

**THE GREATER AND
MEANINGFUL INVOLVEMENT
OF PEOPLE LIVING WITH
HIV/AIDS:**

NOTHING ABOUT US WITHOUT US

AIDS Committee of Ottawa
Annual General Meeting
June 20, 2012

2012

The Year of GIPA/MIPA in Ontario

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Living, Breathing and Transforming Our World

The GIPA Principles

Are a series of principles that encourage the Greater Involvement of People Living With and Affected by HIV/AIDS

recognizing the important contribution people infected or affected by HIV/AIDS can make in the response to the epidemic

creating space within society for their involvement and active participation in all aspects of that response

Denver Principles 1983

The “Denver Principles” set forth standards for human rights and self-empowerment in a health crisis.



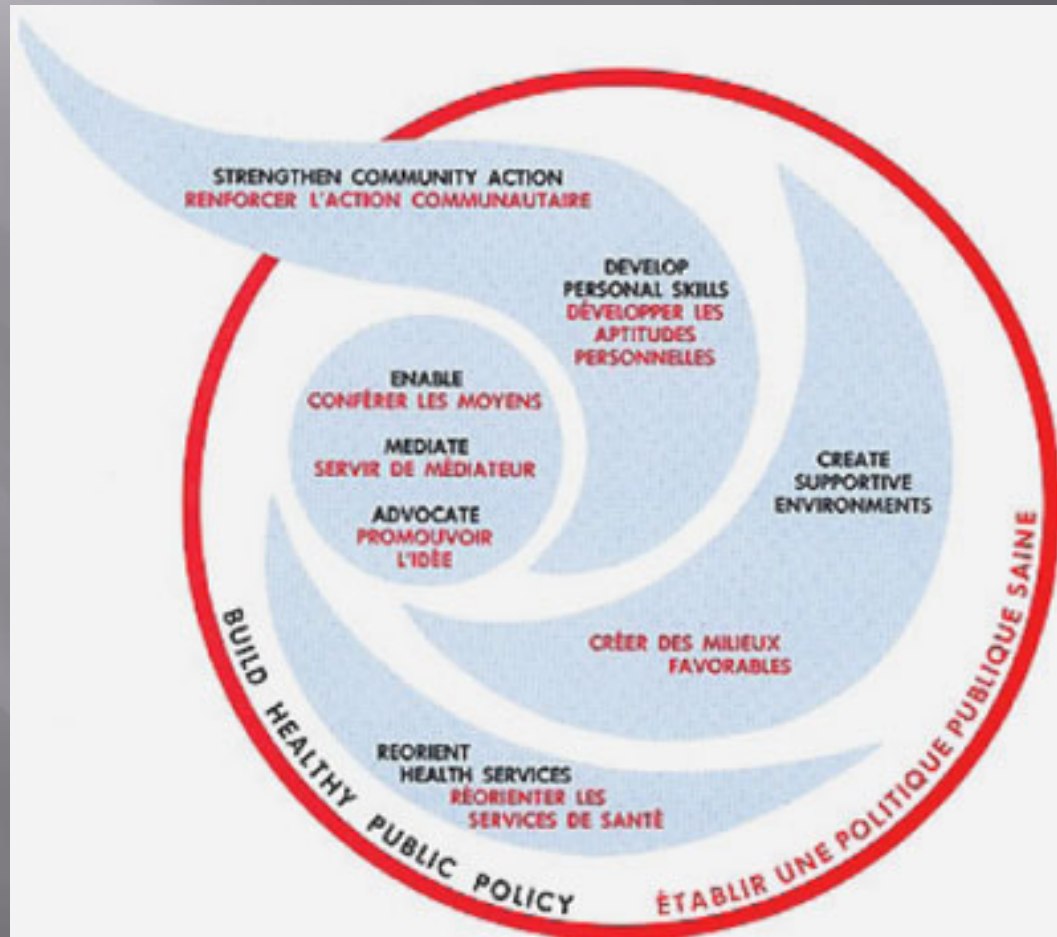
We condemn attempts to label us as “victims”, a term which implies defeat, and we are only occasionally “patients”, a term which implies passivity, helplessness and dependence upon the care of others.

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.

Ottawa Charter for Health Promotion 1986

1st International Conference on Health Promotion



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.

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.

<http://www.hivcode.org/about-the-code/>

The pyramid shows the increasing levels of involvement of PWHA. The GIPA principle advocates for involvement at all levels.

Decision makers: PWHA's participate in decision-making or policy-making bodies, and their inputs are valued equally with all the other members of these bodies.

Experts: PWHA's are recognised as important sources of information, knowledge and skills who participate on the same level as professionals in design, adaptation and evaluation of interventions.

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

Speakers: PWHA's 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.

Contributors: activities involve PWHA's 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 PWHA's, or address them en masse rather than as individuals. However, PWHA's should be recognised as more than (a) anonymous images on leaflets, posters or 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.

Living & Serving:
The Involvement of People Living
with HIV/AIDS in the Community
AIDS Movement in Ontario

Living and Serving

[http://www.ontarioaidsnetwork.on.ca/upload_image/documents/
living_serving_1.pdf](http://www.ontarioaidsnetwork.on.ca/upload_image/documents/living_serving_1.pdf)

Living and Serving 2

[http://www.ohtn.on.ca/documents/publications/
living_serving_report_april07.pdf](http://www.ohtn.on.ca/documents/publications/living_serving_report_april07.pdf)

The Ontario AIDS Network

Living and Serving 3

[http://www.ontarioaidsnetwork.on.ca/upload_image/
documents/
living_serving_3_oct_2011.pdf](http://www.ontarioaidsnetwork.on.ca/upload_image/documents/living_serving_3_oct_2011.pdf)

The Ontario Accord

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.

Basic Components of PHA Involvement

Recognizing the important contribution people living with HIV/AIDS can make in an ethical, effective response to the pandemic

Creating space within our society, our communities and our agencies for PHA involvement and participation in all aspects of that response

In many cases, effective participation requires strengthening the capacity of positive individuals to participate through training and skills building.

- personal empowerment
- communication and presentation skills (may include basic language and literacy skills)
- knowledge of medical, legal and social aspects of HIV/AIDS
- organizing and conducting policy dialogue
- program planning
- organizational governance
- networking
- etc.

THE CANADIAN AIDS SOCIETY ONE FOOT FORWARD

A GIPA Training Toolkit

[http://www.cdnaids.ca/onefootforwardagipa
trainingtoolkit](http://www.cdnaids.ca/onefootforwardagipa
trainingtoolkit)

The Ontario AIDS Network 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.

True practice of GIPA requires total empowerment of PHAs – power that is both generated from within and imparted from outside.

- ▣ The Bangkok Declaration

Thank you