

**Report on the Ontario AIDS Network (OAN)
Future Directions Project Think Tank:
Recommendations for Renewal of the
OAN PHA Caucus and Programs**

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Table of Contents

| | |
|--|----|
| Acknowledgements..... | 1 |
| Executive Summary | 2 |
| Setting the Stage | 3 |
| Purpose of the Future Directions Project Think Tank..... | 3 |
| Results of the Future Directions Project Research..... | 5 |
| Opportunities..... | 7 |
| Reflecting on the Current OAN PHA Caucus Format | 7 |
| Other Organizational Models | 9 |
| Looking Ahead..... | 12 |
| Re-Visioning the OAN PHA Caucus | 12 |
| Recommendations of the Future Directions Project Think Tank..... | 15 |
| Next Steps | 16 |
| Appendix 1: Future Directions Project Research Report..... | 18 |
| Appendix 2: Future Directions Think Tank Agenda | 30 |
| Appendix 3: Flip Chart Notes, Day 1 | 32 |
| Appendix 4: Flip Chart Notes, Day 2 | 34 |

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Executive Summary

The Future Directions Project was undertaken in 2005 as part of the Ontario AIDS Network's (OAN) strategic planning process. The goal of the project was to address the purpose of the OAN PHA Caucus (Caucus), its linkages to the OAN, and the low participation of people with HIV/AIDS (PHAs) in Caucus. The initial phase of the Future Directions Project was a province-wide consultation with OAN and Caucus stakeholders. This represents the most comprehensive and extensive research conducted since the inception of the OAN PHA Caucus over a decade ago. Given the evolving circumstances of PHAs in Ontario, a clear need for changes in Caucus was identified.

The Future Directions Think Tank was convened in June, 2005, to review the results of the research and recommend a new model for PHA participation in the OAN. Delegates to the Think Tank included the PHA Caucus Steering Committee members, and others from diverse backgrounds and regions in Ontario. Together with the research data, delegates reviewed several organizational models employed by other PHA forums in North America. Consensus was reached that the Caucus is in need of a more focused mission, concentrating on the development of PHA leaders in Ontario.

The recommendations from the Future Directions Think Tank are that Caucus should be wound down in 2005 and replaced by an OAN PHA Leadership Forum, whose goal would be to develop a highly involved and informed PHA community in Ontario, thereby enabling people with HIV/AIDS to realize their potential as community leaders. Delegates recommended that the report of the Think Tank be widely circulated, and that a working group be established to develop a strategic plan for implementing the Leadership Forum. Among other things, this working group will address issues related to timelines, funding, future of the Steering Committee, and PHA community engagement in the strategic planning process.

Setting the Stage

Purpose of the Future Directions Project Think Tank

The Ontario AIDS Network (OAN) is a province-wide coalition of community-based AIDS service organizations (ASOs) providing a variety of supports to persons with HIV/AIDS (PHAs). The OAN PHA Caucus (“Caucus”) was formed over ten years ago to establish educational programs, provide advocacy and ensure that PHAs are actively and effectively participating in all decision-making processes of the OAN and its member agencies. Caucus has approximately 300 members, and is represented by an elected steering committee consisting of members from each of the four regions of Ontario. Two seats on the Board of Directors of the OAN are reserved for members of the Steering Committee.

During 2004, the OAN engaged in a strategic planning process, culminating in the presentation of a Draft Strategic Plan at the Membership Meeting in November of that year. At that time, the membership expressed concern that the plan did not sufficiently identify the role of Caucus, nor the structural and collaborative relationships between Caucus and the OAN. There were also concerns that participation in Caucus meetings had dwindled over the years and that participation by PHAs from Toronto was very low.

The OAN membership therefore requested that the OAN examine the current role of Caucus and its relationship to the OAN, determine barriers to PHA participation, and identify future directions. The OAN obtained funding from the Public Health Agency of Canada in support of this work, now known as the Future Directions Project.

The Future Directions Project Think Tank was convened as one element of this project. It followed a research component, undertaken in the spring of 2005 (see the following section for a summary of the research, and Appendix 1 for the complete research report).

The purpose of the Think Tank was to review the results of the research component and use these data to make recommendations for a new model for PHA participation in the OAN.

The meeting was held over two days in June, 2005, in Toronto, Ontario (see Appendix 2 for the meeting agenda). Delegates to the Think Tank were selected based on a diversity of expertise, experience, and geography, and included the ten members of the OAN PHA Caucus Steering Committee. The recommendations that emerged from this Think Tank have been compiled into this report and will be shared with all stakeholders.

During the opening remarks, delegates were told that the process over the two days would be open and flexible, and that efforts would be made to ensure everyone in the room was included. The GIPA Principles (Greater Involvement of People Infected and Affected by HIV/AIDS) were cited as an important foundation for the work of the OAN and the Caucus. Also acknowledged was the contribution of Charles Roy, who argued that the involvement of PHAs legitimizes ASOs (*Living and Serving: Persons with HIV in the Canadian AIDS Movement*).

*The process of change is
always a threatening one.
It takes courage and
strength even to say that
change needs to happen*
-Charles Roy

The context provided for the Future Directions Think Tank was that for the thousands of people known to be diagnosed and living with HIV/AIDS in Ontario, much has changed in the years since Caucus began. As with any organization, change in structure or mandate are necessary to ensure the organization remains relevant and useful to the people it serves. Delegates were reminded that while the process of change is difficult and takes courage, it is ultimately rewarding. To facilitate this, delegates were encouraged to be creative and focus on possibilities rather than limitations and to make decisions in order to set a blueprint for the future.

The questions posed to delegates for the meeting were,

- What should the OAN's focus be with respect to the Caucus?
- How can the Caucus provide leadership?
- How can PHAs be supported and included?

Results of the Future Directions Project Research

Delegates received copies of the report, *Future Directions Project: a Report on the Findings of the Research Component* (Appendix 1), prior to the meeting. The results were summarized in a presentation given by Lea Narciso followed by a discussion.

The research solicited the thoughts of PHAs in Ontario and Executive Directors (EDs) of OAN member organizations. Respondents were asked what their prior participation in or contact with the Caucus had been, if any, and what role they thought it should play in the OAN.

The results overwhelmingly confirmed the need for change. EDs indicated that they do not often hear from the regional representatives of Caucus. PHAs and EDs reported that both the mission and the role of Caucus are unclear, and that it **seems to lack direction, purpose, and concrete action**. Gaps were also identified including the orientation of

“Research is an opportunity to find out what we might not have known, and to document what we do know”.

-Lea Narciso

new Caucus members, meeting facilitation, providing sufficient scholarships to attend meetings, diversity of Caucus participants, and the relevance of Caucus.

Respondents suggested that Caucus support such activities as peer networking, education and information sharing, skills building, leadership development, and advocacy. In addition, they suggested that in moving forward, the Caucus should include better communications and dissemination of information, a commitment to greater diversity, formal mentorship activities, and clear links to the OAN that would both encourage PHAs to participate and enable their voices to be heard within the OAN.

The presenter pointed out that the research report does not recommend a new direction, but that it does provide an opportunity to learn and document what was not known. Judging from the responses, it seems that **the roles, responsibilities and actions of those who participate in Caucus are neither clear nor visible**. Participants discussed the expectations placed on Caucus participants, whom these participants represent and methods and means of reporting back to their communities and respective ASOs. Overall, there was a sense that **Caucus is considered ineffective** and not representative of the people it is meant to serve.

Opportunities

Reflecting on the Current OAN PHA Caucus Format

Following the discussion outlined in the previous section, Think Tank delegates engaged in a dialogue focused on the strengths, weaknesses and needs of the current Caucus format (see Appendix 3 for flip chart notes). They considered how these could be transformed into opportunities for the renewal and eventual improvement of Caucus.

The strengths identified focused on the commitment and will of OAN member organizations to maintain a Caucus and to give a voice to PHAs in Ontario. Delegates felt there is a great deal of **passion** within Caucus for the support it offers. It is grounded in **strong values** and provides a forum for dialogue and **communication**, both among PHAs and between PHAs and ASOs. The joint meetings that have taken place and the opportunities presented for **collaboration** with the OAN were cited as important. The **leadership** that exists, both within the Caucus and among the staff supporting it, was also identified as a strength.

The reputation of Caucus precedes it – people are being advised not to go by their ASOs, support workers and physicians.

-Think Tank Delegate

In discussing the weaknesses of the present Caucus structure, three themes emerged. The first was **funding**: namely, the level of funding has not kept pace with increasing costs and levels of interest of PHAs in participating in Caucus, nor with the ever-increasing agenda of Ontario PHAs. As such, delegates felt the agenda of Caucus should be more focused. The second theme was **accountability**. Delegates noted that without a system to measure success, there could be no transparency around the activities of Caucus, making it difficult to secure new funding. The lack of accountability lead to questions regarding the legitimacy and reputation of Caucus. Delegates also discussed the scholarship program, and whether those who attend Caucus on scholarship should have responsibilities for reporting back to their ASOs or communities.

The third theme was **inclusiveness and diversity**. There were strong feelings that Caucus has been unwelcoming for some, particularly people who attend for the first time or who are newly diagnosed. This is manifest in the use of jargon, which newcomers may not understand, and in fragmentation into sub-groups (e.g., injection drug users, women, long-term survivors) causing formation of cliques and discrimination of Caucus' own members. This has prompted a number of ASOs to recommend against PHAs participating in Caucus.

Reviewing the themes identified, delegates noted several areas of change within Caucus, and framed these as opportunities. The Future Directions Project itself was seen by delegates as a chance to begin with a clean slate, to **renew the mission, goals and expectations** of Caucus. Revisiting the goals also would present an opportunity to **develop indicators of success**, in order to improve the accountability and credibility of Caucus to both PHAs and OAN member organizations. Several concerns related to representation indicated a drive to **clarify roles and responsibilities** in order to ensure

We should be willing to buddy-up in hotel rooms, to save costs so more of us can come to Caucus.

-Think Tank Delegate

that the full diversity of people who have HIV/AIDS in Ontario is both heard and empowered.

Delegates identified areas in which Caucus could **develop mentorship** (for example, educating PHAs on specific issues and governance processes) and **provide skills training** (for example, public speaking, report writing, or media relations). It was also suggested that mechanisms be explored to better **communicate with stakeholders** on the needs of PHAs as well as the mission and activities of Caucus. Responding to the research conducted for Future Directions, delegates suggested that Caucus **use data** to increase the relevance and value of the information it communicates. Finally, delegates cited several ways to **improve meeting structure**, such as coordinating Caucus meetings with other group's events in order to reduce travel costs and increase participation by under-represented groups.

Other Organizational Models

To assist delegates in conceiving a restructured PHA Caucus, several models of PHA forums currently operating in North America were presented. Please refer to the summary chart of organizational models provided on page 11, and to the flip chart notes in Appendix 3.

The **OAN PHA Caucus** and the **Canadian AIDS Society (CAS) PHA Forum** were most familiar to delegates in the room, and discussion focused primarily on details related to governance and representation.

Entre-Nous, a new Quebec-based initiative organized by COCQ-Sida, provides education and peer support to PHAs. Annual meetings include a series of workshops and networking opportunities for personal development. Delegates noted that the focus in this model seems to be on medical issues, such as concerns related to treatment, insurance, co-infection, loss, etc. There is little information in this model related to the social determinants of health, such as housing and employment, which delegates felt to be especially important for PHAs in today's climate

The **HIV Advocacy Network**, based in San Francisco, provides a forum for community organization and advocacy. The Advocacy Network provides information to over 1 000 members, via periodic bulletins and action alerts, demonstrating opportunities for legislative action. It also provides some education, tools for advocacy and issues-based action items. It is the only one of the models presented that has membership of not only PHAs, but to those affected by the epidemic. Delegates questioned whether HIV status is important to participation in a PHA forum. Delegates also observed that the model largely assumes a strong base of existing advocacy skills among PHAs, which may not necessarily be the case in Ontario.

The **Leadership Training Institute**, based in New York State, provides workshops in which PHAs train other PHAs in core leadership skills, encouraging participants to become effective leaders in their own communities. Training is provided through a series

of successive modules. In order to participate, PHAs must set learning objectives, identify specific goals for application of their skills, and report on how the skills they acquired helped them to achieve their goals. Delegates observed that this model represents a focused approach, and does not try to be “all things to all people.” It is also a long-term approach that invests in individuals with the hope that they will then re-invest in their own peers and communities through leadership or passing on their knowledge and skills. The process of setting individual goals and reporting on progress appealed to delegates as a means to measure success. Moreover, this model exemplifies ways in which PHAs can contribute to the organization of their choice (not only ASOs) and participate in their community, as well as being supported by it.

The group discussion of the organizational models gravitated toward the mission and goals of each of the models presented, rather than the structures (membership, frequency of meetings, governance, etc.). Several delegates remarked that they could not address structural issues prior to coming to an agreement on the **purpose**

of Caucus. Delegates therefore agreed to modify the meeting agenda by having a group discussion of the purpose of Caucus prior to breaking into small groups to consider specific organizational models.

“We’re putting the cart before the horse – how can we choose a model before we decide what we want Caucus to do?”

-Think Tank Delegate

Future Directions

| | Participation | Sponsor | Purpose/Focus | Meetings | Governance |
|--|---|---|---|--|---|
| Ontario AIDS Network (OAN) PHA Caucus | All PHAs residing in Ontario eligible | Public Health Agency of Canada, Ontario division | Education, advocacy, and participation in OAN decision-making | 2-3/year, 40-50 participants Some subsidisation | Elected steering committee of 10 members; 2 on OAN Board 1 full-time staff person Voting: those present; no quorum and no decision-making authority |
| Canadian AIDS Society (CAS) PHA Forum | All PHAs residing in Canada eligible | Health Canada, plus corporate and private donations | Networking and skills building Developing into a national voice for PHAs | Annual, 80-90 participants Some subsidisation | No dedicated staff or steering committee Elects PHA reps to CAS Board, by region Voting: those present |
| Entre-Nous | All PHAs residing in Quebec eligible | Coalition of Quebec Community Organizations working in the fight against AIDS (COCQ-Sida) | Networking, education and information (mostly medical) for PHAs | Annual, 300 PHAs | Not applicable |
| Leadership Training Institute (LTI) | All PHAs residing in New York state eligible | NY State and the Ryan White Foundation | Leadership development, empowerment, goal setting | Several workshops/ year, attended by total of 110 PHAs | Not applicable |
| HIV Advocacy Network | PHAs and others "affected by" HIV/AIDS residing in northern California eligible | San Francisco AIDS Foundation, Public Policy Department | Advocacy for legislative action | Annual, plus district meetings and other training seminars 1,000+ members | |

Looking Ahead

Re-Visioning the OAN PHA Caucus

Think Tank delegates engaged in an open discussion of the purpose of Caucus (see Appendix 4 for flip chart notes). Since Caucus was first formed, **situations and circumstances of PHAs have changed**. Some felt that PHAs are not being heard in policy development issues. Others identified that more sophisticated skills are often required to act on the issues of concern. Delegates agreed that Caucus needs to find ways of meeting not only the current but future needs of PHAs in Ontario.

Examples of roles the Caucus could assume included: networking and support; information sharing; skills building; education; a forum for discussion of issues; and a common voice for PHAs. As the list of possible roles of Caucus grew, it became apparent that **there is a need to prioritize activities**; resources are limited and Caucus cannot be “all things to all people”. In making such a decision, delegates noted the following three points. First, the services provided by other PHA organizations should be kept in mind to avoid a duplication of efforts. Second, the results of the research should be taken into account as these data reflect the visions of those whom Caucus has a mandate to serve. Finally, the priorities identified in the recent federal and provincial strategies on HIV/AIDS should be taken into account including a focus on policy development, leadership development, and knowledge translation.

While differences were acknowledged across the province with respect to access to support services, there was general agreement that Caucus is not an ASO and therefore its main function should not be to provide networking and peer support. In a similar vein, delegates felt that Caucus is not an appropriate forum for provision of life skills, as this is more appropriately provided by ASOs. Both peer support and life

“We are losing ground as PHAs in the policy development arena. We should leave life skills to ASOs, and focus instead on leadership”.

-Think Tank Delegate

skills were recognized as important by-products of a PHA organization, but delegates agreed that **Caucus should have a more focused and tangible goal.**

Many ASOs have encouraged PHAs to become involved in advocacy as well as in organizational leadership and decision-making. However, many delegates felt they and

Caucus should empower PHAs to effect change by providing them with the information and skills necessary.

-Think Tank Delegate

their peers did not possess the skills necessary to take part in such activities. The development of leadership skills therefore began to emerge as an important focus for Caucus. For example, skills could be taught related to public speaking, communicating with the media, participating in boards of directors or committees, taking minutes, writing grant applications and reports,

and holding meetings with political leaders. (See Appendix 4 for flip chart notes on aspects of leadership and specific leadership skills to be taught.) Caucus could thus **empower PHAs by providing the information and skills necessary to effect change.**

Delegates remarked that PHAs are people with valuable skills and experience to share with each other and to contribute to a variety of organizations. Those with more developed leadership skills could continue to be involved in Caucus as presenters, teachers or mentors, and in this way could both give back to the community and further develop their own skills as educators and mentors.

It was observed that this focus on leadership training suggested a new and innovative vision and mission for Caucus. Delegates were reminded that they were not charged with developing a new strategic plan. However, general consensus was reached among delegates to re-state the purpose of the OAN PHA Caucus as **the development of PHA leaders in Ontario who represent PHA issues to government, media and ASOs.**

Delegates then worked in small groups to answer the following questions:

- What should be the components of the new OAN PHA Caucus?
- Who should be involved?
- When should this happen?

Detailed responses to these questions can be found in Appendix 4. The group discussion that followed focused on recommendations for the future of Caucus, presented in the following section.

Recommendations of the Future Directions Project Think Tank

Delegates to the OAN Future Directions Think Tank agreed on a few recommendations to bring forward to all of the stakeholders who participated in the consultation, and to the OAN PHA Caucus meeting in July. The recommendations are:

- 1. That Caucus should be wound down in 2005, and replaced by a new entity known as the OAN PHA Leadership Forum, with a focus on supporting the development of HIV positive leaders.*
- 2. That the report of the Think Tank should be circulated to stakeholders including OAN member organizations and to all PHAs on the Caucus mailing list.*
- 3. That a working group should be established to develop and implement a strategic plan for a leadership training program, based on the New York Leadership Training Institute model, with the following suggestions:*

***Name:** OAN PHA Leadership Forum*

***Vision:** The OAN PHA Leadership Forum will enable people with HIV/AIDS to realize their potential as community leaders.*

***Goal:** A highly involved and informed PHA community in Ontario*

Several additional issues were identified for consideration in moving this work forward. There were varying opinions regarding **timelines**, and how quickly the transition should be made from Caucus to a leadership forum. Delegates agreed that there should be opportunity for **discussion** of the recommendations, although there were mixed opinions on the scope of the consultation, especially given the research already done by the OAN through the Future Directions Project.

Staff recommended that the Steering Committee should continue during the transition period, in light of the fact that terms of office continue until November. Moreover, it was suggested that some Think Tank delegates participate in the **working group**.

Finally, **funding** was identified as a concern. While some felt that a new, more focused approach would be appealing to potential funders, there remained reservations regarding the sustainability of a leadership forum.

Next Steps

This report will be circulated to all stakeholders of the OAN PHA Caucus during the summer of 2005, and it will be a focus of discussion at the OAN PHA Caucus meeting scheduled for late July, 2005.

Appendices

Appendix 1: Future Directions Project Research Report

**Future Directions Project:
A Report on the Findings of the
Research Component**

**Prepared by Lea Narciso
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June 2005**

Table of Contents

| | |
|--|----|
| Acknowledgements..... | 22 |
| List of Acronyms | 22 |
| 1. Background | 23 |
| 1.1. Rationale for Project | 23 |
| 1.2. Research Component | 23 |
| 2. Data Collection..... | 23 |
| 2.1. Survey of PHAs on OAN PHA Mailing List | 23 |
| 2.2. Survey of OAN Member Organizations' Executive Directors | 24 |
| 2.3. Focus Group Discussions | 24 |
| 3. Findings..... | 25 |
| 3.1. Relevance | 25 |
| 3.2. The Case for Change | 25 |
| 4. Strategies for Change | 30 |
| 5. Next Steps | 31 |

Acknowledgements

This report is a summary of the Future Directions Project consultations with community members across Ontario. The contents of this report are drawn from these consultations and, as such, this is an ideal time to acknowledge people's contributions so far.

The Ontario AIDS Network and the OAN PHA Caucus Steering Committee would like to thank:

- the people with HIV/AIDS in Ontario who contributed their time and ideas to participating in focus groups and completing surveys;
- the executive directors who thoughtfully completed surveys;
- the OAN PHA Caucus Program Director, Thomas Egdorf, for providing support with the development of the surveys and question guide and other logistical details; and
- OAN member organizations that facilitated many of the logistical components of the project.

List of Acronyms

| | |
|-------------|---|
| APHA | Aboriginal People with HIV/AIDS |
| ASO | AIDS Service Organization(s) |
| GIPA | The Greater Involvement of People Infected and Affected by HIV/AIDS |
| GTA | Greater Toronto Area |
| MSM | Men Who Have Sex With Men |
| OAN | Ontario AIDS Network |
| PHA | People with HIV/AIDS |
| PHAC | Public Health Agency of Canada |

1.0 Background

1.1 Rationale for Project

At the November 2004 Ontario AIDS Network (OAN) Annual General Meeting, the membership of the OAN requested that the proposed strategic plan be amended to better define the relationship between the current OAN People with HIV/AIDS (PHA) Caucus and the OAN. The membership approved the revised mission of the OAN: “The Ontario AIDS Network is a network of people with HIV/AIDS, AIDS service organizations and AIDS service programs that works collectively to advance social justice for people infected, affected or at risk of HIV/AIDS and to improve their health and quality of life.”

To address the questions raised by the membership of the OAN about how Caucus relates to the OAN’s organizational objectives, the OAN created a province-wide consultation to identify barriers to PHA participation; strategies to overcome these barriers; and a plan of action.

In January 2005, the OAN received funding from the Public Health Agency of Canada (PHAC), Ontario Region to initiate this process of examining the role of the PHA Caucus and looking towards future directions. As such, the goal of the Future Directions Project is greater participation and inclusion of PHAs in the OAN and its member agencies in Ontario.

1.2 Research Component

To date, the Future Directions Project has consulted with stakeholders from across the province of Ontario. Between February and April 2005, the Project conducted:

- a survey of executive directors of OAN member organizations;
- a survey of PHAs on the OAN PHA mailing list;
- focus group discussions with PHAs affiliated with OAN member organizations in the Greater Toronto Area (GTA); and
- a focus group discussion with members of the OAN PHA Caucus Steering Committee.

This final report outlines themes found in both the surveys and focus groups and will be a starting point for further discussion and consultation. Findings will be reported at the OAN Future Directions Project Think Tank (June 2005) as well as at the next PHA Caucus meeting (July 2005).

2.0 Data Collection

2.1 Survey of PHAs on OAN PHA Mailing List

The OAN PHA Programs Director maintains a list of PHAs in Ontario interested in receiving information about the OAN, the OAN PHA Caucus and other relevant events in the province. When we conducted this research, there were 265 people on this mailing list. In March, 2005, a two-page survey (Appendix A) was sent by mail with a regular information package to everyone on this list, along with a stamped return envelop. 14 % (n=38) of the surveys were returned.

At the conclusion of the self-administered survey, respondents were asked to provide demographic information. 82 % (n=31) of respondents indicated that they are male and 11 % (n=4) female.¹ 32 % (n=12) of respondents were from Toronto. The average age of respondents was 44 years (range: 26 to 73

years). 68 % (n=26) of respondents indicated that they are gay, 13 % (n=5) straight and 5 % (n=2) bisexual. When asked their ethnocultural affiliation 61 % (n=23) indicated that they are Canadian; 5 % (n=2) African; 3 % (n=1) South Asian; and 3 % (n=1) Latin.

2.2 Survey of OAN Member Organizations' Executive Directors

In March 2005, a survey was sent electronically to the executive directors of all OAN member organizations (Appendix B). 49 executive directors received the survey and we received a response rate of 57 % (n=28). Responses from executive directors from Toronto-based ASOs (n=15) were similar to responses from executive directors from ASOs across Ontario (n=13).

2.3 Focus Group Discussions

Between February and April 2005, 9 focus group discussions were conducted in the GTA. The first focus group discussion was a pilot focus group with the 8 members of the OAN PHA Caucus Steering Committee.ⁱⁱ In total, 71 PHAs participated in the focus group discussions which were held in partnership with a number of OAN member organizations. Member organizations that partnered with the OAN assisted with the recruitment of participants, coordination of logistics and, in some cases, co-facilitation of the focus group discussions. Focus group discussions were held with the support of the following member organizations:

- 2-Spirited People of the 1st Nations;
- Africans in Partnership Against AIDS (APAA);
- AIDS Committee of Toronto (ACT);
- Voices of Positive Women;
- Asian Community AIDS Services (ACAS); and
- Alliance for South Asian AIDS Prevention (ASAP)

These organizations were selected to ensure broad representation and consultation with diverse communities including:

- Women;
- People from East and Southeast Asia;
- Aboriginal peoples;
- People from South Asia;
- Women and men from HIV-endemic regions;
- Men who have sex with men; and
- PHAs who work in AIDS service organizations (ASOs).

Demographic data were collected with all focus group participants excluding the pilot focus group with the OAN PHA Caucus Steering Committee members. Of the 63 focus group participants for whom we collected data, 46 % (n=29) identified as women, 52 % (n=33) as men and one as transgendered. All participants indicated that they live in Toronto, Markham, Scarborough or Brampton. The mean age of participants was 38 years (range: 28 to 50 years). Participants indicated their sexual orientation as: 38 % (n=24) gay, 54 % (n=34) straight and 8 % (n=5) bisexual. When asked to indicate their ethnocultural affiliation, participants indicated the following: African (n=18); French Canadian (n=2) and Canadian (n=3); Aboriginal, Métis, Cree, Mohawk (n=8); Jewish (n=1); Hindu (n=2); Muslim (n=2); Indian (n=3); Caucasian (n=4); Guyanese (n=2); Latin (n=2); European (n=2); and East and Southeast Asian including Chinese, Korean, and Pilipino (n=8).

3.0 Findings

From all of the data collected for this consultation, findings are presented in three sections: Relevance; The Case for Change; and Strategies for Change. The first section, Relevance, demonstrates the importance of not only a forum for PHAs in Ontario but the relevance of the OAN PHA Caucus in particular. The second section, The Case for Change, clearly demonstrates why change is needed. The third section, Strategies for Change, presents ways of improving the OAN PHA Caucus according to focus group participants and survey respondents.

These sections capture both the challenges experienced by the OAN PHA Caucus and, importantly, the opportunities that exist to enhance the role and functioning of the OAN PHA Caucus along with the level of engagement, participation and diversity of PHAs involved in the OAN PHA Caucus.

3.1 Relevance

Relevance of a provincial forum for PHAs

PHAs and executive directors who responded to the surveys believe that an OAN provincial forum for PHAs is both important and relevant. Although there is a response bias in any survey (i.e. the people who responded to the survey are likely the most engaged or interested in the OAN PHA Caucus), 84 % (n=32) of the people who responded to the PHA survey indicated that a PHA forum was either very relevant or somewhat relevant to them. Asked how relevant a provincial forum is to the work of their organization, 46 % (n=13) of the executive directors responded that it is very relevant or somewhat relevant. Only 22 % (n=6) indicated that a PHA forum was not relevant or not at all relevant to their work and 32 % (n=9) indicated that they did not know.

Relevance of the OAN PHA Caucus

The relevance of the OAN PHA Caucus specifically was clear: 64 % (n=18) of executive directors indicated that they believe there is still a need for the OAN PHA Caucus. This is supported by the frequency with which executive directors ensure PHA representation at OAN PHA Caucus meetings. When asked how many times their organization had sent a representative to an OAN PHA Caucus meeting, 44 % (n=12) indicated they had sent a representative 10 or more times, 48 % (n=13) between 1 and 9 times and only 7 % (n=2) had never sent a representative. Ultimately, this report supports one focus group participant's statement that "the PHA Caucus should exist but it needs to be reconstituted."

3.2 The Case for Change

What is evident based on both the focus groups and the surveys is that the OAN PHA Caucus as it currently exists is ripe for change. Feedback during this consultation was very candid yet, coupled with the findings related to its relevance and importance in the HIV/AIDS movement in Ontario, the future of the OAN PHA Caucus is promising.

Limited reach

One telling measure of the need for change is the number of focus group participants who had never heard of the OAN PHA Caucus and/or had never attended OAN PHA Caucus meetings. Excluding the focus

group participants from the OAN PHA Caucus Steering Committee (n=8), of the other 63 focus group participants, 84 % (n=53) had never attended a meeting. This number indicates not only that the Caucus has limited reach but that the Caucus has limited reach within the diverse communities represented at the focus group discussions. Many focus group participants talked about not finding out about the OAN, the OAN PHA Caucus and its meetings even though most were connected with OAN member organizations. In Toronto, where the majority of PHAs live and where the focus groups were conducted, the vast majority of participants had never heard of Caucus. Toronto has many support services for PHAs and it may be the case that the current format of the PHA Caucus with its emphasis on support services or organizational development has little to interest or offer Toronto PHAs.

Relationship between ASOs and OAN PHA Caucus

The issue of communication between AIDS service organizations (ASOs) and the OAN PHA Caucus was highlighted in the survey of executive directors. When asked how frequently they hear from or contact their regional OAN PHA Caucus representative, 68 % (n=19) said never. One Caucus Steering Committee member also expressed his frustration about the lack of a relationship between ASOs and the Caucus. He said that when he started on the Steering Committee, he sent a letter of introduction (as a regional representative) to every ASO in his region yet he received no responses. As one executive director wrote: "...the idea of a caucus is a good one and should not be lost but there is a need for the structure and the reporting process back to the membership to be improved."

"Barking into the Wind"

What really underpins the need for change, however, is the frequent discussions in the focus groups and comments in the surveys about the lack of a clear mission of the OAN PHA Caucus. The lack of clarity in terms of the role of the PHA Caucus and its relationship not only to the OAN but its member organizations was particularly evident in the focus group with the OAN PHA Caucus Steering Committee. While the Steering Committee members, as leaders of and representatives for the PHA Caucus, felt that PHAs needed a "good reason" to participate, they had a difficult time articulating what that good reason should be. Yet the need for change was obvious to one Steering Committee member who felt that the Caucus must "offer something to PHAs other than frustration, lack of respect, debate and confrontation."

For many of the focus group participants who had heard of but not attended Caucus meetings, the OAN PHA Caucus' reputation preceded it. Participants had heard that Caucus meetings were filled with strife and, accordingly, refrained from attending meetings. One PHA survey respondent who had attended Caucus meetings focused on what he felt was the lack of efficacy of the Caucus: "Would I as a [PHA] engage my life energy in an exercise that would have no impact on the livings of persons living with HIV/AIDS? Would I participate in an organization that might make my health more not less precarious for the enormous amount of stress it would bring into my life?"

Several executive directors noted this lack of an articulated purpose. One executive director wrote: "...the Caucus could be used for positive impact but it seems to have lost its sense of purpose and does not have a clear goal and plan to achieve the goal(s)." Another wrote that there is not a "clear understanding or purpose of Caucus: who they represent; what they are responsible to bring back."

With its lack of a clear mission, it follows that respondents to both the surveys and focus groups often indicated that the experience of participating in PHA Caucus meetings was frustrating. According to one executive director, for those PHAs that have attended PHA Caucus meetings: "Many express that it is a stressful experience focused on complaints rather than positive commitment... [and they] don't feel as though any real work is accomplished" and another wrote that from their experience, members of their

organization “hate the complaining of PHAs that have been attending for many years and feel it is a waste of time attending.” One focus group participant likened PHA Caucus meetings to “barking into the wind.” And perhaps these are not new problems. One focus group participant attended a PHA Caucus meeting several years ago and then again recently. He claimed that not much had changed: it was “the same people, the same issues with no direction, no mandate.”

Divergent Roles

This lack of a clear role is not surprising when we consider responses to the question in both the surveys and focus groups about what role the PHA Caucus should play. Responses reflect the full spectrum from PHA Caucus as a forum that addresses individual needs to a forum that addresses issues at a community, regional and/or provincial level. One issue across the focus groups and in the surveys was that the PHA Caucus has to be seen to “actually do something.”

In the survey of PHAs, respondents indicated the following priorities for the PHA Caucus:

- 79 %: peer networking and support
- 68 %: information sharing
- 63 %: skills building
- 55 %: advocacy and informing the work of the OAN

Some survey respondents who had attended PHA Caucus meetings felt that “Caucus is geared to support/networking which I do not rank as a high need for myself” as a way of explaining why they no longer attended meetings.

In the survey of executive directors, respondents indicated what they felt were the priority roles for the PHA Caucus:

- 79 %: peer networking and support and information sharing
- 75 %: leadership development ⁱⁱⁱ
- 71 %: skills building and advocacy
- 54 %: guiding the work of the OAN

One executive director wrote: “...actively recruiting PHAs with skills and/or capacity to be leaders would be needed. The OAN PHA Caucus and AIDS movement overall in Canada has stagnated. Partially because we continue to assign positions of leadership to the same PHAs. Others who are not in the ‘clique’ have been left out and long since moved along for lack of support.”

When asked about what they thought would be the most appropriate role for the OAN PHA Caucus, there was a great diversity of opinion from focus group to focus group. Responses from focus groups can be grouped into four areas. Focus group participants felt that PHA Caucus should be a forum for:

1. Information and Education

All focus groups discussed providing information and education as an important role and a wide range of topics identified included: treatment issues (what’s new; side effects; procurement for people without coverage); employment issues (how to find employment; coping with employment and HIV); immigration status and HIV; legal rights for PHAs (or, as one participant put it: “mixing with people without HIV”); disclosure issues; health and nutrition; financial assistance; pregnancy and HIV; harm reduction; mental health; accessing services; housing and

how to access subsidized housing across Ontario; issues for long-term survivors; issues for people who are newly diagnosed; and HIV and hepatitis C co-infection.

2. Skills Building

Skills building was highlighted during a number of focus groups and skills included: leadership development and how to be a leader; board and governance skills (i.e. professional development tools for PHAs to get involved on boards of directors); how to implement GIPA (The Greater Involvement of People Infected and Affected by HIV/AIDS) principles; how to run a support group; and public speaking.

3. Socializing and Networking

Some focus group participants emphasized the importance of socializing as part of the PHA Caucus. People suggested social functions like a boat cruise or a dance. Other suggested incorporating opportunities to hear other people's personal stories and life experiences. Others emphasized the role of peer networking. For example, according to a focus group participant, the PHA Caucus could provide opportunities for Aboriginal people with HIV/AIDS (APHA) to network, especially those APHAs who are little ASOs themselves.

4. Advocacy

Particularly in the focus group with PHAs working in ASOs, an emphasis was placed on the potential advocacy role that the OAN PHA Caucus could play. As one participant in this focus group said: "there is too much about living with HIV not about being proactive" and "we complain about issues but we do not know how or where to complain." Other focus groups also alluded to this role when they asked questions such as: "is there a place for PHAs to go to say there are problems? to ensure accountability [of ASOs to PHAs]?" and "where do we complain if we have a problem [at an ASO]?" It was felt by some participants that the PHA Caucus could be a forum for defining the issues that are important to PHAs in Ontario and to then instigating change. Participants also talked about the OAN supporting the PHA Caucus where Caucus expresses the issues and the OAN "acts as the voice provincially."

Orientation and mentorship

The need for orientation and mentorship was noted frequently in focus groups and surveys. Asked about barriers to participation at the PHA Caucus, one executive wrote: "Our clients...do not feel welcome, there is no mentorship for new participants and they do not feel that they understand the process or that the issues discussed are relevant for them." As the only focus group participant from Asian Community AIDS Services (ACAS) who had attended a PHA Caucus meeting said: "The first time there I felt awkward. I hardly knew anyone." And another focus group participant discussed the challenges of navigating her way through a PHA Caucus meeting since meetings and meeting materials were not presented in "lay terms." All of these comments point to the need for orientation and mentorship for new participants to the PHA Caucus.

The importance of orientation and mentorship was also discussed at length in the focus group with the OAN PHA Caucus Steering Committee. Steering Committee members felt that people who were new to the Steering Committee should be provided with an orientation to the history of the OAN, the OAN PHA Caucus and their processes. They also saw the need for mentorship for new Steering Committee members by a seasoned Steering Committee member.

Facilitation

The facilitation of PHA Caucus meetings was addressed by several respondents. One PHA survey respondent wrote: “I would suggest having a strong facilitator...to assist PHAs due to the many emotional issues that can impede the delivery of very important items.” Others pointed to the need for a facilitator to ensure that people are included and to manage situations “when someone is freaking out or upset” at a PHA Caucus meeting.

Diversity

One focus group talked about how “the landscape of HIV has changed” with more diverse groups of people being affected yet this diversity is not reflected in either the PHA Caucus meetings or its Steering Committee. While acknowledging the good work of the PHA Caucus, an executive director wrote: “While PHAs have worked hard to sustain the Caucus, it remains a pretty closed group of individuals who can speak for themselves but not all PHAs” and another highlighted the lack of incorporation of diversity: “[PHA Caucus] does not allow for a diversity of PHA experiences i.e. women, employed, straight, racially diverse.”

These sentiments were echoed by focus group participants and by one of the four women who completed the PHA survey. One focus group participant said that she felt that there was an atmosphere of “what are you doing here...this is not about you” while the survey respondent wrote about the resentment she feels “from some members when women’s issues or issues around diversity are brought up.”

This lack of diversity creates a vicious cycle. As a support worker who joined in on a focus group with her clients stated: “I don’t encourage clients to go to the [PHA Caucus meetings]. I wouldn’t put them through that because the experience is not positive.”

Representation

The question of who should attend and participate in the PHA Caucus was raised in the focus group discussion guide and in the surveys. 92 % of respondents to the PHA survey and 68 % of executive directors indicated that the PHA Caucus should remain open to any PHA in Ontario. 8 % of respondents to the PHA survey and 21 % of executive directors said membership should be restricted to PHA members of OAN member organizations.

Disclosure

Fear of disclosure was not discussed in any of the focus group discussions nor was it highlighted as a barrier to participation in the surveys of PHAs. However, several comments about disclosure were made by executive directors. One executive director wrote: “Our clients are children and families. Most of the families are very fearful of anyone knowing their HIV status and avoid situations where their status might be disclosed” and another wrote: “Many of our clients are quite nervous about disclosure [of their HIV status] and very afraid of being outed.” For PHAs who participated in the focus group discussions and PHAs on the OAN PHA mailing list who responded to the survey, perhaps disclosure was not a significant barrier. Presumably these respondents may have already addressed this issue and, as such, other barriers were more pressing.

Language and Interpretation Services

The issues of language and access to interpretation services have a profound impact on some communities’ abilities to participate in the PHA Caucus. This impact is illustrated by one executive

director who wrote: “Some clients who do not speak English as a first language do not feel as though they have voice and equal power in the [PHA Caucus].”

Further, the lack of availability of interpreting services was mentioned in several focus groups. People discussed the need for interpretation services at PHA Caucus meetings and the importance of making people aware that interpretation resources are available. Some participants also noted that materials distributed by the OAN and the PHA Caucus are only available in English and are out of reach for a number of PHAs who do not speak English.

Cost and Scholarships

While costs of attending PHA Caucus meetings and inadequate scholarships provided by the OAN were cited frequently as barriers to participation, especially in the PHA survey, limited detail was provided. Respondents wrote that decisions around scholarships to attend PHA Caucus meetings are problematic and that continuity is a problem as scholarships are available for someone one year but not the next. One person wrote that “the priorities for scholarships put gay men last after first timers, youth, women, etc.” This issue of the “politics of demographics within the scholarship process” was mentioned a number of times.

Location

Some focus group participants and survey respondents felt that the location of PHA Caucus meetings in Toronto presented a challenge. One person suggested that the PHA Caucus consider having meetings in a different city as a retreat for Toronto-based PHAs. Another suggested that distance is a great concern and the PHA Caucus should have separate regional caucus meetings once a year rather than having all four regions converge several times a year in Toronto.

4.0 Strategies for Change

Ideas for the role of the OAN PHA Caucus varied from a forum that provides information and resources to individuals with HIV/AIDS to a forum with a focus on social justice and advocacy. It is an ongoing challenge to determine whether Caucus should exist to provide support for individuals or to create organizational and policy change at the provincial level. Questions arise such as:

- How is the focus of the PHA Caucus work connected with the work of the OAN and its member agencies?
- Is peer support and personal growth the objective or an outcome of our work together?
- What role and responsibility does the OAN and the PHA Caucus have in helping to support the development of HIV Positive leaders in the AIDS Service Organizations of Ontario?

While this consultation did not provide a clear direction for the PHA Caucus, a number of ‘good ideas’ emerged from the data that were collected including strategies to enhance communication about PHA Caucus and to increase and broaden participation. Some of the ideas generated by the focus group discussions and surveys included:

- A communications strategy including a pamphlet for PHA Caucus, regular PHA Caucus newsletters, information available in English, French and perhaps other languages and availability of interpretation services;

- A focus on designating people on the Steering Committee and/or seasoned PHA Caucus participants to act as resources to orient new participants;
- A commitment to providing mentorship for new Steering Committee members to equip members with skills;
- A strategy to ensure “buy-in” to the PHA Caucus from member ASOs and for the OAN to play a role in terms of encouraging ASOs to support PHA involvement in the PHA Caucus;
- A strategy to disseminate information from the PHA Caucus to local ASOs and communities;
- A commitment to greater diversity at PHA Caucus meetings, on PHA Caucus Steering Committee including designated seats on the Steering Committee, for example;
- Providing opportunities to appeal to diverse interests of PHAs and accommodating varying needs;
- Consider resurrecting sub-caucuses that used to exist, i.e. the women’s caucus; and
- Consider holding meetings outside of Toronto.

5.0 Next Steps

The Future Directions Project and the research component in particular have been received as a hopeful, positive step forward. As one executive director wrote: “We are glad that you are soliciting feedback from the OAN membership. [Our] clients have usually been underrepresented at the PHA Caucus. We very much appreciate the opportunity to provide feedback to change this trend and make the process more inclusive.”

In the words of a focus group participant, while it is “good to acknowledge that things are not working I hope that people are open to change.” The next steps in the Future Directions Project will certainly invite change. The focus will be on creating a new model for an Ontario PHA forum by integrating some of the strategies highlighted by research participants and ensuring greater diversity in whatever format is decided upon. To this end, the OAN and the OAN PHA Caucus Steering Committee will host a Future Directions Project Think Tank in June 2005 and a meeting of the OAN PHA Caucus in July 2005. These discussions will shape recommendations to create a new model for PHA participation and to better define the relationship of the OAN and the PHA Caucus.

Notes:

- ⁱ The numbers do not add up to one hundred percent if there were people who did not respond to the question.
- ⁱⁱ The OAN PHA Caucus Steering Committee has a total of 10 seats who are elected by the PHA Caucus: 2 co-chairs (who also sit on the OAN Board of Directors) and 2 representatives from each of the 4 OAN regions (central, south west, south east, and north). At the time of this focus group, there were 2 vacancies on the steering committee.
- ⁱⁱⁱ The “leadership development” option was only available on the list of roles for the OAN PHA Caucus provided in the Executive Directors’ survey. This survey was administered after the PHA survey and the inclusion of leadership development was important to add based on feedback from the focus group discussions.

Appendix 2: Future Directions Think Tank Agenda

Agenda
OAN PHA Caucus and Programs
Future Directions Project
Think Tank
June 23 & 24, 2005
Ramada Hotel and Suites
300 Jarvis Street, Toronto, Ontario

| |
|---|
| Thursday, June 23: Where are we? |
|---|

| | |
|-----------------|--|
| 12:30 – 1:30 pm | Lunch and Registration |
| 1:30 – 1:45 pm | Welcome and introductions Thomas Egdorf and Joseph Van Veen |
| 1:45 – 2:00 pm | Working Together Facilitator |
| 2:00 – 2:15 pm | Why are we doing this project and what is the role of the Think Tank? Rick Kennedy and Steve Harris |
| 2:15 – 3:15pm | Future Directions Project: Consultation Process and Findings Lea Narciso |
| 3:15 – 3:30 pm | Break |
| 3:30 – 5:25 pm | Reactions to what you have read and heard Facilitator |
| 5:25 – 5:30 pm | Wrap Up: Tomorrow is about the future Facilitator |

Friday, June 24: Where are we going?

| | |
|------------------|---|
| 8:00 – 8:30 am | Breakfast |
| 8:30 – 8:45 am | Welcome Facilitator |
| 8:45 – 10:15 am | Presentation of Organizational Models for PHA Inclusion <ul style="list-style-type: none">• OAN PHA Caucus• COCQ-Sida• New York Institute• San Francisco• Canadian AIDS Society |
| 10:15 – 10:30 am | Break |
| 10:30 – 12:00 pm | Break Out Session Into 3 Groups to Discuss: <ul style="list-style-type: none">• What is the purpose of the PHA Caucus?• How can Caucus represent the voice of the more than 15,000 people who have been diagnosed HIV Positive in Ontario?• Are OAN PHA programs meant to “fill the gap” for PHAs who don’t have /are not affiliated with an ASO in their area?• What is feedback from our peers telling us:<ul style="list-style-type: none">○ about Caucus?○ about PHA Programs ? |
| 12:00 – 12:45 pm | Lunch |
| 12:45 – 1:45 pm | Large Group Report Back Facilitator |
| 1:45 – 3:15 pm | Building an OAN model Facilitator |
| 3: 15 - 3:30 pm | Wrap Up and Evaluation |

Appendix 3: Flip Chart Notes, Day 1

STRENGTHS

- Strong mission, values, vision, goals and objectives
 - Staff of steering committee
 - Resilient
 - Will of organizations to have a caucus
 - Focus groups reached new audience
 - Joint steering committee / Board meetings
 - Core of competent individuals who know the history, continuity
 - Capacity of those individuals in issues regarding diversity, ability to represent the community and give it voice
 - Potential: common goals, ability to connect (2-way) between ASOs and PHA caucus – interface between individuals and organizations
 - Inclusive of those “present”
 - Improved board / caucus communication
 - We want to do outreach
 - Dialogue, creativity in problem solving
-

WEAKNESSES / THREATS

- Lack of agenda, workshop choices
 - We can't do everything
 - Meetings only in Toronto
 - Acronyms
 - Action plan, strategic plan
 - Sharing of information: lack of communication, unwillingness
 - Perceptions regarding legitimacy:
 - Buy-in
 - Representation
 - Tangible action
 - Lack of accountability
 - Lack of funds
 - Scholarships and participation
 - Deserving of reputation
 - Cliquish, old guard
 - Representation: “we are only a few of many”
 - We stigmatize ourselves, are unwelcoming to newcomers
 - Fragmentation – divided in diversity
 - Meeting structure: Rob's rules create power imbalances, particularly for newcomers
 - Lingo
 - Language of ‘political correctness’ often excludes the people we try to include – two way street between ASOs and caucus delegates
-

NEEDS / OPPORTUNITIES

- Improve ways to hear voices → empower members to make voices heard
 - Piggy back on events organized by other organizations as a way to bring in under-represented groups
 - OAN support for other organizations
 - Research: use data to increase relevance, value of information
 - Accountability, performance indicators
 - Reach out to new potential members – outreach
 - Renew credibility by talking to people
 - Ability to vote even if not present – way for voice to be heard, improve representation
 - What is a majority?
 - Ways to reduce costs, e.g. “buddying” in hotel rooms, billeting
 - Promote the caucus
 - Mentorship: identify issues and challenges
 - Workshops to identify and discuss the needs of different groups → need more choices
 - Improve meeting structure
 - Better delineate roles and responsibilities (2-way)
 - Incentives: content of meetings relevant and interesting to encourage participation
 - Issue orientation
 - Take meetings outside Toronto, to bring in PHAs from other areas
 - Re-clarify mission, expectations
 - Culturally-sensitive information, processes
 - Needs of immigrant/refugee/non-status
 - “Clean slate”
 - Power through representation of strong collective voice
-

The “WHAT” (skills, models, etc.)

- Infrastructure
 - Advocacy
 - Clearinghouse: single, collective voice
 - Skills training as a model:
 - Outreach
 - Orientation to Rob’s rules
 - Public speaking on behalf of PHAs
 - Leadership development
 - Media training, spokespersons
 - Networking
 - Minutes, writing
 - Proposals for funding
-

Appendix 4: Flip Chart Notes, Day 2

Organizational Models

CAS PHA Forum

Membership: open to all PHAs

Meetings: annual, 80-90 people

Governance:

- elect PHA reps
 - make own resolutions to CAS Board of Directors
 - 5 of 13 rep positions are designated for PHAs
 - regional model
 - voting: must be present
-

Entre-Nous Forum

Membership: open to PHAs in Quebec

Meetings: annual, 300 PHAs

workshops to provide information

Focus: networking, support (not advocacy, governance)

information dissemination

(more medical than social)

Activism, targets for information

PHA Leadership Training Institute

Funding: NY state and Ryan White foundation – pays for all travel and costs of attendance

Membership: open to PHAs from NY state

required to report back (accountability)

Meetings: 3 day sessions, several times/year, plus additional modules

110 attend each year

Focus: leadership development, goal setting, reflexivity, empowerment

HIV Advocacy Network

(San Francisco AIDS Foundation)

Meetings: annual

Membership: anyone “affected” by HIV/AIDS (not limited to PHAs)

Residents of northern California

Focus: advocacy – assumes leadership base

OAN PHA Caucus

Membership: open to PHAs residing in Ontario (self-declared)

Meetings: open

usually Toronto, but may travel
3/year, 40-50 PHAs in attendance
some scholarships provided

Governance:

- 10 member steering committee
- 4 of 10 members of OAN board of directors designated for PHAs
- voting: only those in attendance; no quorum
- acts like committee of the Board
- 1 FT staff person

Challenges: role, identification of issues

need to make co-chairs members of OAN?

PURPOSE of PHA Caucus?

- Information sharing (2-way communication_
 - Skills building
 - Networking
 - Education
 - Voice for ON PHAs
 - **Collection of PHA leaders in Ontario**
 - **Represent PHA issues to government and media and ASOs**
 - Impart skills: “life” or “leadership”??
 - **Be a “leader-ful” organization**
 - Goal: “a highly involved and informed PHA community”
 - Forum for discussion of issues (not for solving)
 - Solidarity
 - Support – a natural by-product of gathering
 - **Lifting people to the best of their abilities – realizing potential as leaders**
-

Break-out Group A

Leadership

- motivation
 - confidence, self-assured
 - good communication
 - open-minded
 - motivator
 - good listener
 - experience
 - connected
 - passion for change
 - transferable skills
 - readiness- personal
 - passion
 - ability to work with people where they are at
 - ability to inspire
 - ability to teach / support learning
 - good problem-solver
 - prepared for failure/rejection – able to learn from and move on
 - resiliency
 - well-organized
 - acknowledgement of mistakes
 - people skills, personability
 - public presence
 - media trained savvy
-

Leadership training

- which skills can be taught? (examples from NY Institute)
which can't? (e.g., passion)
- awakening potential
- people have some leadership qualities, and need to learn others
- role modelling
- understanding of issues can generate passion
- people have different ideas; leaders need to recognize this
- leadership training helps channel, express passion
- accept diversity
- direction of work?
- where are we at 10 years later (after Charles Roy's paper)?
- where will we be in another 10 years?

Goals, outcomes

- more PHAs on boards, ASO staff
 - PHAs in different community sectors (mental health, housing, etc.)
 - PHAs on cross-disability coalitions
 - meaningful involvement – less tokenism
 - changes as a result of PHA involvement (programs, policy, etc. to support PHAs)
 - raising of PHA issues in different communities – cross-pollination
 - PHAs involved in creation of policy change
 - PHAs advocating for politicians
 - re-involvement in HIV/AIDS work
 - recognize PHAs have full lives – may be working etc. – must accommodate needs
 - disclosure – inclusive of different experiences and levels of “outness”
 - PHAs in fundraising activities – government, private industry
 - more community leaders in rural and isolated/non-urban places
 - becoming a leader is a journey
 - channelling anger
-

Program Aspects

- parameters and principles needed
 - broadly applicable skills – to be used in own area of interest, e.g., governance, media savvy-ness
 - skills to navigate the system, to be effective
 - build leadership profile
 - help making the connections
 - help to focus
 - identify gaps in community training
 - navigating the landscape
 - partnership development to create links for PHAs to the program
 - how to facilitate / put on a workshop
 - community / grass roots leadership
 - address diversity issues in all programs
 - utilise partners / knowledge and training that exists already
 - ideally: PHAs training PHAs, at least as co-presenters → build capacity
 - sustainability and growth
 - tie back to OAN – strengthen organizations
-

Break-out Group B

Who?

- PHAs facilitate
- criteria to be determined
- independent selection committee
- express an interest in being a leader
- application process
- PHAs as “students”
- community connected PHAs (not a requirement)

What

- opening doors
- road show
- introduction workshop open to anyone
- apply for different modules – merit system?
- credibility and accountability
- appropriately resourced

Outstanding issues

- main themes – no conclusions
- more work needs to be done

Recommendation

- mechanism with a smaller group (steering committee) to develop a “plan” / program to be circulated to think tank for feedback
- report: comments to think tank → sub-group → analysis, final “outcomes”