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**Update on the Development of the GIPA Roadmap  
Developed by the Canadian AIDS Society  
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## **GIPA as a cornerstone of the HIV movement, and CAS' work**

First named during a preparatory meeting for the Paris AIDS Summit in 1994, the “GIPA” principles (Greater Involvement of People Living with HIV/AIDS) have been a cornerstone of the HIV movement ever since. The concept highlights the importance of meaningfully including people who are living with HIV and/or AIDS at all stages and levels of the response, and in all decisions, matters and interventions that impact their lives.

As a coalition of community members and the organizations that serve them, the Canadian AIDS Society (CAS) has been a leader when it comes to supporting the Canadian HIV movement's ability to understand and apply the GIPA principles. *One Foot Forward: A GIPA Training Toolkit* remains a unique and groundbreaking tool. It provides practical advice and strategies to people who are living with HIV, with the aim of increasing their understanding and involvement in the community response.

In 2016-2017, CAS carried out an extensive survey among AIDS Service Organizations (ASOs) and other Community Based Organizations (CBOs) in Canada, to assess the status of the GIPA principles. The survey revealed a pressing need to update, address and build capacity around the application of the GIPA principles, particularly in a context where funding for HIV-specific activities is decreasing, and organizations are taking on other STBBIs, health and social issues in their activities.

Another testament to CAS' commitment to the GIPA principles lies in the organization of its Annual Forum for People Living with HIV (PLWHIV Forum). This event brings together people with lived experience of HIV from across Canada, to engage in dialogue and share their expertise with the aim of informing CAS' work, as well as the broader national response.

The 2017 Forum was held in Regina, Saskatchewan, and brought together 70 people who are living with HIV, of very diverse backgrounds and experiences. We ensured we captured the voice of PLWHIV that were not accessing services in CBOs, 60% were not. Through a series of facilitated activities and discussions, including a full day Open Space session, participants worked together to identify priority areas and strategies, particularly as they relate to the application of the GIPA principles in community-based organizations. During the Open Space session, participants were invited to consider the following questions:

1. How did grassroots advocacy shape the GIPA principles? (Where we came from)
2. What is your perception of living with HIV, and the integration of GIPA principles, in today's Canadian society? (where are we today in general)
3. How do you currently access services from CBOs? (Where we are today more specifically)
4. Where would you like to see the PLWHIV movement go and how can we integrate the GIPA principles? (where we should be going)

Collaboratively, participants identified 24 relevant topics. They were then invited to partake in small group discussions about these 24 themes, to identify challenges, issues and facilitators pertaining to the current application of the GIPA principles in Canada, as well as key questions and considerations.

A committee was formed at the 2017 Forum to guide this ongoing dialogue, and to help steer and advise the work of CAS as it pertains to the GIPA principles. More specifically, the Committee has been working since the Forum on the development of a comprehensive GIPA Roadmap for 2018 and beyond, a document that outlines the current realities of GIPA, and recommendations to ensure that these principles are upheld and applied moving forward.

Over the course of the meetings held with the Committee, and the Sub-Committees identified and formed by the larger group, it has become increasingly clear that the development of a Roadmap will require additional time and resources. This is not from an absence of interest in the project, a lack of engagement from the individuals involved, or a disinterest on the part of the community. However, as the HIV movement

in Canada undergoes an important period of transition and change, it has become particularly difficult to identify the shared issues, and obtain the consensus required to develop a document like a Roadmap. Prior to launching into a discussion of the work of the Committee, it is therefore useful to paint a cursory portrait of the current state of affairs as it pertains to the HIV movement in Canada.

### **Priority-setting in a time of change**

Canada's HIV community movement is currently undergoing an important period of transition. This shift, which affects both people with a lived experience of HIV, as well as the community-based organizations that serve them, has manifested itself in a number of ways, including:

- Changes to what it means to be living with HIV, with an increasing move towards understanding (and often experiencing) HIV as a chronic manageable condition, in part because of the availability of treatment regimens that are much easier to take and to tolerate;
- Changes to funding models for community-based HIV-related work, including a move towards an integrated approach that combines the response to HIV, HCV and other sexually and blood-borne infections (STBBIs), and a move away from HIV "exceptionalism"; This does not ensure funding to secondary prevention through care and support.
- Diminishing funding for HIV-specific activities allocated by pharmaceutical companies and other private funders;
- The closing of several ASOs as a result of diminished funding; as well as changes in the mandates and service delivery models of other ASOs to encompass a broader array of populations and needs;
- A broader reconfiguration of the health and social services systems in many provinces and territories, with a move towards integrated health and social services.

This moment of transition has and continues to be a very challenging one for the HIV community — change usually is — but in many ways, it also indicates some potentially encouraging news. Unlike the generations of people who were diagnosed with HIV in the 1980s, 1990s and even 2000s, someone who receives a positive test result today will often be able to access treatment and support shortly thereafter. In turn, this contributes to allowing the person to stay healthy and to enjoy an almost identical life expectancy as someone who is not living with the HIV virus.

Many individuals who were diagnosed with HIV prior to this current era of early detection and treatment have also benefited greatly from the therapies that exist to manage HIV. That is not to say that people who are living with HIV no longer experience sickness and side effects from the virus and its treatments, but HIV infection is not the debilitating disease it once was. For an increasing number of people in Canada, HIV infection is shifting to a condition that needs to be closely monitored and managed, but that need not impact one's physical quality of life too drastically.

This being the case, HIV has not reached the same status as other chronic manageable conditions, such as arthritis or diabetes. In addition to the threat of criminalization due to sexual non-disclosure faced by people who are living with HIV, the condition remains socially stigmatized, and one that affects people from marginalized communities in very specific ways. Any consideration of the “90-90-90” goals (90% of people living with HIV aware of their status, 90% treated and 90% virally suppressed) must be accompanied by a recognition of the “10-10-10,” those who are not tested, treated and virally suppressed.

Most of the individuals who fall within the 10-10-10 category face a number of social, economic and other determinants that limit their ability to access socially and culturally appropriate services and care (as a result of poverty, colonization, drug addiction, street involvement and/or underdeveloped health infrastructure in the area where they reside.)

Moreover, many individuals who are living with HIV still require forms of support that extend beyond their medical needs — whether emotional, financial, educational/informational, social, etc. Traditionally, these needs have been met by ASOs

and other CBOs, but as the realities of living with HIV begin to shift, what individuals want and need from these organizations is also changing. For example, with a larger number of HIV-positive individuals remaining in the workforce on a full-time basis, the provision of services must consider new and innovative approaches, including activities on evenings and weekends, and virtual-based methods of engagement.

As ASOs and other CBOs expand their services to include other issues and populations, beyond the more “traditional” community of people living with HIV, there are also some important questions to contend with. These include integrating individuals who are mono-infected with HCV or other STBIs, reaching those who are newly diagnosed with HIV and/or who are not accustomed to receiving services within ASOs, and keeping abreast of new developments in research and prevention. As organizations diversify their services to include sexual health education and prevention, housing, harm reduction and related issues, they must broaden their knowledge and practice-base to account for these expanding portfolios and reconfigure their internal processes, while fighting to secure funding in an increasingly precarious context.

As the HIV movement grapples with these important changes, some have resisted and looked to the past with nostalgia, while others have identified new possibilities and have adapted or are in the midst of adapting their practices and services to mirror this changing context. Faced with a large number of issues, priorities and preoccupations, and a diverse array of reactions to them, it has become particularly difficult to engage individual and organizational community members around common projects.

In this fractured context, the task of developing a GIPA Roadmap, a document that provides meaningful guidance and relevant ideas for the HIV community movement as a whole, has become a particularly challenging one. That is not to say, however, that the project is unimportant or impossible. Quite the contrary, now more than ever, the community could benefit from some support and insights as to how it can continue to meaningfully engage people who are living with HIV in activities, services, decision-making and other processes.

### **An update on the work of the PLWHIV/GIPA Steering Committee**

As mentioned above, the 2017 Forum saw the creation of a PLWHIV/GIPA Steering Committee, tasked with guiding CAS in its GIPA-related activities and the development of the GIPA Roadmap. The Committee is composed of CAS' HIV Committee (members of the Board of Directors who are elected at the Annual Forum) and 6 additional members who were selected and voted in at the 2017 Forum. This ensured equal representatives from all 5 regions plus 2 from Youth. All individuals are living with HIV, and they represent the five geographical regions of Canada, as well as a youth perspective.

At the time of writing this report, the PLWHIV/GIPA Steering Committee has met five times, via teleconference. Meetings were held on October 10, October 23, November 1, November 14 and November 29 of 2017. Meetings were halted during December to account for World AIDS Day activities and the year-end holidays, but they will resume again in 2018. Thus far, the meetings of the Committee have raised a number of key issues and priorities as they relate to GIPA, as well as a process for the development of a GIPA Roadmap.

During the first meeting of the Committee, the group decided to form a Sub-Committee Working Group to provide direction on the creation of the GIPA Roadmap, and to identify approaches to be used in the development of the document. The Sub-Committee Working Group met on October 16, 2017. Following this meeting and the meeting of the larger Committee on November 1, it was agreed that the group would parcel off into three Sub-Committees, structured around major issues as determined through consensus by the group.

The three thematic issues are:

- GIPA Peer Navigation;
- Addressing major issues and ongoing barriers;
- Integrating GIPA into working life.

During the month of November, the Sub-Committees had a chance to meet via teleconference, with the aim of developing reports highlighting key issues, tools and literature within each sub-theme. These reports were shared with the larger Committee, who reviewed and discussed them during the teleconference held on November 29.

So far, these steps have generated the identification of three key themes, associated issues, as well as an outline for the development of the GIPA Roadmap. However, the process has also revealed the need for a much more extensive consultative and research process, in order to develop a document that truly reflects the changing context of the HIV community movement.

For example, some of the questions that have been raised during the process include:

- What does GIPA mean in a context where organizations are also serving individuals who are mono-infected with HCV and/or with other STBBIs?
- What does GIPA mean to someone who is working on a full-time basis, and may not be able to devote as much time to volunteer involvement?
- How can organizations continue to meaningfully integrate GIPA principles within their work, when they are serving a more diverse client-base, and struggling to secure funding to ensure their continued existence?
- How is GIPA affected by new movements and developments within the community, including U = U (Undetectable = Untransmittable), and 90/90/90?
- How can individuals who are facing issues such as poverty, addiction or criminalization be meaningfully engaged in the community movement and the activities of community-based organizations?
- What kind of partnerships and ally-ships can we envision to create environments that are more supportive of people who are living with HIV, both within and outside of the HIV movement?
- How can GIPA address the social and self-stigma that still shapes the experiences of so many people who are living with HIV?
- What are the specific issues that affect youth who are living with HIV, and how must these be accounted for in relation to GIPA? And in turn, what new

perspectives and tools can young people bring to the table in shaping and defining GIPA moving forward?

### **Looking forward – The need for an ongoing dialogue on GIPA**

The work that has been accomplished thus far by the PLWHIV/GIPA Committee on developing a GIPA Roadmap clearly indicates that this remains a fundamentally important issue for the HIV movement in Canada, and one that requires ongoing attention. As organizations and individuals adapt to the changing landscape, they will require guidance and strategies to ensure that this cornerstone of the HIV movement remains at the forefront of processes and services.

However, this work, along with the current state of flux of the HIV movement in Canada, has also revealed the need for a much more extensive and elaborate process. In order to develop a document that will be truly meaningful and useful to the community, we need to better understand the current realities and changing needs of the diversity of people who are living with HIV, as well as the community-based organizations that serve them.

Moving forward, CAS would recommend that an additional year of full-time work be allocated to this project. Working in close collaboration with the Committee and Sub-Committees, this process would include an extensive consultation to address the diversity of experiences in Canada's regions, and the provinces/territories, rural and remote, urban and suburban areas within them. Grounding the consultation in the three thematic areas noted by the Committee will allow for the identification of issues, barriers and practical strategies to address them.

The Committee has also put forth the value of developing an evaluation tool to accompany the GIPA roadmap, in the form of an evaluation toolkit (a checklist and evaluation framework). As always, CAS would look forward to working with the Committee, an extensive network of organizational members and collaborators, and of people who are living with HIV across the country, to shepherd the development of a framework for GIPA that accounts for the new realities of what it means to be living with HIV in 2018 and beyond, and what it means to provide meaningful and relevant services to this diversity of individuals.

In the thirty years since the initial manifestation of the virus, the HIV movement has become a bastion for community involvement in all aspects of prevention, treatment, care, support and mobilization. As guiding principles to this movement, GIPA highlight and capture the fundamental importance of meaningful inclusion and participation in all services and processes. In turn, people who are living with HIV and community-based organizations have staked their position as an essential element in the health-care service delivery system.

As our health systems gravitate towards an increasing recognition of the centrality of the patient in all matters, the HIV community movement has many lessons to share on how to develop interventions that involve and are shaped by the primary people concerned. In addition to constituting a worthy project for the HIV movement in Canada, this deepened inquiry into GIPA will provide key insights and lessons to share with other community groups and movements, and our health care systems more broadly.