Strengthening PHA capacity building initiatives; a forum to share best practices to improve planning and coordination

Forum Report

Toronto Community Planning Initiative & Committee for Accessible AIDS Treatment

November 2007

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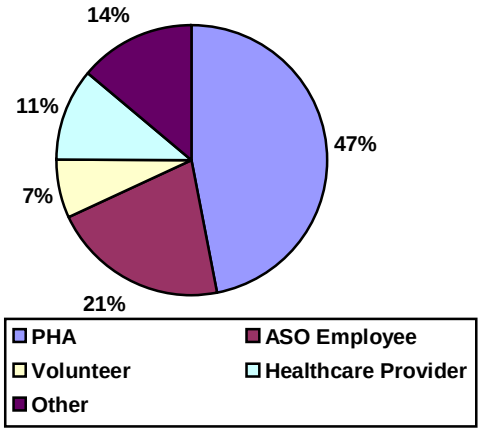
Foreword...

The Toronto Community Planning Initiative planning consultations the Committee for Accessible AIDS Treatment study on mental health service across issues affecting immigrant/refugee PHAs, and the OHTN's Living and Serving II study, all identified the need to assess and advance the training and capacity building needs and initiatives for PHAs in Toronto. To better understand the needs and the current situation, a one day forum was held to examine the issues from the community level.

This think tank was held in November of 2007 with seventy people attending. Attendance was open to all and the actual attendees were from a variety of community groups and service areas.



An invitation went out through an email chain and in the end; the result was that PHAs were well represented at the event. In addition, there was representation from a broad range of ethno-racial groups (see Appendix E for more detail).

The working group had set six objectives for the day (please see objectives listed on page 2). According to the evaluations completed at the end of the day, the six objectives were met. Guest panelists set the tone for breakout discussions in the morning and afternoon.

The morning was spent looking at the lessons learned from current training programs for PHAs. More specifically, the breakout groups focused in the areas of Peer Support, Personal Development, Community Development and Mentorship.

In each of these focus areas; participants developed a body of work that outlines the current best practices that are in use, the challenges experienced in access and delivery, and strategies that might be engaged for moving forward. As the morning workshops progressed and the report back from the four groups was presented, it became evident that the there was a need to look at more systemic issues for moving forward in all of these focus areas.

The afternoon session provided opportunities for participants to examine issues affecting coordinated planning and accreditation of training programs, as well as the development of best practice standards and accountability issues affecting programs for PHAs. The afternoon plenary highlighted issues related to funding structure, partnership models and programs in development related to PHA capacity building at governmental, research and academic institutions.

After the afternoon plenary, participants broke into self-selected breakout groups to discuss the more systemic issues of Coordination, Best Practices and Accreditation. Discussions were passionate and the feedback to the larger plenary identified some key courses of action for moving forward in all three of

these systemic areas. To facilitate some of this future work, volunteers were solicited to assist the working group as we move forward on from this one day forum.

This report will be distributed to all forum participants and to all key community groups. The working group will work to set the path for future action around the "moving forward" sections of this report. We thank all those who participated in the one day forum and look forward to working together to ensure this report does not sit idly on the shelf…

Adhiambo M.J., Women's Health in Women's Hands
Alan Li, Co-Chair, Committee for Accessible AIDS Treatment
Andre Luis Ceranto, Ontario HIV Treatment Network
Emmanuel Ndyanabo, Asian Community AIDS Services
Henry Luyombya, Committee for Accessible AIDS Treatment
James Murray, Ontario Ministry of Health and Long Term Care
Linda Gardner, Women's College Hospital
Luis Jose Lama, Committee for Accessible AIDS Treatmenr
Maureen Owino, Committee for Accessible AIDS Treatment
Randi Reynolds, St. Stephen's Community House
Rosemary Erskine, Co-Chair, African Community Health
Susan Flynn, Planned Parenthood Toronto

This project funded by:

Opening Doors, Ontario Ministry of Health and Long Term Care
& the Ontario HIV Treatment Network

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Capacity Building Project – Background

Building Capacity of Individual PHAs…

People living with HIV/AIDS (PHAs) have been at the forefront of Ontario's HIV/AIDS movement since the beginning of the epidemic. Over the years the populations affected by HIV/AIDS have become increasingly diverse and their needs have also become increasingly complex.

Various organizations and networks have developed many innovative program initiatives and training activities to ensure and promote the greater involvement and leadership of PHAs in addressing the different social determinants affecting their health and well being. This occurred in response to the changing needs of PHAs and the development of the Greater Involvement of People Living with HIV (GIPA) principles (see appendix F).

In addition, recent community planning initiatives and research studies conducted by the Toronto Community Planning Initiative Education & Training Working Group, the Committee for Accessible AIDS Treatment and the OHTN's Living & Serving II study, all identified and highlighted the need to have enhanced planning and coordination on PHA capacity building initiatives. This requires key strategies that will help improve PHA participation and leadership; enhance their physical and mental health; and improve service delivery and coordination in Toronto.

It is recognized that amongst the richness of the programming initiatives related to PHA capacity building, there are significant gaps in comprehensive planning, limited coordination in areas including program collaboration, quality assurance and knowledge transfer, and little formal recognition and deployment by potential employers and organizations for PHAs trained through all these community based training initiatives.

As a result, the organizing groups brought together key community people for a best practice forum on PHA capacity building and mentorship. This is viewed as a first step to take stock and learn from the good work currently undertaken, and to facilitate collaborative and coordinated planning of a more comprehensive curriculum for the future. This curriculum will address the diverse and complex capacity building needs of PHAs as well as exploring innovative mechanisms to further enhance long term quality assurance, accreditation and effective deployment of the rich and diverse skills and talents amongst our PHAs.

Project Goals

- To promote knowledge transfer and exchange amongst current PHA capacity building and mentorship activities in Toronto
- To facilitate improved coordination and comprehensive planning to address PHA's capacity building needs
- To explore longer term measures that will enhance quality assurance and accreditation of PHA training initiatives

Forum Objectives

From the broader goals, the committee set six objectives for the forum which they felt would move the project forward. The objectives are designed to focus the work of the day and to provide tangible points of agreement for moving forward. The six objectives of the forum were to:

1. Assess what works well with PHA capacity building programs
2. Examine the different "types" or models of capacity building programs
3. Recognize points of innovation in existing programs
4. Explore some of the challenges in implementation of programs
5. Determine how and to what extent PHAs are involved in all aspects of implementation
6. Recognize existing gaps and what needs to be improved

To achieve the above, the day was broken into two sections (see agenda – appendix B). The day started with an opening welcome by the co-chairs and an overview of the forum's goals and objectives.

The morning sessions were started off by an address by two PHAs who shared their very different lived experiences within the AIDS movement. Next up was a plenary panel of representatives from existing capacity building programs followed by four break-out sessions. These sessions allowed participants to further explore the currently available training programs for PHAs, their successes, challenges and lessons learned in four key areas (peer support, personal development, community development and mentorship) and closed with a report back to the larger plenary.

After lunch, a plenary panel looked at some existing initiatives to set the stage for discussions around three key areas (coordination, accreditation and best practices) which will provide a framework for moving forward and working on the issues identified in the morning.

At the end of the day, working groups were struck to take the work of the forum to the next level. These groups will meet to verify the day's results and lead the way forward.

Opening Remarks

Rosemary Erskine
Alan Li

The co-chairs of the forum welcomed everyone on behalf of the working group. They went on to set the framework for discussions and outlined the goals of the project. The co-chairs pointed out that this is one initiative of the Toronto Community Planning Initiative and is aimed at improving PHA health, service coordination and promoting knowledge transfer and exchange.

Opening Speakers – The Lived Experiences of PHAs

Evan Collins
Maureen Owino

Evan is a long term surviving gay man who became involved in the AIDS movement in 1985 with the AIDS Committee of Toronto. His experience is very broad but for the purposes of this session, he focused on the work he has been involved in here in Toronto as a PHA.

The key message from his presentation was to assure people that at some point we are all new to this work and that even after many years of being involved, there are days when he feels like he is just starting out. At some point, everyone is in the same place, in the dark about HIV/AIDS. The challenge is not to be discouraged and, like taking a long hike, to know that no matter where you are today, just aim to be in a different place tomorrow, don't hesitate to ask for help, take breaks along the way, take care of yourself and remember to look back and see how far you have come.

A second message from Evan's address was a reminder for us to remember that the AIDS movement is a community based movement and that communities take care of each other. In some ways the movement is unique and strong today because it has historical and continued intersections with four other critical community based movements: the equal rights movement, the feminist movement, the gay movement and the ethno-racial rights movement.

In contrast to Evan, Maureen is woman who quite recently arrived in Canada as a refugee claimant from Kenya. She has a lot of experience as a PHA working in the AIDS movement in her home country and has been active here in Canada since her arrival. Maureen was able to share with the participants her experience of transitioning to life in Canada as a PHA and some lessons we might learn from that experience.

One of the key messages from her talk was the challenge of translating experience from another country to the volunteer and career areas here in Canada. Many training programs are offered in the ASO sector; however it is her experience that these do not translate into something meaningful outside the AIDS movement or even outside an individual ASO.

There was a poignant reminder that people in her situation are not only living with HIV and the challenges that brings, but also living with HIV in a foreign county and challenges us to imagine what that would mean if we found ourselves in that situation.

Maureen outlined some of the barriers and challenges that reflect the experience of those living with HIV who are not only new to Canada, but also, in some cases, new to the AIDS movement. These range from the lack of employment and support to help PHAs find work to the provision of programs that facilitate life-skills in adapting to a new country.

Her talk also reminded the people in the room that issues surrounding stigma, discrimination and gender bias have not been eliminated and continue to be a huge barrier experienced by PHAs at all levels.

Through their varying personal experiences, the morning speakers demonstrated perfectly that while these experiences and history may be very different, there are many areas of overlap and common

ground on which we all have to work together to ensure an environment where PHAs have the capacity building opportunities to meet a number of different needs.

Morning Plenary Panel: Sharing Best Practices

Yvette Perreault – Moderator

To set the stage for the four panel presenters, Yvette reminded us that they would give examples of some programs that build PHA capacity. It was noted that these were not the only four programs but they did represent diverse constituencies and approaches. The participants were encouraged to listen and learn from each other during the panel and throughout the day. Our challenge as individuals and as a community is to learn to recognize and value people's skills, work well together towards a target of strengthening the "selfhood" of PHAs. We will do this by strengthening peoples ability to relate to each other and influence policies and procedures collectively. Then we will be able to challenge and influence the wider social environment and our community.

Keith Wong, Ethno-racial Treatment Support Network

The ETSN is a partnership of Africans in Partnership Against AIDS, Alliance for South Asian AIDS Prevention, Asian Community AIDS Services, Black Coalition for AIDS Prevention, Centre for Apanish Speaking Peoples and the Canadian AIDS Treatment Information Exchange. Since 2003, it has been running a training program called "Learning & Helping Out: Peer treatment counselor training programs for culturally diverse communities". The 9 day training program is open to PHAs from ethno-racial communities and to date there have been 65 PHA graduates from five ethno-racial communities.

The curriculum includes working on HIV treatment information and peer counseling skills through role plays, scenarios, homework, treatment research and is followed up throughout with quizzes to assess progress of the participants. Through the process the participants experience personal capacity building and treatment literacy. Their roles have evolved over time and graduates have become facilitators and collaborators in curriculum training for new peer support trainers.

Some of the key reasons identifying why the ESTN works are:

- A responsive curriculum
- Culturally appropriate and safe
- Individualized mentorship and support
- Group-based peer learning
- Holistic approach
- Creating a community of learning and caring

What a few ESTN graduates shared during this presentation…

Calvin Perreira

Calvin feels he is much more knowledgeable about treatment now. His confidence is greatly increased and through the program his sense of isolation has faded. Graduating from the program in 2006, Calvin has become a training facilitator in 2007 and identifies an additional personal benefit of increased access and participation in decisions about his health as a positive result of being involved.

Claudette Samuels

Claudette shared how much the program has added to her life. She graduated from the program and with the increase in skills and confidence, is now a peer educator, public speaker and peer mentor. For her, the program is truly about peers helping peers and building the skills and confidence to have professionals speak "to" PHAs and not "at" them.

Thomas Egdorf, PHA Program Director, Ontario AIDS Network

One of the key PHA programs for the Ontario AIDS Network is called the OAN PHA Leadership Development Program. The program consists of three levels which takes PHA participants through a structured process of leadership development.

The program is based in the theory that leadership is also about self-development, mastery of the self and setting yourself free. Building confidence is a big part of the program. Through the use of structured positive feedback to build confidence, collage and warm up exercises to explore leadership values and principles, the program aims to build leaders one step at a time. Over the three levels of the program, the key goals are to have PHA participants:

- Explore personal values and philosophy
- Develop leadership skills and practices
- Build community knowledge and awareness

Wangari Tharao, Health Promotion Program, Women's Health in Women's Hands (WHIWH)

Wangari focused on one of many programs of the agency. This program developed from the community because many women were frustrated about how they engaged with service providers. Often problems persisted, women were not involved in an active role, and as PHAs, were often left on their own to deal with complex issues.

It is important for women to understand HIV from their own perspective. Some of the women had lower literacy levels and were given highly technical information without any explanations or support to answer questions. Cultural perspective is very important in the delivery of program as well. An example was given using the term "HIV positive". For many people, the word positive is not a bad thing so something as simple as someone's diagnosis could be misunderstood from the beginning.

Some of the key lessons learned to date from the project have been:

- The location of the project is very important – WHIWH was not an ASO
- Women need a supportive environment that can respond to the complexity of women's lives
- The need for flexibility to deal with emerging issues
- To encourage women to understand the importance of psychotherapy – some come from traumatic environments
- To build in a skills development component
- To build community where peers can deal with things as a group – not as individuals

What a WHIWH program participant shared during this presentation…

Marvelous M.

Marvelous is from Zimbabwe and was very clear that it was important not to just be a "token" but to also have meaningful involvement. Women need to be involved in discussions about the project and decisions surrounding the project.

She went on to highlight the importance of language and the need to interpret the information received from a doctor. Recognizing the cultural limitations that can surround empowering women to talk about sex when it is taboo in many cultures is also important.

Most women live in extended families and may face many different issues surrounding disclosure and confidentiality. It is important that women get proper counseling and they become empowered to challenge policies and services in their communities.

Art Zoccole, Executive Director, 2 spirited People of the 1st Nation

It is important to recognize the cultural reality of the person and his or her living situation. 2 spirited People developed an Aboriginal PHA (APHA) Speakers Manual in consultation with community. The process provides capacity building for individuals and enriches the community work the organization undertakes.

Art shared that the success of the program was based in the fact that they ensure an advisory group is put together to drive the program from beginning to end. Through the process of developing the manual a group of six male APHAs were recruited to complete the final program and a second cycle will target Aboriginal 2-spirited women and injection drug users (IDUs).

The program contains many culturally appropriate learning methods like story telling. This is an Aboriginal tradition of speaking from the heart. As well, culturally relevant ceremonies which are based in the traditions of the Aboriginal community were included.

One of the challenges that Art spoke about on PHA capacity building projects is that PHAs are often on fixed income (i.e. no transit pass or money for lunch) and monetary concerns can be a huge barrier to participation for many. It is important to ensure you have some monetary incentives included to overcome these barriers.

Questions from the floor for the panel…

How do you get volunteers to step forward?

- A sense of belonging to community and contributing is important for volunteers
- Ensure that if you include things like student placements, you do it in a transparent, informed, and proactive way
- Entrench the "For PHAs by PHAs" philosophy
- Value the lived experience of PHAs as a critical skill set
- Ground things in reality – physical, financial and emotional realities – don't create unrealistic expectations

How do you develop PHA guides or mentors?

- Realize that mentorship is a long process – keep people engaged
- Ensure PHAs are invited to speaking engagements and can shadow work engagements with mentors
- Question how agencies are creating the meaningful involvement of PHAs
- Caution that the end goal of meaningful involvement is not always employment
- Highlight that community succession is integral to an organization's strategic plan
- Remember mentorship is not a one way process – mentors and facilitators become enriched as well

Morning Break-out Sessions:

These four sessions explored lessons learned from current available training programs for PHAs in the areas of:

- Peer Support
- Community Development
- Personal Development
- Mentorship

To guide the discussions in each of the breakout rooms, facilitators focused discussion on the sharing of best practices, identifying challenges and improving quality and access to programs.

Peer Support

Best practices: What is working…

Some of the common best practice elements identified amongst participants thtcontributed to the success of PHA capacity building programs include:

- **Partnerships** – using partnerships to bridge organizational gaps in experience, programs and personnel

- **Training** – comprehensive skills training for facilitators and peer support personnel in areas such as speaking, discrimination awareness, dealing with inappropriate behavior, sensitivity training, and areas where peers have a specialty. (e.g. immigration, cultural sensitivity or cultural awareness)

- **Learning** – keeping up-to-date with the current treatment information, new trends, or public policy changes (e.g. criminalization, immigration, drug plans)

- **Environmen**t – critical to the success of any program are all the prerequisites to a "safe space". This includes confidentiality policies, language of services, location of program, and in some cases the audience of the program.

- **Personal Growth** – recognizing the impact of personal journey, marginalization, social skills, life challenges, and discrimination on and individual, and how this can impact peer work.

- **Support** – from the organization and from other peers throughout the process that ensures that a person has the necessary tools and resources at hand

Challenges: Lessons learned…

Peer support programs have existed in many forms since the beginning of the AIDS movement in Canada. Over the years, funding limitations and shifting program priorities have seen these recede and

flow at the community level. The increasing diverse nature of those infected with HIV has also had a significant impact, including an increased demand in areas that are not traditionally within the proficiency of an ASO (e.g. immigration, employment assistance). Additional challenges to peer support identified were:

- **Volunteering** – balancing volunteer time with working for an income is a challenge for many

- **Transferability** – skills are sometimes seen as not transferable outside the AIDS movement and in some cases, even between individual ASOs. In addition, stigma and discrimination related to HIV/AIDS further limits the transferability of the skills and experiences.

- **Policies** – setting policies which deal effectively with confidentiality, "gossiping", inappropriate behaviors and setting boundaries can be a challenge and can also have different meanings depending on where you are from

- **Consistency** – there is a level of discomfort when new people are introduced to an existing group as dynamics change , need to deal with the natural attrition of a group and bringing new people on board

- **Gaps** – there is no process in place for PHAs to get together on a regular basis (not organizationally based) to identify needs and gaps in training

- **Diversity** – many programs do not reflect language or cultural diversity in their approach

Moving Forward: Strategies that improve quality and access…

Many of the best practices outlined in the previous section would definitely apply under this section. However, the participants did identify a few additional strategies:

- **Policies** – develop consistent policies across organizations (ie. confidentiality, information sharing etc.)

- **Access** – create peer program for newly diagnosed PHAs to learn what to expect from "the system" and how to negotiate

- **Skills** – build challenging role play situations into peer training and PHA peer support groups

- **Staffing** – recruit PHAs who have experience in peer support into positions that deliver peer programs

- **Consistency** – keep group cohesiveness until after training is complete – no replacements for attrition

Community Development

Best practices: What is working…
Community can be defined and classified in many different ways. The definition is often highly dependant on the individual. However, when looking at community development, there are some very key areas of consensus which are indicators for successful programs:

- **Focus** – built around people and their lives (ethno-racial, culture, sex, language), this also includes the issues that affect people (violence, sexual assault etc.)
- **Processes** – a continuous process that facilitates people coming together to empower individuals to form supportive community
- **Policies** – policies that support the creation of safe spaces for people to come together to direct the community experience (equity, equality, non-discrimination, cultural sensitivity, homophobia etc.)
- **Unity** – not "us and them" but a "we" focus on common values, concerns, issues, purposes or causes
- **Diversity** – respects the co-existence of similar and divergent paths to achieving goals with an understanding that diversity is a strength
- **Flexibility** – to deal with emerging issues and respond appropriately by evolving, shifting or changing
- **Partnerships** – a core strategy that allows for the inclusion of "smaller" voices , processes to amplify them, and capacity development to cooperate through partnerships

Challenges: Lessons learned…

Community development is often an organic process for many people or organizations involved in HIV/AIDS because traditionally governments have funded programs and projects through this lens and it has become entrenched.

One challenge of community development is "slicing" community too thinly and being too specific on the target "community". You cannot force communities to form and when it is tried, sustainability both in people and funding is difficult. Communities that form naturally from the flow of social networks are the ones who usually will be successful at using community development as a strategy. Some additional challenges were identified:

- **Non-ASOs** – the impact of stigma and fear of HIV creates roadblocks both with organizations and their staff (ie. youth serving organizations, ethno-racial organizations etc.)
- **Resources** – sustaining funds beyond pilot projects and initial funding were concerns raised as those with the most influence determine how resources and priorities are allocated

- **Gate Keepers** – identified as "founder's syndrome" is where key decision makers block buy-in to community development and succession processes out of fear of "giving up" control

- **Dominance** – managing dominant groups who know how to work the system and use community development to exclude others

Moving Forward: Strategies that improve quality and access…

Beyond implementing the best practices section broadly, there were a few focus areas that would make a difference:

- **Tools** – create tools to assess the outcomes of community development qualitatively and also to measure if an organization is meeting its mandate with the services it is providing

- **Language** – translate community development tools to other languages which include a common vocabulary with understandable definitions

- **Barriers** – remove structural barriers to participation such as childcare and accessibility

- **Values** – establish transparency on how organizational values influences decisions around how resources and priorities are set

Personal Development

Best practices: What is working…

This is most likely one of the most complex areas to work with because of the very "personal" nature of personal development. It is influenced by religion, culture, family, peers and any number of other sources. Each and every day there is a new self-professed guru emerging in this field. That being stated, the participants did come up with indicators which signal best practices in their experience with community. Those are:

- **Diversity** – an excellent attitude towards the involvement of PHAs and newcomers contributes to a program working well because of the wealth of learning opportunities it presents to all those involved

- **Progressive** – organizational paradigms that recognize the value and importance of self-development to augment education and meaningful involvement

- **Learning** – formal opportunities through the provision of funds for education and informal opportunities through the provision of group learning activities to improve and build skills

- **Leadership** – one of the most important cornerstones of leadership is knowing who you are and this is achieved through personal development. To develop leaders, we need to work in this area.

Challenges: Lessons learned…

The complexity of personal development is its greatest challenge. It is often viewed as self-gratification by using scarce resources that could be used elsewhere. The idea of education and skills development are often overlooked as key components of personal development. Each person has their own journey, so for broader personal development it will always be difficult to find a "common" path down the centre. Some of the additional areas of challenge identified are:

- **Marketing** – programs are often not promoted in a way that communicates the learning potential to PHAs, and that is if English is their first language. They are often "lost" on those for whom English is not a first language.

- **Definition** – personal development conjures up varying images for people. It is also about learning, training and education and in most cases personal development is a "side effect" of these elements.

Moving Forward: Strategies that improve quality and access…

Most organizations offer training of some type and on-going information sessions. These are in their own way personal development tools. Through the process an individual learns new information and gains skills that improve not only their ability to carry out their volunteer work, but also contributes to personal gain.

For instance, imagine a PHA who has never disclosed their status publicly and takes volunteer speakers training. After shadowing another speaker for a few sessions they disclose their status to strangers for the first time. This person has not only gone through speakers training; they have also undergone an incredible personal development process.

A few additional areas were identified by the participants in this session are:

- **Promotion** – promote all training programs which build capacity or skills in all areas

- **Openness** – take existing "volunteer" programs and realign them to external participants

- **Coordination** – find synergies by coordinating volunteer training, information sessions and skills building seminars, and include centralized sources for this information

Mentorship

Best practices: What is working…

There has been talk of succession planning, supporting peers and organizational development in the HIV/AIDS movement for many years under the guise of "mentoring". In reality the programs are relatively low key and hard to find.

Where mentorship is working, there are some very agreed upon indicators for success. These indicators are:

- **Relationships** – two way and built on trust, honesty and mutual respect; should be supportive and can be formal or informal

- **Supportive** – supports you where you are and provides guidance when you are ready to move forward; often mentors are being mentored themselves

- **Community** – reinforces the sense of community and strengthens "cross pollination" between communities

- **Sharing** – share experiences and skills with others and not standing in their way when it comes time for practice

- **Role Models** – encouraging, open and always willing to answer questions, provide guidance and offer advice when asked

Challenges: Lessons learned…

Mentoring is a two way process and many people have shared the experience of being "mentored" when in reality the person who is charged with mentoring is simply using you as an "assistant". Mentoring definitely is not the "downloading" of work or tasks to make things easier for the mentor.

Beyond this challenge, there are a few more identified:

- **Deployment** – the under-utilization of long term survivors and few opportunities for those with experience to enter into mentoring programs

- **Boundaries** – can become blurred and unhealthy if expectations are not clear and the relationship is not monitored

- **Policies** – that support this type of personal relationship and help to avoid exploitive situations and ensure safety for disclosure and sharing are lacking.

- **Sincerity** – of "mentors" who actually want to teach and support mentees beyond their personal needs and let go when the time comes

Moving Forward: Strategies that improve quality and access…

The AIDS community needs to come up with a clear consensus on what is meant by mentorship. Too many people have been burned by an activity with the mentorship "label" which was truly not mentorship.

Here are a few identified focus points that will help improve action in this area:

- **Language** – write a common definition for what mentorship means and translate it into language which is accessible

- **System** – set up a central system to register as a mentor or mentee which has a flexible structure that monitors progressive use of people's skills and assigning incremental responsibilities

- **Recruitment** – engage volunteers with an interest in mentoring keeping in mind they may not want to do other volunteer work

Afternoon Plenary Panel: Strategies for PHA Capacity Building

Yvette Perreault – Moderator

Yvette set the stage for this phase of the agenda. The participants would spend the afternoon identifying strategies to advance PHA capacity building initiatives. Using the same model as the morning, there would be a brief presentation by three panelists to set the context and basis for later breakout discussions in three focus areas:

- Coordination
- Accreditation
- Best Practice

Simone McWatt – City of Toronto Public Health

Simone reviewed the goals and objective of the AIDS Prevention Community Investment Program and some of the programs targeted at strengthening PHA capacity building. The program allocates just over $1.5 million per year to just over 50 projects.

Everything funded under this stream of funding is project funding which means it has to be strategic, time-limited and targeted. Certainly, issues of coordination and best practice are important in this stream as the funds are limited and there is no anticipated increase in the near future.

Dr. Sean Rourke – Ontario HIV Treatment Network (OHTN)
Dr. Rourke spoke to the participants about a number of initiatives. Supporting community capacity building is a key strategic area under the Community Network initiatives of the OHTN and all three of these focus areas will connect to the work of their organization as things move forward.

In particular, the OHTN promotes best practices in promoting the Greater Involvement of People with HIV/AIDS (see appendix F) through a number of initiatives. This includes ensuring that all funded projects demonstrate meaningful involvement of PHAs, supporting community driven initiatives such as this forum to advance planning and coordination of PHA capacity building and the development of the service learning model which will increase systemic support and utilization of PHAs through various roles in community based research activities.

Michael Johnny – Knowledge Mobilization, York University

Michael spoke to us about knowledge mobilization. This presentation touched on accreditation as their goal is to develop a culture of partnership between academic researchers, decision makers in government, and community organizations.

He defined the goal of knowledge mobilization as, "developing a culture of partnership between academic researchers and decision makers in governments and community organizations to assist in the development of public policy, professional practice and social programming."

Afternoon Break-out Sessions

Coordination Working Group

ASOs and other community groups operate in a world of limited resources, increasing demand and expanding diversity of those served. More and more the only way to keep somewhat abreast of developments is through increased coordination activities both within the sector and with others providing services to the same populations.

In a way, this is a bit of a trap as coordination does not just happen. It takes dedicated time, realigned priorities, and resources to do it right. The participants identified the trend that seems to have developed where community is often a metaphor for coordination and we have to be wary of this.

It is with this in mind that the group looked at the topic of coordination.

Best Practices: What indicates success…

The framework of this session was to explore the benefits and opportunities that exist for coordination and identify key characteristics that would indicate that it is happening. With that in mind the group came up with the following indicators:

- **Partnerships** – working together in partnership to avoid duplication of programs and to augment organizational capacity
- **Cooperation** – strategies such as cross training – participants, clients or volunteers from one agency receive training from another agency
- **Resource Sharing** – better use of resources through cross-agency relationships and initiatives
- **Access** – collaboration on intake and PHA program participation that results in less stress for clients and streamlined referrals for PHAs

Some examples to learn from when it comes to coordination:

Ethno-racial Treatment Support Network, Women's Health in Women's Hands (skills development), OAN Leadership Program, Committee for Accessible AIDS Treatment, Women's College Hospital Research Program, Men Together Networks, Raising Sexually Healthy Children Program

Challenges: Lessons learned from the past…

The HIV/AIDS community has a lot of experience with both the positive attributes and the potential negative impacts of coordination. Based on the experiences of the group, there were some common items that can lead any project or program to fail if they are not considered up-front in the process. Those are:

- **Flexibility** – one size or style of program development, content and implementation does not always fit every organization
- **Independence** – losing organizational autonomy
- **Sustainability** – the extra work load may not be possible for some organizations
- **Equality** – there is a fear that because of the power imbalance with organizations of differing sizes one agenda will dominate and marginalized voices will be lost in the shuffle

Moving Forward: Strategies that improve quality and access…

When it comes to coordination, there were a few areas of agreement on how to move forward. One overall sense was to move carefully and ensure that everyone was moving at the same pace. The main areas of focus for moving forward were:

- **Focused Activity** – create small working groups specific to coordination – ensure involvement of PHAs in all working groups!
- **Sharing** – identify and disseminate information and best practice models for feedback and input
- **Action** – implement recommendations and pilot projects
- **PHA Involvement** – meaningful application of GIPA with a minimum of 50% PHA involvement in developing and implementing programs

<u>Accreditation Working Group</u>

ASOs provide a broad range of training programs for PHAs, volunteers, staff and community. One issue that has been clearly identified beyond the coordination of these programs is a system for providing participants with credits for taking these courses which can be applied to a person's resume of skills training.

It is felt that building core competencies through coordinated programs or courses that are accredited, transferable and recognized within the sector can increase the recognition of these programs outside the sector.

While being new, this approach has a number of potential benefits identified by participants. Two key reasons for accreditation are to provide a Canadian context of training for those PHAs who have recently come to Canada, and to provide experience to those PHAs who, after a long interruption in their work cycle, are looking for ways to return to active careers and need to provide updated resume activity.

For the purposes of the afternoon discussions, accreditation in this context refers to recognition of core competencies that can apply to an individual.

Best Practices: What indicates success…

There are many areas for best practices to draw upon. One of the challenges however is that every person and every group will often have a different perception on what best practices constitute. Within the framework of this discussion, there was agreement with the group that best practice for accreditation will be recognized when the following components exist:

- **Transferable** – skills apply between programs in an organization, between organizations and outside the HIV/AIDS movement
- **Participation** – opportunity to gain additional learning without jeopardizing existing benefits and enhanced motivation for practicum students to participate
- **Experience** – transferable skills are recognized and lead towards improved employment opportunities and volunteer experience applies towards accreditation
- **Equivalency** – standards which recognize both past experience and out of country experience
- **Sensitivity** – accrediting agencies must be sensitive to the specific issues related to HIV/AIDS as well as the impacts of disclosure and discrimination for PHAs
- **Standardization** – ASOs recognize each other's training programs
- **Benchmarks** - practical tests and placements are developed to assess knowledge and skills for diverse PHA groups, including long term survivors, newcomers, people from other cities, other provinces or other organizations

Challenges: Lessons learned from the past…

The HIV/AIDS community has historically honoured the concept of "culturally sensitive and target specific" when developing programs for both HIV prevention and support. This has led to a multiple approaches to similar issues.

One of the fears that arise when the topic of accreditation is brought up is the loss of autonomy for smaller groups to the agendas of larger groups. The discussions surrounding accreditation reflects the community fears and shows in the following theme areas:

- **Perception** – lived experience may be seen as too subjective and individual as well as the ability to translate "lived experience" in a way that coordinates with a set curriculum

- **Clarity** – on the transferability of skills from volunteer work to reference letters and resumes and how to make an inventory of skills attained and number of hours volunteered

- **Quality Control** – in recognizing "out of AIDS sector", "out of Canada", "out of Toronto", or "out of province" programs

- **Recognition** – to have the specialized work and training within ASOs recognized by government and academic institutions

- **Workload** – this is a new area of work which involves ASOs making new linkages to places such as employment services agencies, and learning to understand the conversion of things such as paid work, international recognition, degree granting, and mentoring into the training programs they offer

- **Process** – ensuring that PHAs are involved through the entire course of action and opportunities for meaningful input and contribution are honoured

Moving Forward: Strategies that improve quality and access…

One of the greatest challenges in moving forward on accreditation is the fact that is does not happen in isolation. It requires the involvement of a group of ASOs working in concert on agreed principles to promote the concept within the movement and between organizations; it means working cooperatively with external bodies to evolve existing programs to a point where they will be recognized more broadly.

Some of the strategies that were identified that would help to move this concept forward were:

- **Planning** - develop an action plan to gather as much evidence as possible to build a business case and complete an environmental scan to learn from examples elsewhere

- **Consensus** – take ownership and develop curriculum plan through consultations and mapping out the process on what the steps towards accreditation are

- **Collaboration** - find the experts in the field to obtain funding to put framework together when breaking new ground

- **Exploration** – investigate and consider the use of a micro-business model with ASOs and the impact of accreditation on PHAs

Best Practices Working Group

The best practices discussion touched on a number of areas which covered organizational accountability, standards of training, and quality of care. The group discussions for best practices were framed within the context of organizations, more specifically with a focus on capacity building and training provided by organizations for PHAs.

The participants went further to identify some of the groundwork or framework that needs to be considered to come up with a system of best practices that can openly and transparently identify these practices and some of the related challenges.

Best Practices: What is working…

A best practice on the issue of best practices sounds redundant but it truly is not as there will be components that can be recognized as indicators of success even in this area. The group identified the following as some of those key components:

- **Accountability** – clearly established frame work of guidelines and standards to which all participating organizations are held

- **Sharing** – lessons learned can apply to broad community action and provide synergies in the work and opportunities for collaboration

- **Evaluation** – allows us to assess learning and training. This builds a base for improved current and future practice.

- **Documentation** – gives clear indicators on how a service can be a success and makes them easier to duplicate. This is very important and relevant for initiatives targeted to certain populations and builds a base for improved current and future processes as well as making it easier to establish accountability measures.

Challenges: Lessons learned…

It is important to note that in the absence of formalized "best practices", it does not automatically mean "bad practices" are in play. The concept that best practices are a way to learn from others and to reach tactical efficiencies with a minimum investment of resources and effort needs to be reiterated over and over.

One of the underlying issues of tension evident from the discussion was the idea of whose definition of "best" was being used. People are very sensitive of this concept and there exists a very thin line between an organization feeling like they are being judged and the presentation of the concept of best practices. The following key areas of concern were raised around this topic of discussion:

- **Flexibility** - strict standards can be exclusive and may not take into account shifting community resources and funding. Programs may look different depending on what populations or communities are being served – identifying shared elements is important.

- **Competition** – often larger organizations will drive the process and smaller organizations may not have a voice or any influence on direction.

- **Fairness** – a "level playing field" does not exist as a starting point in this process and there are gaps between theory and practice

- **Motivation** – pressure to "conform" from external sources, more specifically funders and government

- **Trust** – not all at the table have equal voice or influence

Some examples to learn from when it comes to best practices:

Community of Practice: the process of social learning that occurs when a stable group of people who have a common interest in a subject or problem collaborate over a period of time to share ideas, find solutions and build innovative responses.

Community Health Centers Accreditation: the accreditation process for community health centres is called "Building Healthy Organizations (BHO)" and is a peer review system that looks at policies, procedures and best practices of the organization. The goal is to identify gaps for improvement as well as to recognize and document innovation for the sharing of best practices.

Moving Forward: Strategies that improve quality and access…

Some people expressed concern over the source of discussions around best practices. Is it coming from community or being driven by funders? Certainly a community dialogue and consensus building process will need to take place on the idea before significant advancement can be made. However, it was also identified that without transparency and accountability to a defined standards of service, marginalized PHAs with access challenges and problems have little recourse in getting their needs addressed. It is also recognized that if done properly, this can be a model to promote ongoing learning and service improvement. To move forward on best practices, the following strategies were put forward:

- **Consultation** - engage in a healthy critique of the term "best" and establish a clear starting point for everyone

- **Documentation** –document what groups are doing so that we can actually arrive at identifying best practices. Develop a common approach to data collection to identify best practices.

- **Assessment** – identify a process to clearly assess current programs to establish fair and equitable ways to move forward, and identify what organizations have in common so that they can adapt and adopt

- **Involvement** – involve PHAs at all stages of this discussion as well as more work around best practices and GIPA

Wrap-up Session

Rosemary Erskine
Alan Li

After each group reported back on the highlights of their discussion, the co-chairs facilitated a discussion focused on ways to keep the work moving forward. Three working groups were struck to take the topics of Coordination, Accreditation and Mentorship to the next level. One of the key activities for these groups is to review the work for the sessions, ensure that it was reflective of the

process and work together to map out a way forward in each area. Working group members were identified and listed below. The co-chairs thanked everyone for their participation and energy for a productive day and adjourned the Forum.

The three working groups are:

Best Practices:

Marco Gomes	marco@youthaidscoalition.org
Marsha Ray Dragon	volunteers@black-cap.com
Marvelous Muchenje	marvelous@whiwh.com
Claudette Samuels	claudette575@yahoo.com
Anna Demetrakopoulos	ademetra@abpo.org
Yvette Perreault	yperreault@abpo.org
Fatima Barry	fatibarry@yahoo.com
Lisingu Chieza	lchieza@actoronto.org

Accreditation:

Robb Travers	rtravers@ohtn.on.ca
Louise Binder	louise.binder@sympatico.ca
Keith Wong	keithwong@inspiract.com
Brandon Williams	bandon.p.williams@gmail.com
Fanta Ongoiba	ed@apaa.org
Luis Loma	luis.loma@sympatico.ca
Istvan Figura	effendy747@hotmail.com
Devica Hintzen	dhintzen@yahoo.ca
Stella	support@black-cap.com
Marsha RayDragon	volunteers@black-cap.com

Coordination:

Antoney Baccas	support@black-cap.com
Anda Li	ali1@toronto.ca
Believe Dhliwayo	believed@rogers.com
Maureen Owino	owinoachieng@yahoo.caom

Appendix A – Attendees

Participant Name	Affiliation
Adhiambo M.J.	Women's Health in Women's Hands
Alan Li	Regent Park Community Health Center
Amanuel Tesfamichael	Africans in Partnership Against AIDS
Anda Li	City of Toronto Public Health
Andre Luis Ceranto	Ontario HIV Treatment Network
Angel Parks	AIDS Committee of Toronto
Anna Demetrakopoulos	AIDS Bereavement Project of Ontario
Antoney Baccas	Black CAP
Art Zoccole	2 spirited People of the 1st Nation
Believe Dhliwayo	Black CAP
Brandon Williams	Below the Surface Coaching
Brian Huskins	Huskins & Associates Consulting. Inc.
Calvin Pereira	Ethno-racial Treatment Support Network
Charlotte Chagoya	Mt. Sinai Hospital
Claudette Samuels	Ethno-racial Treatment Support Network
Derek Yee	Committee for Accessible AIDS Treatment
Divica Hintzen	Fife House
Emmanuel Ndyanabo	Asian Community AIDS Services
Evan Collins	Hassle Free Clinic
Fanta Oingoiba	Africans in Partnership Against AIDS
Fatima Barry	Committee for Accessible AIDS Treatment
Gladys Kwaramba	
Grace Chiutsi	AIDS Committee of Toronto
Greg Mitchell	Ontario HIV Treatment Network
Herbert Co	City of Toronto Public Health
Hugh J. Bishop	
Istvan Figura	
James Murray	Ontario Ministry of Health & Long Term Care
Joanne Lush	Ontario Ministry of Health & Long Term Care
Jose Luis Lama	Committee for Accessible AIDS Treatment
Kaddu Justine	Voices of Positive Women
Kara Gillies	Voices of Positive Women
Keith Wong	Ethno-racial Treatment Support Network
Krista Jensen	York University
Kristin Jenkins	Canadian AIDS Treatment Information Exchange
LaVerne Monette	Ontario Aboriginal HIV/AIDS Strategy
Le-Ann Dolan	AIDS Committee of Toronto
Lena Soje	Black CAP
Linda Gardner	Women's College Hospital
Lisungu Chieza	AIDS Committee of Toronto

Louise Binder	Canadian Treatment Action Council
Marco Gomes	Youth AIDS Coalition
Marsha RayDragan	Black CAP
Marvelous Muchenje	Women's Health in Women's Hands
Maureen Owino	Committee for Accessible AIDS Treatment
Meskerem Tebeje	Voices of Positive Women
Maureen Mahan	Casey House
Michael Johnny	York University
Murray Jose	Toronto People With AIDS Foundation
Nancy Sun	St. Stephens Community House
Patrick Truong	Asian Community AIDS Services
Paul Lukenage	African Community Health
Peter Richtig	AIDS Committee of Durham Region
Randi Reynolds	St. Stephens Community House
Rene Khodai	Robert Blanshay: Canadian Immigration Lawyers
Robb Travers	Ontario HIV Treatment Network
Ron Rosenes	Canadian Treatment Action Council
Rosemary Erskine	African Community Health
Dr. Sean Rourke	Ontario HIV Treatment Network
Shayna Buhler	York University
Simone McWatt	City of Toronto Public Health
Starla Goggins	Centre of Equity in Health & Society
Stella	Black CAP
Susan Flynn	Planned Parenthood Toronto
Susie Soares-McAdam	
Thomas Egdorf	Ontario AIDS Network
Tony Caines	Toronto Public Health
Yvette Perreault	AIDS Bereavement Project of Ontario
Wanda Knights	
Wangari Tharao	Women's Health in Women's Hands

Appendix B – Agenda

Time/Room	Focus	Who
8:00 – 9:00 Courtyard B/C	**Registration**	Susan F., Randi R., Andre C., Emmanuel
9:00 – 9:15 Courtyard B/C	**Introduction & Welcome**	Rosemary Erskine Dr. Alan Li
9:15 – 9:35 Courtyard B/C	**Opening Speakers**	Evan Collins Maureen Owino
9:35-9:45 Courtyard B/C	**Toronto Program Inventory**	Brian Huskins
9:45 – 11:00 Courtyard B/C	**PLENARY PANEL: Program Experiences** **Moderator:** **Peer Support** ➢ ETSN Peer Treatment Counselor Training **Personal Development** ➢ OAN Leadership Program **Community Development** ➢ WHIWH Health Promotion Program **Mentorship** ➢ 2-spirited People of the 1st Nations **Question & Answer** ➢ From the floor	 Yvette Perreault Keith Wong, Claudette Samuels & Calvin Pereira Thomas Egdorf Wangari Tharao Art Zoccole Open
11:00 – 11:15	**Morning Nutrition Break**	
11:15 – 12:15 Courtyard B Alexander A Alexander B Courtyard (C)	**Group Break-Out:** **Group #1 –** Peer Support **Group #2 –** Personal Development **Group #3 –** Community Development **Group #4** - Mentorship	Facilitator/Notetaker Susan F./Randi R. Rosemary E./Kristin J. Anna D./Linda G. Murray J./Andre C.
12:15 – 12:30 Courtyard B/C	**Group Report Back**	Facilitators or designate
12:30 – 1:30 Courtyard B/C	**Lunch**	
1:30 – 2:00 Courtyard B/C	**PLENARY PANEL: PHA Capacity Building** **Moderator:** **City of Toronto Public Health** **Ontario HIV Treatment Network** **York University**	 Yvette Perreault Simone McWatt & Tony Caines Dr. Sean Rourke Michael Johnny
2:00 – 3:00 Courtyard B/C Alexander A Alexander B	**Group Break-Out** **Group #1 –** Coordination **Group #2 –** Accreditation **Group #3 –** Best Practices	Facilitator/Notetaker Maureen O./Randi R. Robb T. /Linda G. Susan F. /Kristin J.
3:00 - 3:15	**Afternoon Nutrition Break**	
3:15 – 4:15 Courtyard B/C	**Group Report Back & Follow-up Action**	Rosemary Erskine Alan Li
4:15 – 4:30	**Evaluation & Check-out**	Brian

Appendix C – Speaker's Bios

In order of speaking

- **Rosemary Erskine** is the Executive Director of African Community Health Services, since 2005. She is a Life Coaching who consults and coaches individuals, groups and families to effectively develop and implement plans to successfully achieve their goals and objectives.

  Rosemary has over 10 years experience in institutional and community-based healthcare settings, serving on a number of committees including the Women's College Community-based Advisory Committee, Mount Sinai Hospital PHA Access Community-based Research Project and the African & Caribbean Council on HIV/AIDS in Ontario (ACCHO) and is a past chair of the Black Coalition for AIDS Prevention.

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- **Dr. Alan Li** is a primary care physician, community organizer, activist and researcher who has worked in the fields of HIV/AIDS, lesbian and gay rights, anti-racism and other social justice issues for over 20 years. His work has focused on improving treatment and service access for marginalized populations, especially people with HIV who are immigrants, refugees or without full status in Canada. Alan is a co-founder of the Asian community AIDS Services, the Committee for Accessible AIDS Treatment and the Ethno-racial Treatment Support Network.

- **Maureen Owino** is a teacher by profession and has been involved in HIV/AIDS advocacy and sensitization for over seven years. Born in Kenya, she has worked with a variety of organizations including the Kenya Network of Positive Teachers, World Vision Kenya and Young Women Fighting AIDS in Kenya. Since coming to Canada, Maureen has been in involved as and active member and volunteer with many ASOs. Currently she is the program coordinator for the Committee for Accessible AIDS Treatment.

- **Dr. Evan Collins** is a physician, researcher, consultant, advocate and person living with HIV/AIDS. He joined the board of ACT in 1984 and over the years has served on numerous boards and committees. He was co-chair of the Community Programme for AIDS2006 and sits on the CPC for AIDS2008 in Mexico. In addition to living with HIV/AIDS he has survived AIDS-related cancer.

- **Brian Huskins** is an independent consultant who has been actively involved in the AIDS movement since testing positive in 1990. Brian has served on committees for the World Health Organization, Health Canada and represented Canada at the United Nations. Most notably, he is the first person openly HIV+ person to run for public office in Canada when he ran in the 2001 provincial elections in Alberta.

- **Yvette Perreault** is currently the Director of the AIDS Bereavement Project of Ontario and is the co-creator of Project Sustain, a national program looking at resiliency in the AIDS field. She has been a front-line community organizer and counselor for over three decades.

  Yvette also consults on an organizational development and building teams with heart within the community-based not-for-profit sector.

- **Keith Wong** is the Training Coordinator/consultant of the Ethnoracial Treatment support Network (ETSN), and as the Principal Director of InspirAct Consultants which specialize in organizational development and facilitated training. Keith previously served as the Executive Director of Community Social Planning Council of Toronto, Asian Community AIDS Services and Chinese Canadian National Council Toronto Chapter.

Claudette Samuels first participated with the ETSN Peer Treatment and Counseling Training in 2004, and **Calvin Pereira** in 2006. Since then, they have been actively involved with sharing their learning and experiences with subsequent training participants and peers among different HIV/AIDS service organizations in Toronto.

- **Thomas Egdorf** has been the PHA Program Director for the Ontario AIDS Network for the past four years. He oversaw the development and delivery of the PHA Leadership Development Program and has been worked in the HIV movement in many capacities for over 13 years.

  Thomas is a member of AIDS Bereavement Project of Ontario Advisory Committee. He is passionate about meaningful involvement of people living with HIV in the HIV/AIDS movement. He tested positive in 1993.

- **Wangari Esther Tharao** is a health promoter/community based researcher at Women's Health in Women's Hands. Wangari has been involved in the area of HIV/AIDS locally, nationally and internationally for over 15 years. She also currently co-chairs the African Caribbean Council on HIV/AIDS in Ontario and is involved in several academic and community based research projects.

- **Art Zoccole** is Anishinawbe Ogokwe from Lac des mille Lacs First Nation in Ontario and currently resides in Toronto. Art has been involved in activism for the last two decades on issues relating to Aboriginal people and HIV/AIDS. He is a member of the Ontario's Hepatitis C Task Force, a board member of the Ontario Aboriginal HIV/AIDS Strategy, and Canadian Rainbow Health Coalition.

  Currently, Art serves as the Executive Director of 2-Spirited People of the 1st Nations (a not-for-profit Aboriginal social service agency with members comprised of Aboriginal two spirit, gay lesbian, bi-sexual, transgendered and intersexed individuals).

- **Simone McWatt** works as a Community Grant Officers with City of Toronto Public Health, AIDS Community Prevention program

- **Sean B. Rourke** is a Psychologist and Research Scientist with the Centre for Research on Inner City Health at St. Michael's Hospital and Associate Professor at University of Toronto. In the fall of 2004, he accepted the additional challenge of becoming the Scientific and Executive Director of the Ontario HIV Treatment Network. Over the past 3 years, Sean has helped to recreate the OHTN, changing it into a vibrant, responsive, community-based, collaborative, forward thinking, research, action-oriented organization.

- **Michael Johnny** is the Manager of Knowledge Mobilization for York University. Michael has an MA in Canadian and Native Studies from Trent University, having researched Policy Implications for Native Literacy in Ontario.

  Michael has over 13 years of experience in educational research and development with specific skills in program development, strategic planning, program evaluation, stakeholder consultation, and policy development and analysis. His experience includes working in both a university research environment and at the community level planning, implementing and evaluating social programs.

Appendix D – PowerPoint Presentations

Evan Collins

Lesson #1
It's OK if you don't know much

No one else knows much,
…They just pretend they do

1

Lesson # 2
Being involved in the AIDS Movement is like taking a long hike

You have to train for it
You have to take breaks along the way
You have to take care of yourself
If you get lost, don't be afraid to ask for directions
You have to stop occasionally to enjoy the view
At times when your destination seems

2

Lesson # 3
A wise person once said

…very little

3

Lesson # 4
The AIDS Movement is
a community movement

…and communities take care of each other

4

Keith Wong

"Learning and Helping Out" & Beyond:
Peer Treatment Counseling Support & Mentorship for Culturally Diverse PHAs

November 16th, 2007
Toronto

Claudette Samuels, Calvin Pereira
& Keith Wong
(Ethnoracial Treatment Support Network)

Ethno-racial Treatment Support Network

1

- **Who are we?**
  - Africans in Partnership Against AIDS (APAA)
  - Alliance for South Asians AIDS Prevention (ASAAP)
  - Asian Community AIDS Services (ACAS)
  - Black Coalition for AIDS Prevention (BCAP)
  - Centre for Spanish Speaking Peoples (CSSP)

  Our supporting partners:
  - Canadian AIDS Treatment Information Exchange (CATIE)
  - AIDS Bereavement Project of Ontario

Ethno-racial Treatment Support Network

2

How we came together?

- WE first came together (2001) to create HIV treatment information resources in different languages.
- Later it became a resource portal of more than 10 languages.
- www.treathivglobally.ca

3

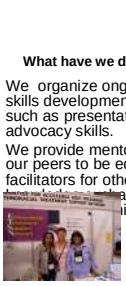
What have we done'

- Conducted 4 rounds of "**Learning and Helping Out"**
  - HIV Peer Treatment Counselor Training for culturally diverse communities

4

What have we done?

- We organize ongoing leadership skills development for our peers such as presentation, facilitation & advocacy skills.
- We provide mentorship support to our peers to be educators & facilitators for other peers and [illegible]hange agents to [illegible]ities.



5

Learning and Helping Out
Curriculum Structure

- 9 days including 2 evenings & 7 full days (incl. a weekend training retreat)
- Covers both HIV Treatment Information and Peer Counselling Skills
- Very interactive and diverse formats of learning: role plays/ practice scenarios/small group & big group work/ [illegible]

6

Learning & Helping Out
Curriculum topics:

Treatment Information
- HIV/AIDS: definitions/disease continuum
- Treatment options, HIV drugs
- Adherence/viral resistance
- Side effects of medications
- Women's health, HIV & pregnancy
- Changing therapies/drug holidays

Peer Counselling Skills
- Confidentiality
- Establishing rapport
- Active communication
- Clear & effective information giving
- Needs assessment/exploring options
- Problem solving and action planning
- Boundary and disclosure issues
- Grief & Loss, self care

7

Dimensions of Empowerment

- **Capacity Building & Skills Development:**
  - Treatment literacy
  - Peer Counseling Skills
  - Facilitation and presentation skills
  - Advocacy skills

8

Dimensions of Empowerment

- **Evolving Roles:**
  - From Student/Service user to
  - Collaborative curriculum planner to
  - Peer trainer/educator to
  - Peer mentor to
  - Service provider

9

Dimensions of Empowerment

- **Resources Enhancement:**
  - Honorarium for participating
  - Contracts as peer facilitators and educators
  - Part time and full time employment opportunities

10

Outcome:

- 63 graduates from 5 ethno-racial communities
- From the first 46 graduates:
  - 12 became peer educators/facilitators for subsequent series of training
  - 19 got HIV/AIDS/Health sector related jobs
  - Together volunteering for over 70 organizations

11

Experience Sharing

- Calvin Pereira
- Claudette Samuels

12

Why ETSN works:

- Responsive curriculum
- Culturally appropriate and safe space
- Individualized mentorship and support
- Group based peer learning
- Holholistic approach to learning

13

Most importantly, we learn and grow together and created a community!

14

Acknowledgement

Funding Support (past and present):

- ACAP, Public Health Agency of Canada (Ontario Region)
- AIDS Bureau, Ontario Ministry of Health and Long-term Care
- Ontario Treatment Support Network

Program Sponsorship:

- *Gold Sponsors:*
  - GSK Shire BioChem,
  - Tibotec
- *Silver Sponsors:*
  - Abbot,
  - Boehringer Ingelheim,
  - Bristol-Myers Squibb

15

Thomas Egdorf

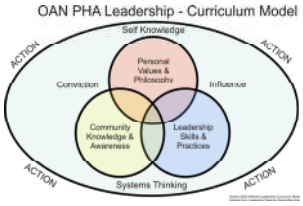
Leadership development is self-development. Engineers have computers; painters, canvas and brushes; musicians, instruments. Leaders have only themselves. The instrument of leadership is the self, and mastery of the art of leadership comes from mastery of the self. Self-development is not about stuffing in a whole bunch of new information or trying out the latest technique. It's about leading out of what is already in your soul. It's about liberating the leader within you. It's about setting yourself free.

Author unknown

1

Ontario AIDS Network
PHA Leadership Development
Program Presentation
For: Strengthening
PHA capacity building initiatives
November 16, 2007

2



3

The Theory
"The Leadership Challenge" by Kouzes and Posner

5 Practices of Exemplary Leadership

- Model the Way
- Inspire a Shared Vision
- Challenge the Process
- Enable Others to Act
- Encourage the Heart

Ontario AIDS Network

4

Confidence Building

- Structured Feedback
- Collage Exercise
- Warm up Groups
- Positive Feedback

Ontario AIDS Network

5

What we have accomplished so far

- First Leadership workshop March 2006
- 8 - Level I – Who am I as a Leader
- 3 - Level II - Communications

Ontario AIDS Network

6

Already Planned

- Level I – Who am I as a Leader – February, May and September 2008
- Level II – Communications – April 2008
- Level III – Organizational Governance - December 2007
- Facilitator Training – With ABPO – March 2008

Ontario AIDS Network

7

Wangari Tharao

Health Promotion and Skills Development Project for African and Caribbean Women Living with HIV/AIDS

Presenters
Wangari Tharao and Marvelous Muchenje
WHIWH

Strengthening PHA Capacity Building Initiatives: A Forum to Share Best Practices to Improve Planning and Coordination
November 16th, 2007

1

History of Project:

- Discussions at the B'CAP retreat in 2002
  - Expressions of frustration with service providers
    - Not being listened to
    - Being directed how to disclose HIV status to family and children
    - Not being provided with opportunities to play an active role in their care, service/program development implementation and/or delivery
    - Many years of accessing services but no change in their circumstances
    - Being left on their own to struggle with complex issues/navigating multiple system - partner notification, disclosure, stigma and discrimination related issues etc

2

History of Project (cont'd)

- Many women had a limited understanding of the highly technical treatment information
- Inherently imbalanced provider/client power relations
- Need for a forum where women's issues emerging from service delivery could be resolved

3

History of Project (cont'd)

- Development of pilot a project in 2003/04 (Moving forward)
- Goal of project was deal with issues identified at the retreat
- Who was going to be involved in this project?
  - Partnership between WHIWH and VOICES
  - Funding:
    - Agouron pharmaceuticals/Pfizer Canada
    - AIDS Bureau, Ontario Ministry of Health and Long-term Care
  - Invited the three black ASOs to become partners and later included USIMA Project
  - Casey House – silent partner
- Evaluated project after one year

4

Lessons from the pilot project:

- Location of project was very important for most women:
  - built in organizational systems that are supportive of African and Caribbean women and the choices they make in their lives
  - Incorporation of HIV within a broader framework of service delivery
  - Understand of multiple
- An understanding of realities of women lives:
  - caught between multiple, complex, intersecting oppressive systems and challenges in navigating them
- Need to facilitate a process where:
  - Newly diagnosed women could be integrated into service delivery
  - women needed to understand the role and importance of counselling and psychotherapy

5

Lessons from Pilot Project:

- Needed to expand project to include a skills development component
- More financial resources were needed to implement the project
  - Pilot had been build on participation of only 25 women/session
    - Session 1 - 22
    - Session 2- 31
    - Session 3 - 39
    - Session 4 - 51
  - Child care issues – could not be provided on site
  - Had planned for two hour sessions but more time was needed per session
- Flexibility to accommodate emerging issues
- Need for a formal agreement between the partners with clearly defined roles and responsibilities
- Based on these lessons we developed the current program

6

Goal of Project

- To promote well-being and foster skills development through increased access to information and services for African and Caribbean women living with HIV/AIDS in Toronto and surrounding areas.

7

Objectives of Project:

- To deliver and disseminate information on HIV disease, treatment and other factors that impact on the health and coping abilities of African and Caribbean women living with HIV/AIDS
- To create a support environment and foster skills development for African and Caribbean women living with HIV/AIDS to increase ability to cope with HIV/AIDS after diagnosis

8

Objectives of Project (cont'd)

- To develop and increase access to culturally appropriate and language specific materials for women and their providers

9

Deliverables of project (1)

- 36 workshops/skills building events delivered in 3 years - 1 session per month/12 per year
  - Topics dealt with include:
    - Treatment information – making decisions about treatment – when to start and why, types of treatment available including alternative therapies, etc
    - Sexuality, sex and sexual expression
    - Employment – skills building programs available, accessibility
    - Child bearing and rearing issues
    - Disclosure of HIV to children, partners and family members
    - Partner notification, moral and legal implications of failure to disclose
    - Self care
    - Trauma and impact of dealing with HIV

10

Deliverables of project (2)

- Linking women to existing skills development activities offered by other organizations
- Development of resources:
  - video/DVD
    - Highlight the lives of 8 HIV positive women
    - Prescreening will be held on December 1st – Bloor Cinema
  - poster/post-cards – on prevention of secondary HIV transmission – will be developed in 2008
- Resources will be available in several African languages:

11

Success of project:

- Overcoming barriers that have prevented most black HIV positive women from participating in group activities
  - Created a learning and supportive system for positive women
- Project is driven by the needs of African and Caribbean women living with HIV/AIDS
- Involvement of HIV positive women in all aspects of the project – development, implementation, delivery and evaluation of project activities

12

Success of project (cont'd)

- Model of service delivery is flexible and allows incorporation of emerging issues and perspectives of women
- Partnership between participating organizations:
  - Roles and responsibilities are defined,
  - Partnership agreement has been signed – this has facilitated organizational management of project with support from all project partners

13

Success of project (cont'd)

- Stable financial resources for three years
- Support from the HIV positive women targeted by the project
- Making Links with other projects
- Lead organization (WHIWH) has capacity to provide administrative and other supports required by the project

14

Simone McWatt

Strengthening PHA Capacity Building Initiatives Forum

Friday, November 16th, 2007

Presented by
Tony Caines & Simone McWatt
AIDS Prevention Community Investment Program (APCIP)
Toronto Public Health

Toronto Public Health

1

AIDS Prevention Community Investment Program (APCIP)

- Established by City Council in 1987

Goal:
- To fund projects that will provide strategic and time limited targeted initiatives to influence behaviours and situations that put people at risk of acquiring HIV thereby reducing HIV transmission.

Objectives:
- Decrease behaviours that put people at risk for HIV infection;
- Enhance access to HIV/STD prevention and sexual health promotion messages;
- Address social and economic factors related to discrimination, poverty, race, sexual orientation, culture, gender, language skills, age, physical or mental ability, seropositivity, etc.

Toronto Public Health

2

APCIP Review Panel

- The Toronto Board of Health is seeking new members for its AIDS Prevention Community Investment Program Review Panel
- The panel reviews applications for prevention and education projects and makes funding recommendations to the Board of Health and City Council.
- Interested persons must reside in the City of Toronto
- We hope to hear from individuals from racial and ethnic minority communities; people with disabilities; women; Aboriginal people; lesbians and gays; immigrants/refugees; **and individuals who are living with HIV or AIDS.**

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3

2006-2007 Funding Period

Number of projects funded	**51**		
Total amount allocated	**$1,513,800**		
Completed workshops	**1,849**	Participants	**35,152**
Outreach Activities	**4,673**	Contacts	**676,018**
Peers – recruited	**131**	Peer Hours	**16,576**
Volunteers -recruited	**368**	Volunteer Hours	**26,093**
Resources/Publications	**13**	Media Interviews	**138**
Full Time Equivalents (Based on 35 hour week)	**28.87**		

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4

ASOs that receive APCIP funding

- APAA (Africans in Partnership Against AIDS)
- ASAAP (Alliance for South Asian AIDS Prevetion)
- ACAS (Asian Community AIDS Services)
- Black CAP (Black Coalition for AIDS Prevention)
- PASAN (Prisoners with HIV/AIDS Support Action Network)
- Toronto People with AIDS Foundation (PWA)
- Voices of Positive Women (VPW)

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5

"The Pink Pages" All APCIP funded groups, projects & activities

www.toronto.ca/health/aids_resources

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6

2 Examples of APCIP Funded Projects that Strengthen PHA Capacity

- **PWA**
- **Voices of Positive Women**

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7

PWA

Employ a Speakers' Bureau Coordinator to:

•Recruit, train and support 5 new HIV positive volunteer speakers who represent underserved communities including women and African and Caribbean communities to provide citywide HIV/AIDS workshops and outreach initiatives that target service providers and youth;

•Train and support 15 HIV positive volunteer speakers;

•Provide a minimum of 225 citywide HIV/AIDS workshops and outreach initiatives;

•Produce and distribute promotional materials that highlight the the Speakers' Bureau.

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8

AIDS & Drug Prevention Community Investment Programs 2008-2009 Proposal Writing Workshops

This year there is a NEW application for both programs!
This workshop will:
•Give you information about the new application
•Offer tips for strengthening your application
•Offer some guidelines for concise proposal writing
•Answer your questions
A guest speaker will provide information on effective writing.

Thursday, December 6th, 2007
1:00 p.m. – 4:00 p.m.
Metro Hall Room 310

Wednesday, January 9th, 2008
9:30 a.m. – 12:30 p.m.
North York Civic Centre
Cmt. Room 3

Toronto Public Health

9

Questions? Contact Us!

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Toronto Public Health

10

Michael Johnny

Knowledge Mobilization and Community Capacity Building

Michael Johnny
Manager, Knowledge Mobilization, York University
November 18, 2007

research impact 1

1

What is Knowledge Mobilization?

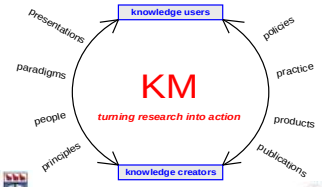
Knowledge has greater value when it is shared and implemented. Knowledge Mobilization (KM) is the active, two-way exchange of information and people between knowledge users and knowledge creators.

research impact 2

2

Goal of Knowledge Mobilization (KM)

To develop a culture of partnership between academic researchers and decision makers in governments and community organizations to assist in strengthening the development of public policy, professional practice and social programming.



research impact 3

3

KM: Building Partnerships for Policy & Practice

Spaces
- -KM in the AM
- -Knowledge Expo
- -Research Forums

People
- -graduate student internships
- -P2P KM group
- -KM Seminars

Partnerships
- -research translation
- -incentive grants
- -community engagement
- -literature reviews
- -matching funding

Success Stories

Mental Health in York Region

MMAH Think Tank

York-CPRN-SHSC Partnership

Ben Levin Seminar

StreetKids International

Aboriginal Transitional Housing

research impact 4

4

KM Collaborations with the HIV/AIDS Community

HIV/AIDS Among African Communities in Toronto

- Project designed to reduce factors to impede access to proper HIV/AIDS education
- Improving education and information into the community

KM Internship: National Consultation on Canada's Global Response to HIV/AIDS

– Development of a consultation document aimed to expand stakeholders' understanding of Canada's global engagement on HIV/AIDS

research impact 5

5

Michael Johnny
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http://www.researchimpact.ca

6

Appendix E – Evaluation Results

72 people Registered – 42 Evaluations = 58% Return

1. a) How did you hear about this forum?

Email direct from organizers	Email from a colleague	Invite Posting	Word of mouth	Other:
43%	21.5%	12%	21.5%	2%

b) I attended the workshop as a…

PHA	ASO Employee	Volunteer	Healthcare provider	Other:
47%	21%	7%	11%	14%

c) Gender -

Female	Male	Trans
61%	39%	0%

d) I would describe my background as (ie. African, Caribbean, South Asian etc.):

African	28%
European	7%
Canadian	20%
None	9%
Caribbean	14%
Caucasian	8%
Asian	8%
Other (Greek, Latin, East European, East Asian)	6%

2. This one day forum met my expectations.

strongly agree	agree	somewhat agree	somewhat disagree	strongly disagree
55%	26%	19%	0%	0%

3. I have a better understanding of what parts of existing capacity building initiatives work well.

strongly agree	agree	somewhat agree	somewhat disagree	strongly disagree
44%	29%	24%	3%	0%

4. The forum expanded my knowledge and understanding of the different types and models of capacity building programs.

strongly agree	agree	somewhat agree	somewhat disagree	strongly disagree
41%	33%	24%	2%	0%

5. I learned about innovative approaches to capacity building programs.

strongly agree	agree	somewhat agree	somewhat disagree	strongly disagree
36%	32%	30%	2%	

6. I have a better understanding of the challenges of implementing PHA capacity building programs.

strongly agree	agree	somewhat agree	somewhat disagree	strongly disagree
55%	23%	15%	5%	2%

7. It is important that PHAs are fully involved in all aspects of implementing capacity building programs in meaningful ways.

strongly agree	agree	somewhat agree	somewhat disagree	strongly disagree
81%	11%	8%	0%	0%

8. I learned about things we need to do better that will support capacity building programs for PHAs.

strongly agree	agree	somewhat agree	somewhat disagree	strongly disagree
55%	23%	18%	2%	2%

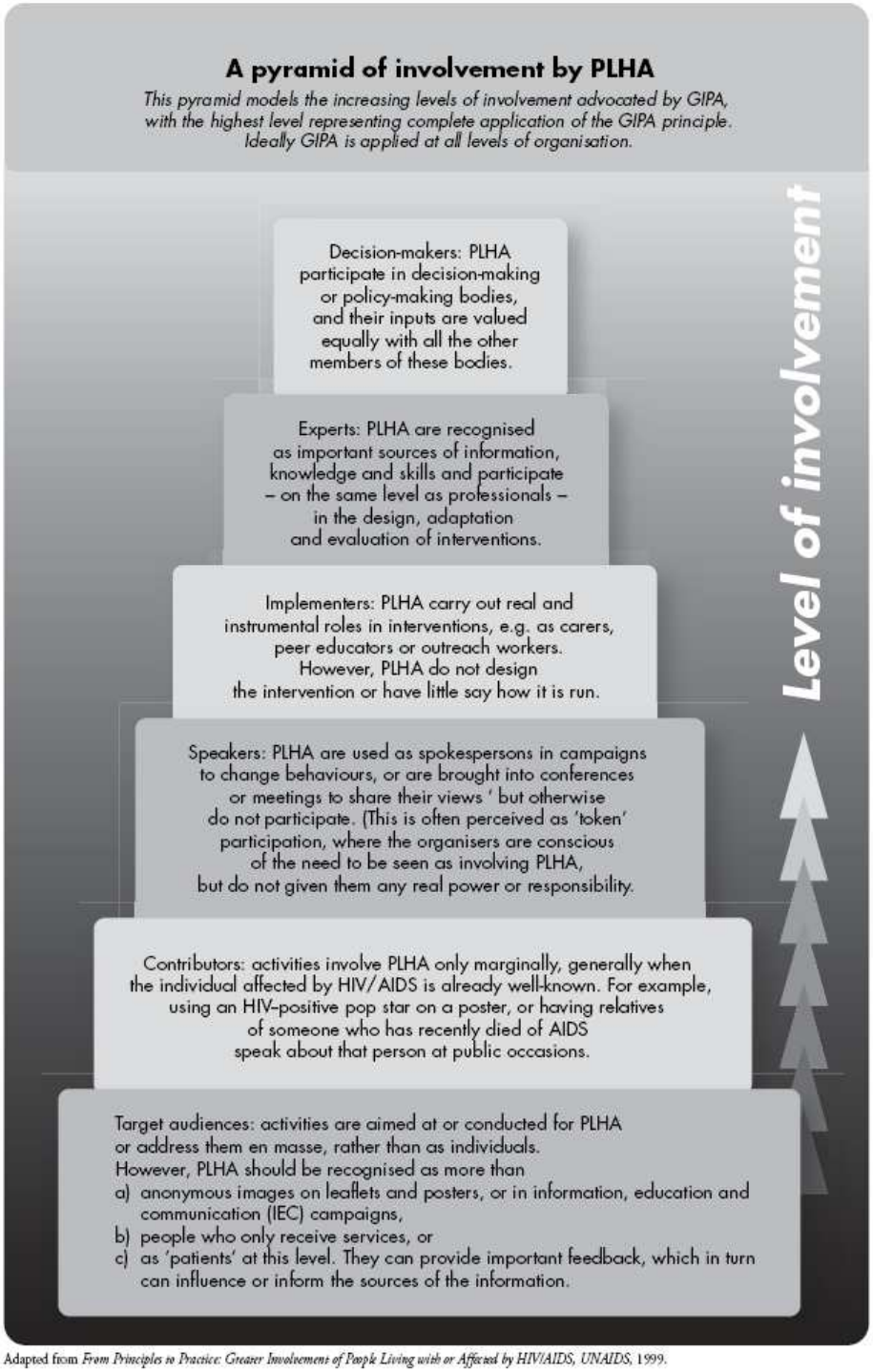
9. What did you like most about the forum?

- Diversity of the participants
- Networking
- Information sharing
- The opportunity to express my opinion
- Safe environment for input from diverse groups with common focus towards strengthening PHA capacity building
- Incorporation of humor with serious nature of forum made it more comfortable for people to participate
- Well organized
- Good food
- Morning session on current programs
- Strategizing on how to move directly into action planning instead of creating a policy document that will sit on the shelf
- I feel like I can get involved
- Small group discussion & Sharing of stories was great

10. What did you like least about the forum?

- This forum needed more time for participants to give their views and ask questions
- Too much/so much to be learned in one day
- Cold room
- Diversity… balance of long term survivors was not really in the room
- Concurrent breakout groups meant choosing a subject…
- Second panel was weak and the time could have been better spent in small group discussions
- More focused report back from small groups
- Did not follow times on the agenda – not respectful of people's time!
- Wrap-up was fast, unrealistic and unclear
- Clearer explanation of how this process links to other processes
- More focus on the building of relationships and collaborations

Appendix F – GIPA Principles



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