections is still men who have sex with men. Some of these do not necessarily self-identify as gay men. Public Health Agency of Canada. 2010. *HIV and AIDS in Canada: Surveillance report to December 31, 200*9.

[2] Estimates of HIV prevalence and incidence in Canada 2008. Public Health Agency of Canada. www.phac-aspc.gc.ca/aids-sida/publication/survreport/estimat08-eng.php

for convenience that an average of 25% of PHAs are unaware of their status, then close to 7,000 people of the estimated 27,000 persons with HIV in Ontario[3] are unaware and not seeking treatment from the health care system or support from ASOs.

It may also be true that most people with HIV are now working since statistics confirm that in December 2008, there were 3,157 recipients of Ontario Disability Support Program payments as a result of HIV as a primary or secondary diagnosis. The number of people on private disability insurance for HIV in Ontario is unknown.

In addition, recent estimates indicate that only a fraction of people with HIV/AIDS are connected to ASOs in Ontario. According to OCHART figures, only 5000 PHAs in Ontario regularly use ASO services. [4] This represents 23% of those who know they are living with HIV and 19% of total PHAs.

If ASOs consider their mandate to include serving all persons with HIV/AIDS, then they are not reaching almost 80% of the PHAs who know they are living with HIV. Whether or not this is a problem is for ASOs to determine. A study conducted in 2005 found that users of Ontario ASO services have complex needs. They are, on self-report, poorer, significantly less healthy, less able to sustain normal activities and more often depressed than those who did not use these services.[5] As many have observed, ASOs today are largely social service providers and most are stretched to the limit in providing services to existing service users.

The reality that most PHAs are not ASO-affiliated raises questions. Are ASOs offering services that are needed and valued by the majority of people who are HIV-positive? Do the unaffiliated have unmet needs and want to be reached by ASOs? For people who work, the ASO may have inconvenient hours or programs that don't reflect their lived reality, such as residual disclosure and workplace issues. How willing are ASOs to engage in new outreach to the unaffiliated? How can they be reached? Do new organizations or new facets of existing organizations need to be created?

Informal evidence shows that many populations are finding alternate ways of connecting as people and as PHAs. Social networking sites are filling needs for connection and belonging. Some of the men using these ways of connecting find alternatives such as the bar scene unwelcoming and experience stigma in these venues if their HIV status is known. They also report not feeling at home in ASOs because of the diversity of populations served. In the words

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[3] Ontario Ministry of Health and Long-Term Care. Ontario HIV and AIDS Infection Rates in 2008. http://www.health.gov.on.ca/english/public/program/hivaids/general/charact_epidemic.html

[4] Ontario Community HIV/AIDS Reporting Tool. https://www.**ochart**.ca/

[5] Williams, P. and others. 2005. Characteristics of People Living with HIV Who Use Community-Based Services in Ontario, Canada: Implications for Service Providers. *J. Association of Nurses in AIDS Care* 16(4) [July/August]: 50-63.

of one man, *I don't recognize myself in the ASO*. *My needs are not housing or disability payments. My experience of HIV is isolated and is even more so in an ASO.*

PHAs are responding to some of these needs through the growing use of electronic social media. GIPA is active when social networks, Facebook, Twitter and blogs are used to encourage participation and involvement with a community defined by PHAs. Examples are POZIAM in the US and PositiveLite.com in Canada, both founded by PHAs. Linking to these networks gets around problems of confidentiality and geographic isolation. Communities of interest can be formed on a variety of issues, given the potentially large numbers of people joining in. Advocacy is an obvious activity that benefits hugely from social media, and communication about a variety of other issues (including treatment news). Skills building can use electronic media in interactive ways. A community of kindred spirits on line can help to create connection and break social isolation. The benefits are many and new ways of connecting and acting are continually being developed. GIPA lives online. Yet the question remains: Does cyber communication create a community that supports disclosure and connection?

The fact remains that there are many PHAs whose needs for social support are not being met. Many do not have access to technology and some may lack the training or means to participate. ASOs will have to decide whether they want to take on this aspect of engagement with GIPA/MIPA. The question is: How organizations work with PHAs to engage in GIPA/MIPA when most PHAs are not affiliated with ASOs? Organizations have traditionally sought to live out GIPA with their existing service users. Is there a mandate in the HIV/AIDS movement to ensure that PHAs who access care in health care centres, general service clinics, social networking hubs in buildings or in cyberspace are full participants and leaders in their care and support? These questions require innovative solutions.

ASOs can also live in cyberspace and connect with a community of unaffiliated PHAs and existing service users. Why not a program for PHAs delivered online? Skills building, confidential and anonymous support groups, and creating community – these are a few of the possibilities that come to mind. What innovations can your ASO create using social networking, cyber-resources and other ways of connecting with PHAs?

5.0 What does GIPA mean for ASOs today?

The greater and meaningful involvement of PHAs remains as important today as it was in 1994. PHAs continue to be under-represented on ASO boards and as staff members. The fundamental human rights of PHAs are not respected when PHAs do not have a meaningful voice in all decisions affecting their lives and when they do not have a meaningful share of leadership power in organizations that serve PHAs. We can do better.

Benefits of living out GIPA/MIPA

The benefits of GIPA/MIPA for ASOs are many and have been described extensively in a variety of publications (see the Resources section of this document). Briefly, the advantages include:

- Honouring basic human rights
- Bringing lived experience and expertise to the organization, which is as important as education and an impressive professional resume; this keeps the organization grounded in reality
- Improving services by making them more relevant and responsive
- Combating and reducing stigma
- Creating environments that support visibility and disclosure
- Increasing credibility in the community and with other supporters and funders
- Increasing the commitment of everyone involved in the ASO, whether PHA or non-PHA, to the cause and the work

Challenges in living out GIPA/MIPA

The challenges encountered in living out GIPA/MIPA have also been named in many publications. They include:

- PHA fear of disclosure and resulting stigma, discrimination, loss of employment and relationships, or physical violence
- PHAs may not want to be involved with an ASO
- Chronic or episodic poor health may limit a PHA’s ability to perform work
- Potential loss of salary and benefits for PHAs compared to jobs in other sectors
- The need for mentoring, support and training of PHAs may be seen as a disadvantage by the ASO in light of limited human and financial resources

- ASO culture may not be welcoming to PHAs who are not currently experiencing physical or economic hardship, or conversely to those who are perceived as doing well and not in need of support
- Boundaries around and support for PHA involvement (staff, volunteer positions, leadership) may not be clearly defined; some PHAs report having to fend for themselves in an ASO without clear expectations, adequate support or training
- The added burden of living HIV 24 hours a day and being the visible presence of HIV in the organization
- PHA staff may not be able to find the support they need because they are seen as serving clients and not having support needs of their own
- ASOs may need to develop conflict resolution processes when differences arise between PHAs and the organization

The persistence of stigma

The continuing influence of stigma is mentioned repeatedly in recent publications dealing with GIPA. Stigma has been defined as: *The identification that a social group creates of a person (or group of people) based on a physical, behavioural or social trait perceived as diverging from group norms*.[6]

The authors of *Living & Serving II* noted that stigma may be less overt than in the past, but that it remains insidious and all-pervasive and is often cloaked by well-meaning postures. It may create a barrier to PHA involvement at higher levels in the hierarchy of an organization. Internalized or self-stigma may exist in the form of feelings of shame, low self-esteem and embarrassment. This can impede a PHA's perception that she or he has a legitimate voice and value to contribute to the community.

Gay positive men who are shunned on the bar scene suffer from stigma. HIV positive women also experience high levels of rejection. PHAs in small communities, either geographical or cultural, suffer from stigma. Those who assume that the diverse, often socially-disadvantaged, PHA populations cannot play meaningful roles in ASOs because they lack life and organizational skills are practising stigma. The challenge here is to continually recognize stigma in its many forms and work to combat it through changed attitudes, actions and organizational policies.

An international project, the People Living with HIV Stigma Index, is a work in progress that has been tested in several countries. In the western hemisphere, organizations in the Caribbean

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[6] *GIPA Good Practice Guide*. 2010. International HIV/AIDS Alliance and the Global Network of People Living with HIV

and Central and South America are primarily involved in developing and implementing it. This may be a useful resource for ASOs. The Stigma Index user guide is available online.[7] The OAN is currently developing a research partnership to address the issue of stigma with the National Association of People with HIV/AIDS in Australia.

Cultural safety

The diversity of people with HIV/AIDS requires that ASOs be competent in serving people from a variety of cultures. This has an impact on GIPA. The degree to which people will be involved because they feel safe and comfortable as service users, volunteers, staff, Board members and affiliates can depend not only on how they are respected as PHAs, but also on how they are respected as members of gay, Aboriginal, racial or cultural communities.

The concept of cultural competence for ASO workers now includes the need to create cultural safety in the organization. The concept of cultural safety arose in New Zealand among nurses working with Aboriginal (Maori) communities and has been adopted in Canada in Aboriginal-specific and other health contexts.

Cultural safety is an outcome that includes, but goes beyond, cultural awareness (the acknowledgement of difference), cultural sensitivity (recognition of the importance of respecting difference, a term often associated with cross-cultural education or diversity training), and cultural competence (skills, knowledge and attitudes).

Cultural safety takes into account an understanding of the power differentials in service delivery and redresses these inequities through education.[8] A culturally safe environment is one where people feel safe in expressing their culture and being who they are without fear of discrimination and hurtful attitudes and actions. It acknowledges that we are all bearers of culture and exposes the social, political and historical context of care and support.

The Canadian Aboriginal AIDS Network has done work to expand these concepts to include relational care, an interactive, caring, respectful path for culturally competent services leading to the well-being of the whole person.

Many resources are available on cultural safety. Links to some of these are provided in the resource section at the end of this document.

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[7] www.stigmaindex.org

[8] Aboriginal Nurses Association of Canada

Strategies for overcoming challenges

Many PHAs and ASOs have developed innovative ways of overcoming the challenges faced in working with GIPA/MIPA. In section 6 below, some of these creative strategies will be described under each topic with examples of wise practice.

Investment in PHA capacity building

Engagement with GIPA/MIPA may require building capacity with PHAs so that they are empowered and enabled to participate meaningfully in the ASO community and beyond. In all aspects of capacity building, it is essential that PHAs be full partners in identifying needs, developing approaches and programs, evaluating their successes and making improvements.

Capacity building may include skills development for occupying positions within the organization (expert advisors, volunteers, staff, and Board members) or on its behalf (advocacy, acting as spokespersons, fundraisers and other representation). It can also include ways of supporting PHAs to engage actively in all spheres of their life, whether HIV-related or not. It may be accompanied by education and training for non-PHA members of the organization to recognize and dismantle stigma and other barriers to PHA involvement.

Several resources exist to help ASOs engage in capacity building. PHA-driven resources include the Positive Leadership Development Institute, a joint initiative of the Ontario AIDS Network and the Pacific AIDS Network, and the Canadian AIDS Society's *One Foot Forward* GIPA training toolkit. Other resources include the AIDS Bereavement and Resiliency Program of Ontario's Facilitator Training, the Committee for Accessible AIDS Treatment's Legacy Project and the various speakers' bureaus that enable people who are HIV-positive to tell their story to the public. Working in partnership with PHAs, ASOs may develop their own unique approaches that are adapted to their realities.

In their own words, here are the experiences of some graduates of the Positive Leadership Development Institute[9]:

> *To me, leadership is all about inspiring people. It's all about encouraging the heart. It's all about modelling so that others will follow*. - Amanuel

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[9] More personal statements can be found in the OAN publication *Positive Change Makers: Positive Leadership Development Institute*. Ontario AIDS Network, 2010.

> *The quality of my volunteer work has changed, not so much the quantity. Being a leader is part of me now. I now take chances to do things that I would probably not have done otherwise*. - André
>
> *There's a little power in you that just surges and you say, you can do it!* - Brigitte
>
> *The principle "inspire a shared vision" is where I really start with my work now.* – Colleen
>
> *Hopefully we can have a spiritual component in this work...spiritual as in being in balance*. – Donald
>
> *I've been going from small and, with all the support, I'm going big.* – Douglas

Equality and equity

The ethical concepts of equality and equity come into play with GIPA/MIPA. Briefly, equality is often seen as equality of opportunity based on the assumption that everyone is equal at the start. For example, access to an educational program requiring an extensive academic background requires may be presented as equally available to all, but the reality is that only those with previous access to a high standard of education and achievement have a chance of making it. Equality of treatment means that everyone gets the same treatment, regardless of their differences or starting points.

Equity acknowledges and respects that people are diverse and have different backgrounds, experiences, abilities and preferences. The impetus behind approaches based on equity tends to be a desire for equal, or fair, outcomes. For example, an equitable approach to the educational program mentioned in the previous paragraph would also include assessing the differences between applicants and building in mechanisms to address lack of previous opportunities through additional tutoring or other supports to ensure a more level playing field for all applicants.

Engagement in GIPA/MIPA will often lead to approaches based on equity – an acknowledgment of diversity and the need to build capacity so that PHAs and others can live and work together in ways that respect and empower.

6.0 Working with GIPA/MIPA in your ASO

Up to this point, we have taken an overview look at the issues involved in engagement with GIPA/MIPA. In this section, we will look at more concrete ways of making GIPA/MIPA real in and through HIV/AIDS service organizations.

Let's touch base again: the foundation of all GIPA/MIPA work is the GIPA principle.

> *GIPA is not a project or programme. It is a principle that aims to realize the rights and responsibilities of people living with HIV, including their right to self-determination and participation in decision-making processes that affect their lives.*[10]

Some of the many ways that GIPA can be lived in ASOs are described in the following sections. For each type of involvement, a brief description of the involvement is provided, with its benefits and challenges and strategies for overcoming the challenges. A real-life example of wise practice from an Ontario ASO is included in each section. In keeping with the spirit of the UNAIDS circles of GIPA, no one type of involvement is necessarily seen as superior to any other. The important thing is that greater and more meaningful involvement occurs and power and leadership are shared.

You are innovators; innovation involves risk-taking and learning. The other important thing to keep in mind is that not everything has to be done at once, but it is important to be moving steadily in the right direction.

The ways of living out the GIPA/MIPA principle described are:

- GIPA as a path of personal development by PHAs
- Expert advisors: Development, implementation, evaluation and improvement of services
- Expert advisors and counsellors: many aspects of ASO functioning
- Staffing
- Governance
- Other ways of living out GIPA/MIPA (e.g. advocacy, research, representing the organization, etc.)

Section 7 provides concrete ways of setting goals and measuring your progress in working with GIPA/MIPA. Your ASO may already have a commitment to GIPA/MIPA in its mission statement,

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[10] UNAIDS. 2007. *Policy Brief: The Greater Involvement of People Living with HIV (GIPA).*

in affirmative hiring practices or in having designated PHA seats on the Board. Developing an organization-wide GIPA/MIPA strategy may be more effective than having a number of different GIPA policies in the various areas of your organization.

6.1 Living and Breathing: GIPA as a path of personal development by PHAs

During the course of consultations to produce this document, the concept of PHAs as living and breathing was born. The words *Living and breathing* contain the images of vitality, freedom, expansion, taking in and giving back to the world. They also imply the freedom for PHAs to choose their path of personal development and involvement in the world. This is a powerful way to embody GIPA for both individual PHAs and ASOs.

In the fan image chosen to represent this image of GIPA (Figure 3), the individual PHA is at the origin and pivotal point of GIPA. Investing in self-development is the right of each PHA to do as he or she wishes. This could involve caring for one's health as a whole person: physical, emotional, spiritual, and relational. It may also involve learning through experience that power can originate in the self. The PHA can choose to live out the principles of GIPA in both private and relational ways. The ASO can connect with PHAs to journey with them and support their development and involvement. Most of these ways of connecting and journeying may be new.

Benefits

- PHAs experience an enhanced sense of self and possibility; actions are grounded in a deep sense of worth and respect for self and others
- ASOs learn to connect with PHAs on deeper levels beyond health and social services
- ASOs and PHAs are true partners in defining a living, breathing GIPA
- ASOs reach the unaffiliated in new ways
- All ASO services are enhanced through the participation of PHAs who find a meaningful place within the ASO and in the wider world of involvement

Challenges

- This new way of thinking has no pre-existing road map; this can be daunting
- A new way of dialoguing with PHAs may be required
- New, as yet undefined, approaches are needed
- ASO resources may be fully committed to existing programs; there may be a perception that new approaches are a luxury

Some strategies for reaping the benefits and meeting the challenges

- Engage PHAs already connected to the ASO and previously unaffiliated PHAs who may be invigorated and challenged by the possibilities of developing ways of co-creating ways of living and breathing with PHAs and ASOs. Some may be involved as volunteers.
- Challenge those responsible for outreach and fundraising in your ASO to see this as a development opportunity

A real-life example of wise practice:

6.1 GIPA as a path of personal development by PHAs	
Wise practice – brief description	***Legacy Project: structured mentorship to maximize life goals*** This project is a partnership among the Committee for Accessible AIDS Treatment, the Ethno-racial Treatment Support Network Peer Treatment Counsellor Training Program (ETSN – described in section 6.2), the AIDS Bereavement and Resiliency Program of Ontario, African and Caribbean Council on HIV/AIDS in Ontario, the Ontario AIDS Network, the Ontario HIV Treatment Network and Toronto People With AIDS Foundation. The Legacy Project supports GIPA/MIPA through facilitating mentoring relationships among PHAs and between PHAs and non-PHA allies with matching needs/skill sets. The relationships provide ongoing support and mutual learning opportunities to enhance life goal pursuit and career track development, promote cross generational/cross sectoral exchange/collaboration, and increase community participation. The project provides orientation training sessions for participants on mentorship roles, responsibilities, communication skills, boundaries and ethics for developing mentoring relationships. It also supports and augments mentoring relationships and learning through ongoing coordination support, group reflective learning circles, group mentoring activities and annual alumni event that include skill building components. The project also systemically employs a PHA peer as coordinator and uses engaged PHA program users as peer facilitators to help coordinate and facilitate subsequent group orientation/training sessions.
What about it makes this a wise practice?	The project connects a vision of community and intergenerational succession/collaboration to address unmet needs in the communities. It builds on the strengths of existing PHA capacity-building initiatives and supports program graduates in applying the skills learned It improves on traditional mentoring models by incorporating innovation

	that capitalizes on the unique strengths and dynamics of HIV communities.
What was the impetus or desire for developing this best practice?	While there are many training programs for PHAs, there is little ongoing structured support for graduates of these programs to apply and practise their skills beyond the training environment. Multiple research studies have identified the need for mentorship support in the sector.
What are the outcomes (results) of this practice?	The mentoring relationships have enabled many participants to: experience an enhanced sense of well being; build new skills and broader networks; clarify/identify career/academic track development; and increase engagement in new volunteer/work activities.
What challenges did you face when you engaged in this practice? How did you overcome the challenges?	HIV communities have unique dynamics and issues that traditional mentorship program models do not necessarily take into account. The project planning team uses a responsive approach to learn about successful models and adapt them to be relevant and sensitive to our communities' lived experiences.
What impact has the practice had on your agencies?	The project has engaged a community network of learning among different generations of PHAs and allies, with very diverse skills and talents. It has enabled many participants to identify/clarify their life goals and pursue new academic/career tracks. It has provided group mentoring activities on diverse topics (e.g. social networking skill building; parenting, etc.). A peer driven newsletter/web bulletin has been developed and many knowledge transfer activities have occurred at different forums. It has also greatly increased internal volunteer numbers and participation levels in all programs in at least one participating agency.

6.2 Development, implementation and evaluation of services

Ontario ASOs deliver a variety of services to a diverse group of service users. As has been suggested by many PHAs, one of the first steps that can be taken in GIPA engagement is to see PHAs as service users and deliverers rather than clients. A service user is seen as a more active and autonomous person than a client, who can be perceived as a passive recipient of whatever the ASO provides.

In order for PHAs to move further beyond being service users to being co-leaders in service provision, PHAs need a real and meaningful voice and power in the process of identifying needs, determining what services the ASO offers and how they are delivered, and evaluating and improving services. Service users can include those actually using services, or potential service users.

Many ASOs do prevention work. Engaging with PHAs to develop and deliver positive prevention[11] and health promotion is a self-evident way to actualize GIPA. Positive prevention empowers persons with HIV/AIDS, promotes healthy relationships with sexual partners, strengthens the overall well-being of HIV-positive individuals, and reduces the possibility of new HIV and other sexually transmitted infections. PHAs are the experts; they have given years of thought and attention to HIV prevention. Their meaningful involvement in all aspects of positive prevention is essential.

Benefits

The benefits of GIPA in creating and implementing ASO services include:

- The 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
- PHAs are connected in community

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[11] Positive prevention involves helping people living with HIV to protect their sexual and physical health, to avoid new sexually transmitted infections, to delay HIV disease progression and to avoid transmitting HIV. UNAIDS. 2007. *Policy Brief: The Greater Involvement of People Living with HIV (GIPA).*

POZ prevention is a term usually applied to positive prevention by and for gay HIV-positive men (Ontario Gay Men's Prevention Strategy, 2008). The term appears to be expanding to include all PHAs.

- PHAs become full participants in decisions affecting their care and support
- PHA capacity to participate and lead is enhanced
- Staff and decision makers share power; this can lead to an enhanced sense of community and higher motivation and morale throughout the organization
- Enhanced ASO credibility in the community

Challenges

Several challenges can impede PHA participation in determining services:

- Fear of disclosure by staff or other service users through consultation mechanisms (e.g. meetings)
- Fear of loss of services if a service user is critical of existing practices
- Power imbalance between staff and others delivering services on the one hand and PHA service users on the other hand. PHAs may fear negative consequences of speaking up. Staff may need training to recognize and counteract the subtleties of power differentials.
- Staff and other providers may resist changes in the way of doing things or in power sharing
- Meaningful PHA involvement can require staff/volunteer time and resources
- Taking purposeful time and intentionality to practise the necessity of GIPA

Some strategies for reaping the benefits and meeting the challenges

Strategies can include the following approaches:

- Develop a variety of consultation mechanisms to identify needs and get feedback on existing services. Some PHAs who have disclosed their status may be comfortable with meeting in groups, while the opinions of those who fear disclosure can be sought through private conversations, surveys, telephone or online communication
- Involve PHAs in data collection and research involved in needs assessments, program design and evaluation
- To counteract fears of loss of services and to deal with power imbalances, reassurances can help but may not be enough. The consultation mechanism may have to be carried out by those who do not provide services. Ways of assuring anonymity and confidentiality will have to be developed. Trust may take time to develop and be strengthened through testing and experience. Staff and volunteers may need refresher training in respecting confidentiality.

- Most people settle into the security and comfort of routines. This includes how power is shared. Staff/volunteers may need training and support in power sharing, which can be unsettling and fearful. Likewise, PHA service users may need support in sharing power.
- Build in mechanisms to report back regularly to service users on progress in implementing change
- The resources required to co-lead with service users in determining services may be considerable, but each ASO will have to look honestly at its commitment to GIPA/MIPA and allocate the resources needed. This can be done over time.

A real-life example of wise practice:

6.2 GIPA in the development, implementation and evaluation of services	
Wise practice – brief description	***Ethno-racial Treatment Support Network Peer Treatment Counsellor Training Program (ETSN)*** This program is a partnership among Asian Community AIDS Services, Africans in Partnership Against AIDS, Black CAP, the Committee for Accessible AIDS Treatment, the Centre for Spanish-Speaking Peoples, the Alliance for South Asian AIDS Prevention, and the Canadian Treatment Information Exchange. This two level intensive 8-day skill building program provides capacity building for PHAs in areas of treatment literacy, health promotion skills and peer counselling and support skills. The program uses a structured progressive engagement model to support peer graduates to become facilitators, presenters and trainers for subsequent rounds of training. Systemic support includes continued and progressive structured training on facilitation and presentation skills, mentored training materials preparation, pre- and post- practice debriefing and group reflective learning that involves peer graduates facilitators/presenters and a group of 6 core trainers made up of both PHA and non-PHAs. For each training program attended by 20 participants, a pool of 4 core peer facilitators coordinate and lead the training, and an additional 6-8 peer facilitators present or facilitate specific components of the training. A mentor/trainer team provides support and feedback to help the peer facilitators prepare their work.
What about it makes this a wise	The program is a model of progressive engagement of peers who are

practice?	trained through the program It provides structured mentorship and resources to support peers to take on progressive leadership roles The curriculum content is grounded in PHAs' lived experiences and is responsive to emerging community needs
What was the impetus or desire for developing this best practice?	The need for increased peer based treatment education/support for smaller/marginalized communities that lack support resources Interest from community members to improve treatment literacy and peer support skills
What are the outcomes (results) of this practice?	Since 2002, the ETSN program has trained more than 100 PHAs and over 30 peer facilitators. 30%+ of our graduates have become ASO staff, and another 30+% are actively volunteering for the sector. The program's model of progressive community engagement has inspired and informed other PHA capacity-building initiatives in the sector.
What challenges did you face when you engaged in this practice? How did you overcome the challenges?	The challenges are: the need for Intensive resources to ensure community succession and continuous education/support for program graduates; and lack of core/ongoing funding for the program. The program is successfully sustained because of its vision of progressive involvement and community succession which has inspired commitment from agency partners, trainers and program graduates to continue to contribute to program.
What impact has the practice had on your agencies?	The program has become training grounds for many PHAs to reconnect to community, increase their volunteerism and gain employment in ASOs. Over 30% of our graduates have become ASO staff and at least another 30% are actively volunteering for the sector. It has also broadened the volunteer base for some participating organizations and facilitated a sense of ownership among the graduates to continue to organize additional continuous education activities for themselves.

6.3 Expert advisors and consultants

PHAs are a diverse group who each have existing skills. Some skills are grounded in the expertise gained from lived experience as a PHA intensively involved in his or her own health care and social support. Other skills may be based in professional and technical expertise: PHAS are lawyers, accountants, artists, writers, researchers, restaurant workers, civil servants, shop workers, social workers, plumbers, information technologists (computer whizzes), electricians, and possess a vast array of skills. Their expertise as PHAs and as people working in many fields can contribute to your ASO. PHAs may be hired as employees or consultants or may volunteer their services (e.g. pro bono legal counsel).

Benefits

- The organization is enriched by the contribution of a wide array of talents
- PHAs have the opportunity to contribute to community building and support
- PHA advisors may have a greater understanding of the ASO's culture and mission than non-PHAs
- PHA advisors whose expertise is based on life experience are validated and empowered through being respected and heard
- PHAs can be empowered to become active in community by the example of PHA role models

Challenges

- Many PHAs may not have disclosed their status and may be hard to identify and reach. They may fear disclosure.
- Paying adequate compensation and benefits may be a challenge for the ASO with a limited budget
- Recognizing life experience as equal in value to professional credentials may be a challenge for both ASOs and PHAs; HIV is not a skill set, although the ability to live well with HIV is.

Some strategies for reaping the benefits and meeting the challenges

- Build discreet networks to identify PHA experts and consultants. Ensure that confidentiality is respected if approaches are made. ASOs use the services of many experts, not all of whom are self-identified PHAs. There is no need for public disclosure in order for a PHA to contribute expertise.

- Advertize outside the “AIDS Aquarium”. Placing an ad or blog posting in a place not reserved for people with HIV or ASO workers helps to promote in-reach and remind others that HIV is present and part of their community.
- Do the internal work in your ASO to value life experience as well as professional credentials. A workshop or sensitivity training for staff and volunteers may be helpful.
- Intentionally create ways and means for the career development and engagement-for-pay of people who are HIV-positive. Even a short-term contract may be the starting point that enables a person to enter or re-enter the workplace.
- It is common practice for many professionals to do some pro bono (free of charge or at reduced rates) work for community organizations. This is something that PHA experts may be willing to do. For those who require compensation or for those whose contribution is best recognized and respected through compensation, the ASO will have to set aside funds. This may limit the number of consultants that the ASO can engage.

A real-life example of wise practice:

6.3 Expert advisors and consultants - 1	
Wise practice – brief description	***Person living with HIV/HCV representation on community Drug Strategy Advisory Committee*** – Réseau Access Network, Sudbury Réseau Access Network (RAN - formerly Access AIDS Network) is a member of the Drug Strategy Advisory Committee established by the Sudbury Regional Police, Public Health Unit and community partners working in the addiction field to identify a growing concern about drug use within the community. As one of the primary Street Outreach Service providers, members of the RAN team including staff, students, volunteers, peers and service users, were asked to provide input and suggestions to the meetings. One of the service users is a young woman who is HIV and HCV+, a semi-active drug user and a sex trade worker. Her input into one of the meetings was invaluable and clearly gave a perspective not shared by others around the table. The presence of service users at this or any other meeting facilitated by RAN would be accompanied by a member of our Education

	Department. We hold ourselves responsible for ensuring that everyone is compensated for their time, preferably by the requesting agency, or through our own agency. While we do not have designated funds on hand for this purpose, our fundraising efforts allow for the purchase of food certificates for use at a local grocery store. A mutually agreed upon amount is given to the participating service user for their time and sharing of expertise.
What about it makes this a wise practice?	It ensures that one of the voices of those we serve is heard. It brings a perspective to the discussion that previously may not have been heard. It acknowledges that everyone is an expert in their own right, and that this expertise contributes value to the discussion.
What was the impetus or desire for developing this best practice?	A recognition that bringing many opinions to the discussion would encourage a broader perspective A desire to ensure that those we serve are included in the decision-making process A desire to provide alternative venues for those we serve to have a voice. Not everyone has the want/need/desire to be directly connected to an ASO Board or committee.
What are the outcomes (results) of this practice?	The participating PHA has received support and accolades for her ability to speak openly and honestly about her experiences as a sex trade worker living with HIV and HCV. Her public speaking skills and her personal self-esteem have flourished. She is being recognized for her abilities as an HIV/HCV/STI prevention educator. She is being recognized financially for her contributions to the community.
What challenges did you face when you engaged in this practice? How did you overcome the challenges?	Finding someone living with HIV and/or HCV who, with assistance and guidance from the Education Department, would agree to speak openly and honestly about issues affecting their lives to various audiences: As people share their stories with staff, they are encouraged to share with small gatherings. As PHAs gain experience and confidence, there is an increase in the size and diversity of the audiences. Ensuring that speakers are adequately financially compensated: We are developing a policy to ensure that a request for compensation, based on the number of hours of the presentation, is made to the requesting agency/audience. If the requesting agency/audience is not able to provide compensation, our Education Department will have a

	discretionary food certificate budget to ensure compensation. We will work with requesting agencies/audiences for booking of presentations as well as assurance of compensation.
What impact has the practice had on your agency?	It broadens the scope of what we are able to provide to the community at large in terms of educational presentations with the inclusion of lived experiences. It strengthens the relationship between our Education Department and those with lived experience. We provide training and assistance to expand knowledge on public speaking techniques and other factors that could assist with presentations. It provides opportunities for those living with HIV and/or HCV to gain new experiences, strengthen self-esteem and gain confidence in the work they do in the community.

6.4 Volunteers

All ASOs have volunteers. Community-based organizations could not function without them. In many ASOs and other community-based organizations, the ratio of volunteers to staff is often close to 10:1 or more. An ASO may have a staff member with responsibility for recruiting, training and supporting volunteers.

Benefits

- The PHA volunteer benefits from the satisfaction of contributing to the community, using existing skills and acquiring new ones.
- Skills acquired through volunteering may translate into paid employment in an ASO or elsewhere. When this happens and if appropriate, find a way to celebrate, and support its reoccurrence
- Volunteering can lessen social isolation and enhance self-esteem
- The organization benefits from being rooted in the community and being able to deliver a wider range of programs and services
- Programs may have greater credibility in the community that sees meaningful PHA involvement

Challenges

- PHAs may not want to be involved in the ASO; there may not be a pool of potential PHA volunteers in the community
- PHAs may fear disclosure of their status and/or stigma through association with the ASO
- Expectations of volunteers may not be clear; adequate training and support may not be provided
- Coordinating volunteers requires significant staff time and resources
- Chronic or episodic poor health may limit a PHA's ability to sustain volunteer commitment
- PHAs may feel undervalued because they are not paid for their contribution or because they see no possibility of paid employment with the ASO in the future

Some strategies for reaping the benefits and meeting the challenges

- Word of mouth among PHAs and service users may be the best way of recruiting volunteers. If volunteers like being involved with your ASO, they will tell others. The ASO must develop mechanisms for good volunteer training and support – these will speak for themselves in the long run. Good resources exist to help ASOs with volunteer coordination.

- Ensure that disclosure of HIV status is not a requirement for PHAs who volunteer
- Build in strong safeguards of confidentiality for PHA volunteers
- If your community is small, look at ways that you can extend it through the internet and social media – many volunteers today work online providing information and support
- Ensure that volunteer work is well defined in terms of expectations and limits – this helps both the volunteer and the ASO and reduces volunteer burnout
- Ensure that your ASO has ways of consulting regularly with volunteers about their experience and needs as volunteers. Ensure that these are acted on and reported back to the volunteers. Practise respect for the voice and self-determination of volunteers in determining their involvement as volunteers.
- Consider an investment in a staff volunteer coordinator as money well spent if your ASO wishes to be closely connected to community and needs their involvement in order to function
- Take into account the reality of episodic health ups and downs for PHAs and build flexibility into the way volunteer positions are filled and backed up
- Ensure that PHAs who volunteer continue to have access to the organization’s services

A real-life example of wise practice: No examples were submitted for this section. Volunteering is often the entry-level involvement in an ASO. In some of the examples provided in other sections, PHAs may be involved as volunteers. The GIPA literature stresses the need for training, support, clearly stated and realistic expectations on the part of the ASO and volunteer, and including the voice of the volunteer in program development, implementation and evaluation.

6.5 Staff: Human resources policies and practices

Hiring PHA staff members is one of the clearest ways of engaging with GIPA. It demonstrates solid commitment by the ASO to the GIPA principle because it literally "puts your money where your mouth is". As always, there are benefits and challenges. The Ontario AIDS Network has created a valuable resource for ASOs to guide their human relations practices: Ontario Provincial Resource for ASOs in Human Resources (OPRAH) (www.ontarioaidsnetwork.on.ca/oprah.htm). This is a comprehensive guide to all aspects of HR management. Although not specific to GIPA, the principles and practices described are grounded in human rights and sound human resources practices.

Some organizations have purposefully developed employment skills training. The AIDS Bereavement and Resiliency Program of Ontario has developed a training course in facilitation for PHAs, the Ontario HIV Treatment Network has trained and employed PHAS as peer researchers and the AIDS Committee of Toronto has had its Employment Action job coaching and placement service since 1999.

Benefits

- The expertise of the PHA staff member enhances the quality of service delivery
- Service users may feel more at home in the ASO when they see that PHAs work there
- The validation of PHA staff expertise sends a positive message to the community about how the ASO values and respects PHAs
- The ASO culture benefits from living the values of GIPA. Everyone in the ASO feels enhanced.

Challenges

- PHAs may not want to disclose status in order to apply for jobs
- Compensation and benefits are lower than in other sectors of the economy
- Some PHAs may lose disability benefits if they work; episodic poor health may require them to have disability benefits as a fallback
- Health and disability benefits tied to employment may not cover PHAs, although this is rare in the ASO sector
- Finding qualified PHA applicants may be difficult, especially in small centres or cultural communities because of the fear of stigma and discrimination

- People wanting to apply for jobs may face the added cost of child care expenses and the need for flexible hours when children need special care
- PHA life experience may not be valued as much as diplomas and a strong professional track record
- PHA staff may be unable to seek the support they need as PHAs now that they are staff. Seeking support may be perceived as unprofessional or risky in terms of confidentiality. PHA staff may not want to tax the scarce resources of the ASO when they are needed by other service users, and may have nowhere else to turn for support.

Some strategies for reaping the benefits and meeting the challenges

- Create affirmative action hiring policies and include this information in advertisements. Labour legislation permits affirmative hiring practices for ASOs.
- Determine whether the staff position requires that a PHA be open about their status. If this is not essential, develop confidentiality safeguards so that only one person (e.g. the Board Chair or the human resources coordinator) knows the applicant's status
- If a PHA is applying for a staff position in your ASO, they probably know that salary and benefit levels are lower than in competing sectors. It is important to stress the benefits of ASO work in terms of value to the community, congruence with personal values, etc. Lower salary levels may be offset by flexible hours, more time off, training opportunities, etc. Regularly review salary and benefit levels so that staff members know that fair compensation is an important value to the ASO.
- Join a larger group through an umbrella HIV/AIDS organization to negotiate better health and disability benefits with insurance companies
- Develop policies and practices that accommodate the differing needs of female, male and trans PHA staff members
- Develop ways of giving credit for life experience and transferable skills as well as professional credentials. For example, a person who has raised children knows a lot about building relationships, planning and crisis management. A PHA who has navigated the health care system probably knows a lot about managing systems, human relationships, assertiveness, research and health care.
- To facilitate applications in communities where stigma and discrimination may discourage PHAs from applying for positions, advertize in another location or negotiate secondments with ASO partners
- Develop ways to support PHA staff members who may need to access your organization's services as clients and who may feel awkward doing this. You will have to consider a number of factors, including confidentiality, personal privacy, potential conflict of interest and the possibility of finding alternatives to the services you provide.

- Create human resources policies and practices to support staff members in dealing with the stress and difficulties associated with work. This may require innovative approaches to help staff members feel comfortable with seeking support and to provide support either within the organization or through arrangements with other organizations; attention will have to be given to respecting confidentiality.

A real-life example of wise practice:

6.5 GIPA in human resources policies and practices	
Wise practice – brief description	***PHA input into hiring practices*** – AIDS Support Chatham-Kent It is our practice to have at least one PHA on the hiring committee when interviewing for positions within the agency.
What about it makes this a wise practice?	PHAs have greater insights about the community and often times the agency. PHAs have knowledge in other areas of the agency as opposed to just "PHA-centred" supports. PHAs who may not know about other areas of the organization are given the opportunity to learn. They also support the meaningful involvement of others (i.e. needle exchange clients as volunteers).
What was the impetus or desire for developing this best practice?	We wanted greater involvement of, relations with, and supports for PHAs.
What are the outcomes (results) of this practice?	A culturally diverse workforce is created, providing a voice representing the diverse community we serve. When PHAs are involved in idea sharing in other areas of the agency, PHAs show more acceptance and participation in other supports and services (i.e. the acceptance of the needle exchange program and its clients).
What challenges did you face when you engaged in this practice? How did you overcome the challenges?	In our small community, many PHAs have previous experience with other PHAs and this may bias them in decision making if the individual being interviewed is someone known to them. To get around this difficulty, we ensure that there are at least three people on the hiring panel. We also make interviewing more objective by using questions that can be tallied by numerical scores.
What impact has the practice had on your agency?	Inroads have been made to communities (partners and new service users) that otherwise might not have accessed services at the agency.

6.6 Governance

GIPA/MIPA in governance means that PHAs serve on the Board of Directors of the organization or on committees that support the Board or agency. Board members primarily set policy and are responsible for long-range strategic planning in consultation with senior staff. They are responsible for the financial and legal well-being of the organization and deal with problems that require their attention. They may take an active role in fundraising, public speaking on behalf of the ASO, and representing the ASO.

Although there can be power at all levels of an organization, the Board is usually considered to have significant power and final decision-making authority. The Executive Director reports to the Board. This means that the Board has the power to set policies and hire and fire the Executive Director, to whom the rest of the staff report. Board members are unpaid volunteers.

The Board has the power to shape the organization and its activities through establishing policy that will be followed at all levels of the organization. In the case of GIPA/MIPA, a Board policy could be expressed as *We affirm GIPA and are committed to the meaningful involvement of persons with HIV/AIDS in all activities and programs of this organization*. From this affirmation can grow policies and by-laws requiring that a designated number or percentage of seats on the Board be occupied by PHAs, or that preference in hiring will be given to PHAs when they have the required skills (valuing lived experience and transferable skills on an equal footing with professional credentials). Policies can cover all aspects of the organization's activity from its mission and which community it serves to how it will grow and develop.

The degree of Board member involvement in day-to-day operations varies with the organization. New organizations often have a working Board carrying out administrative and other duties because the organization has no staff or very few. Older and larger organizations may have a Board that is concerned only with setting policy and general directions, while the Executive Director is responsible for translating policy into action through working with staff and volunteers.

It is wise to be mindful of the possibility of Board members sero-converting while they serve on the Board and to develop respectful approaches for dealing with this whether the person is publicly open about their status or not.

The benefits and challenges of PHA involvement on Board are many.

Benefits

- Meaningful PHA involvement is achieved. PHA Board members share power in their own right and on behalf of the wider PHA community
- Policies and programs become more rooted in the realities of the community served
- The ASO gains credibility in the community and among funders

Challenges

- If there are very few PHAs on the Board and if they are not treated as equals in discussions and decision-making, they will feel like tokens
- PHAs may not want to disclose status in order to occupy designated seats on the Board
- New Board members may not have organizational or policy experience
- There may be problems in bringing new people onto the Board and retiring long-serving Board members (Founder's syndrome)

Some strategies for reaping the benefits and meeting the challenges

- Ensure that there are sufficient Board seats so that PHAs are not tokens. For example, organizations may designate 30% or more of Board seats for PHAs and not have a requirement that they individually disclose.
- Determine whether PHA-designated seats must be for declared PHAs or whether those who have not publicly declared their status are eligible. Some organizations may allow non-disclosed PHAs to occupy Board positions if their status is kept confidential (for example, only the Board Chair may be aware of their status). Recognize that disclosure can be a journey and respect that PHAS, like anyone else, have a right to keep their personal health information private. Subtle pressure to disclose in order to support the credibility of the organization can be offensive.
- In most cases, organizations require that at least some PHA Board members be public about their status.
- Develop orientation, mentoring and ongoing support programs for new Board members, taking into account any specials needs of new PHA Board members
- Ensure that Board members have limited terms of office

Three real-life examples of wise practice:

6.6 GIPA in governance - 1	
Wise practice – brief description	***Service Users' engagement in governance –*** Réseau Access Network, Sudbury Individuals are invited to submit letters of interest, and/or a resume outlining their qualifications, and lived experiences to the Executive Committee of Réseau Access Network (formerly Access AIDS Network) for consideration for a position on the Board of Directors. Service users within the agency, including those living with HIV and/or HCV are encouraged to apply. At present, there are two designated seats for persons living with HIV/AIDS and one designated seat for a person living with HCV. Those holding the designated positions are individuals who have or are willing to disclose their HIV/HCV status publicly. These individuals would be encouraged to represent the Agency at public functions/meetings. Individuals living with HIV and/or HCV who prefer not to disclose their status are also encouraged to apply for a position on the Board of Directors as a non-disclosed member. In this case, the Board of Directors, including the Executive Director and Recording Secretary may, or may not, be aware of an individual's status unless he/she has shared it previously.
What about it makes this a wise practice?	This approach: Encourages active participation of those we serve Assures the Board is representative of the various populations within the community Provides learning opportunities to those with minimal or no previous Board experience; additional learning opportunities are made available through the United Way Board Development program Allows those we serve the opportunity to be involved in the decision-making process which impacts the organization as a whole
What was the impetus or desire for developing this best practice?	The declared Board positions were implemented in the early years of the organization to encourage participation.

	It acknowledges the value of lived experiences.
What are the outcomes (results) of this practice?	Unfortunately, the outcomes have been limited. Lack of Board experience or interest in the mechanics of a Board is always an issue. Many of those we serve are marginalized, dealing with lack of housing, income, access to food and struggles with addictions. Serving on a Board is often at the bottom of their “to-do” list.
What challenges did you face when you engaged in this practice? How did you overcome the challenges?	Lack of interest or experience, or sense of need An Advisory Committee was established as an alternative to service on the Board, to encourage additional participation and input. The Committee is a designated Board Committee with information flowing to/from the Board. Active participation was excellent in the first six months, and then stopped. The Committee is presently inactive. Focus groups have been utilized with better success. Participants have an opportunity to meet those with similar experiences, enjoy lunch, and share information and experiences. Depending on the focus group, participants may be financially compensated for their time and information.
What impact has the practice had on your agency?	The agency has always felt the need to have the voice of those we serve included in the decision-making process. The challenge is to find alternative ways of ensuring that this voice is being heard.

6.6 GIPA in governance - 2	
Wise practice – brief description	***PHA representation on Board/Steering Committee*** - The Committee for Accessible AIDS Treatment (CAAT) We systematically set up our governance policy/structure to ensure that: there is majority PHA representation; and at least one of the Co-Chairs is a PHA. To ensure MIPA and succession planning, CAAT systematically structured individualized paired mentoring of steering committee members to facilitate capacity building in leadership roles.
What about it makes this a wise practice?	The policy provides for the systemic commitment of our agency to have a PHA Co-Chair, and a PHA majority on the Board.

	The structure creates an environment where leadership succession is planned and new PHA leaders are mentored as part of the executive structure. Internal peer based disclosure to the Steering Committee and optional disclosure to the broader community provides flexibility and a safe space to maximize GIPA/MIPA opportunities for many PHAs who still face major stigma in their own communities.
What was the impetus or desire for developing this best practice?	Strong core values, a commitment to the GIPA/MIPA principle and a vision of collective empowerment of the organization's network
What are the outcomes (results) of this practice?	We have successfully supported a governance structure with strong PHA leadership, always exceeding the target standard of PHA representation set in the policy.
What challenges did you face when you engaged in this practice? How did you overcome the challenges?	When our network was established 10 years ago, many of our target group PHAs were facing major challenges in accessing basic treatment and support; PHA participation at governance level was minimal. Through strategic and collaborative efforts to address the health needs of our target communities, we gained trust, built strong partnership with PHAs and were able to engage them in capacity building and increasing leadership roles.
What impact has the practice had on your agency?	Our agency has evolved from a service provider-driven network trying to address treatment access issues to a primarily PHA-driven network that focus more on addressing the holistic empowerment needs of the communities.

6.6 GIPA in governance - 3	
Wise practice – brief description	***PHA representation on the Board –*** AIDS Support Chatham-Kent Our policy states that: In order to ensure adequate involvement of people living with HIV/AIDS, PHAs will be given priority for all directorships. At least 1/3 of the directors shall be persons living with HIV/AIDS. Every effort must to made to ensure that at least one member of the Executive is a PHA.
What about it makes this a wise	Diversity in lived experience, culture and knowledge

practice?	Having PHAs at the table puts a face to HIV and increases credibility in the community and with funders This practice increases the commitment of everyone involved in our agency to eradicating stigma It ensures the adequate involvement of PHAs
What was the impetus or desire for developing this best practice?	Better serving our PHA community, for us, means ensuring that PHAs have a voice in program design and are represented within our organization.
What are the outcomes (results) of this practice?	There are more voices at the table. Putting a face to HIV makes our work on all levels more relevant. We have found that diversity in PHAs contributes to support and ideas by PHAs in other areas of the organization in addition to client services (i.e. Needle Exchange, Volunteer Services).
What challenges did you face when you engaged in this practice? How did you overcome the challenges?	Some PHAs wishing to participate on the Board are from rural areas, which presents the challenge of travel to meetings. To overcome this challenge, some meetings are held by teleconference.
What impact has the practice had on your agency?	PHAs are involved at the Board level and participate on a greater level in other agency-related events and activities, including fund development and community building. These PHAs encourage other less-involved PHAs to participate more actively. Information on opportunities supports and services are better shared within the PHA community.

6.7 Research

The involvement of PHAs in research has grown during the past 20 years because of the growth of community-based research. Community-based research is research that engages communities in all stages of research, from the definition of the research question, to capacity building and integration of community members in conducting research, to active participation in disseminating research results[12]. It begins with a research topic of practical relevance to the community (as opposed to individual scholars) and is carried out in community settings. Community members and researchers equitably share control of the research agenda through active and reciprocal involvement in the research design, implementation and dissemination. The process and results are useful to community members in making positive social change and promoting social equity.[13]

Community-based research is a good example of GIPA in action. PHAs participate in research as partners, rather than subjects. Research can be defined as a project involving many researchers and a funder or it can be on a smaller scale to determine something like whether a new service is needed and whether the ASO can provide it.

In other aspects of research, PHAs participate on research advisory committees for HIV/AIDS-related research, including clinical trials. Increasingly, PHAs present research results at scientific meetings and conferences.

A number of HIV/AIDS organizations engage in research. This has benefits and challenges.

Benefits

- Research is done in the interest of the community
- PHAs are respected as experts for their lived experience and intellectual contribution
- PHAs develop the capacity to conduct research and to disseminate and apply research results

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[12] Canadian Institutes of Health Research HIV/AIDS Community-Based Research Program www.cihr-irsc.gc.ca/e/25835.html

[13] Centre for Community-Based Research. www.communitybasedresearch.ca

- PHAs, ASOs and communities benefit from the research conducted and become empowered as researchers. This has benefits in terms of personal growth, expanded knowledge for all involved and more informed development of services.
- Research results can be applied to creating positive change in the community

Challenges

- Developing capacity to do research
- Finding funding
- Engaging PHAs and other community members in all stages of the research and knowledge transfer/translation
- Finding suitable research partners

Some strategies for reaping the benefits and meeting the challenges

There are many excellent resources for ASOs that want to engage in research. Here are a few ideas to start with:

- Talk to other ASOs who have engaged in research to learn from their experience; the Ontario HIV Treatment Network has several years of experience in effectively training and supporting peer researchers.
- For any scale of research within the ASO, involve PHAs and service users using the principles of GIPA and community-based research
- Dedicate adequate resources to the development work that must be done at each stage of community-based research

Two real-life examples of wise practice:

6.7 GIPA in research - 1	
Wise practice – brief description	***PHA engagement in research*** *- The Committee for Accessible AIDS Treatment (CAAT)* • All CAAT research projects have championed strong GIPA/MIPA approaches that: engage PHAs in all stages of research activities to ensure that all participants who provide input receive feedback when preliminary findings are developed; develop collaborative methodology and forum to ensure PHAs have direct and substantive input into research recommendation development; and involve PHA co-presenters in research knowledge transfer exchange activities.

	- At the staff level, PHAs are engaged as peer research associates and are provided with skill development to carry out their work responsibilities. Meaningful engagement is enhanced through ongoing group learning and debriefing sessions and full participation at the research team level. - In data collection/recommendation stages, results are fed back to PHA community members/participants and then more PHAs are engaged/supported to become peer research associates to collaborate in data analysis and recommendation/strategy development. - CAAT specifically developed a training program to engage and train target group PHAs of the research project *PHA Knowledge Transfer Exchange Ambassador* (KTEA) responsible for research finding dissemination. They are paid to engage in research KTE to enable them to work with other members of the research team to: (a) co-develop key recommendations and communication strategies targeting different stakeholder groups; and (b) conduct knowledge exchange activities via presentations, workshops, community dialogues, conferences, etc. to various target communities/audiences.
What about it makes this a wise practice?	- CAAT uses a holistic community empowerment grounded approach to maximize meaningful involvement of target group PHAs in all stages of research, beyond the traditional role of being utilized only as peer research assistants. - Use of innovative research methodology and technology to maximize PHA input in data analysis/recommendation development (concept mapping) - Development of an innovative training model to support target PHAs to drive knowledge transfer exchange from research (The Knowledge Transfer Exchange Ambassador training program)
What was the impetus or desire for developing this best practice?	CAAT has a strong history of using community-based research methodology for evidence-based advocacy to address community needs; CAAT's approach to research is grounded in community accountability and empowerment values and principles, with the vision of having affected communities drive the research agenda and outcome of projects that affect their health.
What are the outcomes (results) of this practice?	CAAT has trained over 40 peer research associates in different roles/capacities through its different research projects. Many of our peer research associates have: gone back to school to pursue further academic studies; taken up staffing roles in other research studies;

	and increased their engagement in many KTE-related activities from our research activities, such as development of new programs (e.g. the CAAT Legacy Project was a direct outcome of our PHA mental health research study).
What challenges did you face when you engaged in this practice? How did you overcome the challenges?	Planned resources are needed to ensure meaningful engagement of PHAs in research. These include both material and finance resources as well as technical skill development to enable effective participation. The main challenge is the lack of resources for ongoing deployment of trained peer research associates beyond specific projects. We have been working closely with the Ontario HIV Treatment Network to develop the Ontario Peer Research Training Institute to ensure a more long-term stable structure to maximize PHA research engagement.
What impact has the practice had on your agency?	Our model of peer research associates, and especially PHAs as primary knowledge transfer exchange agents, has widely been recognized as a ground-breaking innovative practice in both the HIV and research sectors and the experience has informed and inspired other research studies and models. These practices have also strengthened effectiveness in all aspects of our research studies from community /stakeholder engagement to knowledge transfer activities. It has also produced a pool of PHA researchers who are now actively employed/engaged in research-related activities.

6.7 GIPA in research - 2	
Wise practice – brief description	***Gay Positive Sex*** This is a collaborative research program involving the AIDS Committee of Toronto (ACT), Ryerson University and the University of Windsor. The research program has developed and implemented a small-group intervention led by peers who are trained in Motivational Interviewing techniques.
What about it makes this a wise practice?	The project is advised by the Poz Prevention Working Group of the GMSH (Ontario Gay Men's Sexual Alliance), which is made up of gay men living with HIV. Gay men living with HIV are involved in all aspects of the study (as investigators, as members of the advisory committee and as staff who

	are both research assistants and facilitators for the small groups)
What was the impetus or desire for developing this best practice?	There was a need for HIV prevention interventions specifically developed by and for gay men living with HIV that focussed on issues of pleasure and sexual health in the context of poz prevention (i.e. HIV prevention for positive gay men)
What are the outcomes (results) of this practice?	HIV-positive gay men have increased their skills as facilitators through training in Motivational Interviewing techniques. HIV-positive gay men on the advisory group have increased their knowledge and understanding of research, poz prevention and small-group interventions. HIV-positive gay men who have attended the groups have increased their knowledge, skills and abilities to have safer sex. HIV-positive gay men have shown increased ability to reduce unprotected anal sex with partners of unknown/different HIV status. HIV-positive gay men have learned and shared with their peers and have gained confidence. HIV-positive gay men have a greater understanding of the importance of their sexual health in their overall health and well-being.
What challenges did you face when you engaged in this practice? How did you overcome the challenges?	Given that this is an action-based research project based on Motivational Interviewing (MI) techniques, it requires recruiting and training Peer Research Assistants/group facilitators in this technique; this takes time and requires the facilitators to practise their skills in order to improve. The research project has been able to allocate sufficient time for both MI training and for opportunities for the Peer Research Assistants to practise MI techniques with themselves outside of the group. There was concern amongst potential participants about participating in a research study that was specifically for HIV-positive gay men who have reported unprotected anal sex: fear of others knowing they were a part of this group (stigma) and fear (in the climate of criminalization of HIV non-disclosure) that members may face prosecution. This was resolved by adapting promotional materials so that they focused on a group that was about sexual health for poz gay men (rather than HIV prevention) and reassuring men (who called to inquire about the study) that ALL information would be kept confidential.
What impact has the practice had on your agency?	This study is still occurring; however it has already demonstrated the usefulness of Motivational Interviewing as a technique in small group

	interventions. This study and group have helped to highlight sexual health issues and needs specific to HIV-positive gay men.

6.8 Other ways of working with GIPA

There are many other ways of working with GIPA in addition to those mentioned in the sections above. PHAs can be:

- Advocates on behalf of the ASO and its issues. This is possible for PHAs who have publicly declared their status and often for those who have not. ASOs can build an advocacy base with PHAs who are knowledgeable and willing to speak out publicly or in political and private sector contexts. For example, access to free HPV (human papillomavirus) vaccine for gay PHAs is an issue that requires advocacy. HPV is a known risk factor for anal cancer.
- Opinion leaders in talking with others and raising awareness
- Facilitators of processes within the ASO and with groups in the community linked to the ASO
- Fundraisers
- Sponsors through their businesses
- Role models and mentors
- Web blogs for people who are positive
- Bringers of wisdom and joy

The benefits are clear and the challenges are similar to many named in previous sections.

Two real-life examples of wise practice:

6.8 Other ways of working with GIPA - 1	
Wise practice –brief description	***Turning to One Another: ASO Workers Engaging with PHAs to Bring GIPA to Life*** This is a provincial project coordinated by the AIDS Bereavement and Resiliency Program of Ontario. Since 2008, this project has worked with over 60 PHA Peer Facilitators and 13 ASO pilot agencies to learn more about how to support meaningful involvement. There are parallel components of a three-part, 10-day PHA Facilitator Training program and a 2.5 day training session for ASO Workers to conduct skills-building and

	group learning for participants' local efforts. Topics covered include building group agreements/Code of Conduct, group facilitation skills, learning styles communication competency, conflict and clearing, debriefing and supervision. Through a supervised practicum at agencies, PHA Facilitators are given comprehensive structured feedback on all levels of their facilitation skills. An annual provincial Joint Planning Meeting for all participants contributes to developing an implementation framework based on input from all pilot sites and PHA Facilitators. This pilot project completes in March 2012. For more information and copies of resources including the manual PHA Facilitator Skills, see www.abrpo.org.
What makes this a wise practice?	Participant evaluations have identified that the training process gives a clear sense of empowerment and concrete skills. Learning has provided many participants with increased capacity in areas such as group facilitation, presentation skills, peer support, planning, confidence and conflict resolution. Participants have taken action to serve as community facilitators in their local ASO, creating support groups, nutrition education programs and other peer-based activities.
What was the impetus or desire for developing this best practice?	Feedback from PHAs involved in a Peer Support Training in 2006
What are the outcomes (results) of this practice?	The adult peer learning approach has been critical in the success of PHAs who are shifting into new roles within agencies. They are actively involved in helping agencies to develop new activities, policies and procedures to support all aspects of PHA Peer Leadership.
What challenges did you face when you engaged in this practice? How did you overcome the challenges?	It was difficult to find a funding source for this work. It is difficult to provide support across the province.
What impact has the practice had on your agency?	We currently work with two graduates from the pilot program on our facilitation team and one graduate is the project coordinator. This keeps the work grounded and connected to the lived experience of PHAs.

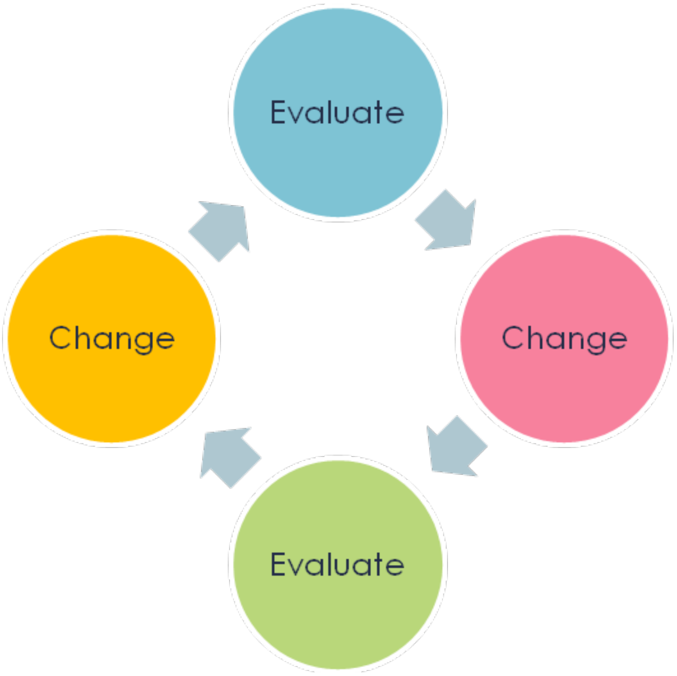
6.8 Other ways of working with GIPA - 2	
Wise practice – brief description	***PositiveLite.com*** PositiveLIte.com, an entirely independent on-line magazine by and for people living with HIV, facilitates numerous PHA writers, activists and those with an event to promote in finding a voice and developing expertise in the use of social media. Its PHA "staff" are also frequent speakers presenting to other agencies and at conferences such as The 2011 Gay Men's Health Summit, The Canadian HIV/AIDS Legal Network's 2011 Symposium and the Canadian AIDS Society's 2011 Annual General Meeting and Forum to educate others about the use of social media in HIV work. They also partner with the Canadian AIDS Treatment Information Exchange, the Ontario HIV Treatment Network and numerous ASOs wanting to take advantage of their skill sets and worldwide distribution network
What about it makes this a wise practice?	It is entirely driven by PHAs, without exception. It encourages others to become involved, worldwide. It is a personal development vehicle for those who participate. PozLite is a one-of-a-kind model started in Canada by Canadian PHAs.
What was the impetus or desire for developing this best practice?	To fill a void - nothing like this previously existed – and to draw on the existing skills of key participants
What are the outcomes (results) of this practice?	A highly successful website with worldwide reach and 15,000 hits a month
What challenges did you face when you engaged in this practice? How did you overcome the challenges?	Funding: it's hard to get funding if you are not an ASO; PositiveLite will eventually need to go outside the movement. Building credibility – it has to be earned; We've done that, but it's a long hard process.
What impact has the practice had on your agency?	This outside-the-ASO-community model demonstrates that GIPA can involve non-affiliated PHAs, a hard-to-reach population at the best of times, in activities that challenge, inform and inspire other PHAs to get involved.

7.0 Monitoring and accountability

This section briefly describes monitoring, evaluation, continuous quality improvement and accountability. Sample report cards, checklists and evaluation questionnaires are provided.

7.1 Overview

Once your organization has reaffirmed its commitment to GIPA/MIPA, how will you know that you have made progress? The steps in finding out usually involve setting goals, measuring outcomes after a chosen time period, and making changes to help you achieve existing goals or set new goals, and beginning the cycle again. The goal-setting part belongs to strategic planning and the evaluation while making changes belongs to what is often called continuous quality improvement.



Continuous quality improvement

At every stage of the monitoring and accountability process, it is important to practise GIPA by involving service users and other PHAs affiliated with your ASO.

Assessing and setting goals

Assessing how well your ASO is engaging with GIPA and setting goals can be part of a linked process. Your organization is already providing services and you probably already have a strong commitment to GIPA. You may set goals independently of an assessment if you know that you must do more to meaningfully involve PHAs in all aspects of your organization. In the absence of assessment, however, these goals may remain general, vague or unmeasurable. If you know where you are now, it is easier to know where you want to go. Assessing your current practice of GIPA is an important part of assessment but, if you stop there, you may not identify the new and emerging needs of your existing service users for greater involvement and you will miss identifying the possible needs and desires for involvement of PHAs who do not currently use your services. The engagement framework included in this document is intended to help you assess your current practices, determine ways to honour GIPA/MIPA and monitor your progress.

Assessment tools include environmental scans, needs assessments, and surveys to identify needs and satisfaction levels. Assessments can include interviews, focus groups and any other means you have of finding out what people think. Confidentiality must be built into the process. You may wish to refer back to the points made in section 6.1 on GIPA in the development, implementation and evaluation of services. In designing your assessments and scans, remember to make your questions open and, if possible, get quantifiable answers. For example, ask, *How involved are you in decision-making at our ASO? Why? When?*, instead of *Are you involved in decision-making?* The latter will give a Yes or No answer but will not provide much useful information.

Once you have a sense of how well you are doing, you can look at your existing GIPA goals and revise or reaffirm them. In setting new goals, continue to practise GIPA. Your Board and senior staff will be involved and you will have to ensure a strong voice and shared decision-making power with service users and other PHAs.

If you are new to setting goals, or if you are revising existing goals, make them as specific as possible. This will make them easier to understand and achieve. Useful guides are Who, What, Why, How and When. For example, your goal could be that *50% of your Board members are PHAs within three years*. The number of seats and the time frame make it easier to develop your action plan for achieving the goal. This is more helpful that a vague goal or target such as *Increase the number of PHA Board members.* For each goal, set targets that are measurable, such as how many, by when, and so on. It is also important to make your goals achievable if possible. Repeated failure to achieve goals and targets can lead to disillusionment and abandonment of real action on GIPA. It is important to be moving steadily in the right direction rather than to meet goals that may not be realistic in the time frames you have chosen.

Measurable outcomes

In order to know if you have achieved your goals and met your targets, you need to measure. Measurement will tell you whether or not you have succeeded and by how much. In the example above, you can measure whether 50% of your Board members are PHAs after three years from the time you set this goal. You may have achieved or surpassed this goal, or you may have achieved 40% PHA representation on the Board and you know how much remains to be done if you keep this target.

There are many good resources on evaluation that you can consult. The general idea to keep in mind is that the more measurable your goals and targets are, the better. Even something that seems non-measurable, such as service user satisfaction with their degree of involvement, can be evaluated on a numerical scale, often called a Likert scale. Surveys and evaluations often use this device. The person answering the question is asked to choose a point on a scale from 1-5 or 1-10 to express their degree of satisfaction, agreement or disagreement. Likewise, open-ended questions such as *How are you involved?* can be analyzed for recurring themes and quantified to an extent. For example, if the answer *Volunteering on weekends* comes up in 80% of responses, you may have an indication that this is an important form of involvement and that many of your volunteers have other commitments during the week. Open-ended questions or comments can also be analyzed for a general sense of how people experience and feel about things.

Accountability

To whom is your ASO accountable for committing to GIPA/MIPA, setting measurable goals and targets, and achieving or surpassing them? Technically, accountability may rest with the Board of Directors and the Executive Director. At a deeper broader level, you are accountable to your service users and all PHAs who could potentially use your services. At the broadest level, you may consider yourself to be accountable to the HIV/AIDS movement and the principles of social justice and human rights that lie at its foundation.

It is important to ensure that you have mechanisms for meaningful participation, feedback and dialogue with PHAs about your GIPA initiatives. If you are achieving your targets, you need to communicate this. If you are not achieving them, PHAs need to know why not and what you plan to do about it.

7.2 Sample evaluation tools

A strong need for evaluation tools was expressed at the consultations that lead to the creation of this document. For this reason, we are providing detailed versions of three evaluation tools in this section. We hope that these evaluation tools will be helpful in stimulating your organization to develop ways of evaluating your progress in working with GIPA/MIPA. These three examples were chosen because they are either based on Ontario experience (the first example) or have been tested and refined by respected international organizations. They are:

- A GIPA Report Card based on *Living & Serving II*, other international documents and consultations hosted by the OAN in London and Toronto in early 2011
- The NGO Code of Good Practice Self-Assessment Checklist
- The Standards checklist developed by the International HIV/AIDS Alliance

GIPA Report Card based on Living & Serving II and 2011 stakeholder consultation

Following consultations held in London and Toronto in early 2011, the consultants involved developed the following GIPA Report Card. The Report Card is based on three themes: Advocacy; Investment; and Opportunity. The Report Card has been modified here to solicit specific information rather than Yes/No answers.

Advocacy

1. How does your organization advocate for PHAs to participate in decision-making or policy-making bodies, and ensure that their input is equally valued?
2. How are the voices of all populations heard at the decision making table?
3. How do you advocate for PHAs to decide who represents them on decision-making committees?

Investment

1. How does your organization invest in defining the roles of PHAs and members of affected communities, and their associated responsibilities?
2. How does your organization invest in the capacity of PHAs and members of affected communities to fulfill those roles by providing the necessary organizational and/ or financial support and mentoring?
3. How does your organization invest in workplace policies and practises recognizing the health and related needs of PHAs, creating an enabling environment that supports their involvement in the organization?
4. How does your organization invest in seeking funding for PHAs and affected community to ensure they have the resources to build their capacity?
5. How does your organization invest in necessary tools to empower PHAs to be peer leaders within and outside their own networks?

Opportunity

1. How does your organization provide opportunities to PHAs to impart information, knowledge and skills to the organization itself and beyond?
2. How does your organization provide opportunities to PHAs to carry out real and meaningful roles in HIV interventions, such as counsellors, peer educators and/or outreach workers or role models?
3. How does your organization provide opportunities to a broad range of PHAs for meaningful involvement in the design, implementation and evaluation of HIV interventions?
4. How does your organization provide the opportunity for PHAs to be engaged and accepted as professionals?
5. How does your organization provide opportunities to PHAs to be active spokespersons in campaigns to raise awareness, change attitudes and behaviours, and to be meaningfully involved in sharing their views at meetings and conferences?

6. How does your organization provide opportunities to be actively involved in the development of HIV information, education, and communication resources as well as the provision for feedback that will influence the ongoing development of future resource initiatives?
7. How does your organization give priority to PHAs in hiring processes?

NGO Code of Good Practice Self-Assessment Checklist

This checklist is available online at www.hivcode.org: *Meaningful Involvement of People Living with HIV*. It has been condensed and modified here. The Checklist has three sections: Advocating for MIPA and affected communities in all aspects of the HIV response; Fostering MIPA for PHAs and affected communities in our work; and a guide for creating a MIPA action plan. The Checklist questions framed to solicit Yes or No answers are rephrased here to solicit more detailed information.

Advocating for the meaningful involvement of PHAs and affected communities in all aspects of the HIV response

1. How does your organization advocate for PHAs to participate in decision-making or policy-making bodies and ensure that their input is equally valued?
2. How does your organization advocate for PHAs to be recognized as important providers of information, knowledge and skills?
3. How does your organization advocate for PHAs to carry out real and meaningful roles in HIV interventions such as senior staff, counsellors, peer educators and/or outreach workers?
4. How does your organization advocate for a broad range of PHAs to be meaningfully involved in the design, implementation and evaluation of HIV interventions?
5. How do PHAs participate at the same level as professionals in the design, implementation and evaluation of HIV interventions?
6. How are all voices heard at the decision-making table?
7. How does your organization advocate for PHAs to be active spokespersons in community campaigns and meaningfully involved in sharing their views at meetings and conferences?
8. How does your organization advocate for PHAs to meaningfully contribute to public awareness-raising activities and act as role models in the HIV response?

9. How does your organization advocate for PHAs to be actively involved in the development of HIV information, education and communication resources, and the provision of feedback that will influence the ongoing development of these initiatives?
10. How does your organization advocate for the meaningful inclusion in the HIV response of voices of PHAs who are marginalized because of gender identity, sexuality, age and/or lifestyle choices?
11. How do PHAs decide who represents them on decision-making committees?

Fostering the meaningful involvement of PHAs and affected communities in our work

1. How does your organizational environment foster non-discrimination and value the contribution of PHAs and affected communities?
2. How does your organization recognize and encourage the involvement of a diverse range of PHAs and members of affected communities in your work?
3. How does your organization ensure that PHAs and people from affected communities have a variety of roles at different levels within the organization?
4. How does your organization clearly define the roles of PHAs and members of affected communities, and their associated responsibilities?
5. How does your organization support the capacity of PHAs and members of affected communities to fulfill those roles; for example, by providing the necessary organizational and financial support and mentoring? Is a PHA scholarship or internship program available?
6. How does your organization ensure that your workplace policies and practices recognize the health and related needs of PHAs and create an enabling environment that supports their involvement in the organization?
7. How does your organization ensure that PHAs and members of affected communities who work with your organization are supported to be accountable to their members; for example, by assisting them to establish processes that enable them to represent the views of their membership?
8. How does your organization support capacity building within PHA and affected community organizations and networks?
9. How does your organization recognize the specific need to support the capacity-building of PHAs who may experience reduced access to education and other learning resources because of their disempowerment and impoverishment in the community?
10. How does your organization fund and/or advocate for funding for PHAs and affected community organizations to ensure they have the resources to build their capacity and empower others within their own networks?

Action Plan

Develop your organizational action plan using the following framework:

1. Expected outcomes: What do we want to achieve?
2. Key activities: What do we need to do?
3. Action points: How do we do it?
4. Resources: What kind of support do we need to do it?
5. Timeframe: When will we do it?
6. What and when can we celebrate?

Standards Checklist developed by the International HIV/AIDS Alliance

This Checklist is contained in the *GIPA Good Practice Guide* (2010) published by the Alliance and the Global Network of People Living with HIV. The guide is available at www.aidsalliance.org/includes/Publication/GPG-GIPA-English.pdf.

The Checklist is based on three Standards:

1. Our organization is committed to ensure equal and full participation of all stakeholders, especially potential program beneficiaries, at all stages of the program cycle
2. Our organization is committed to the effective engagement with the GIPA principle throughout all areas of our organization
3. Our programs promote and/or provide an enabling and protected environment to facilitate the participation of people with HIV

The complete Checklist is presented here in a slightly modified form.

Standard	Description	Implementation actions	Markers of progress
Standard 1: Our organization is committed to ensure equal and full participation of all stakeholders, especially potential program beneficiaries, at all stages of the program cycle.	Participation is not simply understood as a tool to better implement programs, but as a mechanism to foster community mobilization that will result in advocacy for the full realisation of the right to health and other related human rights. Our organization includes all relevant populations in the initial planning of programming and advocacy activities, especially those populations that programs are directed at. There is commitment within our organization to understand the diversity within specific population groups, such as within groups of people with HIV and key populations, with varying needs, experiences and expertise.	Develop strategies for the meaningful involvement of target populations at all stages of the project cycle. Develop policies and governing rules that ensure confidentiality and privacy in all aspects of the organization's work. Develop or support networks and build links with organizations which represent key populations and people with HIV. Have office hours that make programs accessible to people who work or have daytime commitments.	Our organization has documented strategies in place to ensure the meaningful participation of all stakeholders, with special emphasis on those populations that are intended to benefit from programs. Memoranda of Understanding have been signed with organizations representing specific sub-populations to ensure cross-fertilisation of program planning and implementation. Minutes of meetings with stakeholder groups at all stages of the program cycle are kept and shared with these groups. Our organization has a workplace policy that ensures confidentiality, privacy and meaningful engagement of

Standard	Description	Implementation actions	Markers of progress
	We provide a safe space and respectful environment for diverse groups to participate at each stage of the program cycle.		people with HIV and key populations. Program objectives reflect involvement of key populations in planning, implementation and evaluation of all projects.
<u>Standard 2:</u> Our organization is committed to effective engagement with the GIPA principle throughout all areas of our organization.	GIPA is wise practice, is a commitment, and is a way of working. GIPA calls for the active and meaningful participation of people with HIV in the inception, development, implementation, monitoring and evaluation of policies and programs across all aspects of the HIV response including prevention, treatment, care and support. GIPA aims to ensure that people with HIV are equal partners and decision-makers in the HIV response. Effective engagement with the GIPA principle improves	Assess organizational policy and practice for GIPA to ascertain current practice, using an approach that acknowledges the specific needs, expertise and experiences of people with HIV as a diverse group. This assessment includes measuring current levels of involvement and opportunities for people with HIV to participate meaningfully in the governance, policy and decision-making of the organization, and includes people with HIV participating at all stages of the project cycle. Undertake a GIPA commitment	An organizational GIPA assessment, including an assessment of government structures, has been carried out and is documented. A vision of and commitment to GIPA has been established by leaders of our organization. A GIPA policy with a corresponding implementation strategy has been developed, published and disseminated which includes minimum targets for participation of appropriately qualified and experienced people with HIV in

Standard	Description	Implementation actions	Markers of progress
	the credibility, relevance, acceptability and effectiveness of our programs. We acknowledge the importance of applying GIPA in all areas of our organization's structure. This commitment cascades down from the governance level to program design, implementation and evaluation. The full and meaningful engagement of people with HIV has a direct positive impact on public health. For example, involving PHAs in the development of programs to meet their needs helps to create services that are welcoming and sensitive to their needs. This then results in greater uptake of services and the improved health of PHAs and affected others. Develop a strategy to	workshop to establish the vision and commitment to GIPA, defined with people with HIV. Develop a GIPA program and/ or policy, which is: defined with people with HIV; that ensures that key populations with HIV are provided with equal opportunities to be involved; is based on the Alliance *Good Practice Guide on GIPA* and the *NGO Code of Good Practice*	governance, policy and decision-making bodies and at the level of program implementation. GIPA principles are integrated in strategic plans, annual plans and workplans, including performance appraisal plans. Monitoring and evaluation reports highlight successes and challenges on GIPA, and next steps to address challenges. Documentation of the increased involvement of appropriately qualified and experienced people with HIV in governance, policy and decision-making structures exists. The capacity of people with HIV to participate has been assessed and meaningfully documented. A GIPA capacity-building program has

Standard	Description	Implementation actions	Markers of progress
	meaningfully involve appropriately qualified and experienced people with HIV in governance, policy and decision-making structures, based on the findings of the assessment. Develop a capacity-building program for people with HIV to strengthen their capacity to participate in governance, policy and decision-making structures, and to be involved at the program planning and implementation level. Establish monitoring and evaluation structures to ensure engagement with GIPA, defined with people with HIV.		been established which is funded, promoted and implemented. Minimum targets have been set for the number of people with HIV who will be trained to strengthen involvement at governance level and at the level of program planning and implementation. Program plans demonstrate participation of people with HIV. Participation of people with HIV is documented and measured, along with successful program and public health outcomes resulting from meaningful engagement in GIPA, as part of the organization's monitoring and evaluation activities.
<u>Standard 3:</u> Our programs promote and/ or provide an enabling	We acknowledge that the meaningful involvement of people with HIV must take place within an enabling	Assess employment, recruitment and retention policies to measure how enabling the workplace	An assessment of employment, recruitment and retention policies has been undertaken and documented.

Standard	Description	Implementation actions	Markers of progress
and protected environment to facilitate the participation of people with HIV.	environment. This means promoting access to our programs by overcoming barriers, along with providing protection against stigma and discrimination for all populations. We demonstrate a commitment to the value of involving people with HIV by creating a supportive workplace in which people with HIV are supported and protected from discrimination.	environment is for people with HIV and to identify barriers and/or opportunities for participation. This assessment pays particular attention to the need for capacity building; financial remuneration; mentoring; meeting needs such as childcare; and ensuring the involvement of key populations. Develop a recruitment, employment and retention policy to allow for the meaningful involvement of people with HIV and key populations at all levels of the organization, paying particular attention to opportunities for people with HIV and key populations to be recruited for specific projects. Include HIV positive people in interview teams and encourage them to self-identify and reply in confidence to job postings.	A minimum target has been set for the number of people with HIV working at different levels within the organization and for retaining people with HIV within it. A documented HIV in the workplace policy has been developed that addresses recruitment, employment, benefits, development, retention and support for/of staff with HIV. HIV in the workplace policy is implemented and communicated throughout the organization.

8.0 Framework for engagement in GIPA/MIPA

8.1 Introduction

This framework aims to provide a set of structures for AIDS service organizations to:

- Assess current relationships and practices of GIPA/MIPA
- Develop an organizational “mind-set” about GIPA/MIPA
- Determine a progressive, sustainable and measurable plan to honour GIPA/MIPA
- Monitor and set up accountability practices to deepen the progression and sustainability of GIPA/MIPA

The three sections in this framework offer a process for:

- Getting engagement
- Having conversations about GIPA/MIPA for forward movement
- Setting up a direction

The framework is based on the assumptions that GIPA and MIPA is:

- a process of expanding self determination
- a principle grounded in human rights and social justice
- an example of the enactment of human rights
- a code of practice
- a standard of effective HIV community organizing and service delivery
- a key to dismantle and transform stigma and hate into a person’s and community’s rightful and empowered place in society
- a beacon to PHAs that involvement in life is transformative and health giving
- a component of organizational health of an ASO

8.2 Getting engagement – four perspectives

No person is an island. No ASO has the capacity to control overall. No network can predict what may enliven it. All have the capacity to self-determine even in the worst of struggles and all will react to that which comes its way.

This section attempts to look at engagement itself as being highly personal or particular to an individual or organization’s orientation to the world. This moves us from thinking about task to thinking about natural fit and areas for experimentation. It involves getting to learn how a person or a system sees the world and using that as the starting place. It also offers consideration for how a person or an agency may have a perspective they do not emphasize very much, yet may be useful.

We offer here four perspectives to assist agencies and individuals in recognizing different ways of seeing the world and ways that people connect with engagement.

These four perspectives or lenses are ways that people see as their first natural fit and “home” as they engage with life. All four perspectives are at play in us as individuals and as organizations. These perspectives describe the ways that we “see”, or orientate ourselves to reality. While all four are at play, we generally have one predominant perspective. The four perspectives are:

1. Individual
2. Community, the “We”
3. Action
4. Systems

1. Individual

This perspective is of those who need to mull things over before acting or connecting. “Let me think about it” is where this person or system lives. This person or system is constantly taking the inner psychic temperature and is most concerned with what is meaningful on the inside.

GIPA for this individual or system will be highly personal and movement will mostly likely occur when the inner and deeper “rightness” is sensed.

This lens lives in emotional, mental experiences. There is a constant search for meaning, subjective truth and a belief that others will not truly get it, because it lives inside.

For ASOs, this may manifest as keeping separate from jumping in with others until a deep connection is sensed. For an individual, great emphasis is placed on waiting for what is “felt” as the right moment.

2. Community (the “We”)

The community can be two or 5000 people. This way of seeing the world requires the person or system to be in relation with others. Only by being in the company of others will this perspective have power. A collective resonance is built and it is within the relationships that the world makes sense. It can be seen in the natural drive among some gay PHAs in pushing for “poz prevention”. While not identified as GIPA, gay men are unfolding a new field of HIV prevention based on shared values and a common desire to work together wherein the communing itself produces ideas and momentum.

Communities by definition are the act of coming together. The momentum only happens with others. A collective resonance is built and nurtured by all.

The engagement for those who see the world this way will best work through coming together and enabling the connection itself to produce ways forward. The meaning is in relationship – belonging to a tribe.

3. Action

This perspective involves the forward movement of doing something that resonates individually. It is doing-doing-doing! AIDS Action Now!, ACT-UP, and Keith Haring's artwork of "silence equals death" are examples of energy that focus totally on action. From time to time, protest, dissent, removal of Boards of Directors by memberships and other actions are ways that "get things done". For some, this is the most powerful way to be and to create change. For many PHAs this is not "the greater" and "the more meaningful" involvement of PHAs, but is The Involvement of people living with HIV/AIDS in their vision and its manifestation.

The first impulse of this perspective is to get things done and once that is done to identify the next thing to do.

4. Systems

This perspective involves the stand-back-and-look approach of wanting to know how things work. This person or system loves to think about frameworks, systems, theories and results of performance. This may involve new partnerships, integration, collaboration and re-alignments. For PHAs and GIPA, this often shows up in ASO organizing and service delivery, for example, ideas about new programs, making connections to other services, looking at progress and performance and seeing which things work well and which are not producing results.

How to work with these four perspectives

If we think about how the person sees the world, a different universe is opened. Each of us has a favoured way of seeing the world and while all four are within each of us, we usually have one that we emphasize and one we do not emphasize very much. If we are asked to operate in the one that we do not emphasize, we will most likely experience this as a stretch.

By better understanding how the individual or the system sees the world, we are more able to connect with their world-view and to align the energy of our activity to their perspective.

At the same time, we can identify ways for people and systems to expand. For example, if an ASO mostly sees the world through pulling people together for conversations (Community/We), it may be a wise stretch for the organization to do something - one concrete act (Action). If the organization is always “doing” things and getting tired of this, it may be wise for the agency to stand back and look at systems. For the individual PHA who, for example, loves to mull things over and rarely acts, it may be a growth stretch for her or him to risk some actions or to stretch into collaborative work. Any stretch into one of the other three ways of seeing that is not the dominant one will raise consciousness. This will have expanding impacts overall for both the ASO and the PHA.

The following are some examples of using the four perspectives in GIPA engagement.

1. PHA engagement

Historically we have looked at GIPA/MIPA in ways that require the PHA to fit into existing ways. Most common has been to consider the PHA as a volunteer or staff. For example, as a potential board member or member of speakers bureau, both of which are a skill sets or roles.

By better understanding how the PHA sees the world of his or her engagement, there is a greater likelihood of engagement of meaning.

If an agency only offers engagement as a role or skill set it will in large part only appeal mostly to those who want to get things done. This will probably be very frustrating for a PHA who joins a policy-focussed board. If the agency recruits PHAs only to a speakers bureau the appeal for many will be limited. It is more likely that the speaker’s bureau will have greater meaning for those who like to work in relationship. Not only does this limit engagement is restricts expansion of consciousness generally.

Here are some suggestions for the PHA:

A. Individual

Ask them to:

- Think about something that is a question for the agency
- Review papers or ideas the agency is considering
- Ponder challenges facing the agency

- Act as an advisor to a manager or Executive Director
- Be a touchstone
- Suggest what might work as a research question

B. Community/ We

Ask them to:

- Join in committee work
- Answer the question “What should we do?”
- Take on a collective project
- Solve a problem: Let’s sit down and solve this!
- Do anything that requires a group
- Design a program

C. Action

- Organize events or demonstrations
- Physical activity – ask 20 people to serve a meal, staff a food bank, staff tables at the AIDS walk
- Do things for people in their homes
- Make phone calls for fundraising

D. Systems

- Board work
- Liaison work
- Ideas on partnerships
- Ideas on how to get things done
- Strategic planning
- Designing frameworks for action
- Advising Boards
- Knowledge translation

These are just a few examples intended to stimulate thought. When someone gets engaged from his or her own perspective, the energy will flow in a meaningful way. The fit will feel right.

Someone may like to stretch into another way that is new to them and an agency could support that. The one who generally does things alone may want to stretch into working with others, and the “doer” may want to think about things with a group.

At base these four perspectives provide a new way for agencies to create a greater flow of energy by aligning people to their natural way of meaning and by providing stretches to expand meaning. Not only does this serve the agency and the individual, but also it generates new possibilities.

2. For the ASO

ASOs grew out of the grass roots response to AIDS. They were often bred, birthed and fed by people who saw themselves as outsiders, created by the communities most affected when "nobody else gave a damn". Today ASOs are most often systems connected to other systems and can be adjusted, fine-tuned, expanded, increased and decreased. They may be part of larger networks and systems that provide services, do outreach, and help others to develop resources with and for PHAs.

"Doing" happens. Some agencies hold fundraisers, community forums and/or undertake activism. Some ASOs are now part of greater systems and consider this as one of their greatest influences. While collectives are less evident than before, there are multiple forms of coalitions in which understanding underpins ideas.

Margaret Wheatley, in her book Leadership and New Science, maintains that any system or organism only has the capacity to react. It responds to what comes its way, whether it be information, insight or pressure of some kind. What that agency has learned about itself and how it works will determine the kind of reaction or new direction it will take.

We have presented the four aspects of awareness - individual, collective/we, action and systems - as ways of seeing from an agency perspective to encourage a comprehensive and expansive mind-set. The expansive mind-set considers how we are with GIPA and where we want to expand, practise, experiment or commit to change with the greater or more meaningful involvement of people living with HIV/AIDS.

GIPA therefore can be enacted through any of the four perspectives and any combination of them. In fact, the most powerful and conscious approach occurs when all four are employed by an organization to consider how GIPA may be understood and encouraged to evolve.

For example, an agency may discover it that it has never had a conversation about GIPA/MIPA, and is unaware of what individuals think (the Individual perspective). Another agency may never have had a group discussion with PHAs about what GIPA/MIPA means (Community/We). Similarly, an agency never considers what it can do in the here-and-now to solve one problem about GIPA/MIPA (Action). Finally, an agency may never think about GIPA/MIPA and its role in their partnerships with other organizations (Systems).

The agency can therefore ask:

- What is the way I (as an agency member) or we see GIPA now?
- What is our default position and belief system about GIPA (i.e. which of the four perspectives is our natural home base?)
- What parts of these four perspectives are foremost for us and which ones are on the perimeter?
- Which is our least natural and most resisted of these four perspectives?

Expansion into all four perspectives provides an individual and an agency with an increased consciousness about GIPA/MIPA. Without all four perspectives being examined, it is difficult to see the whole picture and to define where the agency needs to expand its efforts. It might be that the agency needs to expand its:

- Own understanding of how it sees GIPA, based on how the individuals associated with the agency see and act on GIPA/MIPA (Individual)
- Relationships with others in developing GIPA/MIPA (Community)
- Ways of doing something about GIPA/MIPA (Action)
- Ways of looking at how its systems work both internally and as part of external systems (Systems)

Here are some examples:

1. An agency sees its role as serving PHAs and having some PHAs on its Board. For the most part, it relies on a few PHAs to help guide programs. The agency notices that not a lot of new PHAs are linking with the organization. This might be a mixture of the Individual and Community perspectives in that the agency sees itself as the central place for PHAs. Conversations always happen with the same “We”; in other words, we are always the same people talking about the same thing.

   This agency might consider how to connect GIPA to its broader systems in the community and how to engage the wider health and social service network in GIPA (Systems). It may also decide that it will hold an annual PHA Summit (whether 10 or 100 people) to celebrate safer sex week (a mix of Action and Community).

2. A rural agency has been working for a long time to build PHA representation on its Board, but distance prevents people being physically present, and “being out” as a PHA is a barrier (System).

   This agency may wish to consider an on-line monthly forum that has the sole purpose of connecting people and allowing issues and solutions to be self made (using the Community perspective and then using all four perspectives to create a way forward.)

3. An agency serves a large geographic area including an urban core, or an agency with a specific population that is spread across the province, is spinning its wheels on how to engage PHAs province-wide (Community).

   These agencies may undertake to combine “Action” with Community and create one action that connects people to provincial resources and to key discussions. For example, the agency may focus on web-based connections as its signature piece.

Consider how your agency sees GIPA/MIPA. What are the patterns and the consciousness with which you see it? See where you fit into the four perspectives. What stretches might you see if PHA engagement became livelier by engaging in one, or a combination of the other four perspectives?

8.3 Conversations to move GIPA forward

The following four steps provide both individual and agency an embrace of the complexities of change in a simple process that can be at the pace most serving progress. It is a consciousness raising process that invites in the story of what is seen, its impact, the energy of the experience and the changes forward. This model is based on the belief that for change to happen it is vital to be conscious of what we hold so that we can let go and let the new have freedom. This means being fully human.

The four steps are:

- Recognize
- Acknowledge
- Accept all that is
- Set the change

1. Recognize

Every ASO and every PHA already has a perspective and a position on GIPA. Even a non-articulation is a position. The chosen perspective holds energy and action, even if others cannot perceive it. By acknowledging where you are in the present, it is possible to enter into a relationship with what now exists. This step involves recognizing what is and being explicit about what needs to be recognized and doing so in a succinct and honest way.

This is grounding and provides a base for seeing what is and what is happening. The generosity in recognition is that it enables an agency or an individual to take stock and to do so without comparison, which always results in a negative experience.

The benefit of this step is to honestly say, “We have a problem”, “This is important to us”, “Something is not right”, or “I see something”.

For an agency it may be that “We struggle with GIPA/MIPA” or “We are in conflict with GIPA/MIPA” or “We have to create our own way, but do not know what”. It may be “We are completely stuck with how to move forward with GIPA”. For a PHA it might be “I am tired of not getting action on GIPA/MIPA”, “I have no idea about where to get involved”, “GIPA/MIPA is a mystery to me”.

This is the beginning of the transformation. Truth begins to have space and air.

2: Acknowledge

It takes courage to acknowledge the truth, to say, “This is where we are now”. This is the beginning of connecting to power. We can see “what is” and its impact. Without judgment or comparison, a conversation can begin about the impact of the currently held perspective, position or state of being about GIPA/MIPA.

This acknowledgement begins to take the understanding into the human realm and the lived experience of the current situation. It makes room to see the real experience of individuals and the agency’s struggles with GIPA/MIPA.

Truthful acknowledgement opens up space in conversation. Probably most famous example of the acknowledgment stage is the Truth and Reconciliation Commission undertaken by the South African government under the leadership of Nelson Mandela. A similar Truth and Reconciliation Commission is now at work to help heal the residential schools experience for Aboriginal Canadians.

Here are two examples that show the power of recognition of what is and its impacts.

Example 1

Step 1. Recognition:

As a Board we think we are practising GIPA/MIPA, yet many are still unhappy with how we walk the talk with GIPA/MIPA.

Step 2. Possible impacts:

- The three PHAs on the Board feel like tokens and feel like a minority. They only speak the truth with each other and must always agree to stay together.
- Because there are only three PHA-designated seats, the Board makes sure that the three are fully qualified and can really do the work before they are let in as Board members. It gets the work done, but nobody feels great about it.
- Other Board members defer all program decisions to the three PHAs. While "whatever seems right to you" appears to honour GIPA, privately the other Board members find themselves agreeing to services that are costly and are not really connected to HIV. Board members are left feeling silent; there is constant turnover of Board members.
- The three PHAs on the Board feel they have to meet all the needs of the other PHAs to whom they feel accountable because they are the "real voice". Unrealistic expectations arise , the stress level of the three PHAs builds and retention of three PHAs as Board members becomes an issue for the Board. As such, local PHAs see the Board as "not getting it".

Example 2

Step 1. Recognition

We put PHAs in jobs, but they burn out and it is hard to find PHAs who can do the job.

Step 2. Possible impacts:

- The Executive Director feels good about the agency's intentions with respect to GIPA/MIPA, but it is stressful to constantly have short-term staff and truthfully "we are not delivering".
- PHA staff members are often asked "What should we be doing for PHAs?" and it gets to be onerous to be the ones who are always asked. Resentment builds.
- The Executive Director thinks she is honouring GIPA, but finds it hard to deliver services because of the ongoing staff turnover

- PHA staff finds it difficult to have private social time in the community and cannot turn to the agency for support

3 Accept all that is

The brave part of this stage is to “be” with all of the impacts and to create a space for all of the impacts to have air. It is the opportunity for a full exploration of the impacts. Making sure all stones are turned allows for all voices to have had their place and for everyone to become aware of what is. This is a process of raising awareness, not problem solving.

The key to this step is to honesty see and accept the impacts, not to move into blame or any negative process of attribution. Compassion is essential. In this step we “take in” and embrace all of the impacts, the stories and the difficulties as a passage to making a place for change.

Full exploration of the impacts will have raised many issues from the past, coupled with personal and organizational tensions. These need to be acknowledged non-judgementally, allowing us to look at the past, and ourselves, with compassion.

It may be discovered that the resilience so far leads us to praise and celebration of our achievements and the learning that has taken place through past failures and challenges.

The strength of this process is to clear the ground for change. If the ground is not fully cleared, this will limit the creativity and growth that can emerge.

By fully grasping the impacts our past actions and positions, and by fully letting go of what was, imagination flourishes and regeneration can take place. In agency terms, planning can begin.

Here are two examples:

<u>Example 1</u>

Step 1. Recognition.

We have a tough time getting PHAs involved.

Step 2. Impact

- The Board Chair has given up on this issue and thinks it is better to concentrate on services. She gets irritable with the issue and sees it as an urban idea.
- Most of our PHAs do not want to bother with us and we concentrate on prevention
- The few local PHAs are always putting us down and we don’t speak to them anymore

- As long as we get one PHA on the Board and we know that some are going to PHA meetings in Toronto, we're OK. It feels unfulfilled, but it's the best we can do for now.
- As a PHA, I'm tired of my local agency and I give up.

Step 3. Accept all that is

The Agency embraces its:

- Frustration
- Isolation from PHAs
- Tightness in holding the "no speaking"
- Flatness in settling for second best

The PHAs may have to embrace:

- Anger
- Local disconnection
- Isolation from each other
- Frustrated desire for services and connection

Example 2

Step 1. Recognition

We are stuck in implementing GIPA/MIPA

Step 2. Impact

- The E.D. is drained of ideas on how to do this
- The Board Chair "doesn't get it" and questions its use – after all, we are a policy Board
- Staff are cautious because PHAs so far have not got the skills and other staff are tired of picking up the pieces
- We talk and talk and never get anywhere
- If only the province would develop a training program for PHAs, then we could see possibilities

Step 3. Accept all that is

- The E.D. "doesn't know" and feels he should
- The Board Chair wants it to go away

- Staff have settled into a feeling of “It doesn’t work”
- It’s not our problem, but the province’s – feelings of resignation and of no influence – powerlessness

Arrival at the truth about what is takes the issues out of the closet, out of just thinking about it and out of talking about the idea of GIPA.

Arrival at the truth about what is frees up conversations and takes them away from previous patterns and ways of dealing with the issue. It frees up the next level of energy and welcomes in people and creativity as people are able to see differently.

In all of the above examples, when the human experience is fully honest there is a transformation, a letting go of the tied-up energy. Once that has been honoured and allowed its place, then creativity can flow.

4. Set the change

Now that the full personal and organizational issues have been recognized, brought into conscious awareness on all fronts and embraced, the agency and individuals will have cleared a space and be ready to create.

With refreshed energy we can ask the question: How do we want to move forward with GIPA/MIPA? We can go back to our four ways of seeing:

- Individual
- Collective (We)
- Action
- Systems

Both the individual and the agency can expand from their current view into all four ways of seeing.

Individual: How will the agency ensure that all people within the agency know what GIPA/MIPA means? What does the agency want to learn about what GIPA/MIPA means to individuals? How does the agency see the individual PHA – as empowered, or as a passive recipient of services?

Collective/We: What collaborations does the agency want to develop in order to expand its commitment to GIPA? What needs to be in place to ensure that GIPA and MIPA are embraced and enacted within its own organizational components such as the Board, staff, volunteers, members, and donors?

Action: What will the agency do immediately to show that it grasps change and is making a difference in GIPA/MIPA? What three things can we do right now? And how will we know if we have been successful?

Systems: What needs to be thought about for GIPA/MIPA with the agency's systems such as human resources, financial planning, mission, vision and strategic planning? What external systems/agencies need to be considered as resources in the agency's desire to expand GIPA/MIPA?

By connecting with all of these four ways of seeing, an agency moves forward immediately and creates long-term sustainability built on a clearer vision, released from past blockages and acting from (or inspired by) an enlivened imagination of the individual and collective process.

8.4 Setting a direction

With an articulation of GIPA/MIPA using this Guide and Framework, ASOs are in a good position to create plans for GIPA/MIPA to be part of organizational culture as an ever-evolving process.

All steps can be included and will be a necessary part of every ASO's:

- Governance
    - Vision and mission statements
    - Board position statements on GIPA – the agency's belief about PHAs "Living and Breathing"
    - Policy development
    - Strategic planning
- Management and operations
    - Human resource development
    - Communications to PHAs and beyond
    - Membership development
    - Fundraising
    - Organizational development
    - Advocacy
    - Program development

- Evaluation, monitoring and accountability frameworks
- Leadership development
- Research and knowledge development
- Networking

Creating concrete action plans for all of these steps make them specific, measurable, accountable, resonant and empowering of people living with HIV/AIDS.

The following grid may help you to create your action plan for engaging in GIPA. The monitoring and evaluation tools presented in section 7.0 of this document may also help you in planning.

Areas for change for GIPA/MIPA				
	Year 1	**Year 2**	**Year 3**	**Year 4**
Vision and Mission				
Board policy/position statements				
Policy development				
Strategic Planning				
Management and operations				
Human Resource development and training				
Communications to PHAs				
Membership development				

Areas for change for GIPA/MIPA				
	Year 1	**Year 2**	**Year 3**	**Year 4**
Fundraising				
Organizational development				
Advocacy				
Program development				
Monitoring, evaluation and accountability				
Leadership development				
Research and knowledge development				
Networking				
Other action areas				

9.0 Afterword: Beyond the ASO

Living and Serving 3 is one element in a global process that began in Denver in 1983 and will go on long into the future. The OAN is committed to keeping the Living and Serving project a living work and ensuring that the province-wide organizational assessment first developed by Dr. Charles Roy be updated every five years. In future it may also issue certificates of recognition to GIPA-committed organizations.

Many of the themes presented in this document raise issues that go beyond the capacity of individual ASOs to deal with. Questions such as GIPA requirements from funders, and the development of campaigns to reach unaffiliated PHAs, for example, may be best dealt with at the provincial or national level. Provincial umbrella organizations such as OAN can develop resources that will serve all their members, such as the human resources site (OPRAH) and the PHA leadership initiatives. They can also identify widespread concerns and emerging patterns when they hear from their members. It is important to keep voicing your concerns and reporting on developments from the field in order to stimulate the development of processes and resources that can help all ASOs. That is how this guide and engagement framework came to be developed. Your voice matters.

10.0 Resources

Foundation documents

1. Denver Principles (1983). www.actupny.org/documents/Denver.html and on other websites

2. Montreal Manifesto (1989). www.gaylib.com/text/misc12.htm and other websites

3. Paris Declaration (1994). http://data.unaids.org/pub/externaldocument/2007/theparisdeclaration_en.pdf

4. UNGASS (2001), section 33. www.un.org/ga/aids/coverage/FinalDeclarationHIVAIDS.html

5. UN High-Level Meeting (2006), section 15. http://daccess-dds-ny.un.org/doc/UNDOC/GEN/N05/503/32/PDF/N0550332.pdf?OpenElement

6. UNAIDS (1999): *From Principle to Practice: Greater Involvement of People Living with or Affected by HIV/AIDS (GIPA)*. http://data.unaids.org/publications/IRC-pub01/jc252-gipa-i_en.pdf

7. UNAIDS (2007): *Policy Brief: The Greater Involvement of People Living with HIV (GIPA)*. http://data.unaids.org/pub/BriefingNote/2007/jc1299_policy_brief_gipa.pdf

8. UNAIDS (2010): Getting to Zero 2011-2015 UNAIDS Strategy. http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2010/JC2034_UNAIDS_Strategy_en.pdf

9. Roy, C. 1995. *Living & Serving: Persons with HIV in the Canadian AIDS Movement.* Out of print.

10. Ontario HIV Treatment Network and Ontario AIDS Network. 2007. *Living & Serving II: 10 Years Later: The Involvement of People Living with HIV/AIDS in the Community AIDS*

Movement in Ontario. www.ohtn.on.ca/Documents/Publications/living_serving_report_April07.pdf

11. International HIV/AIDS Alliance and Global Network of People Living with HIV. 2010. *Greater Involvement of people living with HIV (GIPA): Good Practice Guide.* www.aidsalliance.org/includes/Publication/GPG-GIPA-English.pdf

12. HIV Code. Undated. *NGO Code of Good Practice: Self-Assessment Checklist: Meaningful Involvement of PLHIV and Affected Communities (MIPA).* www.hivcode.org/silo/files/final-mipa-.pdf

13. Canadian AIDS Society. 2009. *One Foot forward: A GIPA Training Toolkit.* http://www.cdnaids.ca/web/casmisc.nsf/CL/cas-gen-0169. The resource can also be ordered from the CATIE Information Centre at www.catie.ca. The facilitator's guide can be ordered separately.

14. Stigma Index. 2008. *People Living with HIV Stigma Index*. www.stigmaindex.org/

15. Asia-Pacific Network of People Living with HV/AIDS (APN+) and Asia-Pacific Council of AIDS Service Organisations (APCASO). 2005. *Valued Voices: GIPA Toolkit – A manual for the Greater Involvement of People Living with HIV/AIDS*. www.gnpplus.net/cms-downloads/files/2005%20Valued%20Voices%20-%20A%20GIPA%20Toolkit.pdf

16. Ontario AIDS Network. http://ontarioaidsnetwork.on.ca.
    a. OAN Positive Leadership Development Institute at http://ontarioaidsnetwork.on.ca/site/pha-leadership/
    b. OPRAH: Ontario Provincial Resource for ASOs in HR. www.ontarioaidsnetwork.on.ca/oprah.htm (password required which can be requested from OAN)
    c. Parmer, J. And R. Lees. 2011. *The Investment of People Living with HIV/AIDS in the Community AIDS Movement in Ontario*. http://ontarioaidsnetwork.on.ca/

Websites

17. Ontario HIV/AIDS Reporting Tool (OCHART). www.ochart.ca

18. Ontario HIV Treatment Network. Peer Research Training Institute. www.ohtn.on.ca

19. Canadian Institutes of Health Research. HIV/AIDS Community-Based Research Program. www.cihr-irsc.gc.ca/e/25835.html

20. Ontario Organizational Development Program (OODP). http://oodp.ca/

21. Centre for Community-Based Research. www.communitybasedresearch.ca/

22. Cultural safety resources are available at these websites and many others:

    a. Canadian Aboriginal AIDS Network. 2008. *Relational Care: A Guide to Health Care and Support for Aboriginal People Living with HIV/AIDS*. http://caan.ca/new/wp-content/uploads/2010/03/RelationCare-Report-EN.pdf
    b. University of Victoria http://web2.uvcs.uvic.ca/courses/csafety/mod3/
    c. Aboriginal Nurses Association of Canada, Canadian Association of Schools of Nursing, and Canadian Nurses Association. 2009. *Cultural Competence and Cultural Safety in First Nations, Inuit and Métis Nursing Education*. www.cna-nurses.ca/CNA/documents/pdf/publications/Review_of_Literature_e.pdf

23. *Poz Prevention Definition, Values and Principles*. 2008. Provincial Advisory Body of the Ontario Gay Men's HIV Prevention Strategy. http://.ohtn.on.ca/Documents/Publications/poz_prevention_definition_values_principles_j.pdf

24. www.positivelite.com. Social networking site (Canadian)

25. www.poziam.org. Social networking site (US)

26. AIDS Bereavement and Resiliency Program of Ontario: www.abpo.org/

Book

27. Wheatley, Margaret. *Leadership and the New Science: Discovering Order in a Chaotic World*, 3rd edition. Berrett-Koehnler Publishers Inc.; 2006.