

One Foot Forward

A GIPA Training Toolkit

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

MODULE

10

ACTIVE, AGING AND HIV+

CANADIAN
AIDS
SOCIETY



SOCIÉTÉ
CANADIENNE
DU SIDA



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RBC Foundation

Canada's Research-Based
Pharmaceutical Companies



Les compagnies de recherche
pharmaceutique du Canada

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INTRODUCTION

This module is one of a series based on the Greater Involvement of People Living with AIDS (GIPA) principles and intended to assist people living with HIV/AIDS (PLWHIV/AIDS) to become more meaningfully involved in their communities. It is intended for older adults with an interest in learning more about the GIPA principles, how an agency works and where they might contribute, finding and discovering their own voice and interests, learning about some of the ways aging intersects with HIV, and the value they bring through sharing their experiences. This module will not make decisions for you, nor will it offer all the information available to help PLWHIV/AIDS to become more meaningfully active and engaged. But it will start you on a path to engagement and active living.

Each section contains exercises you can do to explore and sort through what you think and feel. At the end of each section you can evaluate for yourself how much you learned and consider what else you might need to know and think of some questions you may want to have answered.

The Canadian AIDS Society gratefully acknowledges the participation of Michael Yoder, Project Consultant, Kevin Falkingham, Patrick McIntyre and Kim Thomas, Canadian AIDS Society staff, as well as the National Advisory Committee:

- Stephen Alexander
- Glenn Betteridge
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- Romari Undi

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WORDS TO THE WISE

So... you're older now. You may think that you have nothing to offer, or that what you do have to offer is of little value because you may not be hooked into the latest technologies and trends. The reality is that you are experienced and have a lot to share. Whether you are volunteering or working, retired or semi-retired, or none of the above, this module will help you to examine how you can be active in your own life, and in the life of your communities, through sharing your experiences.

This module will look at the ways in which you can remain active and engaged in your involvement with HIV issues and your peers. You will learn about the basic structures of a community-based agency and about the GIPA principles. There will be opportunities for you to explore your interests, and to find and use your voice to communicate and share your experiences in the activities you choose to pursue.

This module will examine where HIV and aging meet, whether at the doctor's office or in your own mirror. Knowing more about how aging and HIV interact in your own body can help you discover ways to keep healthy and active. Keeping active and involved in your health care as you age helps you maintain your vitality as you continue to learn, pass on your knowledge and life lessons and contribute to the growth of your community, young and old. This module will also look at how income security and housing needs change as you get older.

You have so much to offer – and a lot left to do! Turn the page and learn how your lived experience is valuable both to your community and to your active life.



SECTION ONE

GETTING STARTED

In this section, you will learn more about GIPA principles (Greater Involvement of People with AIDS), and how to assess how these principles are used in your local community agency.

For many people, joining a local agency can be an active way to meet peers, share experiences, and contribute to community life. In some provinces, the term “society” or “organization” may be used rather than the term “agency”. For this module, please consider the terms interchangeable. We will explore agencies in greater detail in the next section.

If you aren’t connected to an agency, look around the community and see what’s available for your possible involvement. Simply because you are living with HIV doesn’t mean you have to work or volunteer for an AIDS service organization (ASO). There are many groups that can use your skills and talents. Explore what’s out there and see what the best fit is for you.

GIPA 101

The principles of Greater Involvement of People Living with HIV/AIDS (GIPA) written by and for People Living with HIV/AIDS (PLWHIV/AIDS) were declared in 1994 by the United Nations at the Paris AIDS Summit. GIPA ensures that people living with HIV/AIDS are fully involved in all decisions that affect their lives. One goal of GIPA is to “...stimulate the creation of supportive political, legal, and social environments.”¹

Simply put, these principles mean “Nothing about us without us!”

Some groups are peer-based and operate primarily through these principles. Other groups may have aspects of GIPA in their programming and governance, but may be lacking GIPA principles in other areas. Organizations may offer varying levels for GIPA involvement and activities for GIPA participants might range from front-line work to behind-the-scenes efforts.

“The beginning,
as the proverb says,
is half the whole.”

– Aristotle

¹ The Paris Declaration. Section IV. Paris AIDS Summit. UNAIDS 01 December, 1994

Assessing the ways that GIPA is applied in your organization can give you a better sense of the culture and ways in which it might improve. And you might be a part of that improvement.

Assessing your agency

If you have decided that you want to become involved (or further involved) with an ASO, take a look at the GIPA principles and explore a way for you to assess or ask appropriate questions to help determine how inclusive your agency is for those living with HIV. This can also help you to decide if you want to become more meaningfully involved.

The following are the GIPA Principles. Look around the agency and see if there is work being done to incorporate these principles in the agency's activities. For more information about GIPA and assessing your agency, read *Module 2: Assessing Your Agency*. This and other modules can be found online at the Canadian AIDS Society website: www.cdnaids.ca.

Declaration of the Paris AIDS Summit, 1 December 1994²:

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

² The Paris Declaration. Section IV. Paris AIDS Summit. UNAIDS 01 December, 1994

Aging adds another factor to consider when assessing your agency through these principles:

- Does the agency have a collective memory of the past and those who contributed a long time ago? If so, then how is this collective memory stored and/or shared?
- Does the agency value the opinions and ideas of elders? What changes do they make based on these ideas and opinions?
- Does the agency have strategies in place to support those who are growing older with HIV?
- Does the agency actively involve an aging population in decision making, based on the lived experience of older people living with HIV?

All these questions can help you start to get a better picture of where the agency stands on GIPA, and issues surrounding living with HIV and aging.

SELF ASSESSMENT

After completing this section I learned:

Three horizontal lines for writing.

I still need more information about:

Three horizontal lines for writing.

My strongest areas right now are:

Three horizontal lines for writing.

My weakest areas right now are:

Three horizontal lines for writing.

My next steps will be:

Three horizontal lines for writing.

I can complete my next steps by: _____

Circle the number that you think fits.

	Very confident			Need to work on this	
I spent enough time on this section	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

SECTION TWO

YOUR COMMUNITY-BASED AGENCY

This section reviews some common elements found in many community-based agencies. It will examine common agency structures, including the important role of the Board of Directors.

Each agency has its own culture, values, vision, mandate and mission. As well, each agency will have its own staffing structures (discussed below). The following items are fairly typical and found within most agencies:

- **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:** usually stated in a Values Statement or Belief Statement. You may have to ask to see a copy of the agency's value statement. Not all agencies have these statements.
- **Vision:** another statement for the broader direction of the Society. 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 Peer Organizations. An ASO may have staff people who are living with HIV, but many do not. The Board of Directors may reserve seats for PLWHIV/AIDS and ASOs may have peer-based programming.

An HIV Peer Organization is a group run by and for PLWHIV/AIDS. Generally, members of the Board of Directors (the Board) are PLWHIV/AIDS, with the exception of advisory members. While a peer group may have staff people who are not living with HIV, the services are nonetheless directed by and for PLWHIV/AIDS.

Culture

The culture of an agency may not be easy to figure out. You may have to do some observation on your own to judge for yourself the culture or working environment of the agency.

Culture is the way people interact with each other and is based on generally accepted societal norms. Some larger agencies have a more “corporate” culture: they are more structured and perhaps more bureaucratic than smaller agencies. Some agency 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 who access its services.

Organizational Charts

Some organizations develop “Organizational Charts”: visual representations of how the agency is built and/or how processes and communication takes place.

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 for volunteers and staff.

What is “Governance”?

The Canadian International Development Agency (CIDA) defines governance as that which

“...encompasses the values, rules, institutions, and processes through which people and organizations attempt to work towards common objectives, make decisions, generate authority and legitimacy, and exercise power...”

Governance looks at the policies, practices and processes that provide the most benefit to the people being served.

For a non-profit agency, governance defines the vision, values and common rules for the Society, rather than dealing with the day to day operations.

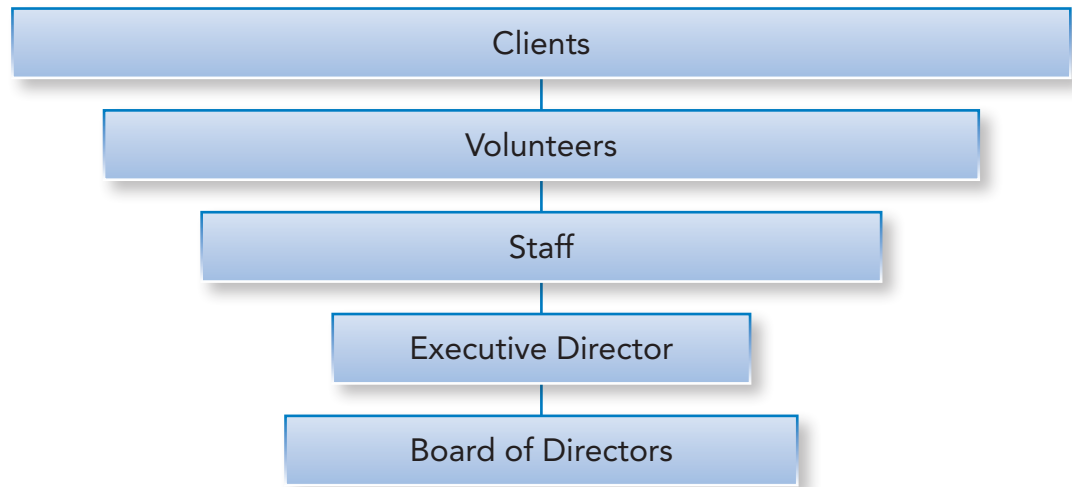
Under a governance model, the Board of Directors sets a vision for the agency and the Executive Director and the staff carry out that vision. The Board does not get involved in the daily activity of the agency. There are usually restrictions for staff and volunteers in terms of talking directly to Board members about agency business. Generally, requests to speak or present to the Board may have to go through 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” that appears to be “bottom-up” where the organizational chart above is flipped upside down.

In a Stewardship model, the “clients” are at the top and everything below is there 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 and being more involved in every action and program or service.

A Stewardship model might look something like this:



GIPA and Boards

For any agency following GIPA principles, a certain number of seats on a Board may be designated for PLWHIV/AIDS. If not, it may be appropriate to question why this is not so. Each agency may have a differing number of “positive” seats based on the size of the agency, whether the agency is rural or urban, etc.

Peer organizations, operated by and for PLWHIV/AIDS, may have 100% of their seats for PLWHIV/AIDS, but they may also have a few seats for “advisors”: people who have expertise that is useful even though the person may not be living with HIV.

Having PLWHIV/AIDS on a Board of Directors is useful for several reasons:

1. They are often more connected to the clients/members of an agency;
2. They experience living with HIV first hand, with all the treatments, tests, illnesses and so on – they can speak to the reality of HIV;
3. They are a valuable voice when planning for programs and services and in discussions with funders; and,
4. They bring legitimacy to the whole purpose of an AIDS service organization.

TYPES OF BOARDS

Increasingly, governments are requiring a governance model in managing non-profits. This does not mean that a Board cannot be operational, but the governance aspects of their work must be clearly defined to ensure sound management.

Governance Boards

A Governance Board provides leadership to an agency by developing a vision, plan and overarching policies and principles.

A Governance Board usually communicates only to the Executive Director, who in turn relays information from the Board to the staff. The Board of Directors is the employer of the Executive Director and does not get involved in daily activities of a Society.

Operational (Working) Boards

Operational or Working Boards, for the most part, use a hands-on approach. The Board structure is the same as other Boards, but the Board members are involved in the daily activities of the agency. An Operational Board is the employer of the Executive Director, but the members must be able to distance their "Board" role from their role as a volunteer with the Society. This means that when a Board member is working with a staff person, the staff person could be the one who is in charge and supervising the work.

Operational Boards can be very useful for peer and smaller agencies because they lend a visioning aspect as well as helping to get the work done.

Consumer Boards

These Boards are made up of people directly affected by the issue (eg. HIV). Consumer Boards can follow a governance model or be operational.

The positive side of Consumer Boards is that they actively draw on the people affected. The negative side is that they can be highly emotionally attached to the issue and find it difficult to see a broader picture.

Sometimes, Consumer Boards will have a limited number of seats for “non-affected” – people who have some distance from the issue and can be somewhat more objective. Usually these people sit in an advisory capacity and often have no vote at meetings.

Other forms of governance

Some Boards may use culturally specific forms of governance. First Nations groups may reject a hierarchical structure, preferring a collective response and include elders more fully in the process. A Board representing an African, Caribbean, and Black (ACB) community would likely draw on the experience, needs, and resources from its own community members, particularly leaders in the community.

Other ways that groups may use good governance is the inclusion of clients or members in the development of policies, procedures and planning and by adopting a community development model where partner agencies are also part of the planning for the agency.

General positions on Boards

All Boards must follow a structure as set out in Acts governing non-profit agencies. The three or four positions that must be filled are:

- Chairperson (or President)
- Vice-Chairperson (or Vice-President)
- Secretary
- Treasurer

The position of Secretary and Treasurer can be combined into one, the Secretary/Treasurer.

All Boards can have no less than those three directors. All other seats might have titles for the position, or may have other members called “Directors at Large”, or “Board Member at Large”.

The four main positions above have specific duties attached to them, discussed below. Directors at Large do not generally have specific duties, but may be given authority over different committees or areas of work.

Chairperson/President

The Chairperson is usually the person responsible for leading Board meetings and Annual General Meeting (AGM): setting the agenda, guiding the meeting, etc. and is also usually the direct supervisor of the Executive Director, keeping in touch with staff issues, current politics, financial resources, etc. The Chairperson does not vote at Board meetings unless there is a tie.

The Chairperson is often one of the main spokespersons for the agency and usually has signing authority for cheques.

Vice-Chairperson/Vice-President

The Vice-Chairperson is usually the person who leads Board meetings when the Chairperson is unavailable. The Vice-Chairperson must also keep themselves informed about the issues facing the Society, politics and finances.

When necessary the Vice-Chairperson is the “stand-in” for the Chairperson.

Secretary

The main role of the Secretary is to record minutes of all Board meetings, or at least to ensure they are recorded. The Secretary makes sure the other Board members are informed and up to date on matters concerning the Board and often prepares necessary paperwork such as agendas and minutes of previous meetings. The Secretary also reviews the Society’s by-laws, makes sure the notice and other documents for the AGM are sent, and keeps records of Board interactions. Secretaries sometimes, but not always have signing authority for cheques and banking.

Treasurer

The Treasurer keeps track of the finances of the Society. They are responsible for updating the Board on the financial status of the Society as well as reporting on the finances at the AGM, and preparing (often with the help of an accountant) the annual budget for the Society. Treasurers usually have signing authority in order to be accountable for money being spent. Ultimately, all Board members are responsible for the finances of the Society.

The Secretary/Treasurer position is simply a combination of the two positions above.

Directors or Board Members at Large

A Director at Large may not have specific duties on a Board. Nonetheless, Directors at Large are equally responsible to ensure the sound management of the Society and its business. Directors at Large participate on committees, in debate and discussion and in the visioning and guidance of the Society.

Ex Officio

The Executive Director, and sometimes outside advisors, are called “ex officio” meaning “without office”. These positions on a Board provide opportunities for information and clarification by those who have expertise or have previously held significant Board or Society positions, but they do not vote. For example, a former Chairperson may have an ex officio seat on a Board to provide needed historical information and advice to Board Members.

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: this person is responsible for the overall day to day operations of the agency and answers directly to a Board of Directors.

Volunteer Coordinator/Manager: coordinates the recruiting, screening, training, placing, evaluating and recognition of all volunteers in the agency. Usually reports to the Executive Director. If you are going to get involved somewhere, then you’ll probably be speaking with this person.

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, etc). These positions usually report to the Executive Director

Other general staff positions may include:

Executive Assistant: assists the Executive Director in their work

Office Manager: oversees the administration of the office

Human Resource Manager: is responsible for all of the staffing issues including contracts, benefits administration, building administration, job postings, etc. within an agency.

There may also be positions dealing with specific programs such as Care Coordinator, Health Promotion Coordinator, Case Manager, Communications/Public Relations, Development and Fundraising, etc.

Ask to speak with someone about the staffing structures and how the positions all fit in your agency.

Community Voice

The Board is the volunteer community voice of the Society, and the names and contact information for a Board of Directors is public information. If you want to contact a Board member, that information should be provided to you. If you are a volunteer or staff person in the organization, then be mindful of any organizational procedures and follow the proper channels for communicating with Board Members.

For more information about Boards and governance you can refer to *Module 4: Boards and Governance*.

SELF ASSESSMENT

After completing this section I learned:

Three horizontal lines for writing.

I still need more information about:

Three horizontal lines for writing.

My strongest areas right now are:

Three horizontal lines for writing.

My weakest areas right now are:

Three horizontal lines for writing.

My next steps will be:

Three horizontal lines for writing.

I can complete my next steps by: _____

Circle the number that you think fits.

	Very confident			Need to work on this	
I spent enough time on this section	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

SECTION THREE

WHAT ABOUT ME?

In this section we'll look at our personal history and how that can contribute to the work we do at our agencies and in the community.

First things first...

You are a whole and complete human being; you are not only a person living with HIV. You have a past, a present and a future. You have lived a good long time and continue to have experiences.

Sometimes, you might seem to be defined by your diagnosis; maybe not by yourself, but by others around you. By accepting that limited definition of who you are, you limit yourself. You may see only the virus and not your whole being. Living with HIV is just a facet of your everyday life. HIV will be with you the rest of your life, but HIV does not always determine the path for your future.

You are a beautiful creation with many varied interests, most of which have nothing at all to do with HIV.

What do I have to offer?

Consider that you have done a lot in your life. However old (or young) you are at this point, there are a number of skills you've developed and those skills can assist in making a decision about where you want to put your energy.

Skills I've gained at work/volunteering include... (check all that apply)

- Computer
- Writing
- Management
- Small business
- Hospitality (including restaurant or retail)
- Accounting/bookkeeping
- Creative work (art, music, theatre, design, etc)
- Organizing or supervising projects
- Other: _____

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Now you can break these down into components that really show what you know.

For example, management skills include teamwork, listening, scheduling, training, record keeping, report writing, and more. Creative work may include aesthetics, design, visual appeal, math and more.

Everything we've done is not just one thing, it's many things!

Skills I've gained at home include (check all that apply)

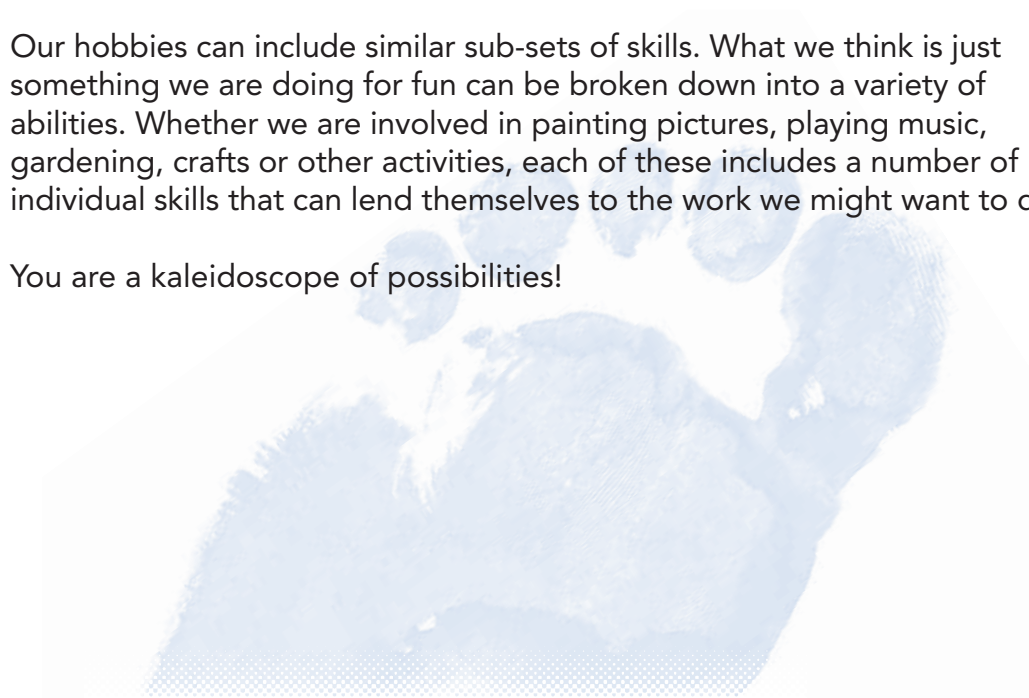
- Child rearing
- Cleaning/cooking
- Relationship skills
- Planning and hosting parties
- Arranging an attractive living space
- Home renovations
- Home repair
- Domestic financial planning/budgeting
- Other: _____

Now consider this: child rearing, which is something we often believe just comes with being a parent includes a massive amount of juggling. It requires patience, counselling skills, listening, scheduling, conflict resolution, first aid, and most importantly – love.

Home renovations include skills such as organization, planning, sketching and design, shopping wisely, bargain hunting, constructing, deconstructing and more.

Our hobbies can include similar sub-sets of skills. What we think is just something we are doing for fun can be broken down into a variety of abilities. Whether we are involved in painting pictures, playing music, gardening, crafts or other activities, each of these includes a number of individual skills that can lend themselves to the work we might want to do.

You are a kaleidoscope of possibilities!



Life Lessons

You've come a long way in your life and in that time, you've gathered a great deal of knowledge. Imparting that knowledge to youth living with HIV is a way to honour the past and those we've lost, as well as celebrate all that you and others have to offer. If you are a long term survivor of HIV, you were there in the era before better treatments and when most agencies were small and staffed with people who were not professionals but hard-working volunteers, many of whom were living with AIDS. You, like everyone else at the time, stumbled your way through it all, learning as you went. You didn't have branding or the internet and email, never mind texting. You had only what you could create and you learned, laughed, cried, and carried on; just as the youth today do while fighting their battles.

If you are more recently diagnosed you still have your lived experience – raising a family, careers, failed and successful relationships, and many other things that have brought you to where you are today.

You might believe that you don't have enough education or training in specific areas to contribute anything of value to the agency. But whether you've earned a PhD or you've had very little formal schooling, you can contribute. By refocusing on what you know, rather than worrying about what you don't, you can move forward.

Youth can gain a greater clarity from the wisdom and life lessons you can provide. You might want to consider being a mentor to younger people living with HIV. You might want to think about recording the history of the earlier days of the AIDS movement. Or you may want to record your own story and the stories of those you remember who have passed.

SELF ASSESSMENT

After completing this section I learned:

Three horizontal lines for writing.

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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

SECTION FOUR

SPEAKING OUT!

There's a lot to be said for saying what you have to say and telling it like is. You do have a voice and you deserve to be heard – but effective communication involves more than just speaking your mind.

In this section, we'll look at the ways you can constructively express yourself as an elder in the HIV community. We'll look at the choice to disclose HIV status when joining a community agency, and the agency's obligations to protect your personal and confidential information. We'll highlight the important role long-term survivors have in connecting our present to our past, and in preventing us from re-inventing the wheel and repeating past mistakes. We will close by stressing the importance of being objective and respectful when communicating with others with respect.

"Free speech is intended to protect the controversial and even outrageous word; and not just comforting platitudes too mundane to need protection."

– Colin Powell

Learning to Listen.

Communication is a tricky thing. Most of what people communicate is done through body language rather than the words. Much of what is taken in is filtered through your own experiences, perceptions and beliefs.

Learning to listen is the first step in learning how to communicate effectively.

Think about a movie or favourite TV show. When you are engrossed in the plot and characters, you are paying attention in a way we rarely do with others. Part of the way you can improve your listening skills is to use that same sense of interest you have with story lines. Everyone's telling their own story, whether it's at a meeting or over coffee. People in your presence can be fascinating characters.

Try this simple exercise.

For one minute, close your eyes and listen. Make mental notes of what you hear. Afterward, consider what you heard. What was close to you? What was further away? What distracting thoughts were floating in your head?

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Listening means trying not to pay attention to all the little things that go on around you but focusing on what the person is saying.

Using your voice

When you are considering what it is you want to do, you will need to think about where and when to use your voice.

If you are volunteering, think about the context of communication in that position. If you're on a Board of Directors or in a committee, you have been selected because what you have to contribute is valuable to the group process. Seize opportunities that interest you.

But just talking isn't good enough. There are a lot of talking heads and people who are able to fill dead air with noise. The key here is to really consider what you have to say before you say it. That means you need to listen and weigh the options of contributing.

- What will your opinion and ideas add to the conversation?
- Are you being constructive in what you have to say?
- If you disagree with an opinion or idea, what would work better for you?
- If someone disagrees with you, what would work better for them?
- Do you feel defensive? (if you do, you might want to explore what's bothering you)

It's important to consider the value of your offering and respect the value in others.

DISCLOSURE OF YOUR STATUS

Disclosing your status is your choice. You have to consider how disclosing your status 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 quickly, and you may not want your neighbours finding out through gossip. On the other hand, being open may be a way to gain your neighbours' support while educating them and others.

Unfortunately, HIV stigma and discrimination are very real. 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 because they are living with HIV/AIDS. As an elder you have the opportunity to dispel myths through educating and talking experientially about living with HIV/AIDS. You can share how we've been resilient to, and thereby help end, HIV stigma and discrimination.

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. We are not expected to “come out of the closet” about our HIV status unless we choose to.

You can inform your choice whether or not to disclose by inquiring about how your agency handles confidential information.

GIPA, PRIVACY AND CONFIDENTIALITY

GIPA principles apply to all areas of our lives (within the context of our involvement in ASOs). Although PLWHIV/AIDS might measure our level of involvement at an agency by how well we feel GIPA Principles are followed, we can also assess our involvement based on how the agency acts to protect our personal information. Our agencies (like our health care providers) are expected to uphold and maintain privacy laws and to keep our private information private.

You can ask about protection of private information at your agency and look into privacy laws in your province or territory. You can also ask how the agency addresses situations where private information has not been protected.

Long Term Survivors

If you're a long term survivor, you have a wealth of experience and history that you can bring to the table. Your ability to recall what was can assist a group in seeing what is and what could be. You can also offer hope to others by the mere fact of being here! Long term survivors can be the thread sewing clarity together.

ONE FOOT FORWARD

More and more people are mired in “progress”, but progress isn’t always progressive. The human condition has been around as long as people have, and exploring the emotions of grief and loss, telling the stories of “long ago” adds to the fabric of what is now. You can appreciate better what you have now if you acknowledge the things you had to go through to get here. Passion feeds progress; what is your passion?

You are in the now, but the past has brought you to where you are. A long term survivor can recall that past and colour the present and future for others. Remember that many young people and newly diagnosed people do not have that memory of “the bad old days”. Telling the story reminds them and the staff in our agencies that the history remains important.

Another aspect and benefit of having been around for a long time, is that you may have seen trends and changes within the movement or even your own agency. The changes may be dramatic or they might be subtle, but noting and talking about those trends are ways in which you can contribute to the conversation. Recalling those successes, failures, issues, and challenges can be extremely fascinating to those who were not there. We are veterans of a war of life and have come a long way.

By becoming – or staying – involved in either a volunteer or paid capacity with your agency, you have the opportunity to keep up social connections, and make some new ones. Feelings of loneliness and isolation may cause some to withdraw and can contribute to a loss of social ability and can even bring on health conditions such as the earlier onset of dementia.

You may feel you have nothing to contribute anymore, and nothing could be farther from the truth. Your voice in this is significant and important. And in voicing your concerns you could be helping many others who have the same concerns but are not able, or who are not yet comfortable speaking up. So, add your voice to the mix of voices that contribute to bringing everyone into the movement.

RESOLVING CONFLICT

At different points in your life, you will be in conflict with someone. You have your own personality and experiences, and you hold your own personal opinions, philosophies, and beliefs. Sometimes you may experience a conflict or “clash” with others’ opinions, philosophies, beliefs and personalities. Agencies often have guidelines for resolving conflicts that arise – ask your agency for a copy of theirs.

For more information about conflict resolution you can refer to *Module 1: Community-Based Groups*.

BE OBJECTIVE

When you are thinking about how, where and when you want to contribute, remember to think about issues as objectively as possible. You won't be completely able to do this: objectivity is subjective. Everything you think and say is filtered through your own experiences and belief systems.

Check the following list and see how much applies to you.

- I listen carefully before I speak
- I don't interrupt people when they're speaking
- I consider all the options in front of me before I make a decision
- I can change my mind if someone makes a good point
- If I'm feeling upset about what someone has said, I don't just get angry at them
- If I'm angry I try to find a solution to the issue
- If someone's angry with me, I can listen to them without being defensive
- I say what I mean and mean what I say
- I believe that everyone has something important to contribute
- The best results happen when everyone is equally involved in making decisions

If you were completely honest about this list there are probably parts that fit for you and parts that don't. Surprise! You're a human being!

When you're working at being objective, it doesn't mean that you give up your own way of thinking; it just means that you're open to the ideas and opinions of others. You honour the lived experiences and beliefs of those around you.

In a word, it's called respect. If you want it from others, you must be prepared to offer it as well.

"Everyone should be respected as an individual, but no one idolized."

– Albert Einstein

SELF ASSESSMENT

After completing this section I learned:

Three horizontal lines for writing.

I still need more information about:

Three horizontal lines for writing.

My strongest areas right now are:

Three horizontal lines for writing.

My weakest areas right now are:

Three horizontal lines for writing.

My next steps will be:

Three horizontal lines for writing.

I can complete my next steps by: _____

Circle the number that you think fits.

	Very confident			Need to work on this	
I spent enough time on this section	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

SECTION FIVE

MIRROR, MIRROR...

When you look in the mirror, your mind may be saying “I’m only 19 years old! Who’s that old person?!” As much as you are living with HIV, you are also living with the reality of an aging body. It may be a case of ‘mind over matter’, but sometimes bodies trump minds.

“You’re never too old to become younger.”

– Mae West

In this section, we’ll look at things to consider when we’re learning to establish a balanced life in this new – or not so new – reality. We’ll also make the connection to GIPA, and learn how engaging in greater and more meaningful involvement with our agencies and community can help find that balance.

Holistic approach

A holistic approach to your life is the best way to maintain balance. By looking at different parts of your life, and not only at what you can see in the mirror, you can begin to see those areas that are in balance, and those that need a little attention to restore that balance. It can be helpful to look beyond the mirror, and to take stock of where you are at in key aspects of your life. Consider the following areas:

Physical

- What is going on with my body?
- How do I express my sexuality?
- How fit am I and what is my level of stamina?

Emotional

- What do I feel?
- How do I express my feelings?
- Do I repress any of my feelings?

Mental

- Am I still learning and open to learning?
- What do I do to keep my mind active and engaged?
- What stimulates my thinking?

Spiritual

- How do I express and explore my spirituality?
- How important is my spirituality to me at this point in my life?

By really examining your whole self, you can get a better handle on how you approach the world and the activities you choose to pursue.

Being realistic about aging can actually help you in regaining the youthfulness you may no longer experience. Being actively engaged in your community through volunteering can also help keep you young, as long as you recognize and respect your limits.

Energy levels

Whether you're getting involved in volunteering or work, thinking about your level of energy is important to make sure you don't overdo it. Think about the following things and your level of capability. Check off as many as apply to you:

Physical energy

- I can climb several flights of stairs without tiring
- I can walk for 1 kilometer without needing to rest
- I can lift at least 10 lbs with no problem
- I can stand for more than 15 minutes without feeling uncomfortable
- I can sit for more than 15 minutes without feeling uncomfortable
- I can do physical labour without needing to stop frequently
- I can bend and kneel and get up without needing to lean on something

Mental energy

- I can listen and remain focussed on a conversation for at least 20 minutes
- I can focus on computer work for at least 15 minutes
- I can learn new tasks quickly and with little instruction
- I can remember a list of at least 5 items without having to write it down
- I can work without being distracted by external noise
- I can be patient while I'm doing mental work

There are many more aspects you might want to consider, but this is a good beginning as you examine your level of energy.

Hormones, Aging, and HIV

Low energy levels can be the result of many factors, including mental and physical health or illness. Hormone levels may point to another possible factor. Hormones play a key role in keeping our body in balance. After the age of 35, it is common for both men and women to experience a decrease in hormones. For PLWHIV/AIDS, this can happen earlier than in the general population. As a PLWHIV/AIDS, being aware of your hormone levels over time can give you a more complete picture of what is happening in your body as you age.

There are no 'male' and 'female' hormones. Everyone has both androgens (like testosterone) and estrogens (like estradiol). What is different in everyone is how our bodies need and use these hormones. What is the same for everyone is the need to ensure that whatever hormones we do need are in balance.

You can't look at one test of one hormone level and have a complete picture. For example, testosterone contributes to your energy levels and your sex drive. When you have low testosterone, you can lose interest in some daily activities, sex and exercise. But this can also be the case if you have high testosterone and high estradiol, as testosterone's normal activity is blocked by the interaction of these hormones.

Having your care provider regularly check your hormone levels can assist in maintaining health and avoiding complications due to levels that are too low or too high.

While many businesses advertise the effectiveness of their hormone treatments to address a wide range of issues, your symptoms could have other causes. You should always consult with your health care provider and determine if hormone therapy is the best course of action for you. Using hormones without medical supervision is extremely dangerous and could be life-threatening.

Creativity and play

While you may be getting older there is still a need for creativity and play. Play doesn't just mean batting baseballs or climbing monkey bars. Play is any recreational activity that brings pleasure and allows the imagination to soar.

Creativity is equally important. Everyone is creative in different ways. Creativity doesn't necessarily mean painting and poetry – it can be everything from cooking a delicious meal or arranging a lovely home, to playing piano, gardening, singing in the shower or writing in a journal. Creativity is a way that you express yourself and your emotions or spirituality. It doesn't matter *what* you do to engage in your creative self – it matters only *that* you do it!

Make sure you give yourself time for play and creativity – your mind and heart will love you for keeping yourself 'young' and fit!



SELF ASSESSMENT

After completing this section 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: _____

Circle the number that you think fits.

	Very confident			Need to work on this	
I spent enough time on this section	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

SECTION SIX

DOCTOR, DOCTOR

“Never go to a doctor whose office plants have died.”

– Erma Bombeck

In this section, we’ll look a little more at the physical issues related both to aging as well as HIV and how these relate to family medicine and your relationship with your care provider. For more information about doctor patient relationships see *Module 8: Can We Talk? Treatment and Options, A New Dialogue*.

The section ends with a discussion about talking about your health with your health care providers.

The HIV/Aging conundrum : is it HIV or is it Aging?

Fewer and fewer PLWHIV/AIDS in Canada are dying from complications due specifically to HIV. While Canadian PLWHIV/AIDS are living longer with HIV, they are increasingly experiencing age-related illness and disease.

While there are increased concerns about health issues to do with HIV and the complications that can arise through illness or with treatment, there are also more concerns about aging in general.

Sometimes, it isn’t always clear what is affecting you. Knowing whether what is affecting you is caused by HIV, aging, or both, can help you determine the best way to move forward in your life.

Consider the following statements and ask yourself if they apply to you:

“My joints hurt more than when I was younger, but I didn’t have these issues before I was HIV positive.”

“My medications have contributed to increased issues around diabetes and fatigue.”

“My eyesight is getting worse and I have more “floaters” than before I was HIV positive.”

“I get more colds and flu than before I was HIV positive.”

“Sores tend to take a lot longer to heal than in people I know who are not living with HIV.”

“I’m more affected by changes in the weather than before I was HIV positive.”

Of course, these things cannot always be attributed to HIV. Some of these things – aches and pains, sensitivity to the weather, fatigue, “floaters” – may simply be effects of aging. But HIV can cause joint problems, fatigue, increased risk for diabetes and other symptoms including cognitive functioning. HIV can make changes in your body that the general population may not experience until their later years. It’s important to talk with your health care provider and explore with them what might be causing your physical ailments.

Medications can also have an effect on the body, and not just those for HIV. You’ll need to discuss the potential side effects of medications with your health care provider. That includes the interaction between medications for treating different diseases.

Where HIV and aging meet

While most people who are aging experience some similar life and body changes, PLWHIV/AIDS may be at a higher risk for specific types of illness and disease as they age.³ Here are some of the more common issues that PLWHIV/AIDS are experiencing as they age. A well-informed health care provider will know to look for these and other issues when screening – and if they don’t, then you, as a well-informed PLWHIV/AIDS, can share this information with them.

Kidney function

The kidneys are the organs responsible for filtering blood and removing waste through urine. They also help the body maintain balance by producing some hormones, regulating levels of salt, water, electrolytes, and amino acids. As the study of kidney disease is called nephrology, kidney disease specialists are called nephrologists.

³ Adapted from *Aging Gracefully with HIV: The Need for a Coordinated Clinical Response*, a presentation given by Dr. Gordon Arbess, in a Satellite session at the Canadian Association on Gerontology, Ottawa, October 21, 2011 titled “Learning Across Borders: HIV and Complex Chronic Illness as We Age”.

Almost 1/3 of PLWHIV/AIDS at all ages have some issues with kidney function. This may be due in part to the side effects of treatment, but aging kidneys also have the tendency to function less effectively. This is why it continues to be important for PLWHIV/AIDS to have their kidney function tested regularly as they get older.

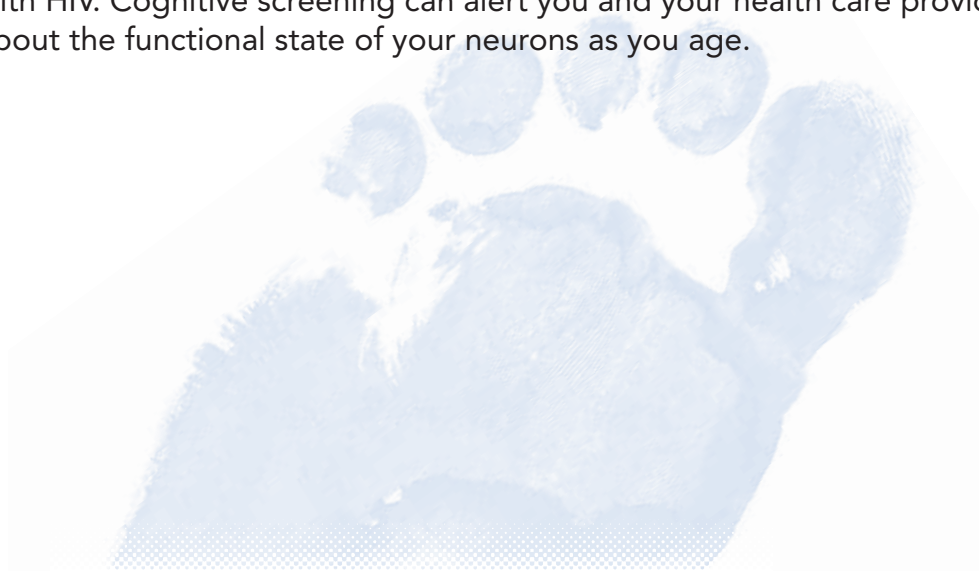
Bone disorders

Bones serve many functions. They provide a structure to support the body and to protect major organs. They work with other systems to produce movement, balance and hearing. They produce blood cells and hormones, and they store minerals, metals, fats and growth factor.

Many people experience problems with bone density as they age. Osteoporosis, or reduced bone mineral density that results in fragile bones, and osteopenia, a precursor to osteoporosis, are two bone diseases that are commonly seen in seniors. 63% of PLWHIV/AIDS who are 50 years or older experience issues with osteoporosis and osteopenia in their spines, hips and forearms. With all the functions bones provide, PLWHIV/AIDS should ask their health care provider about bone health screening.

Neurocognitive dysfunction

While memory loss is often associated with old age, more than 50% of PLWHIV/AIDS experience memory loss, forgetfulness, problems with focussing and other issues related to brain function. Recent studies have attempted to distinguish whether cognitive dysfunction results from untreated HIV, or if it can also be related to the chronic inflammation found in treated HIV. Something for long-term survivors to consider is that younger PLWHIV/AIDS may also experience neurocognitive problems at an earlier age than their counterparts who are not living with HIV. Cognitive screening can alert you and your health care provider about the functional state of your neurons as you age.



Cardiovascular disease

While older people generally have an increased risk of heart disease, the chances of having cardiovascular issues are slightly greater in PLWHIV/AIDS – especially women. There is a 75% increase in the risk of heart attack for PLWHIV/AIDS. What's more, certain HIV treatment options may be impacted by having existing or past heart disease, or by having underlying risks for cardiovascular disease. Just as in the general population, eating and sleeping well, exercise and stopping smoking may assist in reducing the risk of cardiovascular disease. Screening for cardiovascular risks in PLWHIV/AIDS will help both heart health planning and HIV treatment planning.

Cancer

The list of AIDS-defining opportunistic infections includes some forms of cancer that occur only rarely in the general public, like Kaposi's Sarcoma, non-Hodgkin's lymphoma and invasive cervical cancer. Studies now show that older age in PLWHIV/AIDS can be predictive of an increased risk of non-AIDS defining cancers such as vaginal, anal, liver, lung, colorectal, prostate, renal and melanoma.

Talk with your health care provider about your personal risk. HIV and aging may contribute to an elevated risk for cancer, but if someone in your family has cancer, then you are already at a higher risk. Since cancers can appear in many different parts of the body, it is important to be in tune with any changes in your body and let your health care provider know about them immediately. Comprehensive screening may require a variety of tests from pap smears, tissue samples and blood tests, to visual and digital exams.

Primary Care and HIV

While HIV care has frequently been provided by specialists (with or without a primary care physician), aging care is more often handled by family physicians. Family doctors who regularly provide care to people over 50 years old may have as much, if not more, experience with aging care as any specialist.

ONE FOOT FORWARD

Many people in Canada do not have a family doctor. For those who do, maintaining a healthy relationship, where all aspects of your life can be explored is important. Your family physician needs to have an understanding about HIV as well as your personal history, and the two are not separate things.

If you rely on clinics, it's equally important to establish a good working relationship with the doctor. In many clinics, it's possible to have a preferred doctor – you don't have to take whoever comes up next on the list. Make sure that your clinic doctor is up to speed about your HIV status and medications and talk with them openly about what's going on for you and your body.

Managing your own health care has always been important. As you age, you must continue to insist that the decisions you make about the treatment you receive is based on all the best available information.

Your parents' generation generally held the notion that the "doctor knows best": they rarely argued or disagreed with a doctor's opinion or decision about diagnosis and treatment. Being an empowered patient is the only way to ensure that you are completely in control of what happens in your health care and your life.

Empower yourself with the tools and information you need to make decisions for yourself!

If you consider GIPA principles in relation to your personal health care, you need to think about how your health care provider engages you in making your own decisions. Does your care provider fully involve you? Or do they tell you what you should do or what treatments you should be on for any given condition?

You are in a partnership with your health care provider. You have the responsibility to ensure that you are living as healthy and full a life as possible, and your physician has the responsibility to hear your concerns and reasonably address them as well as respecting your decisions.

You have a lot of strength and resilience. You've lived this far, haven't you? Think about how you can live a "positive" life – both with and without the health concerns you might experience.

Some questions you might ask yourself about your relationship with your care provider might include:

- Does my health care provider understand HIV-related health and treatment issues?
- Does my health care provider spend enough time with me during our appointments?
- Does my health care provider listen to my concerns and look to address them?
- Am I offered different screening tests for my health issues?
- Does my health care provider respect my decisions about treatment?

A good relationship involves give and take – you get as much out of it as you are willing to invest. Make sure you are getting the best care that you need! Remember, if you are sensing a conflict or tension with your health care provider, talk to them and explain your concerns. It is totally okay to search for the health care provider that best fits your expectations. You may not find them on the first visit, but it can happen.

Appointments

As you age, you may find that you need to visit your health care provider more often than when you were younger.

Think about the number of appointments you usually have in a month. Some of these may be routine, but there might be other appointments you need to make for health issues that arise suddenly.

Consider how you can ensure that you are maintaining your health related appointments along with a schedule of volunteering or work. There is an aspect of “reasonable accommodation” that employers must allow. And in an aging population, increased medical appointments are understood as part of that accommodation.

SELF ASSESSMENT

After completing this section I learned:

Three horizontal lines for writing.

I still need more information about:

Three horizontal lines for writing.

My strongest areas right now are:

Three horizontal lines for writing.

My weakest areas right now are:

Three horizontal lines for writing.

My next steps will be:

Three horizontal lines for writing.

I can complete my next steps by: _____

Circle the number that you think fits.

	Very confident			Need to work on this	
I spent enough time on this section	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

SECTION SEVEN

INCOME & HOUSING AS WE AGE

In this section, we'll look at public income security plans and programs, and consider how to assess housing needs and options.

"Everything should be made as simple as possible, but not simpler."

– Albert Einstein

CPP/OAS

This section addresses the Canada Pension Plan and Old Age Security benefit (CPP/OAS) and how your income may be affected by the work in which you choose to engage. While volunteer work may not affect your income, paid work will most likely affect it. We'll also provide a link to information about provincial and territorial offices you can contact regarding benefits for seniors. Also consider the Guaranteed Income Supplement (GIS) as another option for topping up your income. This supplement is especially for low income seniors and provides additional money to the OAS.

Remember that CPP and OAS rules and regulations might change from time to time. Always consult with your local CPP/OAS service providers to get the most up to date information that might affect your eligibility.

The federal government administers both the CPP and the OAS pensions⁴. It sets the age at which you can apply and qualify to receive these pensions. The age at which you choose to retire and are entitled to claim a pension can depend on your circumstances. When you choose to retire you need to consider your budget.

CPP benefits are based on what you've contributed over your working life. For people who have been self-employed you've paid both the employer and employee deductions. For those who had a steady job, your employer will have deducted a certain amount of employee contributions determined by your level of income. You will have had to be a contributor to CPP during your working life in order to access that program.

OAS is not tied to your employment history or contributions. The GIS is also not tied to your previous contributions or work history.

⁴ In Quebec, the Regie des Rentes administers the Quebec Pension Plan, or QPP. Contributions to both CPP & QPP plans are integrated. If you live in Quebec, you can get more information from : <http://www.rrq.gouv.qc.ca/en/accueil/Pages/accueil.aspx>

For more information and some helpful answers to FAQs, visit Service Canada's Canada Pension Plan website at <http://www.servicecanada.gc.ca/eng/isp/cpp/cpptoc.shtml> and you can contact their office toll free at 1-800-277-9914 (TTY: 1-800-255-4786).

For Disability benefits you can also find information and application packages online at the Service Canada website. The address for that page is <http://www.hrsdc.gc.ca/cgi-bin/search/eforms/index.cgi?app=pro file&form=isp1151&lang=e>

Paid and Unpaid Work

If you're continuing to work, you can first find out if any of your benefits will be deducted due to your income. In some provinces, people receiving provincial disability benefits may be allowed to make a certain amount of income before deductions occur. You'll need to check these out with your local resource office and/or staff within your agency might also know how income is affected by earnings.

Some provincial supplement programs may deduct dollar for dollar any income that you make, including OAS. GIS has a threshold for earned income and will deduct money after that has been reached. CPP has a maximum amount you are allowed to earn per year, and will deduct or suspend benefits while you make that money. Again, it's important to talk to people at CPP/OAS to see how your income is affected.

If you're volunteering, there may be extra benefits allowed to you. Agencies will generally provide reimbursement for out of pocket expenses, or for travel. Check with your agency to see what they will allow and not allow before committing yourself to spend your own money.

Provincial Programs

You can check out provincial programs and see what benefits might be available to you. You can find a list of programs with contact information by province at: <http://www.canadabenefits.gc.ca>. (You can also find this link by searching for Provincial Pension Plans Canada "I am a senior".)

As each province will provide different benefits, we encourage you to check these out for yourself. Being informed and in touch with workers in your area can give you a better idea about what's available to you as well as how benefits might affect your income.

It's all about weighing your options and deciding what makes the most sense for you and your situation.

Housing

If you are maintaining your own housing, that's terrific, but you might want to think about what housing could look like if you begin to suffer from mobility issues.

Stay independent for as long as you can! This is important to physical and mental well-being. You can check your home for potential hazards, including loose cords, misplaced furniture and things that you might trip over. Area rugs can be a hazard if they aren't firm on the floor; you can use double sided tape to hold them in place. Make sure you have a non-slip surface in your shower or a rubber mat. Look around and decide where the most convenient placement is for your furniture and appliances and move things around until you feel comfortable.

If your income decreases you might want to consider subsidized housing. Most provinces and communities have some form of subsidized housing to assist you. Subsidized housing ensures that you only pay a certain amount of your income towards rent or a mortgage. The standard theory is that we should only pay one third of our income toward housing. Do some research and ask around to see if there are units or portable subsidies available for you.

With the Boomer generation aging around us, there are diverse and changing housing options for you to consider, assuming you have the resources. Retirement communities are everywhere you look, but they may be cost prohibitive, especially on a fixed income. If you are looking at retirement facilities you should consider the changing level of care that you may require as you age.

If you are experiencing a decrease in mobility or need to move into shared accommodation or supported living, these changes can be difficult and you'll need to consider how you will continue to participate and remain active, while balancing the need to maintain a decent living standard. Many retirement communities offer a variety of activities and services – both social and health related. You may want to consider these when looking at a retirement community.

In larger cities you may be lucky enough to find senior's housing models in both the public and private sectors that are inclusive of or even designed for specific populations (like PLWHIV/AIDS, or LGBTQ) and can meet their needs. But the truth is that many of us will live out many of our senior years in our own homes. Most municipalities have services for people requiring assistance with keeping a home, such as:

- Subsidized support for light housekeeping;
- Assistance with dressing;
- Assistance with getting meals;
- Respite care for caregivers; and,
- Assistance with medical costs and supports.

Should you eventually need additional care than you are able to get while living in your own home, the following are some things you may want to consider when choosing a Nursing Home / Long Term-Care Home:

- What types of services are offered at the facility:
 - Pastoral Services
 - Physiotherapy
 - Occupational Therapy
 - Social Work
 - Recreation
 - Complementary Care
 - Art Therapy
 - Palliative care (end of life)
 - Music Therapy
- Is the facility for profit or non-profit?
- Are respite services available?
- Is the facility inclusive and able to meet my needs?
- Are private companions allowed to work with clients?

A comprehensive checklist can be found at:
<http://www.torontonursinghomes.com/resources/checklist.html> (English)
or <http://www.indexsante.ca/articles/article-46.html> (français). The internet is an excellent source of information on different housing options in your region.

Don't forget that no matter where you live, you can make your home a sanctuary! This is where you can find and maintain peace in your life. Surround yourself with things that bring happiness and comfort to you.

SELF ASSESSMENT

After completing this section 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: _____

Circle the number that you think fits.

	Very confident			Need to work on this	
I spent enough time on this section	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

SECTION EIGHT

DOING WHAT YOU LOVE

In this final section we'll ask questions that offer you the opportunity to explore your interests more fully and assess the best ways you can contribute without burning yourself out. We'll also explore self care and what that means for an active aging person.

What interests me

Sometimes your hobbies can give you insight into the kinds of activities that keep you engaged. In a previous section, we looked at how different activities have more than one aspect to them. Think about the skills required for each of your hobbies – you might be surprised at how much talent you possess!

And don't be afraid to toot your own horn!

What kinds of things do you love to do?

- Writing
- Visual art (painting, collage, etc)
- Performing arts (theatre, singing, etc)
- Carpentry and woodwork
- Cooking and meal preparation
- Shopping
- Decorating (home, parties, etc)
- Conversation
- Hosting friends and family
- Other: _____

What are your skills?

- Computer
- Math
- Budgeting
- Writing technical material
- Teaching
- Public speaking



- ___ Physical labour
- ___ Analyzing and evaluating different materials
- ___ Statistics
- ___ Reception
- ___ Hospitality (food service, etc)
- ___ Food Safe
- ___ Other: _____

Now consider your work history. You've done a lot in your life and your previous employment may give you an idea about specific areas where your abilities can be the most useful. Of course, if you didn't really enjoy the work, don't feel that you're boxed in to that particular framework.

For each of these, jot down where it was and if you enjoyed the activity:

- ___ Working in a team: _____ Liked it? ___yes ___no
- ___ Working by myself: _____ Liked it? ___yes ___no
- ___ Retail/hospitality: _____ Liked it? ___yes ___no
- ___ Physical labour: _____ Liked it? ___yes ___no
- ___ Mental work: _____ Liked it? ___yes ___no
- ___ Creative work: _____ Liked it? ___yes ___no
- ___ Fast pace: _____ Liked it? ___yes ___no
- ___ Slow pace: _____ Liked it? ___yes ___no
- ___ Other: _____ Liked it? ___yes ___no
- ___ Other: _____ Liked it? ___yes ___no
- ___ Other: _____ Liked it? ___yes ___no

There may be many other aspects to your working life that you might want to consider. Those jobs can be a part of what you coordinate into the work you do within an agency, whether that's paid work or volunteering.

What can I do?

Every agency is different. Programs and services vary widely between smaller and larger agencies, rural and urban agencies, and how the agency is governed. You'll need to look at what's available in your organization and see how you can fit into those positions with your own unique interests and abilities.

ONE FOOT FORWARD

Here are some of the potential positions that might be available for you to explore (check those that might be of interest to you):

- Peer counsellor
- Public speaker
- Outreach worker
- Administrative assistant
- Receptionist
- Client/member support worker
- Housing outreach
- Needle exchange worker
- Food service assistant/coordinator
- Events planner
- Newsletter contributor/editor
- Communications worker
- Transportation volunteer/worker (e.g. driver for clients/members)
- Other: _____
- Other: _____

Learning New tricks...

As you age, you might find it more difficult to focus on learning new things. But there's nothing in the rule book that says you can't learn. Be open to learning new techniques, new technologies and new tricks. Just be patient with yourself and give yourself time to learn.

What's next?

Now that you have more information about your interests and abilities, understand the clinical aspects of dealing with HIV and an aging body and brain, the kinds of things you need to consider about your time, energy and income and the potential positions available within your agency, you can make the decisions that are best for you using all the information at your disposal.

Think about where to put your energy and skills.

- Are you interested in working with a group to improve services and programs?
- Would you like to head up a team of people to help welcome newcomers to the agency?
- Are you artistic and want to use those talents to help with a poster campaign or advertising for the agency?

There are so many things that you can do! Using the insight you've gained from the self-assessment exercises throughout this module, you are better prepared to talk with the Volunteer Coordinator at your agency about the positions available. Take all the information about your skills and abilities, your energy level, your hobbies and interests and use it to guide you to find the position(s) you want to do – and, perhaps more importantly, the ones you don't want to do!

You are older, and you have a mind, a body, a soul and a lot to offer. It just takes putting one foot forward...

SELF ASSESSMENT

After completing this section I learned:

Three horizontal lines for writing.

I still need more information about:

Three horizontal lines for writing.

My strongest areas right now are:

Three horizontal lines for writing.

My weakest areas right now are:

Three horizontal lines for writing.

My next steps will be:

Three horizontal lines for writing.

I can complete my next steps by: _____

Circle the number that you think fits.

	Very confident			Need to work on this	
I spent enough time on this section	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

