

One Foot Forward

A GIPA Training Toolkit

*Designed by and
for People Living
with HIV/AIDS*

MODULE

2

ASSESSING YOUR AGENCY

CANADIAN
AIDS
SOCIETY



SOCIÉTÉ
CANADIENNE
DU SIDA



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Working together for a healthier world™

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TABLE OF CONTENTS

GIPA PRINCIPLES	1
THE GIPA PYRAMID	2
ASSESSING YOUR AGENCY USING GIPA	3
Getting to Know Your Agency	9
Ethical Behaviour in an Agency	10
Pitfalls	10
Accountability and Responsibility	11
Do NOT Pass "Go"	11
Personality Conflicts	12
Agency Politics	12
Required Skills	12
Size of the Agency	13
Availability of Positions	13
Professional Qualifications	14
TERMS IN THIS MODULE	14
SELF ASSESSMENT	15



In this module, we'll look at ways that you can assess your agency and how it incorporates GIPA principles into its operation.

All AIDS agencies should ideally include GIPA as a part of their philosophy. The capacity and size of the agency may mean that different aspects of GIPA are practised more than others.

GIPA PRINCIPLES

Let's go back to the GIPA principles and explore a way for you to assess or ask appropriate questions to help determine how inclusive your agency is. This can also help you decide if you want to become more meaningfully involved.

- 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/AIDS¹.
- To protect and promote human rights in our work.
- To apply public health principles within our work.

¹ Declaration of the Paris AIDS Summit, 1 December 1994.

THE GIPA PYRAMID

Below is an illustration developed by the Joint United Nations Programme on HIV/AIDS (UNAIDS) of how PLWHIV/AIDS can be involved in an agency at different levels.

There are many ways to be involved. Where would you like to be in this pyramid?

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 PWHAs 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

ASSESSING YOUR AGENCY USING GIPA

Now let's look at each point separately.

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.

You can assess some of these issues almost immediately.

Does your agency:

- support PLWHIV/AIDS;
- offer a social environment for PLWHIV/AIDS;
- encourage PLWHIV/AIDS to talk together about issues that affect them directly; and
- offer a way for PLWHIV/AIDS to talk about issues with staff and board members?

Support can mean very different things to different people. Some agencies may have a drop-in for PLWHIV/AIDS; others may offer one-to-one support.

Does your agency provide some level of support that is meaningful and useful to PLWHIV/AIDS? Are PLWHIV/AIDS included in providing support?

A social environment can include anything from volunteer activities to events and social groups.

Are events planned for PLWHIV/AIDS at your agency? Are there informal social groups, like movie nights or coffee get-togethers? Do PLWHIV/AIDS participate in the planning?

Talking about issues that affect you means more than talking about medications. Agencies should ideally include PLWHIV/AIDS in planning programs and services that meet their needs, and even in delivering those programs.

Are PLWHIV/AIDS consulted and included in program planning at your agency? Are there groups where they can discuss issues important in their lives?

Engaging in discussions with staff and board members is a way that PLWHIV/AIDS can be engaged in the operations of the agency, including policy development, program development and governance.

Does your agency make it easy for PLWHIV/AIDS to discuss issues with staff and board members? Are there ways that your agency includes PLWHIV/AIDS in policy and program development and planning?

If the answer to some of these points is “no”, there may be problems with how the GIPA principle is applied. There may also be issues of capacity. In smaller agencies, there may be fewer staff to meet the greater needs of PLWHIV/AIDS. If this is the case, it may be an opportunity for you to talk about improvements and to assist in working toward greater inclusion and involvement.

Don't think that just because some things don't feel right that there's a reason for alarm. Check it out for yourself and talk with other people before drawing conclusions.

To involve PLWHA fully in decision making, formulation and implementation of public policies

Does your agency:

- discuss programs and projects that directly affect PLWHIV/AIDS before proceeding;
- involve the clients/members in developing programs that affect them;
- have dedicated seats on the board of directors for PLWHIV/AIDS;
- encourage PLWHIV/AIDS to apply for paid positions as they become available; and
- actively seek PLWHIV/AIDS to volunteer in programs?

This area is key to the GIPA principle. Every agency should strive to involve PLWHIV/AIDS in all aspects of their work, including planning, delivering and evaluating programs and services, especially when it directly affects the lives of PLWHIV/AIDS.

Dedicated seats on a board mean that people with HIV are not only encouraged, but are required, to assist in leading the agency and its work. PLWHIV/AIDS bring a different perspective to the board and can bring their lived experience to the table.

Actively seeking people with HIV to deliver programs and services, whether through volunteering or paid positions, is another way to ensure that PLWHIV/AIDS are involved in the operation of the agency.

If you answered “no” to any of the questions above, there may be serious issues in the agency that need to be addressed. If the agency subscribes to the GIPA principles, and there is little inclusion and involvement of PLWHIV/AIDS in programs and services, talk about your concerns with staff members you trust, or ask to speak with a board member.

Make sure you are clear about what you wish to discuss and try to develop solutions that will enhance the involvement of PLWHIV/AIDS.

To protect and promote the rights of individuals, in particular those living with or most vulnerable to HIV/AIDS, through legal and social environments

Does your agency:

- provide advocacy for PLWHIV/AIDS;
- provide referrals to appropriate organizations that engage in advocacy or offer legal advice;
- speak to issues in your community that affect the rights of PLWHIV/AIDS;
- work toward ensuring that services and programs in the community are accessible to PLWHIV/AIDS; and
- work toward educating the public about living with HIV, and the rights of PLWHIV/AIDS?

Protecting and promoting rights of individuals is another key area supported by the GIPA principles. Agencies should, to the best of their ability, strive to:

- educate the public and address issues in each community about the realities of living with HIV;
- communicate the facts about transmission and prevention; and
- convey the importance of PLWHIV/AIDS being able to access services and programs freely and without discrimination.

ONE FOOT FORWARD

If you answered “no” to any of the questions above, you may want to discuss it with the agency to ensure public awareness and education are taking place and that issues that affect the lives of you, your peers and the community at large are being addressed.

To make available necessary resources to better combat the pandemic including adequate support for PLWHA, NGOs and CBOs working with vulnerable and marginalized populations

Does the agency:

- involve people with HIV and support marginalized populations (e.g., IDU, women, Aboriginal communities)?

The crux of this point is more about governments than about social agencies, but it is valid to ask how the agency provides support to PLWHIV/AIDS.

Does your provincial government have a dedicated AIDS portfolio? Does your provincial government address HIV in Aboriginal communities, ethno-cultural communities and the gay community?

You may also want to talk with agency staff or the Executive Director about provincial and federal government assistance available to the agency to fund programs and services. There may be some work you can do to assist the agency in securing the financial resources needed to improve programs.

To strengthen national and international mechanisms connected to human rights and ethics related to HIV/AIDS

This point again refers to government responses. You can speak about these issues with agency staff. You may be interested in helping the agency become more involved in the areas of human rights and ethics at a national or international level.

Some agencies are involved in “twinning” projects, in which one group in Canada pairs with a similar group in another country. In some countries, PLWHIV/AIDS have no freedoms and live in constant fear of physical harm. Twinning is a way in which groups can support each other and help PLWHIV/AIDS to overcome adversity.

To protect and promote human rights in our work

Does your agency:

- have clear policies about the rights of staff/volunteers;
- have clear policies for staff/volunteers who are HIV positive;
- actively involve staff/volunteers in all areas of development in the agency (including developing job descriptions and evaluation tools);
- ensure that the rights of staff/volunteers are upheld; and
- ensure that there are mechanisms within the agency for people to appeal decisions?

You can ask to see the agency policy manual and do your own review to look for policies and practices that support the rights of PLWHIV/AIDS, volunteers and staff people.

If you answered “no” to any of these questions, you may want to explore more. Ask to see any of the agency’s staff and volunteer policies. If there are no policies that clearly take into consideration PLWHIV/AIDS, ask why not.

Perhaps there’s room to work in the agency to make sure policies and support mechanisms are in place.

If there is no mechanism for appeal or for conflict resolution, again ask why not and see if you can assist in developing those tools.

To apply public health principles within our work

Public health principles outline the best ways to ensure that the physical, mental and emotional health needs of the community are met.

In Canada, we have a population health model through the Public Health Agency of Canada:

Our understanding of what makes and keeps people healthy continues to evolve and be further refined. A population health approach reflects the evidence that factors outside the health care system or sector significantly affect health.

A population health approach considers the entire range of individual and collective factors and conditions – and their interactions – that have been shown to be correlated with health status. Commonly referred to as the “determinants of health,” these factors currently include:

1. income and social status
2. social support networks
3. education
4. employment/working conditions
5. social environments
6. physical environments
7. personal health practices and coping skills
8. healthy child development
9. biology and genetic endowment
10. health services
11. gender
12. culture

Other issues that affect our overall health can include homophobia/heterosexism, stigma, discrimination, aging, mental illness and psychosocial factors.

Not all agencies will be working with all aspects of the population health model, but there will be some parts that apply.

Does the agency:

- work toward improving income and social status for PLWHIV/AIDS (through advocacy, support programs and involvement of PLWHIV/AIDS);
- create social support networks by forming support groups and by offering social activities;
- provide education programs for PLWHIV/AIDS and the community (promoting and educating about informed decision-making in health care, available services in the community and HIV prevention);
- support PLWHIV/AIDS who are working, or employ them in key areas of the agency;
- create environments (e.g., support groups and social events) for PLWHIV/AIDS to interact with each other;

- create safe and clean physical environments, such as clean drop-ins;
- offer information about personal health practices and support people making healthy decisions about nutrition, safer sex and safer using, for example;
- support parents and children who are living with HIV or caring for a family member with HIV (by offering support groups and activities);
- acknowledge that a person's biology, genetics and age can play a role in health;
- provide health services or referrals to appropriate health services for PLWHIV/AIDS;
- acknowledge gender differences and how those differences affect PLWHIV/AIDS; and
- acknowledge cultural differences and work to support people from different cultures (e.g., Aboriginal people, Asian cultures and gay men's subculture)?

If you answered "no" to ALL of these, there's an issue; but if the agency works toward ensuring that PLWHIV/AIDS are included and supported, regardless of their social status, income or life background, they are moving in the right direction.

Ask about how population health models are used to develop the programs and services in the agency.

Getting to Know Your Agency

Becoming familiar with your agency means watching, asking, listening and learning. Every agency is different and getting to know an agency will mean that you have to do your own homework.

Explore the programs and services offered. Do they make sense? Do they work well? What do the participants think about the services and programs?

What's the culture in the agency? Is it relaxed and friendly? Is it large and bureaucratic? Is it large and friendly? Culture is not always easy to define and our perceptions are very personal. Ask other people what they think and feel about the agency.

Ethical Behaviour in an Agency

Ethical behaviour boils down to one thing: DO NO HARM.

When you look at the work of the agency, the question to ask is, “Is there any harm being done to a person or group?”

Most agencies are highly ethical in their actions. The majority of people working for them are well-intentioned – they don’t mean for anyone to be harmed by their actions or decisions.

Sometimes, it’s unclear. You may hear from someone that they aren’t happy about a course of action or decision taken.

Don’t jump to conclusions.

“The first step in the evolution of ethics is an enlargement of the sense of solidarity with other human beings.”

– *Albert Schweitzer*

In most cases, there are two sides to every story, with the truth lying somewhere in the middle. Always try to listen to all sides of a story before making conclusions. In some cases, confidentiality will be an obstacle to gaining access to all the information.

If you feel that the agency, a staff person, volunteer or even a client, is causing harm, report it to the Executive Director or the board of directors and write down everything you can about the incident in question.

Pitfalls

When you become involved in the work of an agency, whatever the program or area of involvement, you run the risk of being emotionally involved because you yourself are living with HIV every day.

Being that close to a particular issue may cloud your judgment, cause you to become involved in the internal politics of the agency, bring on stress that you don’t want and otherwise turn the experience sour for you.

Always be aware of how getting caught up in office politics will affect you personally and try your best to avoid it.

Conflict of interest, a topic we’ll discuss later in the modules, is another issue to be aware of. Being in conflict, or in a perceived conflict, is a serious issue for board members and staff persons alike.

If you think you are getting too involved, it's good to take a step back and reassess how you're doing and why you're doing the work.

Accountability and Responsibility

When you decide to become more involved, you need to understand that you are accountable and responsible for what you do.

You are responsible to yourself to:

- keep yourself healthy;
- keep yourself sane; and
- keep your mind clear.

You are responsible to the workplace and colleagues to:

- do what you say you'll do;
- act in good faith and with only the best intentions;
- be honest when you don't know or understand, and to seek more information;
- be open to hearing others' ideas and opinions; and
- follow the guidelines you're given.

When you think about being accountable, being honest with yourself is a good base to start from. When you agree to do work, you need to be honest about your level of commitment to the work.

It's about what counts to you.

Do NOT Pass "Go"

Some PLWHIV/AIDS have reported problems when trying to become involved with agencies. There are many reasons.

Here are some potential roadblocks:

- personality conflict with a staff person or volunteer;
- agency politics;
- lack of skills;
- size of agency;
- availability of positions; and
- professional qualifications.

Next, we'll offer some strategies to overcome those obstacles.

Personality Conflicts

Not everyone gets along with everyone all the time. There will be times when you don't like a co-worker or staff person and they don't like you. You may be able to resolve the issue just by talking. If you feel able, try to have an honest talk with the person with whom you have the conflict.

If that doesn't work, or you feel uncomfortable, you can ask for another person you both trust to act as a mediator to try to resolve the conflict.

If that doesn't work, you may want to ask yourself if it's worth being involved with that program. There may be other areas where you are more comfortable or feel more appreciated.

Agency Politics

This roadblock is not so easy to resolve. If the political climate in your agency leads to PLWHIV/AIDS being excluded from involvement, there's a problem.

If it's politics between staff, ask why that's happening.

If it's politics about clients, and you feel comfortable doing so, go to the ED or a board member and have an honest and open discussion about your concerns.

If the politics make the place uncomfortable for many PLWHIV/AIDS, see if there are others who will go with you to the board to express your concerns. Write down your concerns beforehand. If you have solutions, provide them in writing, too.

Required Skills

If you are told you lack the necessary skills for a particular program, ask what those skills are and if skills building or training is available.

In many programs, a skills assessment often takes place within the first three months. At the end of that time, if a volunteer, or staff person, doesn't show the level of skill required, they may be asked to leave.

This is often called a probationary period. It's meant to ensure that the best quality services are provided. Probationary periods are subject to certain requirements too. All criteria being assessed in a probationary employee's performance must be clearly measurable. If a requirement reads "Be a team player," it is not measurable. If it reads, "Must attend all meetings," it is measurable.

Whatever the case, you can ask how you can improve your skills, or seek advice on an area of work that's better for you.

Size of the Agency

Although it sounds like an excuse, in small agencies, there may be barriers simply because physical space in the office is limited, the programs and services are very specific or staff people aren't available to supervise lots of volunteers.

BINGO! There's your "in."

Perhaps you can assist the staff in getting people meaningfully involved, which can improve the agency's work and offers the staff more human resources to make things happen.

Never say never with a small agency. Recognize that staff and volunteers may feel overwhelmed with work and offer to help out where you can. You can probably assist in many ways!

Large agencies, on the other hand, may require and be able to accommodate many volunteers, unless they employ professionals who require licensing to provide services (e.g., nurses, therapists, social workers). Even if that's the case, there may be an opportunity to help professional staff in some aspect of their work. Accompanying nurses as a peer support person is one example.

Also, larger agencies usually have volunteer departments. Start there and see what's available.

Availability of Positions

Again, it may seem an excuse, but sometimes there are limited volunteer or paid positions available in an agency. For any agency, if volunteers outnumber the tasks to be done, the volunteers may get bored and just leave.

ONE FOOT FORWARD

You may want to explore with the agency the possibility of creating positions to meet a need that isn't being addressed well.

You can show leadership by offering to help develop positions that are meaningful and improve the agency's work.

Professional Qualifications

Professional qualifications should not be an issue for volunteering, unless the nature of the volunteer work requires very specific skills and knowledge (e.g., legal aid). However, if you think you have the necessary knowledge and skills, you might ask to be allowed to participate on a trial basis to show you are able to do the work.

In most volunteer positions, professional qualifications should not matter, since training is usually provided to ensure you have the skills you need.

If you are told you need professional qualifications to volunteer, ask to see the job descriptions and policies for that position. If you disagree with the policies and believe you could do the work, you might speak with the ED or board about your concerns. Write down your concerns and your reasons for them.

TERMS IN THIS MODULE

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.

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.

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

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.

SELF ASSESSMENT

After completing this module, I learned:

I still need more information about:

My strongest areas right now are:

My weakest areas right now are:

My next steps will be:

I can complete my next steps by: _____

Rate the statements below by circling the number that you think fits.

	Very confident			Need to work on this	
I spent enough time on this module.	1	2	3	4	5
I'm using my energy wisely.	1	2	3	4	5
I know where to find more information.	1	2	3	4	5
I can find a person to help me out.	1	2	3	4	5
I know how to apply what I learned.	1	2	3	4	5