

One Foot Forward

A GIPA Training Toolkit

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

MODULE

1

COMMUNITY-BASED GROUPS

CANADIAN
AIDS
SOCIETY



SOCIÉTÉ
CANADIENNE
DU SIDA



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Working together for a healthier world™

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In this module, we will outline the most common types of programs offered by community-based AIDS service organizations. We will also look at how to assess the inclusive policies of an agency and explore how to become meaningfully involved.

Keep in mind that there are many types of agencies in your community that provide a broad range of services to all kinds of people, and with their own way of doing things. Being HIV positive does not mean you must align yourself with an AIDS service organization.

“Alone we can do so little;
together we can do so much.”
– Helen Adams Keller

Most AIDS groups focus on two common areas: prevention of HIV and support for people living with HIV/AIDS (PLWHIV/AIDS) and their loved ones. A scan of Canadian AIDS Society member agencies shows the following to be the most common types of programs and services offered:

- counselling and advocacy (e.g., financial advocacy, emotional counselling);
- education for specific populations (e.g., people who use injection drugs, gay/bi men);
- education for the public (e.g., schools, care workers);
- resource library/ information;
- newsletter;
- drop-in programs;
- support groups for specific populations (e.g., women, youth);
- support groups for ethno-cultural groups (language or country-specific);
- support groups for Aboriginal persons;
- support groups for PLWHIV/AIDS;
- support groups for people living with HCV;
- peer support;
- needle exchange;
- outreach (generally street outreach);
- housing support; and
- youth support and outreach.

Other less common programs include:

- food and meal provision;
- community kitchens;
- gay/bisexual community outreach and support;
- prison outreach; and
- sex trade worker outreach.

Each agency offers variations on these programs, depending on its size and budget.

You have the opportunity to explore any one of these areas, depending on your interests.

Ask to speak with the coordinators of various programs to find out more about what they do, who the program serves, the commitment involved and the training and support provided to volunteers or workers in the program.

If the agency has a volunteer coordinator, that person may have useful information to help you in making a choice.

BASIC INFORMATION ABOUT PROGRAMS

If you're interested in volunteering at an agency, becoming familiar with the different programs and services offered is important. By asking questions about how each program works, you can then decide which program is the right one for you.

Agencies often have training sessions for volunteers throughout the year. You may need to wait for a formal training session before becoming completely involved in the program of your choice. If you need to wait for a formal training session, it's worth asking if you can help the program in other ways. Some kinds of support work (e.g., photocopying, computer work, research) can help you learn more about the program and become involved right away.

The following are some examples of how programs and services are structured; however, each agency will have its own approach to the work.

Peer Support and Counselling Programs

Peer support programs connect PLWHIV/AIDS to other PLWHIV/AIDS, or connect people who share similar backgrounds. However, the fact that you are living with HIV doesn't always make you a peer. There are other factors that might qualify you as a peer, such as:

- lifestyle;
- sexual orientation;
- street-involvement or substance use issues; and
- gender.

Usually in peer support and counselling programs, a great deal of attention is paid to communication skills. These are essential tools for providing high quality peer support. Good communication skills help you:

- know how to listen;
- know when to respond;
- know how to respond; and
- assist your peer in figuring out their own answers.

If the agency does not have peer support programs and you think they might help, discuss it with a program coordinator, volunteer coordinator or the executive director to see if there is a need and if the necessary resources to create one are available.

Peer support and counselling can help you and your peers understand each other and provide the necessary information to make informed decisions about health care.

Remember that it's not about YOU. When you're providing peer support, it's about THEM.

Some counselling programs employ registered social workers or therapists. Not every agency has a peer-based program. Ask to find out what types of peer programming are available.

Advocacy

Advocacy means “to speak for.” Many advocacy programs deal with:

- financial aid (e.g., income assistance programs, CPP, EI);
- housing issues (e.g., assistance in finding housing, maintaining housing, landlord disputes); and
- health services (being able to access care and treatment as necessary).

But there may be other areas where advocacy is useful. Ask about the main areas and about training that may assist you in being an advocate at your agency.

Advocacy can be very intensive work, so you should be prepared to devote the necessary time and energy. There is a lot to learn about systems and how they function. In the end, you will learn things that could be valuable to you in your personal life.

Support Groups

Support groups can be general in nature (i.e., for ALL PLWHIV/AIDS), or specific (e.g., women’s groups or youth groups). If being involved in support groups interests you, ask the agency about its support program and how it works.

Facilitating (leading) a support group can be challenging. Dealing with the sensitive issues that may surface can be very emotional. Facilitating such groups often involves specific skills for which you should receive training.

You must keep in mind all the aspects of privacy and confidentiality, if you are involved in any support position, be it with a group or one-on-one. Breaching confidentiality is very serious and very easy to do. Make sure you know all the policies about confidentiality – they’ll help you to understand and fulfil your role.

Support in Smaller Communities

If you live in a small community or rural region, there may not be an AIDS group in your immediate area. If you are interested in providing support programming to other PLWHIV/AIDS, you may want to contact the nearest AIDS group to assist you in developing programming in your area.

You might also seek a supportive non-AIDS agency (e.g., the Cancer Society) that might also be able to guide you in how to provide services in your community.

You may also refer to online chats and forums, e-mail list services, phone support and more to provide you with details about the types of services your community needs. It will take some work, but it can be done.

Educational Programs

Most organizations have an education program. Some deal with particular groups and issues (e.g., legal concerns, health care providers) and some cover a broader range of issues (e.g., working in schools, serving the general public or awareness campaigns).

Inform yourself about the education programming of the agency to see how you might become involved in its work.

Does public speaking intimidate you? Not to fear! There are many ways to be involved in education, such as creating posters, writing articles and doing research. Any one of these skills is very valuable in helping to educate others about HIV/AIDS and HCV.

Speakers' Bureaus and Lived Experience

A speakers' bureau is a group of people who provide education to a broad range of audiences, including:

- schools;
- health care providers; and
- the general public.

If you think you might be interested in becoming involved with an agency's speakers' bureau, ask yourself these questions:

- Am I comfortable in front of groups?
- Am I willing to practice?
- Am I comfortable offering my experience as a person with HIV?
- Do I know the latest information, and if not, am I willing to spend the time to learn?

All these traits and qualities are very important in public speaking. You do not have to offer your own experiences as a person living with HIV, but those experiences can teach others a lot.

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If you think you can offer your experiences, talk with the coordinator of the speakers' bureau and see how you might fit in. If a training program is provided, great! The more information and practice you have, the better you will be in making presentations.

Often, speakers are paired up to provide support and expertise in different areas. Although you might not know everything about transmission and prevention, your partner might be able to fill in the gaps. If your partner hasn't been on medications and you have, you can offer that experience. It's about balance and making sure the audience receives the information it needs.

Lived experience offers the audience the chance – often their first – to hear from a PLWHIV/AIDS. Its value is immeasurable. It gives you the opportunity to share your story, while enriching your audience. If you do not feel safe, or if you are in a small community, you may choose not to offer your story. That's okay, too. Work at the level at which you are most comfortable.

Newsletters and Resource Libraries

Many agencies have a newsletter as a means of communicating with volunteers, clients, members and the public.

Ask about the agency's newsletter and how you can contribute.

Resource libraries are not in every agency. Some groups may only keep on file clippings and items from the newspapers or the internet. Other groups have a collection of books, CDs, DVDs and tapes. If you enjoy work that involves collecting and sorting through information, getting involved in a library project might be right for you.

Needle Exchange

More and more agencies are becoming involved in needle exchange and other harm reduction programs. This type of program generally involves training in HIV/HCV transmission/prevention, collecting and disposing of needles, working with people who use injection drugs, dealing with difficult behaviour and knowing how drugs and addiction affect a person.

Some agencies have "fixed site" exchange in a building; other groups may have a mobile exchange or foot outreach.

If you want to be involved in needle exchange programs, ask for information on the type of training and support you need and/or will get. You might ask if you can “shadow” a needle exchange worker to see what the experience is like and if it’s right for you. If you are already involved in needle exchange programs, you could be a mentor for new volunteers.

Whatever program you are interested in, never be afraid to ask for information about the program or service before becoming involved.

GENERAL AGENCY STRUCTURES

Each agency has its own culture, values, vision, mandate and mission. As well, each agency will have its own staffing structures. The following are fairly typical components of an agency’s strategic framework, which guide agency operations.

- **Mission:** the main work or purpose of the Society.
- **Mandate:** similar to the mission, but more focussed, it outlines who the agency works with.
- **Values:** the organization’s beliefs or ideals. They are usually communicated in a values statement. You may have to ask to see a copy of the agency’s value statement. Not all agencies have one.
- **Vision:** another statement for the broader direction of the Society, it defines where the organization is going. Again, you may need to ask to see if there is a vision statement.

AIDS SERVICE ORGANIZATIONS AND PEER ORGANIZATIONS

While all AIDS groups provide services and programs for PLWHIV/AIDS, there is a distinction that we make between an AIDS service organization (ASO) and a peer-based organization. An ASO may have staff people who are living with HIV, but many do not. The board of directors of ASOs should have designated seats for PLWHIV/AIDS and may have peer-based programming as well.

A peer organization, such as Toronto Persons with AIDS Society, is a group run by and for PLWHIV/AIDS. All board seats, with the exception of those for advisory members, are for PLWHIV/AIDS. While a peer group may have staff people who are not living with HIV, the services are, nonetheless, directed by PLWHIV/AIDS.

CULTURE

This area is not so easy to define. You may have to do some observation to judge for yourself the culture or working environment of the agency.

Culture is the way people interact with each other and generally accepted norms. Some larger groups have a more “corporate” culture: they are more structured and, perhaps, more bureaucratic than smaller agencies. Some cultures are relaxed and informal, while some are chaotic and may seem to have an underlying tension.

Each agency is unique and its culture will reflect the norms of the people who work there and of those who access its services.

STAFF

Each agency will have its own staffing structure, depending on the size and budget of the organization. Some standard staff positions are:

Executive Director: the “boss.” This person is responsible for the overall operations of the agency and answers directly to a board of directors. Sometimes, you’ll hear people talk about the “ED,” which is just the acronym for the title.

Volunteer Coordinator/Manager: coordinates the recruiting, screening, training, placing, evaluating and recognition of all volunteers in the agency and usually reports to the Executive Director.

Program Coordinator/Manager: This position is completely dependent on what types of programs are offered by an agency. There may be a coordinator for each program offered (e.g., an outreach coordinator, peer support coordinator, counselling program coordinator). These positions usually report to the Executive Director.

Other general staff positions may include:

Executive Assistant: assists the ED in their work.

Office Manager: oversees the administration of the office.

Human Resource (HR) Manager: this person is responsible for all of the staffing issues in an agency.

There may also be positions, such as Care Coordinator, Health Promotion Coordinator, Case Manager and Communications/Public Relations Coordinator, that deal with specific programs.

Ask to speak with someone about the staffing structures and their organization within your agency.

ORGANIZATIONAL CHARTS

Some organizations develop charts, visual representations of how the agency's positions are structured and/or how communication flows.

Many charts might look like this:



There are many possible variations for charts. Some agencies do not use charts. If you're interested in learning more, you could ask if there's an organizational chart.

Some agencies follow a "governance" model. You'll read more about this model in the Boards and Governance module, but briefly, governance means that the board of directors sets a vision for the agency and the Executive Director and staff carry out that vision.

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Under a governance model, the board does not get involved in the daily activity of the agency. There are usually restrictions for staff and volunteers with respect to talking directly to board members about agency business. Generally, requests to speak or present to the board may have to go directly to the Executive Director.

STEWARDSHIP MODEL

While many organizations follow a governance model that appears to be “top down,” other groups have adopted a “stewardship” model. In stewardship, the organizational chart of the governance model is flipped upside down.

In a stewardship model, the client is at the top and all other positions are below to provide support. The board supports the Executive Director, who in turn supports the staff people, who support the volunteers, who support the clients. Communication is free-flowing, but the most important information comes from the client to the rest of the organization, informing every action and program or service.

A stewardship model might look something like this:



DISCLOSURE OF YOUR HIV STATUS

Disclosing your HIV status is your choice. You have to consider how disclosing will affect your life, both positively and negatively.

In small urban and rural areas, disclosing your status may not be a safe thing to do. Information spreads and you may not want your neighbours to find out. On the other hand, being open may be a way to gain support.

The fear of stigma and discrimination is very real. Even this many years after the HIV pandemic started, people still fear both HIV and PLWHIV/AIDS. People still lose their jobs, their housing and their friends and family.

Think about what you might lose, and gain, before disclosing your status. If you think the risk is worth it, then choose carefully to whom you disclose. A trusted person would be the best place to start. And if you decide that disclosing would be too great a risk, then don't.

It is always up to you.

GIPA AND PRIVACY ISSUES

While GIPA principles apply to all areas of our lives, our agencies and our governments are also responsible for maintaining privacy and keeping your personal information confidential. GIPA principles are discussed more in depth in Module 2. You are not expected to “come out of the closet” about your HIV status unless you choose to.

Disclosing your status is always your decision. Never feel pressured to disclose because you are living with HIV. If you do choose to be open about your status, you are still protected by rules about who can discuss that and with whom.

If you decide to “come out” as a person living with HIV, you may choose to do so among a select few, and you don't have to talk about all of your personal life.

You can ask about protection of private information at your agency.

CONFLICT

“When you have discovered a stain in yourself, you eagerly seek for and gladly find stains in others.”

– Berthold Auerbach

At different points in your life, you may be in conflict with someone. People have differing opinions, philosophies, beliefs and personalities, which sometimes “clash” with those of others.

Although it’s unpleasant, it’s part of human nature.

What is conflict?

While you may disagree with someone, or they with you, you aren’t necessarily in a conflict. A conflict occurs when communication breaks down, becomes toxic and makes the working environment either unsafe or uncomfortable.

Sometimes people will engage in email battles, arguing points and pointing fingers. Sometimes people can become openly hostile and consistently argumentative in the workplace. Sometimes the conflict can be over the ways in which we do our work or the parameters of our work or volunteering.

Sometimes, and more subtly, conflict can be a tension that exists between people when no one talks and nothing gets done because we simply can’t function well.

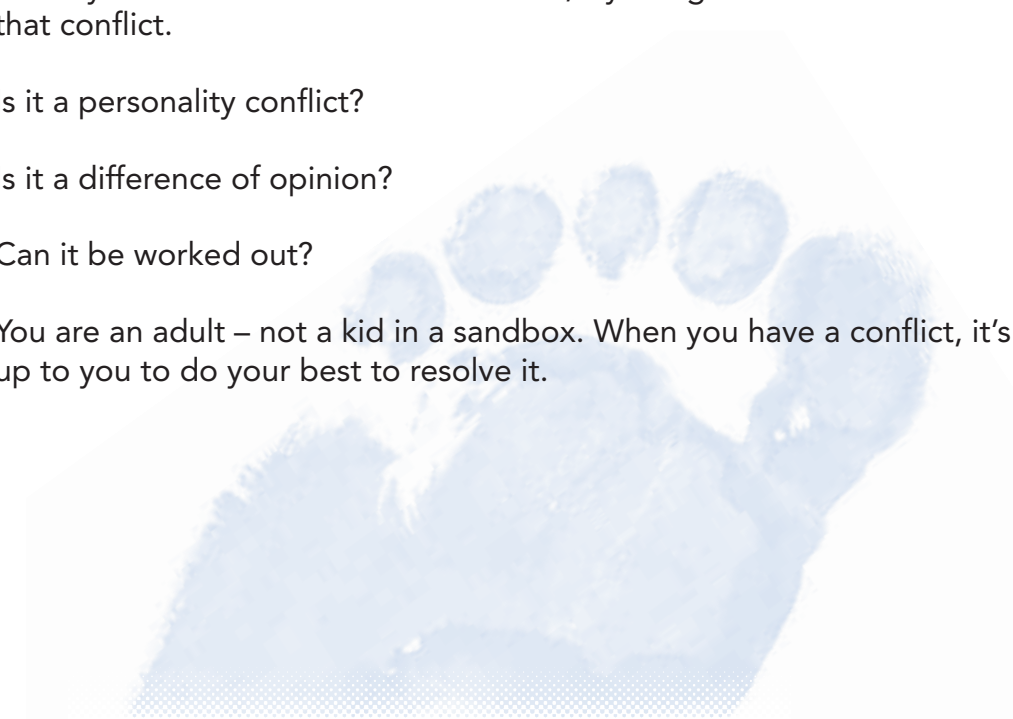
When you have a conflict with someone, try to figure out what led to that conflict.

Is it a personality conflict?

Is it a difference of opinion?

Can it be worked out?

You are an adult – not a kid in a sandbox. When you have a conflict, it’s up to you to do your best to resolve it.



Step 1: Talk about the conflict. If there is a person you trust, talk with them about what you're feeling and see what they think. Try to be as objective as you can – no name calling, no gossip. Next, talk to the person with whom you have the conflict and see if you can work it out.

Step 2: If that didn't work, see if there's a conflict resolution policy and talk formally with a staff person about the conflict. Again, be objective: talk only about the facts, not crushed feelings. The staff person may have some ideas about other ways to resolve the issue.

Step 3: If that doesn't work, formally use the conflict resolution process.

Step 4: If the agency doesn't have a process, you may have to decide if it's worth seeking an advocate from another agency, or you may decide to move on.

The decision is yours.

Of course, before even taking these steps, it's preferable to avoid conflict.

Always be open and honest about how you're feeling and what you're thinking. And do it from a place of genuine caring. Think before you start talking and consider how it would feel to you if you were told what you're about to say to the other person.

Avoid...

- gossip;
- rumour;
- innuendo;
- name-calling; and
- getting dragged into politics.

"There can be hope only for a society which acts as one big family, not as many separate ones."

– Anwar al-Sadat

Essentially, avoid all the stuff that doesn't feel right and that doesn't help anyone.

You can ask yourself two things: "Does this help a person living with HIV?" "Does it keep someone from getting HIV?"

If the answer is "no," leave it alone.

TERMS IN THIS MODULE

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.”

Agency: Any non-profit group. You will also hear “organization” and “Society” as well.

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.

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.

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 PLWHIV/AIDS.” It is a direction for the focus of the Society’s work.



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

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NOTES

Lined area for taking notes, consisting of multiple horizontal lines.

