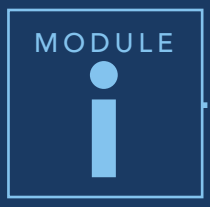
One Foot Forward

A GIPA Training Toolkit

Designed by and for People Living with HIV/AIDS



INTRODUCTION

CANADIAN AIDS SOCIETY
SOCIÉTÉ CANADIENNE DU SIDA

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MODULE i

INTRODUCTION

Pfizer

Working together for a healthier world™

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ONE FOOT FORWARD

A tool kit for the Greater Involvement of People with AIDS (GIPA)

This set of modules is designed to help people living with HIV/AIDS (PLWHIV/AIDS) develop basic skills to become more involved in their communities. These modules will not make decisions for you, nor do they offer all the information available to help PLWHIV/AIDS to become more meaningfully active and engaged.

"Greater" involvement does not always mean meaningful involvement. You must decide what kind of involvement has meaning for you, and seek out those opportunities. If it feels right for you – that's a good fit!

GIPA

In 1994, the United Nations developed a set of guiding principles based on the idea that PLWHIV/AIDS needed to be more involved in all decisions affecting their lives. The following are those principles:

- To support the greater involvement of people living with HIV and AIDS (PLWHA) through initiatives to strengthen the capacity and coordination of networks of PLWHA and Community Based Organizations (CBOs) stimulating the creation of a supportive political, legal and social environment;
- To involve PLWHA fully in decision making, formulation and implementation of public policies;
- To protect and promote the rights of individuals, in particular those living with or most vulnerable to HIV/AIDS, through legal and social environments;
- To make available necessary resources to better combat the pandemic including adequate support for PLWHA, NGOs and CBOs working with vulnerable and marginalized populations;

- To strengthen national and international mechanisms connected to human rights and ethics related to HIV/AIDS[1];
- To protect and promote human rights in our work; and
- To apply public health principles within our work.

These principles are intended to guide the work of community-based and government agencies.

Assessing how GIPA principles are used in your agency and other services in your community takes careful watching and listening, and a time commitment.

GIPA principles are not law – there is no rule that says a group must follow them – but agencies serving PLWHIV/AIDS have a duty to actively involve people with HIV in all aspects of work that affects the life of a PLWHIV/AIDS.

Suggestions for Using the Modules

At the end of each module, we've defined terms that may be unfamiliar to you.

Most of the modules have exercises that can help you focus your thinking on each issue. We encourage you to work through the exercises to gain a better sense of where you are in the process of choosing where to concentrate your greater and meaningful involvement.

A self assessment questionnaire at the end of each module offers you a chance to reflect on how well you have taken in the information provided for you.

Getting more involved in your community is an adventure.

We congratulate you on putting one foot forward.

[1] *Declaration of the Paris AIDS Summit, 1 December 1994.*

THANKS

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CAS also thanks the following Advisory Committee members for their contributions to the development and preparation of this tool kit. Without the wisdom of our own community, the work cannot be accomplished.

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One Foot Forward

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A

Act: In this module, "Act" refers to the government's formal documents regarding a "Society." Governments have many different kinds of Acts that guide and determine a process for all activities.

Agency: Any non-profit group. An agency is also referred to as an "organization" or "Society."

Agenda: From a Latin word meaning "that which is to be done," agendas keep meetings focussed on the work to be accomplished. It is usually a list of items to be covered.

AIDS Service Organization: Often referred to as "ASO." ASOs provide direct services, but are not necessarily peer-based agencies. Peer-based agencies can provide direct services, but are not commonly called "ASOs."

B

Blogs: A web log -- pages on the internet where people can express their personal views and ideas online.

Board of Directors: The group of volunteers in an agency that provides leadership to the agency and ensures it is operating in an accountable way.

Bureaucracy/bureaucratic: A bureaucracy is an office with many administrators. Bureaucracies are seen as moving slowly and having a lot of red tape, rules and regulations that slow things down.

C

Capacity: The ability of a person or group to do a particular thing. Often we hear about "capacity building," which means helping a person or group to develop abilities to do work.

Client: A client is a person who accesses the services and programs of an agency. Some groups, especially consumer groups, use the term "member" to describe a person who accesses services.

Committee: A group that meets to do particular work, which is often, but not always, associated with the work of the board. Committees are discussed more in the Boards and Governance module.

Computer literate: Being able to use the computer to a competent level.

Consumer: A consumer is a person who uses a service or program. In this module, "consumer" means a person with HIV or another person who uses a service. Consumer groups are groups that are run by and for people affected by an issue, such as HIV.

Contraindications: When you take a medication, it may interact badly with another medication or may not be appropriate if you have another existing condition. That alerts the pharmacist that it is "contraindicated." That is, the medication should NOT be taken with the other medication or with the other existing condition.

E

Ethics/Ethical: Moral principles often accepted as behaviour that provides the best outcome for everyone and does not cause harm.

Executive Director: The most common lead staff person in an agency, who is also often referred to as the "ED"

H

Harm reduction: In HIV work, harm reduction means actions that reduce the chance of transmitting or contracting HIV, such as using clean needles and other drug equipment, or using condoms when having anal or vaginal sex.

HCV: Hepatitis C virus.

Heterosexism: An expression related to homophobia, an irrational fear of homosexual people. While most people in our society are not afraid of homosexual people, heterosexism is the dominant belief that it's better to be straight than gay.

HIV: Human immunodeficiency virus.

L

Literature Review: Also called a "lit review," it is any research of available literature, papers and studies that covers a particular topic.

Lypodystrophy: "Lypo" means "fat," "dystrophy" means "distribution." Lypodystrophy is a side effect of HIV medications that causes fat to be redistributed in the body (e.g., buffalo hump, extended belly). As for "lypoatrophy," it means a loss of fat. Most people experience lypoatrophy in their face, but some also experience fat loss in their buttocks, arms and legs.

M

Mandate: The main purpose of a group or person. The mandate of an ASO may be "to reduce the spread of HIV and to provide support to people living with HIV." It is a direction for the focus of the Society's work.

Member: Member can refer to either a regular member of a Society or to a board member. The two are different. A board member can both attend and vote at board meetings, while a regular member can only attend board meetings. The regular member can, however, both attend and vote at the Annual General Meeting. A regular member can also participate on committees and vote, if the committee allows.

N

NGO: Non-governmental organization. Any community-based group that is not directly connected to government is an NGO.

P

Pharma: Pharmaceutical company.

PLWHIV/AIDS: A person living with HIV/AIDS. You will also hear people say "PHA" or "PWA."

Q

Qualifications: A quality, ability or background that makes a person the best choice for a particular kind of work. This sometimes involves work experience or education, but not always. Sometimes lived experience is the best qualification.

R

Regimen: A course of medications.

Resolution: A resolution is a decision that guides the activity of the Society.

S

Sero-status: Whether or not you develop antibodies for a specific antigen. In this document, your sero-status refers to whether you have HIV or not. If you are seropositive, you have the virus, whereas, if you are seronegative, you do not.

Society: In other modules, we used the term "agency" and "organization." These are common terms for "Society." A Society (capital "s") is a registered non-profit organization. Many Societies are also registered charitable organizations, but not all are. In this module, we use the term "Society" because it is an official title that refers to the work of a board of directors.

Spreadsheet: A document that organizes data in rows and columns of cells. Each cell may contain words, a number, or a formula. Often, calculations can be made with the numbers in other cells. It is often used to present a society's financial statements.

Stigma: A mark of disgrace. Many people with HIV feel the stigma of living with the virus because some people think that having HIV means you had many sex partners or shared and used drugs.

Syndrome: A syndrome is a collection of symptoms or illnesses. AIDS stands for Acquired Immune Deficiency Syndrome, a collection of symptoms and illnesses diagnosed after infection with HIV.