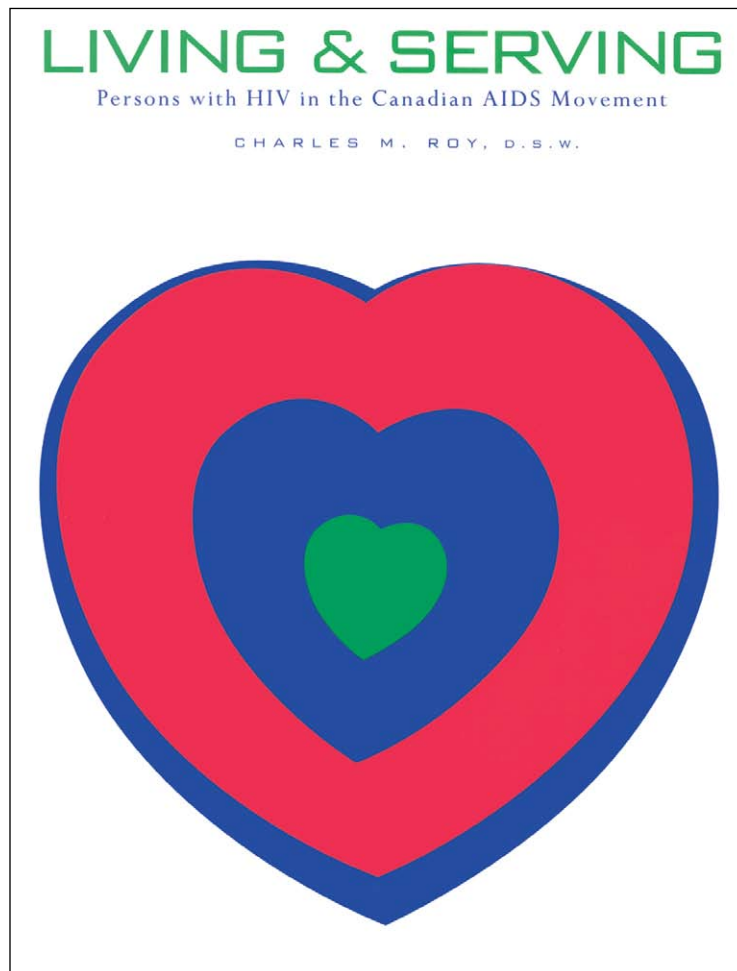
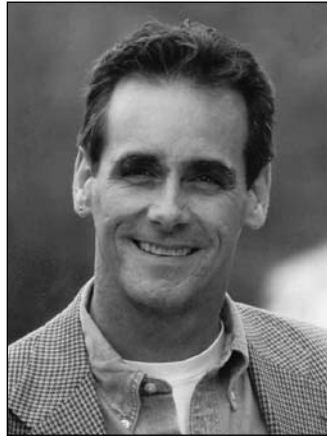


LIVING & SERVING II: 10 YEARS LATER

The Involvement of People Living with HIV/AIDS in the Community AIDS Movement in Ontario

Dedicated to the memory of Charles Roy and his commitment to ensure the greater involvement of people living with HIV in the AIDS movement in Canada.



The cover of the original *Living & Serving: Persons with HIV in the Canadian AIDS Movement* report.

LIVING & SERVING II: 10 YEARS LATER

April 2007



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List of Acronyms

AIDS	Acquired Immune Deficiency Syndrome
APHA	Aboriginal People Living with HIV/AIDS
APN+	Asian Pacific Network of People Living with HIV/AIDS
ASO	AIDS Service Organization
Black C.A.P.	Black Coalition for AIDS Prevention
CAS	Canadian AIDS Society
CBAO	Community-Based AIDS Organization
CIHR	Canadian Institute of Health Research
GIPA	Greater Involvement of People Living with HIV/AIDS
GNP+	Global Network of People Living with HIV/AIDS
HAART	Highly Active Anti-retroviral Therapy
HIV	Human Immunodeficiency Virus
ICW	International Community of Women Living with HIV/AIDS
IFRC	International Federation of Red Cross
NGO	Non-governmental Organization
OAN	Ontario AIDS Network
OCAP	Ownership, Control, Access, Possession
ODSP	Ontario Disability Support Program
OHTN	The Ontario HIV Treatment Network
OODP	The Ontario Organizational Development Program
PHA	People Living with HIV/AIDS
PASAN	Prisoners' HIV/AIDS Support Action Network
PHAC	Public Health Agency of Canada
TAC	Treatment Action Campaign
UNGASS	United Nations General Assembly Special Session on HIV/AIDS
UNAIDS	Joint United Nations Programme on HIV/AIDS

Executive Summary

The *Living & Serving II* report provides findings from a follow-up study to Charles Roy's (1996) report, *Living & Serving: Persons with HIV in the AIDS Movement in Canada*, which examined the involvement of people living with HIV/AIDS (PHAs) in community AIDS organizations across Canada.

There were five components to our follow-up study: (1) a *literature review* that examined the recent academic and community literature on the greater involvement of people living with HIV/AIDS, sometimes referred to as GIPA; (2) a *community consultation* with 35 individuals who play various roles in community AIDS organizations and in advocacy and policy development in Ontario; (3) a series of 12 *focus group discussions* with HIV-positive and HIV-negative individuals about the benefits of and barriers to the involvement of PHAs in the movement, what facilitates greater involvement, and what has changed in the past decade; (4) an *on-line survey of AIDS organizations in Ontario* about their policies and practices with regard to PHA involvement; and (5) a *workshop with Executive Directors and board chairs* of member organizations of the Ontario AIDS Network that identified recommendations for action to promote the greater involvement of PHAs in the Ontario AIDS movement.

Benefits of PHA Involvement

Focus group participants reported that PHAs can benefit personally from becoming involved in AIDS work: they can derive a sense of purpose, improved self-esteem, and greater knowledge about HIV/AIDS. Involvement can help reduce feelings of isolation and depression that can accompany an HIV diagnosis. HIV/AIDS services can also benefit from PHA involvement; this was seen to be particularly true for support services. The presence of PHAs in agencies can make them less stigmatizing environments and improve their credibility. Discussion in our Aboriginal focus groups also suggested that involvement of Aboriginal people living with HIV/AIDS can increase their sense of connection to community and their knowledge of cultural traditions.

Barriers to PHA Involvement

Stigma remains one of the most significant barriers to PHA involvement in AIDS organizations, particularly in smaller settings and in some culturally specific communities in larger cities. Participants also noted that concern about protecting their confidentiality remains a barrier for many PHAs, who choose not to become involved in AIDS work out of fear that their HIV status might be revealed. Health status can be a barrier: poor health reduces PHAs' ability to become involved in paid or volunteer work, and good health often means that PHAs continue to work full-time in other fields, leaving them little time and energy for AIDS work. PHAs who are already working may be reluctant to begin employment

in AIDS organizations if it means giving up workplace health benefits. Participants believed that improvements in medical treatments have had the result of making it more difficult to motivate PHAs to become active and engaged in the AIDS community. The professionalization of AIDS organizations is another barrier. Some AIDS organizations are seen to more highly value formal qualifications and professional experience over the personal experience of living with HIV. PHAs may not feel welcomed, adequately supported, or sufficiently skilled for work in such agencies. The long-term involvement of some PHAs in AIDS work creates a challenge in that they bring needed skills and experience, but they risk burning out, and participants felt that their presence can sometimes make it difficult for new people to move into positions of leadership. We heard statements from Aboriginal participants, women and people from ethnoracial communities that they sometimes feel excluded from AIDS organizations. Tensions that can sometimes arise in AIDS work between HIV-positive and HIV-negative individuals, or between different groups of PHAs, can discourage some people from becoming more involved. Finally, our findings suggest that PHAs are unlikely to want to become more involved in AIDS work unless adequate services are in place to meet their basic needs.

Changes over the Past Decade

Our project examined what has changed since Charles Roy conducted his study a decade ago. Many of the issues he identified remain, but our study also reveals a number of changes. Stigma and discrimination continue to be an important concern, but stigma is now seen as more insidious. Some study participants believed that gains have been made in terms of PHA involvement, but PHAs still face systematic discrimination, particularly at higher levels in the hierarchy of organizations. Disclosure of one's HIV status was seen to have become more complex as a result of improved HIV treatments, which can undermine PHA involvement in AIDS work. Participants felt that there has been an increase in the visibility of diverse communities of people living with HIV, and concerns about ongoing racism, homophobia and discrimination were cited. AIDS organizations were seen to become increasingly professionalized, bureaucratic and inflexible, leading some PHAs to no longer feel at home or welcome.

Successful Strategies to Involve PHAs

Participants believed that PHAs need to be provided with training to develop the skills required by AIDS organizations. Agencies may need additional resources to provide training and ongoing support to PHAs. Mentoring was also seen as important in building skills, instilling confidence, and developing leadership skills. Like training, building leadership and mentoring are long term investments that require time, resources, role models and opportunities for practice. PHAs also need to be given roles that they find interesting and that use their skills. Agencies need progressive hiring policies and practices, as well as succession planning. These strategies and their resource implications need to be addressed by funders and government policy makers.

Survey of AIDS Organizations

In addition to our focus groups, we conducted an on-line survey of member organizations of the OAN about their agency's policies and practices with regard to PHA involvement. Findings show that over 33.3% of surveyed organizations have no self-declared PHAs on staff. In terms of representation on Boards of Directors, our findings show that 66% of organizations have less than 50% PHA representation and 10% of organizations have no PHAs at all on their Board of Directors. Beyond staff and board roles, the findings indicate a wide range of ways that PHAs are involved in the work of AIDS service organizations. Nearly all respondents (90%) indicated that the involvement of PHAs helped their agency respond to the needs and concerns of their clients. PHA involvement also provides other benefits, such as providing role models for other PHAs, helping to reduce stigma, and keeping agencies grounded in the realities of living with HIV/AIDS. The three barriers most frequently identified were: poor health of PHAs, PHAs worries about the disclosure of their HIV status, and side effects of medications.

Discussion and Recommendations

The report concludes with a discussion of our findings and how the situation of PHA involvement seems to have changed over the past decade. We discuss the implications of our findings for local AIDS organizations. A workshop of Ontario AIDS organizations' board chairs and Executive Directors was convened by the Ontario AIDS Network on January 26, 2007 to inform the research team's development of recommendations from the study:

1. We recommend that the Ontario AIDS Bureau strike a Working Group on PHA Involvement to discuss the study findings and recommendations on an on-going basis and draft a plan for implementation of these and related measures.
2. We recommend that one of the first actions of this Working Group be to develop a set of core values related to PHA involvement and these values be printed on a poster. This poster should be distributed to AIDS organizations and displayed to all service users, board members and staff.
3. We recommend that this Working Group apply for a Canadian Institute of Health Research (CIHR) *Knowledge to Action* grant to help implementation of measures to improve PHA involvement in the Ontario AIDS movement.
4. We recommend that the OAN, and its member agencies, review the International Code of Practice for NGOs responding to HIV/AIDS and be encouraged to become signatories to this Code.
5. We applaud existing initiatives that foster the training and skills development of PHAs. These initiatives include the OAN Leadership Training Program, speakers bureaus of various community agencies, the Committee for Accessible AIDS Treatment's HIV and Immigration Service Access Training Program, and the Ontario Organizational Development Program (OODP). We recommend these types of initiatives be expanded and coordinated.
6. We recommend that more AIDS organizations publish profiles of best practices around PHA involvement, as well as individual profiles of different PHA roles in the movement.

7. We recommend that all AIDS organizations engage in their own internal review of PHA participation in their individual organizations and adopt a vision of what involvement should look like and a plan to achieve this. To aid in this internal review process, we recommend organizations use this report, and the appendices: literature review, and the questions for AIDS organizations. Technical support for this review process could be provided by OODP.
8. We recommend that AIDS organizations implement yearly internal reviews of PHA involvement in their AIDS organizations.
9. We recommend that all AIDS organizations develop specific hiring policies that encourage the recruitment and retention of PHAs as staff.
10. We recommend that the Working Group on PHA Involvement identify existing templates that promote best hiring practices and in their absence develop new templates to aid organizations.
11. We recommend that all AIDS organizations develop specific volunteer policies that encourage the recruitment and retention of PHAs as volunteers.
12. We recommend that the Working Group on PHA Involvement identify existing templates that promote best volunteer practices and, in their absence, develop new templates to aid organizations.
13. Given the importance of confidentiality as a barrier to involvement, we recommend organizations ensure that adequate confidentiality policies and practices are in place and are relevant to service users, volunteers, board members and staff.
14. We recommend that the OHTN plan a study of confidentiality policies and practices in AIDS organizations and the complexities of ensuring confidentiality especially in smaller, community-based AIDS service organizations.
15. Given that stigma continues to be one of the greatest barriers to PHA involvement, we recommend that all agencies ensure that adequate policies and practices are in place to eliminate stigma and discrimination.
16. We applaud the current research on stigma and discrimination by various stakeholders and recommend their research expand to study stigma and discrimination policies and practices in AIDS organizations, especially as it relates to PHA involvement.
17. We recommend that the OAN and all relevant organizations intensify their advocacy efforts for adequate benefits and return-to-work policies for PHAs throughout the province. Such policies should recognize the episodic nature of HIV and the challenges inherent in return-to-work decisions.
18. We recommend further research be conducted on PHA involvement especially in settings beyond community-based AIDS organizations (e.g., government advisory committees and non-HIV specific agencies).
19. We recommend continued research and policy development on the social determinants of health, especially as they relate to PHA involvement.
20. We recommend an intensification of advocacy efforts to improve direct funding of AIDS services at a community level. We believe that meaningful PHA involvement will never be possible without adequate, comprehensive and well-funded community-based AIDS services.

1

Background

This report provides an overview of a follow-up study conducted ten years after Charles Roy's report, *Living & Serving: Persons with HIV in the AIDS Movement in Canada*. Roy's report, which was published by the Canadian AIDS Society in 1996, examined the involvement of people living with HIV/AIDS (PHAs¹) in AIDS service organizations (AIDS organizations) across Canada. Roy's study highlighted the benefits of PHA involvement for individuals and organizations, the barriers to their involvement, and strategies to promote greater PHA participation. In 1994, around the time when Roy was completing his research, a declaration at the Paris AIDS Summit established the principle of the Greater Involvement of People Living with HIV/AIDS (GIPA). Aside from Roy's study, little research has been conducted related to GIPA, although the principle is said to be well-accepted in the AIDS movement. This follow-up study uses the same general questions that Roy posed ten years ago to examine how well established GIPA is in Ontario today. This follow-up study will help us understand issues relating to PHA involvement in the community AIDS movement in Ontario and how they have changed over the past decade.

The Original Living & Serving Study

Charles Roy completed the *Living & Serving* project as a doctoral thesis at the Hunter College School of Social Work in New York. Data were collected between 1992 and 1994, with the thesis being completed in 1995. The Canadian AIDS Society (CAS) collaborated in the project by assisting in the development of the research instruments and the recruitment of respondents. Charles presented his preliminary findings to the CAS Annual General Meeting in 1993, and engaged about 150 people in discussion about the implications of the findings. In 1996, CAS published a reworked version of the thesis and distributed it to its member organizations.

Roy's study found that 20% of board members and less than 10% of paid staff members in local and national AIDS organizations were living with HIV. Further, his findings showed that more than 60% of AIDS organizations had no PHA employees at all. Although this level of participation was seen as low, the leadership in AIDS organizations acknowledged that PHA involvement was important and that PHAs have unique skills and knowledge to offer, as well as passion and commitment. His study detailed the value of PHAs in keeping organizations focused in their education and support services and argued that PHAs ensure that principles of "health from below, self-help, client-centered and community-based care are practiced, not just preached" (p. 68). The study also acknowledged that having PHAs involved was politically wise and lent credibility to the organizations. Barriers that either prevented or discouraged involvements were numerous and diverse and included disclosure risks, low wages, lack of adequate benefits, and health issues. Finally, the study argued that based on the fact that organizations were often small and in early stages of development, the stress and politics involved in the work kept PHAs away. The study concluded with a set of twelve recommendations to guide organizations in providing a more supportive environment for PHAs:

- 1 Respect PHAs right to privacy and confidentiality (whether for clients, volunteers, directors or staff)
- 2 Change the community's perception of PHAs through public education
- 3 Create supportive environments for PHAs
- 4 Develop strategies to make PHA participation a priority
- 5 Communicate the agency's position on participation to the community
- 6 Provide positive role models for PHAs
- 7 Respond to the cultural diversity of PHAs in the community
- 8 Offer skills-development opportunities
- 9 Learn from other self-help, client-centered organizations
- 10 Promote and develop volunteerism
- 11 Provide more competitive salaries
- 12 Provide more attractive benefit packages.

1 In this report we use "PHA" to denote persons living with HIV/AIDS but recognize that there are different acronyms that people choose to identify themselves, including "APHA" which refers to Aboriginal persons living with HIV/AIDS.

The Living & Serving II: 10 Years Later Project

Our follow-up study, ten years after Roy's original, emerged from discussions with the Ontario AIDS Network (OAN), the Ontario HIV Treatment Network (OHTN), and the two principal investigators. Each organization supported the project in a number of ways. OHTN provided research funding and staff support. The OAN helped promote the project and assisted with recruitment. The two Co-Principal Investigators, in collaboration with the OAN and the OHTN, invited a number of people with experience in both the community AIDS movement and in research to participate as part of the team. We aimed to create a group that represented a variety of community perspectives. PHAs comprised about half of the research team.

Research Process

We started the project by conducting a review of the literature, both published and unpublished, on the involvement of people living with HIV/AIDS. Our literature review, which is attached as Appendix 1, updates the one that appears in Charles Roy's 1996 report.

A community consultation was held in May 2006 with 35 individuals from around the province. These individuals play a variety of roles in AIDS organizations including service, advocacy and policy development, and research. At the day-long consultation, we presented the discussion paper and literature review, outlined our plans for the study, considered some of the broad changes in the AIDS movement over the past decade, and sought input into our research questions and design. Participants provided useful feedback and suggested a number of changes to our research plan. For example, they suggested recruitment strategies to ensure a more diverse sample of study respondents. We also discussed the challenges faced in collecting meaningful survey data about PHA volunteer participation in AIDS organizations. In the second half of the day, attendees were invited to participate in focus groups to discuss the benefits of PHA involvement, barriers to their greater involvement, strategies to facilitate their involvement, and changes that have occurred over the past ten years.

Following the community consultation, and throughout the summer and fall of 2006, we conducted a series of additional focus groups. The findings from our focus groups are discussed in Section 2 of this report. We also conducted an online survey of all member organizations of the OAN and the results of this survey are described in Section 3. In Section 4, we discuss the implications of the findings from both the focus groups and the survey of organizations, and compare them to Roy's original study. Finally, recommendations are presented in Section 5. Many of the recommendations arose out of a workshop of Executive Directors and Chairs of Boards of Directors of member organizations of the OAN, where the study was presented and participants were asked to help develop recommendations.

We adopted a broad definition of what constitutes "involvement," similar to that which Roy used in his original study. Although in reality involvement spans a broad spectrum, from service user to decision maker, we were more interested in PHA roles in the movement beyond just accessing services. Various roles that constitute involvement include: volunteer, peer counselor, staff member (whether front-line or management), board member, advisory committee member, community researcher, etc.

2

Focus Groups

We conducted a series of focus groups with HIV-positive and HIV-negative individuals about the involvement of PHAs in the Ontario AIDS movement. Our 12 focus groups ranged in size from three to 16 people. A total of 82 people participated in this component of the study. Two focus groups included Aboriginal participants, one was comprised of women, one among people from ethnoracial communities, one of persons who use injection drugs, one of youth, and the remaining seven focus groups included a mix of participants. Groups were held in Thunder Bay, Ottawa, and Toronto.

Similar to Charles Roy's original study, key questions included:

- What changes, if any, have you noticed in the past 10 years with regard to PHA involvement in AIDS organizations in Ontario?
- What are the benefits of PHA involvement in the work of AIDS organizations and elsewhere in the HIV/AIDS movement?
- What are the costs and tensions associated with PHA involvement?
- What factors or conditions facilitate PHA involvement?
- What factors or conditions are barriers to PHA involvement?
- What kinds of actions and policy changes are needed to support an increase in the extent and meaningfulness of PHA involvement?

Looking at the focus group participants, 32% were female (26/82) while 68% were male (56/82). There were no transgendered participants. Participants' age ranged from 18 to 62 years, with a mean age of 40. A slight majority of respondents (57%) were gay, lesbian, bisexual or two-spirited and 43% identified as heterosexual. The majority of the sample (88%) was HIV-positive. Volunteers within AIDS organizations accounted for just under two-thirds of the sample (62%), and close to half of these were board members. Another 17% were paid staff in an AIDS organization. Almost half (43%) of the sample had been involved in AIDS work (paid or otherwise) for 10 years or longer.

Benefits of PHA Involvement

Participants in our focus groups were asked to discuss the benefits they saw as a result of involving PHAs in AIDS organizations. In this section, we summarize the key themes that emerged from these discussions.

Benefits to PHA Well-being

First and foremost, involvement is seen to benefit PHAs themselves. Respondents identified improvements to PHA well-being as a result of involvement in AIDS work. Many respondents spoke about how getting involved had the potential to improve the mental health of people living with HIV. Respondents described a sense of purpose and improvements to self-esteem that resulted from their involvement in AIDS work.

I think this goes back to mental health and self-esteem...How do you deal with this without having lots of issues, sometimes necessarily, around shame, sometimes really feeling really isolated, unclean.

A benefit of particular concern in our focus groups of people from ethnoracial communities, Aboriginal people, women, and youth, was that involvement helped them break down the social isolation they experienced. For example, newcomers to Canada talked about their isolation after arriving in the country. By getting involved in AIDS work they were able to meet new friends from whom they did not have to hide their HIV status:

I think that for some of us, the trouble is we come here not knowing anyone in the country and we find ourselves in this situation. The only friends we make most of the time are the friends we make in these organizations. They become part of our family...When you come here, you find consolation. It comforts you. It changes your mentality because at least you have someone to talk to since we don't have anyone in the country.

The involvement of PHAs in AIDS work can provide other PHAs with important role models. Members of the youth focus group discussed the importance of having positive youth mentors in AIDS organizations:

The difference between you [an HIV-negative young person] and [an HIV-positive young person] is that [the positive person] gave me hope. I was in a black hole of 'oh my god, oh my god' and he was such a successful, self-empowered, self-directed person who, as a role model, gave me hope for the first time.

Other respondents noted how their involvement has made them feel more knowledgeable and empowered.

A participant in our focus group for injection drug users talked about the benefits he derived from participating in HIV prevention work (handing out condoms to other drug users). For him, giving back makes up for previous behaviours:

It makes me feel good because like, I don't know, it's weird. I don't want to sound corny or nothing, but it's almost like I'm giving something back...It's nice to know what I've been through has got value and I can actually help. It sounds corny. When I think about it, it sounds corny. It makes you feel good. I've been happier the last year than I've been most of my life.

Benefit to Services

Respondents felt that the services of AIDS organizations were improved by the involvement of people living with HIV/AIDS. In particular, the presence of PHA staff members and peer counselors improved support services to PHAs. The mechanism for this most often seemed to be the ability of clients to better relate to other PHAs. An analogy was made around how former addicts were seen to make the most informed and empathic addiction counselors. One participant who used injection drugs noted:

You can't understand it, not unless you've experienced it, you know. Like I said earlier about a drug addict, to me a recovering drug addict or alcoholic understands better than somebody that's book learned.

Having a counselor with whom you share many experiences can facilitate communication and understanding. For example, participants in our youth focus group agreed that they felt much more comfortable having a PHA working with them. One participant in this discussion talked about the importance of having an HIV-positive counselor:

[...] the person was asking me questions and I wasn't open with her. She was [HIV-] negative, so I was hiding stuff. I was afraid to say everything. I think it's really important to have someone with whom you feel you have something in common. You feel so free and open.

A number of respondents described how having HIV-positive staff and volunteers can change the culture of AIDS organizations, making them less stigmatizing environments for clients:

It actually enhances the services. It makes them more comfortable, like you can talk about it and not feel embarrassed or ashamed or whatever.

Increased credibility was often cited as a benefit of having PHAs involved in AIDS organizations. Having PHAs involved can be seen as a sign that their organization is respectful and responsive to

their needs and concerns. The direct involvement of PHAs is also seen as a way of keeping agencies focused and accountable in their work. As a result, organizations were seen to be more credible to funders, to the community, and to other people living with HIV:

[...] it rubs off on the community as to whether or not they are a good place to give your money to, give your support to, if you see an organization is being used, and people talk positively about it. We've all seen in the movement how when an organization loses its focus, its fund raising dries up, no one goes on the board, it can't get volunteers, it can't get staff, and things shrivel up.

Community Benefits

Participants in the two Aboriginal focus groups identified unique benefits for Aboriginal people living with HIV/AIDS (APHAs) who are actively involved in HIV/AIDS services for their communities. APHAs may not have a lot of knowledge about their own culture and may not have close ties with their communities. As a result, participation within AIDS organizations can lead to a stronger sense of community connection through the knowledge they gain about their culture:

A number of APHAs may not know their culture, so becoming involved in the movement – and we are using traditional healers, story tellers, elders and those kinds of things – what they also learn about is who they are as an Aboriginal person, which helps to build their self confidence and the way that they think about themselves. They actually change.

This kind of cultural engagement through AIDS work is important for many APHAs, particularly those who have moved to cities, since they may not have many community ties or much connection with Aboriginal culture.

It's sort of like an extended family so to speak because when you don't have your family there or say in another province and you're here, it's just like it's good to see a friendly face.

Aboriginal communities are also seen as benefiting from the participation of individual PHAs. The future of Aboriginal communities is seen to rest on the engagement of individual members.

It's different in our community – it's the love of our community that keeps us doing this, because we want our community to have a future. If you just look at the data – women and youth – there is no future unless you engage. So that is where the passion and commitment come in...Our community needs to have all its people involved in the healing process or else it's not going to survive.

Barriers to PHA Involvement

Despite the many benefits of PHA involvement identified by our respondents, it was also noted that there are a number of barriers to be overcome. Some of these barriers are shared among all AIDS organizations, while others seem more relevant to groups in particular contexts. In this section, we review seven of the major barriers identified in our focus groups.

Stigma

Twenty-five years into the epidemic, stigma still remains one of the most prominent barriers to PHA involvement. Stigma can be associated with being HIV-positive, injecting drugs, working in the sex trade, or identifying one's self as gay. This is true in all settings but is particularly so in Aboriginal communities and in non-urban areas where HIV is less common, as well as within culturally specific communities in larger cities. AIDS organizations usually do not require disclosure of HIV status as a condition of involvement, but in some places, particularly smaller communities, the stigma of simply being seen at or associated with an AIDS organization is strong enough to keep PHAs away. The potential for violence remains a worry for those in smaller communities. Coming from a small northern town, one man stated,

It's totally different than living in a large city where you have options, here you only have one option and that's it. That's a big barrier for a lot of people, disclosure.

Similarly, a worker in an Aboriginal service organization observed,

There is enormous stigma and discrimination [around HIV] outside the area of Toronto, where you can come to the office and share offices and programs and stuff, and there is a feeling of community there. But in other areas of the province, it's often that Aboriginal people won't come into the office, they will speak to me outside so they don't disclose. They are worried about their confidentiality.

Closely related to stigma were the many fears and concerns our respondents had relating to confidentiality. These concerns were often about whether other HIV-positive service users would reveal their sero-status. One woman, a recent immigrant living in Toronto, described her concerns about confidentiality in her community:

There's too much gossiping, no confidentiality and it's like the minute you take yourself out there you have put yourself at risk. So I have a few friends who are from my country and they've been positive for a while. They know, they will try to hide and go through some other organization. But now they've just given up. They just don't go there anymore because any time they go somewhere the same people who are sitting there are the same people who will be going around telling people that you're positive.

Health Concerns

The health status of PHAs can be a barrier to their involvement in a number of ways. Poor health clearly reduces a PHA's ability to work in the field and to be involved in AIDS organizing. Because AIDS is an episodic illness, even when PHAs recover from a health set-back, they may be understandably reluctant to give up the security of disability benefits or health insurance from previous employment and instead take-on full or part-time work in an AIDS organization. Even at the level of volunteer work, PHAs may be reluctant to commit to a program if they feel their health might be compromised.

Good health can also have a negative impact on PHA involvement. Prior to the introduction of highly active anti-retroviral therapy (HAART) many PHAs went on long term disability after diagnosis and were consequently available to join advisory committees or sit on boards. However, PHAs who have been diagnosed in the last decade are less likely to go on long-term disability and they continue to work at jobs that may not be related to HIV/AIDS. In this case, ironically, improved health may lessen the pool of available PHAs to participate in AIDS organizations. Working in AIDS organizations can compete with other opportunities for paid employment.

People are getting well and if they are, there are other issues and other employment opportunities that might actually take them away [from AIDS work] and they might consider community-based organizations as a dead end job.

Participants believed that improvements in medical treatments have had the result of making it more difficult to motivate people with HIV/AIDS to become active and engaged in the AIDS community. Instead, people with HIV/AIDS are seen as looking beyond their illness and concentrating on other priorities in their lives such as parenthood, careers, and education. In a similar way, participants in the youth focus group talked about their long term career plans and their desire to pursue their education. There was much discussion in this group regarding the barriers they faced in pursuing post-secondary education or career paths. Even those who might consider work in an AIDS organization, recognized the need for higher education in many positions.

I want to work, too. I don't want to be on ODSP [the Ontario Disability Support Program] for the rest of my life. Sometimes it feels cool, so young and already retired for the rest of my life. It's great, but I want to work. Like all of us, we have goals, if it's not working, maybe going to Europe...but my problem here in getting a job is that [I will lose health benefits I have while on ODSP]...But if I am working, I am not going to have those benefits.

Finally, for some PHAs, getting involved in AIDS work represented another way that HIV was taking over their lives. For them, resisting HIV meant resisting AIDS work. Wondering aloud about why there are not more PHAs involved in the movement, one participant observed how many long-term volunteers often feel the need to stop and move onto other things:

Twenty years pass, and twenty years of being involved in one layer or another. It's a good example, like yourself, that you are saying 'gotta put it on the shelf for a while, and I'm going to actually go live another part of my life.'

Professionalization

In the second decade of the AIDS movement, the pressure to 'professionalize' organizations and services has created tensions in some community-based organizations and created a barrier to fuller PHA participation. Respondents reported that positions previously held by PHAs were increasingly given to non-PHAs with more formal training in specific areas and PHAs who were involved sometimes required extensive training to meet the demands of the job. Many respondents were involved in AIDS work but felt that AIDS organizations were valuing professional qualifications and formal education over their personal experience of living with HIV. A fairly common sentiment among our participants was that the "lived experience" of HIV is not sufficiently valued in AIDS organizations.

When we looked at hiring policies and the attitudes toward PHAs – and we have had PHAs that have applied, but their experience level has not been as relevant as the social workers...People don't get it. They are not valuing the lived experience and you have to build that into your policy if necessary.

Participants mentioned that AIDS organizations are increasingly looking for board members and volunteers with formal skills, for example in fundraising or finance, what one participant referred to as being a "policy geek" or a "bylaw geek." This leaves many PHAs either stuffing envelopes or being left out.

Is a board with a governance model the kind of place that a grass roots activist is going to feel either comfortable in or able to make any difference? Probably not. But that is one example, I think where we are actually becoming more sophisticated and more professional, so that the kind of people who are now involved are people with professional skills – you know the white middle-class folks coming in. Because those are the kind of people, the ASOs think they have skills that are needed. And they are quite explicit about it – 'yeah, we want a PHA who has fund-raising skills, who is able to read financial statements.' Not the PHA who believes in the cause and wants to advocate for whatever.

Revealing some of the complexities of PHA involvement, some agencies tried to give PHAs meaningful roles, but they did not provide the support and training that was required. One woman spoke about the lack of training that accompanied being placed as a PHA in certain volunteer positions and the challenges and anxieties that this created for her.

We have to take into consideration we didn't go to school for counseling. We didn't do our Masters. We're just like the everyday person. So when you're putting PHAs in the line of fire, that's really... what it's about is emotional well-being. I think that makes the client and the service providers very volatile and vulnerable to certain aspects...not so much the confidentiality piece, but just like everyone said before, there's parts of us that haven't been trained to separate ourselves. We didn't go to school for that...we don't have those skills in place...I felt as a volunteer I was given too much authority. I felt I wasn't receiving enough training...I feel I've been overlooked many times and pushed into environments I don't want to be pushed into.

The pressure to professionalize may relate to the changing nature of the work for staff members, board members and volunteers, alike. More emphasis is now placed on meeting organizational and funding demands:

The job description is different than 'you just need to be passionate, and get out there and fight about AIDS.' It's not about that anymore.

Long Term Involvement

Several respondents mentioned that many PHAs currently involved in AIDS work have been involved for a long time. While these PHAs bring needed skills, experience and stability to AIDS services, two issues stemmed from this long term involvement. First, with people staying in the movement longer, whether as activists, volunteers or staff, they risk burning out and need to take a break.

I am only working in HIV for almost seven years, but what I sense from many of what I call 'veterans' in this movement, either affected or infected, is fatigue. There is participant fatigue, involvement fatigue, volunteer fatigue, like 'if I go to another focus group, I am going to shoot myself.' Its many factors, not just being positive, but time passes, right?

Second, our respondents identified the need to make room for new people. Several participants – including long-serving PHAs – felt that people are sometimes remaining in place too long and preventing a new level of PHA leadership from rising up. This appeared to be a particular concern for youth and people from diverse backgrounds.

I wonder if part of the problem is also getting some people out of the way to make room for new comers. Ten years ago – and here is the tension – you could count on people getting sick and needing to leave, and people dying and leaving, so there was almost this perverse built-in people moving in and out of positions. Whereas today it's hard to leave AIDS work [or] leave with a clear conscience.

Another respondent noted:

There are a lot of us old timers who are just too comfortable, and are almost in a state of elite privilege, and maybe there isn't succession planning and who cares.

Exclusion

Despite the statements we heard about PHAs being less willing or able to come forward and be more involved in AIDS work, we also heard a number of statements from Aboriginals, women, ethnoracial communities, and youth that they feel alienated from existing AIDS organizations and are not always made to feel welcome. Participants in the women's focus group discussed the idea that certain individuals who have positions of leadership in organizations serving people with HIV act in a way which excludes others from participating. "They tend to change the organization into the way they see it and into the way they want it to be," said one participant.

They mess it up for other people that want to come and want to be part of the organization...it's run by certain people and certain people tend to tell you 'No, you can't come. Yes, you can come', and I think that's wrong because if you're a PHA, all of us should be welcome.

Aboriginal participants spoke of the racism they can sometimes experience in non-Aboriginal services. One respondent described confronting non-Aboriginal people's assumptions or stereotypes about Aboriginal identity:

Three different people – they all went in for services in a non-Aboriginal AIDS Organization, and they were asked if they wanted a needle exchange, and they weren't there for that. And well, that was an assumption immediately.

Tensions

Numerous tensions were described by participants, many of which had been mentioned in Roy's original study. One was the tension between HIV-positive and HIV-negative individuals. For some sero-negative respondents this manifests as resentment towards positive people for seeming to have special status; for some sero-positive respondents there was a feeling they were relegated to tokens in their role. For others, there was no tension in their organizations but they did feel there was an ever present distinction between "positive and negatives" whether on a board or on staff.

A commonly cited tension was between groups within large AIDS organizations that serve multiple communities, for example different ethnoracial groups and varying risk categories such as injection drug use and gender. For example one female participant said:

I'm not saying this happened to me personally, but I've heard that there are organizations where women won't feel very comfortable going. They say when you go there, some of the men look at you in very funny ways and they don't really want to help and it's like you're invading their privacy meant to be for men only.

In contrast some involved with ethnoracial specific agencies said there was greater comfort and familiarity to receiving service and serving as a volunteer. As one person of colour stated:

They don't have much family here. They don't know who to turn to...and they feel alienated. They don't feel part of this culture. So then you have an organization where the people are like you. Like I don't speak any of their languages but I look like them. So...there's a communication there without saying a word.

A final tension that was mentioned related to the difficulties in receiving support and care when PHAs work within AIDS organizations. The boundaries between being both a service provider and a service user can be very difficult to negotiate:

It's very difficult to get effective care that you would be eligible for as a service client. As an employee, if I would benefit from counseling because there is something going on in my life, maybe disclosure in a new relationship or something, I am not going to go to counseling from my staff, nor am I likely to go to a community partner agency, because it is very complex to actually get care and services.

Inadequacy of Services

A final barrier that was implied in many focus group discussions was the dissatisfaction many respondents experienced with available services. Much of the discussion in a number of focus groups concentrated on involvement as service users as opposed to involvement as services providers or other roles in AIDS organizations. It was almost as if adequate service provision was a prerequisite for getting further involved in an agency. If PHAs are overwhelmed by their own health needs, poverty, marginalization, or other factors, they are not going to be in a position to become more involved in the movement.

Changes Over the Past Decade

One of our objectives in this follow-up project was to understand how the situation surrounding PHA involvement has changed since Charles Roy completed his study 10 years ago. Our findings revealed many of the same issues identified by Roy, suggesting that some concerns have not changed. But our findings also suggested a number of significant, if subtle, changes that have taken place.

Stigma and Discrimination

Many participants in our focus groups felt that HIV stigma and discrimination, so characteristic of the general public's original response to AIDS, was still alive and well in the third decade of the epidemic. They felt that the nature of stigma and discrimination had changed, becoming more insidious and difficult to detect, but not improved.

I think it's different. I don't know if this is true or not, this is just my perception. I got involved in '89, and at the time things were so dire, that PHAs had no option but to get together because the world wasn't really helpful, and we were circling the wagon to protect ourselves...now there is a different kind of stigma, and I don't know how to articulate this...there is a self-esteem rot for PHAs. I look at what's happening among safer sex practices among PHAs or disclosure that's coming out of the research, and how PHAs are coming out now or are not coming out now. Now they are living more isolated lives, in some ways.

In contrast, some respondents felt that the situation had improved, resulting in a more compassionate response and creating new opportunities to educate.

Back then you had to keep it quiet, you had to keep it under your hat and stuff and you didn't want anybody to know and now it's like who the fuck cares if I'm HIV [positive]. I just want to like to tell everybody and educate everybody. It's a bit more open. Well it's a lot more open now. You don't have to put your shield up anymore.

Participants believed that while gains had been made in terms of the involvement of people living with HIV/AIDS in organizations and decision-making processes which impact on their lives, stigma and discrimination against people living with HIV still existed at these more institutional levels. For example, even when involved in AIDS organizations, participants noted that PHAs were often limited to positions lower in the organizational hierarchy.

There has been greater involvement of people living with HIV, and also empowerment in AIDS organizations that I know of here in Toronto, because I am fairly new in this country. But in general, I believe that people living with HIV still face stigmatization, even at HIV/AIDS organizations. Its not shown in some instances but its there

you know. For example, you take positions of ED or General Managers, and few times will you hear of a PHA being the leader of an agency...We keep talking about GIPA, but it is not meaningful involvement. So, what is lacking is meaningfully being involved in what ever part of the discussion, program design, development and also monitoring and evaluation of programs.

Simply working in an AIDS organization can be stigmatizing. As one respondent said:

For some communities, having worked in ASOs is still stigmatizing. It's not necessarily the proudest part of your resume.

There were some notable exceptions in focus group discussions on the nature of stigma and discrimination over the past 10 years. Aboriginal focus groups, in particular, noted that the adoption of OCAP (ownership, control, access, possession) principles, regarding research in the community, has had very positive results in overcoming discrimination:

So we are not objects of research anymore, we are fully engaged participants.

Increasing Complexity of Disclosure

A number of focus group participants felt that it was easier in some respects to disclose one's HIV status than it was a decade ago because of improved public attitudes towards HIV. Advances in treatments were seen to play a role in people's willingness to disclose their HIV status and to confront AIDS stigma:

Ten or 15 years ago we saw people...but you had nothing to lose; you were probably going to get sick soon, so what the heck, just jump in, if people reject you – whatever. But now we are seeing a long life ahead of them with HIV and also the discrimination still exists so the weight – the reason that we don't like to always disclose – exists on the same level if not more. But what is missing now is that urgency and that shorter time line.

Participants noted, however, that disclosure had become a more complex issue. Some spoke about what they perceived as increased pressure to disclose.

Oh, it's easier to disclose now than it was 15 years ago, so there is that extra pressure that you should be doing it. But the disclosure issue is more complicated now, if you are thinking about longer career issues. If you are working at the same time, disclosure is more complicated now.

Others felt that while it may now be easier to disclose, the argument for doing so is less compelling. One focus group participant suggested that the diminished need to disclose can lead to decreased involvement in the AIDS movement.

It's hard to put oneself in the mindset of someone who is newly diagnosed – I can't imagine. The argument for disclosure I think is much weaker now than it ever was. If you are carrying on at work, if you are taking your medication which basically maintains your health in relatively good standing, if there is still stigma out there, why would you disclose now? You know in my case – I am quite out now – but the thing that caused me to disclose was when I stopped work and my whole life changed so much that I had to account for that somehow. But without those major life changes, why would you disclose, why would you join a movement? If you are not disclosing, the chances of you joining the movement are rather slim.

Diversity and PHA Identity

Although the notion of a “PHA identity” was never monolithic in the first decade of AIDS, there appeared to be less diversity among people with HIV/AIDS. Participants noted that an increase in visibility of diverse communities of people living with HIV/AIDS has significantly changed over the past ten years.

I was at a meeting to do with [agency name] recently and I felt in the minority as a white woman. I was about the only white woman in the room, and also who wasn't a prostitute. So things are changing in terms of diversity. Now maybe the people that were long term survivors, now we go into an organization and we don't see ourselves.

Many observed that the increased diversity in the AIDS movement has been accompanied by tolerance, but examples of ongoing racism, homophobia, and discrimination were cited by participants.

I heard a comment one day from a couple of people that work at [agency name] which kind of totally blew me away. It was, 'why in every group do we have so many Caribbean people here? All those Caribbean women are coming and they're only here for the childcare and that's all they come for and they come with attitudes.'

Changing Nature of AIDS Service Organizations and the AIDS Movement

Many participants described an idealized past when AIDS organizations were passionate, volunteer-based, and responsive, and a present where these organizations seen as coldly professional, bureaucratic, and inflexible. This change, some believed, has made people with HIV/AIDS no longer feel “at home” or welcome as employees within AIDS organizations. For many, the role of activist

in AIDS organizations was more prominent a decade ago and since then, many participants observed, PHA leaders have been absorbed into the mainstream or have left the AIDS movement altogether due to frustration, illness, or burn-out.

The huge amount of turn-over in terms of staff in AIDS organizations, the people that are coming to work as paid staff in AIDS organizations are in many cases coming with the best of intentions but coming from – but this is linked to the professionalization – you are getting social workers or you are getting people who studied community work or health promotion. They are not from the communities that we are actually working with...I will speak specifically about the role of PHAs in organizations, because a lot of us aren't there anymore...So what that means for some of us who are PHAs in organizations is that we kind of feel we assert an identity that doesn't quite jive with those who are working in the organizations anymore. So we go back into the closet.

A number of participants lamented that the AIDS movement and its organizations have evolved from a grassroots movement to something more bureaucratic. In this sense, people felt that an energy and spirit have been lost.

I have been pondering the whole notion of the PHA and where that idea came from, and the notion of "the movement" and there have been various stages of having a vision of people with HIV: getting rid of the word "victim", collective organizing, confronting public policy, getting drug rights, etc. And I am wondering what the vision is now? What is it that would excite and resonate with people? And I don't know what that is.

Successful Strategies to Involve PHAs

This section details themes identified by focus group respondents related to successful strategies for increasing the meaningful involvement of PHAs.

Training and Mentoring

A number of respondents talked about how their organization valued specific skills more highly than the experience of living with HIV/AIDS. Many stressed that it would be useful to provide training to PHAs, so that they would possess the skills required for specific positions. Many participants said they felt PHAs needed opportunities to learn skills, but that this did not happen often enough.

There was a three day skills building workshop on fundraising. It was excellent, excellent and I've certainly used it myself and frankly I think anyone who took seriously what was taught over those three days would be able to put an

excellent fundraising program together if they had any imagination. But that sort of stuff, why aren't we training PHAs to fill those staff positions because there are certain skills sets you need. But again it's not rocket science.

Participants noted that groups might require certain resources to mount needed training. For example, groups from the North cited a lack of training opportunities for PHAs in smaller communities. Training opportunities were infrequent in these locations, and there were insufficient resources to allow participants to travel to them.

I will give our support staff here kudos for the work that they do, but unfortunately they don't get the same type of training as a support worker in Toronto would because we don't have the expertise here that Toronto does. They get workshops left, right and centre in Toronto. They're updating their support workers...We don't get that here. Sometimes the workers here are fortunate enough to go to one of these workshops. But sometimes they're not because they just can't afford to go to it and we don't have that up here

Participants stressed that in addition to training, having mentors was also important in building skills and confidence to do the work and to ensure the development of leadership skills.

One of the things we do in the Aboriginal community is – well we are getting older, we are not going to be around – we have to build in the mentorship process right from the beginning so that PHAs benefit from our leadership.

Building leadership and mentoring are long term investments. It takes time, resources, role models, and opportunities for practice. One respondent described an innovative effort in his agency to move a PHA into a position of greater responsibility:

One thing we actually did with one of our projects...was purposefully written in the funding proposal was that...hire a professional person to coordinate a project, and it requires a peer or HIV peer position in the second year...because the person's role is to train other people...one of the success indicators is that PHAs would be able to take on that role by the second year.

Several participants said that they had participated in training but there was no follow up to maintain their interest or use their energy and ideas afterwards. Engagement and mentorship needs to follow right away.

I think that when you do the training...There is a piece about mentorship afterwards that needs to happen. So you have the training, so what? Now what? You have to engage them right away.

Beyond training and mentoring, organizations can support PHAs in other ways. Volunteers, for example, need to be given roles that they find interesting and that use their skills. Without this, it is a setup for failure and boredom, leading to a rapid turnover of volunteers. Participants said they sometimes felt they were placed in roles because the organization needed a PHA or because it was work no one else wanted. One participant described how organizations had to be flexible and imaginative in finding good roles for new volunteers:

We have a good volunteer coordinator and I have to give credit to that. An academic came in...and we were thinking, "Wow, you are just too qualified. What are we going to do with you?" But what he did was set up a book club... There is a place for everybody.

Volunteer coordinators can play a key role in recognizing and supporting volunteers:

[We] had a volunteer coordinator who was the most amazing volunteer coordinator I've seen in my life...He knew every single volunteer's birthday. He knew their anniversaries. Every single one of them would get an individual handwritten birthday card in the mail. That's a huge thing in just boosting morale and making people feel like they are doing something good and they're appreciated.

Policy Development

Respondents stressed the importance of progressive policies within agencies to support and encourage greater PHA involvement.

One of the things that has been enormously helpful has been the policy on the inclusion and engagement of PHAs. My board adopted it as part of its policy and procedures. So that's really significant. That has meant two things that I can do: I can hire people, and our policy and procedures manual treats HIV like any thing else, long term illness with its fluctuations; and also it authorizes me to go out and actively do that, and actively recruit board and staff, and build whole capacity building programs for both, volunteers, what ever. So having that policy, there is no way that the board can in anyway say, 'no, we can't hire'...they can't discriminate in any way, and it de-stigmatizes.

Many respondents believe that hiring policies need to directly address the issue of PHA involvement.

It's a systemic issue that can be addressed if AIDS organizations had a better understanding of the value of the lived experience and make allowance for that in the hiring procedure.

It's a kind of hiring scheme, and self-disclosure and I think it's important in terms of how the hiring process and life experience and HIV/AIDS, and that it's really integrated as a substantial percentage of scoring in your hiring practice.

Succession planning was another area that was identified as needing formal policy. A comment that was repeated throughout our focus groups was that the AIDS movement had not done an adequate job of training new PHA leaders to replace previous generations.

I think the biggest failing is that we, as PHAs, we never trained anyone to come after us. We were it. We were the ones who were going to save the world and then when we all somehow got burnt out or died...

A critical component of policy development relates to issues of funding. These include the availability of long term funding rather than project grants, adequate resources for training and volunteer recognition, the availability of child care, support to cover transportation costs, and the need for more comprehensive health benefits for employees. Our findings also have implications for government policy and programs, like the Ontario Disability Support Program (ODSP), which restrict the amount of paid work PHAs can do without losing their benefits.

3

Survey of AIDS Organizations

In addition to our focus group discussions, we conducted an on-line survey of member organizations of the OAN about their policies and practices with regard to PHA involvement. The survey was based on many of the same questions that Roy addressed in his Executive Director survey. Organizations were asked to provide basic information (budget size, number of staff members, number of board members, number of clients, and number of volunteers), as well as information on the strategies they employed to ensure the involvement of PHAs, including the benefits, costs and tensions associated with this involvement.

Characteristics of Participating Organizations

In total, 30 out of 48 organizations solicited responded to our survey (62.5%). Of these, the survey was completed by 19 Executive Directors, eight managers or program coordinators, two board members (one of which was the chairperson), and one staff person.

Of the 30 organizations that responded to our survey, 17 (56.7%) were AIDS service organizations, six (20.0%) were AIDS organizations that served a specific ethnoracial or cultural community, two (6.7%) were advocacy groups, two (6.7%) were housing organizations, one (3.3%) was an HIV/AIDS program within a social service agency, one (3.3%) was a research organization, and one (3.3%) was a HIV health care facility. A basic profile of these organizations is summarized in Tables 1 through 3, which briefly outlines the organizations' budget size, number of staff persons, and number of board members.

Table 1: Annual budget size of surveyed organizations

Annual Budget Levels (CAD\$)	Number of Organizations	Percentage
< 500,000	11	36.7%
500,000 – 1,000,000	7	23.3%
> 1,000,000	9	30%
<i>No answer provided</i>	3	10%
Total	30	100%

Table 2: Number of staff in surveyed organizations

Number of Staff Members	Number of Organizations	Percentage
5 or less	8	26.7%
6 – 10	10	33.3%
11 – 15	5	16.7%
> 15	5	16.7%
<i>No answer provided</i>	2	6.7%
Total	30	100%

Range = 1 to 78; Mean = 12; Median = 8

Table 3: Number of board members in surveyed organizations

Membership Size of Board of Directors (or equivalent governing body)	Number of Organizations	Percentage
< 10	11	36.7%
10 – 12	8	26.7%
> 13	8	26.7%
<i>No answer provided</i>	3	10%
Total	30	100%

Range = 5 to 21; Mean = 11; Median = 10

Survey respondents noted having clientele ranging in number from 25 to several thousand individuals.

PHA Involvement as Staff Members

Survey respondents were asked about the number of self-declared PHA staff members presently in their organizations. Responses of the 30 organizations are as follows:

- Ten organizations (33.3%) indicated they had no staff members who were self-declared PHAs;
- Sixteen organizations (53.3%) had at least one PHA on staff, and two of these organizations (6.7%) reported having five or more self-declared PHAs as staff members;
- Four organizations (13.3%) did not answer the question, including one organization that did not provide a response citing reasons of confidentiality.

When asked whether their organization had any staff positions specifically designated for PHAs, only one respondent reported having a PHA-designated position related to public speaking and education. Another agency had a PHA-designated position in the past that was no longer available due to the discontinuation of project funding. Of the agencies that did not have designated PHA staff positions, several mentioned that they actively strive to hire PHAs whenever job opportunities become available. One respondent stated:

We have always endeavoured to hire [people] living with HIV, but recognizing that [they] face health challenges that may prevent them from being able to work and that the positions need first and foremost specific skills and experience, we do not have PHA designated positions.

Overall:

- Twenty-three (76.7%) of the 30 respondents reported having a hiring policy or equal opportunity statement that applies to, or makes reference to, PHAs; and
- Twenty-five (83.3%) reported inviting applications from PHAs when advertising for available staff positions or those related to HIV/AIDS programs within the agency.

PHA Involvement on Boards of Directors

To understand the extent to which PHAs were involved in the governance of AIDS organizations, respondents were asked to report the number of positions on their Board of Directors (or equivalent governing body) designated for PHAs as well as the number of self-declared PHAs currently serving on their Board. Responses to these questions were tallied in the form of percentages to account for the differences in the size of the board across organizations. These results are summarized in Tables 4 and 5.

Table 4: Percentage of designated PHA seats on the Board of Directors of surveyed organizations

Percentage of Designated PHA Seats on Board of Directors	Number of Organizations	Percentage
0%	6	20%
1 – 24%	9	30%
25 – 49%	5	16.7%
50 – 74%	4	13.3%
75 – 99%	0	0%
100%	3	10%
<i>No answer provided</i>	3	10%
Total	30	100%

Table 5: Percentage of self-declared PHAs on the Board of Directors of surveyed organizations

Percentage of Self-Declared PHAs on Boards of Directors	Number of Organizations	Percentage
0%	3	10%
1 – 24%	11	36.7%
25 – 49%	6	20%
50 – 74%	3	10%
75 – 99%	1	3.3%
100%	2	6.7%
<i>No answer provided</i>	4	13.3%
Total	30	100%

The majority of the agencies surveyed had bylaws that required PHA representation on their Board. While many of these organizational policies clearly outlined the minimum number or proportion of PHA-designated seats on the Board, only a few mentioned the requirement for such PHA positions and left the actual number of seats as the subject of interpretation. For example, one respondent wrote: "there is no specific number for designated [PHA] seats but the interpretation is that approximately half of the board would be the minimum." Another organization reported a policy that required its board to include individuals either living with or affected by HIV/AIDS, leaving the actual number of seats designated to either group unclear.

When respondents were asked whether they faced difficulties filling designated board positions with PHAs, of the 21 agencies that responded, 10 (47.62%) replied affirmatively. Many of the respondents who reported difficulties recruiting PHA board members were from agencies that serve a specific ethnoracial, cultural, or geographic community. PHAs from these particular regions or communities may face greater socioeconomic barriers to becoming involved at the board level. One respondent stated: "Our client populations do not tend to come on to our board due to their living situation. Although we actively recruit [them], we do not get many takers." In addition, HIV-related stigma in some communities served as a barrier for PHAs to be public about their HIV status and to becoming a board member. Another survey respondent wrote: "People do not always want to be 'declared' [about their status] and making this happen in our region is much more difficult." Similarly, one organization reported having increased difficulty recruiting youth PHAs on its advisory committee. Several organizations also mentioned that it is particularly difficult to recruit PHA board members who have skills related to organizational governance.

PHAs Involved as Volunteers

Most of the surveyed organizations reported having PHA clients involved in their organizations as volunteers. Survey participants noted volunteers ranged in number from two to 50 individuals per organization. One agency, however, mentioned that a conflict-of-interest policy of the organization disallowed clients to also work as volunteers.

Other PHA Roles

Apart from becoming a board or staff member, survey participants noted the ways that PHAs can participate in the work of their organizations as follows:

- Providing feedback on agency services and/or evaluation of services (90%)
- Sitting on advisory committees (83%)
- Peer education (76%)
- Assisting in fundraising efforts (73%)
- Administrative tasks (73%)

- Participating in agency research (73%)
- Participating in community outreach (70%)
- Assembling materials for distribution (70%)
- Peer support (63%)
- Providing practical assistance to service users (36%)

Seventy-nine percent of survey participants reported being 'very satisfied' or 'satisfied' with their agency's efforts to involve PHAs.

Organizational Benefits

A range of organizational benefits that resulted from PHA involvement were noted by survey participants. Nearly all survey participants noted that PHA involvement helped to keep their agency responsive to PHA priorities and concerns (90%). Other frequently noted benefits of PHA participation were that it:

- Provided role models for other PHAs (87%)
- Helped to reduce stigma (87%)
- Kept agencies grounded in the realities of living with HIV/AIDS (83%)
- Lead to a healthier community (77%)
- Reduced fears and myths about HIV (73%)
- Increased organizational credibility in the community (73%)
- Lead to more effective support services (70%)
- Helped keep staff and volunteers committed to the movement (67%)
- Lead to more effective prevention services (63%)
- Helped keep the organization motivated and dedicated (57%)
- Helped create a compassionate environment (57%)
- Increased the organization's credibility with funders (57%)
- It brought a greater sense of compassion (53%)

Twenty-three percent of survey participants noted other benefits of PHA involvement including that it offered PHAs an opportunity to engage with communities, provide a sense of purpose, support skill building, support self-worth, self-esteem, enable and promote independence, support learning, build leadership skills within the PHA community, and build community and a sense of ownership for the organization.

Obstacles Encountered

PHA involvement in AIDS organizations can be accompanied by obstacles. Survey participants noted obstacles their organizations faced including:

- Poor health of PHAs hampering their ability to become involved (73%)
- PHAs worrying about the disclosure of their HIV status (67%)
- Side effects of the medications hampering their ability to be involved (57%)
- PHAs not interested in becoming involved (50%)
- PHAs feeling stigmatized by coming forward (47%)
- PHA involvement was becoming too stressful (43%)
- Community attitudes leading some PHAs to worry about the repercussions resulting from their involvement (40%)
- PHA involvement being too demanding (40%)
- PHAs being seen as lacking the required skills and background (37%)
- Inadequate benefits for paid staff making it hard to hire PHAs (27%)
- PHA involvement feeling like tokenism (13%)
- The individual agency climate being seen as unwelcoming of PHAs (7%)
- There not being a great need for PHA involvement (3%)

Three percent of survey participants noted other obstacles to PHA involvement including: preferring to have a balanced life of work and hobbies, struggling with poverty-related issues such as food insecurity and homelessness, injection drug use, challenges with establishing friendships and relationships, violence, conflict with the law, low interest in doing the types of work that are part of the agency's mandate, lack of skilled mentors to support new PHAs to take leadership roles, feeling upset with the mention of HIV/AIDS, and stress for agency staff when PHAs have committed to projects and then for health or personal reasons have to stop and leave the project. Survey participants also noted that some PHAs express feelings such as that:

- Working in or volunteering for an AIDS organization feels like their lives are too focused on HIV when they are also living with the disease; and
- The situation with respect to HIV/AIDS in Canada is sufficiently under control so they do not need to be as intensively involved as they might have been in the past.

Tensions Encountered

Five organizations referred to tensions arising from not honouring confidentiality, and more specifically in relation to disclosing the HIV status of clients. Three organizations noted the lack of skills as a source of tension when, for example, varying skill levels resulted in less capacity or discomfort participating as board members, or when limited skill sets of PHAs led to issues or extra work for staff. Training, orientation, teaching GIPA principles, and chairing meetings to support everyone's involvement were noted as methods for addressing skills-related concerns.

Other examples of tensions were offered:

- A misunderstanding about the roles of staff versus volunteer PHAs (addressed through a discussion about the benefits of each role and how they can support each other)
- A perceived 'disconnect' with the PHA community when PHAs took on paid positions since, with employment, there may be a marked difference in economic status
- Reduced ability to socialize or make friends when PHAs took on volunteer and staff roles because of boundaries, stigma, and perceptions in the community
- Complications with program delivery and equitable provision of services resulted from when PHAs expressed a sense of [over] entitlement to services
- When PHAs felt that others were not considerate of their condition
- Problems resulted from an inappropriate use of power among PHA agency members, PHA board members, and staff when [an overly] strong sense of ownership was felt
- Territorial tensions arose when long-involved PHAs shut out newly involved PHAs
- When PHAs strongly expressed their dissatisfaction with an organization and its programs, tension resulted (later addressed by the introduction of an annual survey to support quality assurance and provide a more helpful way for PHAs to provide feedback)
- Difficulties for PHA staff in getting the personal support they need, which can be especially true for Executive Directors who are unlikely to turn to either their staff or board for support, (Provincial resources such as the AIDS Bereavement Project of Ontario and the Ontario Organizational Development Program were described as useful for responding to these challenges)

Successful Strategies

A variety of strategies for supporting meaningful PHA participation were described by survey participants including:

- Skills building on topics such as access to treatment
- Referring to clients as 'service users' not PHAs
- Applying GIPA principles to personnel policies
- Developing program policies, and by-laws
- Inviting PHAs to apply when recruiting staff or volunteers
- Working with respect and an inclusive approach
- Creating PHA designated staff roles and board seats
- Creating a 'limited disclosure' policy that requires PHAs to disclose to the board chair only; developing an 'accommodation' policy to ensure that individual staff's needs are supported appropriately and in a timely fashion
- Asking clients what helps them participate
- Stating the need for PHA involvement in the mission statement
- Providing lunch vouchers, reimbursement for transportation, parking, and childcare; matching skill sets to assignments and providing tutoring and support
- Clearly defining roles; offering mentorship that is structured and formalized; ensuring PHAs are in decision making roles
- Ensuring PHA involvement is integrated throughout the organization not just a designated board seat
- Providing food or nutritional supplements as appropriate to meetings/events
- Having a PHA in a paid managerial or Executive Director position sets an organizational climate that can influence greater participation

4

Discussion

The Research Team of the *Living & Serving II* Project set out to update Charles Roy's 1996 study of PHA involvement. Employing a research design that was based on Roy's study, we sought the advice of a group of experienced leaders in the Ontario AIDS movement. We asked HIV-positive and HIV-negative people who are involved in the movement about their experiences and opinions about PHA involvement, and invited representatives of AIDS organizations in Ontario to complete a survey on a range of questions relating to PHA participation. Our findings provide a status report of PHA involvement in Ontario and an opportunity to reflect on what is working and what can be improved.

While much remains consistent with Roy's findings from 1996, both our focus groups and organizational survey highlight some significant changes. An important change relates to the availability of new treatments for people living with HIV. People are now living longer, healthier lives than when Roy collected his data. As a result, our participants did not talk about their immediate health worries to the same degree as Roy's participants. Many of our respondents have returned to work – and many of those more recently diagnosed never stopped working. Further, the lives of many PHAs today are not as centered around surviving HIV as was the case prior to more effective treatments: they focus on completing their education, their longer-term career interests, their hobbies, and their relationships and may have less time and need, to participate in AIDS organizations whether as service users, staff members, or volunteers. If they are accessing services at an AIDS organization it is frequently with needs related to the social determinants of health such as income support, housing, benefits, etc.

Another change since Roy's study is the increasing recognition of the diversity of communities of people living with HIV. His study focused on specific ethnoracial communities and recognized the many challenges presented by diverse communities affected by HIV, but in both components of our study it was felt that PHA communities have become increasingly diverse – or at least that there is an increasing recognition of their diversity – over the past ten years. Our findings highlight some of the complexities that underlie GIPA principles, as our respondents' involvement in AIDS work was often shaped by factors other than HIV status, such as ethnoracial identity, gender, race, sexual preference, social class, education, history of drug use, etc. Some respondents reported being subjected to racist, homophobic or sexist attitudes and behaviours in AIDS service organizations, and many talked about how they felt alienated from organizations in which they were a minority. A commitment to PHA involvement clearly requires organizations to attend to the many social and cultural differences that exist within the community of people living with HIV, and to ensure that all PHAs are made to feel welcome to contribute.

The changing nature of AIDS organizations also has an impact on the willingness of PHAs to get involved in AIDS work. The ongoing professionalization of services means that agencies seek skilled, educated, and experienced workers for many key roles. Boards of Directors focus on issues like strategic planning and a range of governance issues; staff members focus on the provision of professional counseling or prevention services to diverse communities that are often facing complex

Public hysteria surrounding AIDS has largely disappeared, but our findings remind us how much stigma and discrimination continue to be a reality for PHAs in Ontario.

problems relating to drug use, poverty, inadequate housing, and overstretched health and social services; and, administrators respond to increasingly complex demands for accountability from funders. Time and time again, we heard how our focus group respondents were left feeling that their experiences as PHAs were not sufficiently valued or respected in the increasingly professionalized world of AIDS services. Our participants recognized the need for advanced skills and broad experience, but they nonetheless felt the lived experience of being HIV-positive needs to be more highly valued in

organizations that were established to meet their needs. Most would agree that being HIV-positive is not a sufficient background in responding to today's epidemic, but that more weight should be given to HIV status in hiring decisions and board and volunteer recruitment.

As was found in Roy's original study, many of our focus group participants, and the organizations themselves, believed that more emphasis needs to be placed on training and supporting PHAs to develop needed skills. This requires not only a commitment on the part of organizations, but additional funding and resources to create opportunities and to sustain skill development through training and mentoring. A component of training and mentoring that was not discussed in Roy's study was the importance of succession planning to ensure that new leadership is developed and long-standing veterans of the movement do not burn-out. A cadre of experienced PHAs is seen as necessary for stable and mature organizations in the ongoing work of fighting HIV, but they also require the energy and ideas that new PHAs bring to the work. PHAs need support when coming into AIDS organizations – and when moving into new roles or exiting the organization.

Public hysteria surrounding AIDS has largely disappeared, but our findings remind us how much stigma and discrimination continue to be a reality for PHAs in Ontario. This is particularly so for those from smaller communities or from closely knit ethnoracial communities in larger cities, where it is often felt that 'everyone knows everyone else's business' and where HIV/AIDS can be highly stigmatized. The stigma surrounding HIV/AIDS may not be as obvious as it once was, but it continues to shape the lives of many PHAs and their willingness to become more involved in the AIDS movement. Our findings show how PHA decisions about disclosure and participation in AIDS work are now more complex than years ago. As PHAs have increasingly focused on work and career interests, disclosure can feel risky, and involvement in AIDS work can raise unnecessary questions about their health status. People are healthier and focusing on their lives beyond their HIV infection, so they may feel that they have less reason to disclose their HIV status to others – which, in turn, can make them less likely to get involved in AIDS organizations and activism.

Closely related to issues of stigma and disclosure were participants' many concerns about confidentiality. A number of respondents worried about whether their identities and personal information would be kept private in their involvement with AIDS organizations. Several, for example, had experiences in which other support group members would talk about what was revealed in discussions, and a number expressed concern about the level of gossip they perceived in their organization. While most of these issues related to other clients and volunteers rather than staff members, concerns about confidentiality can undermine respondents' willingness to become more involved in the work of the agency, and it sometimes led clients to minimize any contact they had with the AIDS organization. Concerns about confidentiality have clear implications for organizations' efforts to provide services and encourage greater PHA involvement. Agencies need to clearly articulate policies and expectations about confidentiality, and to actively promote an organizational culture that does not tolerate breaches of privacy.

Our focus group questions asked participants to talk about issues relating to PHA involvement, but it seemed that many could only talk about their frustrations with service provision. It was as if, for some, involvement in community AIDS organizations was restricted to the role of client, despite our efforts to focus discussion on other forms of participation. It seems that if the needs of PHAs go unmet, which appeared to be the case with a number of our respondents, it is difficult for them to consider how they might contribute to the work of the organization. PHAs will be more willing and able to get involved in roles beyond receiving services when they are supported and provided the services they require. Promoting greater involvement of PHAs in the Ontario AIDS movement requires that we also continue to ensure that adequate services in place.

Findings from our survey of AIDS organizations complement and reinforce what we heard in focus group discussions. Survey findings show that over 33.3% of participating organizations have no staff members who are self-declared PHAs. In terms of representation on Boards of Directors, 66.6% of surveyed organizations have less than 50% PHA representation and 10% of organizations have no PHAs on their boards at all. Beyond staff and board roles, the findings illustrate the many ways that PHAs are involved in the work of AIDS organizations. While comparison with Roy's study is difficult, since his was a national study and the manner of analysing the data was slightly different, his study showed more than 60% of organizations having no PHA employees, and 19% of organizations having boards with no PHA membership. Quantitatively at least, things are improving regarding PHA representation on staff but staying the same, and even slipping, regarding boards of directors.

In both components of the study we focused on involvement in the community-based AIDS movement. As such, we were less able to consider the experiences of advisory committee members and staff of government, provincial and national agencies, clinics and hospitals and the private sector. We hope that future research can address PHAs involved in these settings. Another limitation was the degree of diversity in our focus groups. Although we had specific focus groups for women, ethnoracial communities, youth, injection drug users, and Aboriginal people, the numbers remain small, thus making conclusions about communities and comparisons between groups difficult. It also would have been desirable to have other groups to represent the perspectives of prisoners,

transgendered people, and other important constituencies. Further, in our organization survey, only 30 of 48 organizations surveyed (62.5%) responded despite repeated prompting from investigators. For many surveys this may be an adequate response rate as many organizations are small and have limited capacity; still we feel that we should have had a better response rate. A final limitation is that our study was Ontario-specific which makes direct comparison to Roy's national study more difficult.

Despite such limitations, our project shows how many organizations are successfully involving PHAs, and that this participation continues to have broad benefits for individuals, services, and the AIDS movement. Still in some areas, PHA participation remains modest and there are significant barriers to meaningful involvement that could, and should, be addressed through strategies at both the organizational and provincial level. An example of one such barrier is that if the major service needs of PHAs are not addressed, then their involvement in organizations, beyond the role of client, will remain impossible. In the end we take satisfaction that there is continued support for the principles of GIPA in Ontario, and hope this study will build a commitment to work to further improve PHA involvement in the AIDS movement.

5

Recommendations

A workshop of Ontario AIDS organizations' board chairs and Executive Directors was convened by the Ontario AIDS Network on January 26, 2007 to help the research team develop recommendations and a dissemination strategy for the study. After presenting the findings of both the focus group and the survey components of our study, various issues were discussed in small groups with a view to focusing on the development of specific recommendations. Some of the issues discussed included whether there was an ideal level of PHA involvement and if this can be mandated; the impact of the social determinants of health on PHA involvement; strategies to reduce stigma; skills development; organizational support strategies; and tensions within organizations.

Workshop participants agreed that the study findings showed important areas where PHA involvement could be improved and numerous recommendations were put forward. There was general consensus that no one level or type of PHA involvement should be mandated for organizations. Each agency has to determine for itself what PHA involvement, and the strategies used to achieve it, are most appropriate for them. To aid in organizational reflection on PHA involvement in their agencies, we have developed a list of questions for AIDS organizations attached in Appendix 2.

Regarding a dissemination strategy it was agreed that the final report of the *Living and Serving II* study, and executive summary, be distributed to all OAN member agencies and through the OHTN online distribution system. This will insure that the report reaches all community-based AIDS organizations plus research and policy stakeholders in the HIV sector. Further the study team will write plain-language summaries of the research to be distributed to community agencies for inclusion in newsletters, websites and communiqués.

Informed by the OAN workshop with Executive Directors and board chairs, and by discussions among the research team, we propose the following 20 recommendations. The first recommendation is around striking a permanent Working Group in the province that can consider these and

other recommendations, draft a plan for implementation and monitor PHA involvement going forward. Recommendations 2-4 are actions that encourage adoption of values related to PHA involvement; recommendations 5-17 are strategies to address barriers identified in our study; and recommendations 18-20 are strategies for long-term development of PHA involvement.

- 1) We recommend that the Ontario AIDS Bureau strike a Working Group on PHA Involvement to discuss the study findings and recommendations on an on-going basis and draft a plan for implementation of these and related measures.
2. We recommend that one of the first actions of this Working Group be to develop a set of core values related to PHA involvement and these values be printed on a poster. This poster should be distributed to AIDS organizations and displayed to all service users, board members and staff.
3. We recommend that this Working Group apply for a Canadian Institute of Health Research (CIHR) *Knowledge to Action* grant to help implementation of measures to improve PHA involvement in the Ontario AIDS movement.
4. We recommend the OAN, and its member agencies, review the International Code of Practice for NGOs responding to HIV/AIDS and be encouraged to become signatories to this Code.
5. We applaud existing initiatives that foster the training and skills development of PHAs. These initiatives include the OAN Leadership Training Program, speakers bureaus of various community agencies, the Committee for Accessible AIDS Treatment's HIV and Immigration Service Access Training Program, and the Ontario Organizational Development Program (OODP). We recommend these types of initiatives be expanded and coordinated.
6. We recommend that more AIDS organizations publish profiles of best practices around PHA involvement, as well as individual profiles of different PHA roles in the movement.
7. We recommend that all AIDS organizations engage in their own internal review of PHA participation in their individual organizations and adopt a vision of what involvement should look like and a plan to achieve this. To aid in this internal review process, we recommend organizations use this report, and the appendices: literature review, and the questions for AIDS organizations. Technical support for this review process could be provided by OODP.
8. We recommend that AIDS organizations implement yearly internal reviews of PHA involvement in their AIDS organizations.
9. We recommend that all AIDS organizations develop specific hiring policies that encourage the recruitment and retention of PHAs as staff.
10. We recommend that the Working Group on PHA Involvement identify existing templates that promote best hiring practices and in their absence develop new templates to aid organizations.
11. We recommend that all AIDS organizations develop specific volunteer policies that encourage the recruitment and retention of PHAs as volunteers.
12. We recommend that the Working Group on PHA Involvement identify existing templates that promote best volunteer practices and, in their absence, develop new templates to aid organizations.

13. Given the importance of confidentiality as a barrier to involvement, we recommend organizations ensure that adequate confidentiality policies and practices are in place and are relevant to service users, volunteers, board members and staff.
14. We recommend that the OHTN plan a study of confidentiality policies and practices in AIDS organizations and the complexities of ensuring confidentiality especially in smaller, community-based AIDS service organizations.
15. Given that stigma continues to be one of the greatest barriers to PHA involvement, we recommend that all agencies ensure that adequate policies and practices are in place to eliminate stigma and discrimination.
16. We applaud the current research on stigma and discrimination by various stakeholders and recommend their research expand to study stigma and discrimination policies and practices in AIDS organizations, especially as it relates to PHA involvement.
17. We recommend that the OAN and all relevant organizations intensify their advocacy efforts for adequate benefits and return-to-work policies for PHAs throughout the province. Such policies should recognize the episodic nature of HIV and the challenges inherent in return-to-work decisions.
18. We recommend further research be conducted on PHA involvement especially in settings beyond community-based AIDS organizations (e.g., government advisory committees and non-HIV specific agencies).
19. We recommend continued research and policy development on the social determinants of health, especially as they relate to PHA involvement.
20. We recommend an intensification of advocacy efforts to improve direct funding of AIDS services at a community level. We believe that meaningful PHA involvement will never be possible without adequate, comprehensive and well-funded community-based AIDS services.

6

Appendices

APPENDIX 1

Literature Review

Introduction

The purpose of this paper is to update the literature review conducted by Dr. Charles Roy in 1995 regarding the participation of people living with HIV/AIDS (PHAs)¹ in the Canadian AIDS movement. Where possible, the current review focuses on PHA² involvement in the Ontario AIDS movement; however, work with a national focus is included. International literature is also considered insofar as it has implications for Canada.³

The overall aim of this review is to examine the socio-political context for the current involvement of PHAs in the AIDS movement between 1995 and 2006. The extent and nature of current PHA participation, the advantages of and barriers to PHA participation, and the strategies that support PHA participation in current AIDS organizing are discussed. The paper concludes with a brief discussion of questions for further investigation.

While the involvement of people living with HIV/AIDS (PHAs) has been a vital aspect of AIDS organizing around the world, it has received surprisingly little attention from social scientists (Roy and Cain 2001; Stephens 2004). Aside from studies by Roy (1995) and Roy and Cain (2001), there is little published in the social science literature on PHA involvement in the Canadian AIDS movement. Published research has focused on PHA involvement in the education of health professionals

- 1 We will use the acronym PHA to refer to people living with HIV/AIDS. We note, however, that PHA is seldom thought in Canada to meaningfully refer to Aboriginal people living with HIV/AIDS (APHAs). We recognize that the experiences and concerns of Aboriginal people and other ethnoracial groups have differed historically from the experiences and concerns of non-Aboriginal people living with HIV/AIDS.
- 2 In the literature, use of the terms 'PHA', 'PWA', 'PWHA', and 'PLWHA' are not necessarily restricted to those who have tested positive for HIV. While it is commonly agreed that these terms refer to people living with HIV/AIDS there is some disagreement around the meaning of 'living with'. The terms are sometimes used to refer solely to those who have tested positive for HIV. At other times they are used to refer to those who are both infected with HIV and affected by it. For example, the Global Network of People Living with HIV/AIDS (GNP+) and the International Community of Women Living with HIV/AIDS (ICW) have "officially adopted the term 'PWHA' to designate people infected with or affected by HIV/AIDS. This includes people who are seropositive and the people who surround them (such as loved ones, parents and friends)" (UNAIDS 1999:1). The much touted Brazilian response to HIV/AIDS was also based on the definition of PHA as those who are infected and affected. In this paper, we use 'PHA' to refer to those who have tested positive for HIV and the term 'infected or affected by HIV/AIDS' to encompass the broader category. We have retained the use of other acronyms when referring to the original documents in which they were used.
- 3 Formal sources were located through PubMed, ScholarsPortal, and WebofScience search engines using such key words as 'PHA', 'PLWHA', 'participant involvement', 'client involvement', 'GIPA', 'community response' and 'AIDS organizing' to name a few. Searches for grey literature were conducted using Google, hiv-cbr.net and internal search functions for the lending libraries located at the Canadian HIV/AIDS Clearinghouse and the AIDS Committee of Toronto. Bibliographies from appropriate books and articles were also helpful in identifying suitable sources, as were individuals with some knowledge of the subject area.

(Solomon et al 2005), PHA activism (Silversides 2003; Brown 1997) and PHA involvement in building coalitions, networks and new organizations (Maguire et al 2004). There is a slightly larger body of work from the US, the UK and Australia, but nonetheless, the details of efforts to promote the meaningful involvement of PHAs has not been a subject of particular interest to academics.

The grey literature has been more forthcoming on these issues. Several non-government organizations (NGOs) and community-based AIDS organizations (CBAOs) have reported on PHA involvement in particular aspects of Canadian AIDS organizing. These include PHA involvement in treatment literacy and advocacy (Bresalier et al 2003), the contribution of PHAs to community-based research (Van Clieaf 2003; Casey House 2001), the involvement of PHAs in the development of policy at several levels (Ibanez-Carrasco et al 2003; Peng and Letner 2005; Jurgens 2005), and the importance of PHAs in peer prevention, education (Barker 2000) and support (Mumford 2002; AOHC 2005). The fact that community-based organizations are interested in and writing about the greater involvement of PHAs in AIDS organizing is perhaps, as Jurgens (2005) points out, implicit recognition that the current involvement of PHAs is limited.

The same might be said for PHA involvement at the international level. In recent years, we have seen a rash of studies by NGOs on the involvement of people living with HIV/AIDS in AIDS organizing. Almost exclusively, these studies have focused on understanding, implementing and monitoring the Greater Involvement of People Living with HIV/AIDS (GIPA) in the developing world (UNAIDS 1999, 2000, 2005; GNP+ 2004; GNP+ & IFRC 2004; APN+ 2004; POLICY Project 2003, 2004a, 2004b, 2005, 2006; Stephens 2004; Magaz & Hardee 2004; Horizons 2002; Cornu & Attawell 2003).

A Word on GIPA

GIPA stands for the Greater Involvement of People Living with HIV/AIDS. This term first appeared in the Declaration of the Paris AIDS Summit in 1994, in which 42 countries, including Canada, committed themselves to ensuring an effective and ethical response to HIV/AIDS through increasing participation of PHAs at all levels of AIDS organizing. The declaration did not set out a definition of GIPA nor did it define a process, in part, because the capacities and needs of each country are different and therefore require a different response. The term GIPA is used liberally in international literature but sparingly in the literature of North America. In a study of GIPA in five countries, Stephens (2004) notes that some of his respondents questioned the value of referring to the involvement of PHAs using the terminology of GIPA. He and others have noted that GIPA may be an overly bureaucratic term that is under-recognized by those in the HIV/AIDS field and altogether unrecognized by those working outside the field. We use the term here when original texts do so.

How did the Current PHA Movement Develop?

One of the most striking aspects of community and organizational responses to AIDS has been the insistence by those infected and affected to play an integral role in the decision-making that impacts their lives (Roy and Cain 2001; Cain 2002; McKibbin 2004; Miller 2003). Pushed into action by a combination of fear, indignation at government non-response to the emerging health crisis and compassion for their loved ones, first actions against AIDS were invariably taken locally by those who were most affected, and often infected, by the disease (Silversides 2003; O'Malley et al 1996). The first Canadian case of AIDS was reported in March 1982; however, prior to this, members of gay and lesbian communities in Toronto and Vancouver were already mobilizing to respond to AIDS after hearing rumors from San Francisco and New York of deadly disease among gay men (Silversides 2003; Brown 1997). Drawing on their experiences of successful activism in the gay rights and the women's health movements, gays and lesbians joined forces to advocate for and provide services to those for whom "existing health and social service organizations showed little interest in developing the necessary programming" (McKibbin 2004:9; also see Roy and Cain 2001). In other words, while the Canadian government ignored the threat of AIDS⁴ and healthcare providers reacted with fear and prejudice, those most affected by the disease – gay men and those who loved them – organized themselves to provide AIDS education, prevention and care when and where it was needed (Brown 2000; Silversides 2003; Miller 2003; Stoller 1998; Epstein 1996; Weeks 2000).⁵

By the mid 1980s, it was apparent that attempts to define AIDS as a 'gay disease' were misguided. AIDS was indeed infecting gay men in alarming numbers, but women, hemophiliacs, injection drug users, sex workers, and people of colour (particularly Haitians) were also being diagnosed with this illness that doctors knew little about (Stoller 1998; Kirp 1998). Partly in response to the changing epidemic and partly in response to continued government non-response, People with AIDS (PWA) groups began to form across the country (Barker 2000; Miller 2003) and around the globe (Hows 2004). These groups made initial attempts to define their common interests and continued to demand a say in the decisions that affected them. The 'Denver Principles', a product of the first PWA group in North America, were an early effort to promote principles of self-empowerment and to formalize PHA involvement in the global response to AIDS. The 'Montreal Manifesto', declared at the 1989 International AIDS Conference, built on this early effort and advocated for an international code of rights that would continue to advance the notion of self-empowerment (Roy and Cain 2001). By the early 1990s, it seemed that the advocacy and activism of PHAs had paid off. At the Paris AIDS Summit, 42 governments, including Canada, endorsed the principle of PHA involvement in AIDS organizing at all levels and recognized that PHA involvement was crucial to 'ethical and effective national responses to the epidemic' (UNAIDS 1999:1). This was the backdrop from which the GIPA principles, "the most enduring legacy of the Paris Declaration" (Stevens 2004:v), emerged.

4 In the early days of the epidemic, most governments took this position. The exceptions are the governments of Australia and Brazil who consulted and collaborated with affected communities from the beginning of the epidemic. These countries were able to stabilize the epidemic early on and keep it from spilling over into other populations (Hulse 1997).

5 The development of the women's health care and the consumer health movements were critical to the development of the AIDS movement. See Roy (1995) and Roy and Cain (2001) for a synopsis of the impact these movements had on AIDS organizing.

Just as the mobilization of gay and lesbian communities, the formation of PWA groups and the hard-hitting activism of groups such as ACT UP! or AIDS ACTION NOW! characterized the North American response to HIV/AIDS in the first decade of the epidemic (see Roy and Cain 2001 for a synopsis of AIDS organizing to 1998) the second and third decades are characterized by an increasingly diversified epidemic in the developed world, the introduction of highly active anti-retroviral treatment (HAART) and the 'globalization' of AIDS (Patton 2002:127).

GIPA stands for the Greater Involvement of People Living with HIV/AIDS. This term first appeared in the Declaration of the Paris AIDS Summit in 1994.

As the epidemic continued unabated into the 1990s, it affected more marginalized groups who frequently struggled with issues of poverty, substance use, mental health, homelessness, and more. Many community-based organizations were not prepared to deal with the diverse clientele who sought services, and they scrambled to develop appropriate programming. This caused tension in many organizations that led to changes in the way services were delivered (Cain 2002; McKibbin 2004). Another result of this increasing diversity was the establishment of PHA groups and community-based organizations that served particular populations of PHAs, such as Aboriginal people living with HIV/AIDS (e.g., the Canadian Aboriginal AIDS Network and the Ontario

Aboriginal HIV/AIDS Strategy), women (e.g., Voices of Positive Women and the Positive Women's Network), youth (e.g., Positive Youth Outreach), Afro-Caribbean (e.g., BlackCAP), Asian (e.g., Asian Community AIDS Services), South Asian (e.g., Alliance for South Asian AIDS Prevention), immigrant and refugee communities and prisoners (e.g., PASAN).

Following the 1996 International AIDS Conference in Vancouver, the epidemic changed again with the introduction of highly active anti-retroviral therapy. People were suddenly living longer, healthier lives with HIV, forcing PHAs and AIDS organizations to re-orient their work one more time. The focus of service provision and activism shifted from end of life issues to quality of life issues. Substance use, mental health, income security and stable housing became priority issues for many PHAs, while back to work or stay at work issues were priorities for others. Treatment advocacy (e.g., Canadian Treatment Action Council) and treatment literacy (e.g., Canadian Association for Treatment Information and Education), including microbicide and vaccine research and clinical trials, still demands a great deal of attention from PHAs and community-based organizations. Despite these ongoing needs, the numbers of AIDS activists appear to be down from previous years.

In an overview of AIDS activism in Canada, Margolese (2002) notes that Ontario AIDS activism is currently uninspired and seems to have difficulty recruiting new bodies. This may be because many of the old activists are gone and those who were diagnosed when combination therapies were available have managed to "stay at work and not make AIDS the entire focus of their lives" (2002). In contrast, Lattig asserts that AIDS activism is alive and well, however, the tactics of activism have changed. Not only does new AIDS activism rely more on technology and therefore does not always require large numbers of demonstrators, but "AIDS activism, like the epidemic itself, has gone global" (2001). International alliances, non-government organizations and PWA groups abound. PHAs are better connected and better informed than ever before leading to renewed efforts to set aside differences between communities of PHAs and to link the local to the global. For instance,

demonstrations that were once framed in national terms are now framed in international terms such as "Medication for every nation!" (Lattig 2001).

The International AIDS Conference in Durban (2000) is commonly thought to be the turning point for the 'globalization' of AIDS. While 'the north' had been aware of AIDS in Africa and other developing countries for some time, "hosting of the conference in Africa highlighted the growing disparities between the developed world, where antiretroviral therapies [were] increasingly available, and the Third World where they remain[ed] largely unknown" (Smith 2001). North American AIDS activists returned home from the conference with the realization that AIDS was a global issue that required a global response (See Gonsalves 2001 for a summary of TAC's – Treatment Action Campaign – role in changing the outlook for global HIV treatment). Shortly after the International AIDS Conference in Durban, the United Nations General Assembly Special Session on HIV/AIDS (UNGASS) convened in New York City in 2001. The outcome of this Special Session was, among other things, a renewed international commitment to the greater involvement of people living with HIV/AIDS.

What are the Advantages to PHA Participation?

There are a number of advantages to PHA involvement in AIDS organizing. First and foremost, the benefits flow to PHAs themselves. Because HIV/AIDS can be a shaming and stigmatizing illness, one of the many benefits of PHA involvement might be the restoration of a non-stigmatized identity. Involvements in AIDS organizing can neutralize feelings of shame, stigma and depression and relieve PHAs of the social isolation that often accompanies HIV/AIDS (Stephens 2004; Wingood and DiClemente 2000). It can help re-establish social relations and feelings of self-worth (Stephens 2004; Barker 2005; APN+ 2004), increase personal empowerment (Roy and Cain 2001; Ramirez-Vallez and Brown 2003), build up motivation (GNP+ 2004b), and increase independence (Meyers 2004), confidence and self-awareness (Solomon et al 2005). Increased knowledge and understanding of HIV (Solomon et al 2005), improved physical health due to access to information about care and treatment (Bresalier et al 2002; Horizons 2002), and reductions in risky behaviours (Ramirez-Vallez and Brown 2003) have also been associated with PHA involvement.

On an organizational level, PHA involvement in policy development and service delivery increases organizational credibility with other PHAs and with funders (Roy and Cain 2001; Horizons 2002). In fact, in Canada, PHA involvement is often a requirement of funding where organizations are asked to demonstrate meaningful involvement of PHAs, in particular, in the identification of need or in advisory capacities or paid positions. PHA involvement leads to more effective and appropriate services (Ramirez-Vallez and Brown 2003; Jenkins 2004; Stephens 2004; Horizons 2002) and helps keep priorities and issues in focus (Roy and Cain 2001). Since AIDS organizations and the governing bodies that fund them are predominantly staffed by people who are not HIV-positive, the involvement of PHAs who bring "a high degree of personal investment, motivation, dedication, compassion and commitment to the work" (Roy and Cain 2001:425) can remind workers of their *raison d'être* and bring a sense of urgency and groundedness to their daily tasks. It also ensures a continuity of commitment to 'the cause' inasmuch as PHAs are more likely to remain committed to

AIDS organizing than those who are neither infected nor personally affected by HIV (GNP+ and IFRC 2004).

On the societal level, PHA involvement in AIDS organizing recognizes the rights of PHAs to be involved in their own care (PHAC 2005) and gives a 'human face' to the epidemic resulting in reduced stigma and discrimination (GNP+ 2004; Solomon et al 2005; PHAC 2005). It breaks down barriers of fear and prejudice and challenges commonly held myths and misconceptions about HIV/AIDS. This makes PHAs powerful educators (Solomon et al 2005; Menadue 2005), counselors, peer supporters (Mumford 2002), policy makers and natural role models for other positive people who may not yet have found the courage to disclose or get involved in AIDS organizing (APN+ 2004).

What are the Costs of PHA Participation?

While the benefits of PHA involvement in AIDS organizing are many, they can come with a price. 'Going public' with one's status is difficult for even the most self-confident, self-affirming of individuals. Public disclosure opens the PHA to the possibility of rejection from friends, family or community, discrimination, stigma, violence and in some cases even death (CAS 2004b). Once a PHA has made this decision to become involved, the potential difficulties do not stop. AIDS organizing or work in AIDS organizations can be extremely demanding and the stress that this creates can be, in some cases, detrimental to the mental and physical health of PHAs (Mumford 2002; Roy and Cain 2001). One aspect of this stress is that PHAs who are open about their status and have taken steps to participate in AIDS organizing are often called upon to sit on multiple advisory committees or participate in multiple projects or programs. This can lead to 'burnout' if PHAs are not careful about the amount of work, paid or volunteer, they take on. In addition, once a PHA has 'gone public' he or she often becomes a role model for other PHAs, some of whom have not yet found the courage to disclose. PHAs who find themselves in this position sometimes report that they feel pressure to be 'perfect' PHAs. An extreme example of this is the peer counselor who feels that they can not admit to feelings of depression or the educator who can not admit to any degree of risk behaviour (Roy and Cain 2001). One last cost of PHA participation is the difficulty that some PHAs may have negotiating the boundaries between their work and personal lives. Taking a position in an AIDS organization, whether paid or volunteer, can compromise pre-existing relationships with both service providers and other PHAs.

What are the Barriers to PHA Participation?

There are many barriers to PHA participation in AIDS organizing that are largely dependent on the context of involvement. Twenty-five years into the epidemic stigma and discrimination remains one of the most prominent barriers to PHA participation. Fear of 'being found out' still prevents PHAs from disclosing their status or becoming associated with an AIDS organization (CAS 2004b). This is true in all settings but is particularly so in non-urban areas where HIV is less common and Aboriginal or other ethnic communities where HIV/AIDS is highly stigmatized (Ramirez-Vallez & Brown 2003; APN+ 2004; GNP+ 2004; Van Clieaf 2003). While AIDS organizations do not require

disclosure of HIV status as a condition of involvement, in some places the stigma of simply being seen at or associated with an AIDS organization is strong enough to keep PHAs away.

Another aspect of discrimination that acts as a barrier to involvement is the discrimination that occurs between groups of PHAs. For example, several authors (GNP+ and ICW 2005; Jurgens 2005;

The increasing diversity of the PHA population also requires careful attention on the part of organizations to refrain from adopting a 'one-size-fits-all' approach to programming that does not adequately address the needs of any particular population.

CAS 2002) have noted the absence of the voice of injection drug users within the PHA community. Others have noted the difficulty of bringing various PHA groups together to participate in the same event (Menadue 2005), largely because of ethnoracial differences in affected communities. The increasing diversity of the PHA population also requires careful attention on the part of organizations to refrain from adopting a 'one-size-fits-all' approach to programming that does not adequately address the needs of any particular population (Horizons 2002).

The health status of a particular PHA can also be a barrier to involvement. Remis et al (2004) estimated that only 63% of people living with HIV/AIDS in Ontario are aware of their serostatus. This implies that many people are or will be diagnosed late in disease progression and some will already have an HIV-related illness. Poor health clearly reduces a PHA's ability to work in the field and to be involved in AIDS organizing at the level of service delivery or policy

development (APN+ 2004). However, a similar situation exists for long-term survivors. Because AIDS is an episodic illness, even when PHAs recover from a health set-back, they may be understandably reluctant to give up the security of disability benefits or health insurance from previous employment to take full or part-time work in an AIDS organization (Roy and Cain 2001:427; CAS 2004). Even at the level of volunteer work, PHAs may be reluctant to commit to a program if they feel their health is or will be compromised. For example, work in an AIDS organization can be extremely demanding and the stress that this creates can be, in some cases, detrimental to the mental and physical health of PHAs (Mumford 2002; Horizons 2002). As Roy and Cain (2001) point out, this leaves AIDS organizations in the difficult position of wanting to accommodate PHAs but having limited financial and human resources to do so. Another health-related issue that impacts the involvement of PHAs in AIDS organizing is the success of anti-retrovirals. Prior to the introduction of anti-retrovirals many PHAs went on long term disability after diagnosis and were available to join advisory committees or sit on boards. However, PHAs who have been diagnosed while anti-retrovirals have been available are less likely or able to go on long term disability and they continue to work at jobs that may not be in the field of HIV/AIDS. In this case, ironically, improved health may lessen the pool of available PHAs to participate in AIDS organizing (Margoese 2002).

A related finding by Williams et al (2005) also has implications for the greater involvement of PHAs, particularly at the level of AIDS organizations. The study found that users of Ontario community-

based AIDS organizations are, on self-report, significantly less healthy, less able to sustain normal activities and more often depressed than those who did not use these services. They reported physical disabilities more often and were a great deal poorer and more reliant on government income supports. These findings suggest that making the transition from service user to service provider will be challenging for clients of AIDS organizations.

Another organizational barrier to PHA participation in AIDS organizing includes 'tokenism' (GNP+ and IFRC 2004). In part because PHA involvement is looked upon favorably by funders, PHAs who sit on community advisory boards sometimes feel like 'tokens' – like they are filling a chair but their voice is not really being heard. At times the decision-making is not truly shared between PHAs and professionals, and at times the boards they sit on do not have any significant decision-making powers (Roy and Cain 2001). At other times still, PHA participation on community advisory boards falls largely to a limited number of PHAs who already do this kind of work. This lack of commitment to building the capacity of PHAs, especially those from marginalized communities, means that the same PHAs often sit on numerous committees while Aboriginal people, Asians, Afro-Caribbeans, women, youth and people who use injection drugs are not frequently involved (Jurgens 2005). This leads to an unfortunate situation in which a PHA from one group is left to speak on behalf of all PHAs from all 'at risk' groups. It also leads to 'burnout' for these individuals as they struggle to keep up with the demands of involvement on multiple boards or committees. These kinds of divisions led Roy and Cain (2001) to speculate that PHA participation may be an issue of social class as much as an issue of gender, culture or a particular identity.

In the second decade of AIDS organizing, the pressure to 'professionalize' organizations and services has created tensions in some community-based organizations (Miller 2000; McKibbon 2004; Cain 2002) and created a barrier to full PHA participation in others. While early AIDS organizations often felt like 'home' for many PHAs – in part because they helped to create them and in part because many of their friends were also involved in the organization – as AIDS organizations matured and they struggled to serve increasingly diverse populations, the demands on staff and volunteers increased (Hows 2004, McKibbons 2004). This meant that positions previously held by PHAs were increasingly given to non-PHAs with more formal training in specific areas and those PHAs who were involved sometimes required extensive training to meet the demands of the job (APN+ 2004). In some cases, this also resulted in "judgmental and paternalistic attitudes about PLHA and their involvement by professional health and social workers" (Horizons 2002:9).

There are also a number of barriers to the greater involvement of PHAs in AIDS organizing that need to be addressed at the movement level. Numerous authors have noted the discrepancy between GIPA in principle and GIPA in practice (Stephens 2004; GNP+ 2005; UNAIDS 1999; Horizons 2002; APN+ 2004). Despite promotion of GIPA principles at national and international levels, there is relatively little commitment to involving and integrating positive people in programs providing AIDS care, support, prevention and education. (APN+ 2004:5).

That PHAs themselves are largely the ones who push the GIPA agenda is a testament to the above, as is the lack of GIPA monitoring mechanisms. At the international level, monitoring mechanisms

were never established to measure the progress of GIPA or GIPA related activities (Stephens 2004)⁶ but they were established for the Declaration of Commitment on HIV/AIDS that was signed in 2001. However, despite the commitment to involve PHAs in AIDS organizing set out in this declaration, and despite the recognition that there is a positive correlation between HIV prevalence and involvement of PHAs at all levels of policy-making and programming, involving PHAs is not included as an indicator in the UNAIDS guidelines on the construction of core indicators for the Declaration. "In fact, the guidelines only recommend that HIV positive people are consulted" (ICW 2005). At the Canadian national level, it can also be said that no monitoring mechanisms exist that might hold governments accountable for the promises and commitments they have made for the involvement of PHAs in AIDS organizing at all levels.

What are the Strategies that Support PHA Participation?

Strategies that support PHA participation range from those that are specific to particular kinds of involvement, such as community-advisory board member (Cox et al 1998; Poindexter & Lane 2003; Mamary et al 2004), educator (Solomon et al 2005) or peer researcher (Barker 2000), to more general strategies that promote PHA involvement across the board (Roy and Cain 2001; Stephens 2004; UNAIDS 1999). PHAs are ideally involved at all levels of AIDS organizing, from service user to decision-maker, and hence, it is important that strategies to increase PHA involvement address participation at each of these levels. It is equally important that strategies at one level are supported by strategies at higher levels. For instance, a strategy of making PHAs feel welcome in an AIDS organization might be supported at the organizational level by a policy of non-discrimination, which in turn, is supported at the provincial or federal level by non-discrimination legislation. The first three sets of strategies outlined below are strategies that organizations can implement to increase PHA involvement. These are followed by recommendations to governments on how they can support organizations that aspire to involve people living with HIV/AIDS in AIDS organizing.

HIV can be devastating to the mental, physical, spiritual and emotional health of an individual. Therefore, strategies are required to strengthen the personal resources and coping mechanisms of PHAs so they can manage their lives effectively while living with HIV (APN+ 2004). This might mean providing or enabling peer support groups to assist PHAs in coming to terms with their diagnosis (Wingood and DiClemente 2000), or providing financial or material resources, such as food or public transit tickets, to aid PHAs in meeting the demands of daily life (Horizons 2002; Mamary et al 2004). It might mean empowerment workshops, increasing self-esteem, or addressing issues of mental health or substance use. It might also mean building treatment literacy, nutrition literacy, or basic awareness of their legal and human rights (UNAIDS 1999). Respecting PHAs' privacy and confidentiality is essential at this level, as is the promotion of a positive and non-discriminatory environment (Horizons 2002; UNAIDS 1999; Mamary et al 2004).

Increasing the involvement of PHAs as service providers, be it as employees or volunteers, requires a different set of strategies. At this level, PHAs might benefit from training and on-going support in public speaking, advocacy, organizational management skills, peer counseling or peer prevention

(UNAIDS 1999). HIV-negative staff and management might benefit from training and orientation to ensure that myths and misconceptions about HIV/AIDS are dispelled and that the political and organizational will exists to create varied opportunities for PHA involvement (Horizons 2002;

Another organizational barrier to PHA participation in AIDS organizing includes 'tokenism' (GNP+ and IFRC 2004).

Cabassi 2004). Networking with other organizations and PHA groups will foster PHA involvement and continue to build PHAs' confidence and capacity (Horizons 2002; Cabassi 2004), and organizations should ensure that a diverse range of PHAs are involved and that "workplace policies and practices recognize the health and related needs of PHAs" (Cabassi 2004:41-42). For example, marathon meetings lasting more than eight hours

might be considered too exhausting by PHAs if not counter-balanced by appropriate down-time or opportunities to socialize (Mamary et al 2004).

Strategies that support PHA involvement at the level of policy and decision-making include further PHA training in communication and presentation skills and skills for organizing and conducting policy dialogue (UNAIDS 1999). This might mean providing technical support, for example, in HIV/AIDS treatment or human rights advocacy or it might mean mentoring support for policy involvement (Stephens 2004). It might also mean building research capacity to enable PHAs to carry out their own research, design and implement their own programs and be an equal partner in the design of policies that will protect their rights and improve the quality of their lives (APN+ 2004; Meyer 2004). Discussion among decision-makers should be in everyday language, avoiding as much as possible scientific or policy jargon that might not be familiar to PHAs (Meyer 2004). When seeking PHA representatives, organizations should recruit more than one PHA (Meyer 2004), ensure that PHAs and networks are accountable to their members and that processes are in place to ensure that the views of their members are presented (Cabassi 2004; Jurgens 2005).

Organizations should ensure that policies and practice provide for PHAs to receive information that will enable them to participate, prepare and give meaningful input on program or policy decisions before these decisions are made: this means involving PHAs in the planning stages of interventions (Meyers 2004). Finally, organizations "should fund or advocate for funding for PHA groups to ensure they have resources to build capacity and empower others within their own networks" (Cabassi 2004:41-42; see also Jurgens 2005).

While organizations have immense power to increase the participation of PHAs in AIDS organizing, governments also have a significant role to play in "creating an enabling environment that supports involvement" (Cabassi 2004:41-42). For example, Jurgens (2005:48) recommends that the Public Health Agency of Canada provide funding to establish a national association of people living with HIV and that they provide funding for a plan to increase PHA involvement in the national response to HIV/AIDS that is designed by and for PHAs. He also advocates for funding for a variety of initiatives that would be designed to remove barriers and increase participation of PHAs in AIDS organizing.

To What Extent are Canadian PHAs Participating and What are they Doing?

As noted above, the extent and nature of PHA involvement in the Canadian AIDS movement has been of little interest to academics since Roy (1995). While some authors have concerned themselves with the mechanics of PHA participation in particular aspects of AIDS organizing, such baseline questions as 'how many', 'where' and 'what are they doing' have largely gone unasked. As a result, there is no way of knowing the true extent to which PHAs are currently involved in Canadian or Ontario AIDS organizing or what those who are involved are doing. In a discussion paper prepared for the Canadian Strategy on HIV/AIDS, Young suggested that "fewer PHAs are now involved in HIV/AIDS policy development" than in previous years (2000:5), yet he offers no evidence to substantiate his claim.⁷ However, we do know from the existing literature that PHAs are involved to some degree at every level of Canadian AIDS organizing.

The hierarchical model on the next page, the pyramid of PHA involvement, was developed by UNAIDS (1999) to help move GIPA from principle to practice. It is instructive here to help us conceptualize how PHAs are participating and at what levels. The model represents increasing levels of PHA involvement, with the highest level representing complete application of the GIPA principle. Ideally, GIPA is applied at all levels of AIDS organizing. In Canada, PHAs are involved at every level of this pyramid, although the numbers and proportion of each is unknown. At the lower levels of the pyramid, PHAs perform valuable functions as 'target audiences', 'contributors' and 'speakers' on a regular basis; PHA involvement at these levels is a common and expected element of Canadian AIDS organizing. At the mid to upper levels of the pyramid, PHAs also perform valuable functions as program 'implementers', 'experts' and 'decision-makers'. PHA involvement in the education of health professionals (Solomon et al 2005) or as peer supporters and counselors (Mumford 2002) are examples of PHAs as 'implementers' while PHA participation on community advisory boards and in HIV prevention in Ontario speaks to the 'expert' level of the pyramid. As Guenter et al have noted, "community input has become the established norm in the development of HIV prevention programs" (2001: 29; see also Guenter et al 2005).

At the 'decision-maker' level, PHAs have skillfully leveraged social and cultural capital to build bridges between communities, to found organizations (Maguire 2004) and to create the political will necessary to mobilize communities and governments to mount an adequate response to HIV/AIDS (Peng and Lettner 2005). As founding members, activists, Executive Directors and senior program managers of various AIDS service organizations, PHAs have also been instrumental in shaping the Canadian AIDS movement in general (Silversides 2003; Miller 2003). While it is true that some of these roles offer more opportunity to determine the impact of HIV/AIDS on the lives of PHAs than others, all are legitimate forms of PHA participation that contribute in their own way to an effective national response.

6 In fact, of those attending the UN session on GIPA in New York, not all were happy – some felt GIPA was a "white-wash" and didn't go far enough to recognize things like diversity, etc.

7 Young lists Roy's (1995) study as one from which he drew information for his report. It could be that when he made this comment he was relying on Roy's finding that "just over one-fifth of board members in community-based AIDS organizations are PHAs. But fewer than one in ten people employed by a community-based AIDS organization in Canada are infected with HIV" (1995:68).

A Pyramid of PHA Involvement⁸

This model and others have been designed to measure progress towards the greater involvement of people living with HIV/AIDS (GIPA) and do so by measuring the degree to which PHAs are able to influence and direct policy. That examples from the Canadian AIDS movement are easily found for all levels of this framework is encouraging, but it does not mean that we, as Canadians, can rest on our laurels. As Jurgens points out, "while there is a strong commitment to greater and more meaningful involvement of people living with HIV in the Canadian response in principle, in practice much remains to be done" (2005:13-14). This is affirmed in *Leading Together, Canada's new action plan on HIV/AIDS (2005)*. By asserting the need for more PHAs to be meaningfully involved in policy and decision-making processes, the plan implicitly recognizes that current PHA involvement at these levels is limited.

Decision-makers: PLHA participate in decision-making or policy-making bodies, and their inputs are valued equally with all the other members of these bodies.

Experts: PLHA are recognized as important sources of information, knowledge and skills, and participate – on the same level as professionals – in the design, adaptation and evaluation of interventions.

Implementers: PLHA carry out real and instrumental roles in interventions, e.g., as carers, peer educators or outreach workers. However, PLHA do not design the intervention or have little say in how it is run.

Speakers: PLHA are used as spokespersons in campaigns to change behaviours, or are brought into conferences or meetings to 'share their views' but otherwise do not participate. (This is often perceived as 'token' participation, where the organizers are conscious of the need to be seen as involving PHAs but do not give them any real power.)

Contributors: Activities involve PLHA only marginally, generally when the individual affected by HIV/AIDS is already well-known. For example, using an HIV-positive pop star on a poster or having relatives of someone who has recently died of AIDS speak about the person at public occasions.

Target audiences: Activities are aimed at or conducted for PLHA or address them en masse, rather than as individuals. However, PLHA should be recognized as more than a) anonymous images on leaflets and posters, or in information, education and communication campaigns; b) people who only receive services; or c) as 'patients' at this level. They can provide important feedback, which in turn can influence or inform the sources of the information.

(Adapted from *From Principle to Practice: Greater Involvement of People Living with or Affected by HIV/AIDS*. UNAIDS, 1999)

8 This model was revised by Stephens (2004) for *Out of the Shadows*, an in-depth analysis of PHAs in policy development. It was resurrected by Cabassi (2004) in *Renewing Our Voice: Code of Good Practice for NGOs Responding to HIV/AIDS* and by Jurgens (2005) in his review of the greater involvement of injecting drug users in the response to HIV/AIDS. In a study of 17 NGOs Horizons and the International AIDS Alliance (2002) came up with a simplified, evidence-based framework similar to the one above. Categories of PHA involvement include: access to services (similar to 'target audience'); inclusion (roughly equivalent to 'contributors' and 'speakers'), participation (roughly equivalent to 'implementers' and 'experts') and greater involvement which is the highest level of PHA participation (roughly equivalent to 'experts' and 'decision-makers'.)

What is Left to Do?

As might be expected, the above review raises a number of questions for further investigation. Paramount among them is what has changed in AIDS organizing from the time of Roy's review? Are we seeing new barriers to PHA participation in AIDS organizing, perhaps as a result of longer, healthier lives; an increasingly diverse PHA population; or a focus on the global epidemic? Are we seeing new strategies that support PHA participation at the local level? Regional level? National level? International level? What role do governments play in this? Twelve years after the GIPA principles were documented, do PHAs feel that they are still making progress towards greater involvement in AIDS organizing, or has the movement stagnated? Is there a sense from PHAs that their 'place at the decision-making table' is secure, and if so, what does that mean for future involvement of PHAs? Is there a relationship between the policy and practice of GIPA? Do these issues differ according to the PHA group? What exactly do we mean by 'greater involvement'? Is the term 'GIPA' known to PHAs and those who work with them? Or is there a more appropriate term to use in the Canadian context? Do Canadian PHAs feel connected to the global AIDS movement? These questions and others might be worthy of future investigation.

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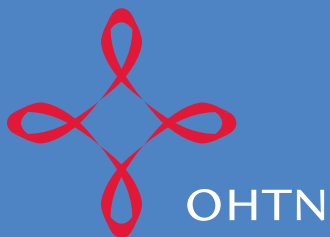
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APPENDIX 2

Questions for AIDS Organizations

- 1 How are PHAs involved in your organization currently?
- 2 How should the level of PHA involvement vary in relation to factors such as size of organization, mandate of organization, regional issues, and diversity of the population served?
- 3 What are potential roles where PHAs could be involved in your organization?
- 4 What barriers, benefits, costs and tensions identified in this study relate to your organization?
- 5 What factors need to be considered in relation to determining the optimal level and type of PHA involvement?
- 6 What policy development or other activities are required to entrench ideal levels and types of PHA involvement?
- 7 What strategies would address the social determinants of health as it relates to PHA involvement?
- 8 What strategies and tools would reduce stigma, support PHAs to feel less fearful, and support social inclusion?
- 9 What strategies and tools would promote confidentiality and other aspects of PHA safety?
- 10 What practical supports can be offered to support PHAs to have appropriate skills for volunteering on Boards of Directors, working as staff, or otherwise contributing and offering leadership in the movement?
- 11 What can be done to strengthen the capacity to provide strong benefits packages and address other practical health-related needs for PHA employees?
- 12 Which strategies are best developed at the organizational level, and which require support and investment from other players such as government, policy makers, and funders?
- 13 How might additional research enable policy development or other activities toward supporting greater involvement of PHAs?



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