

POSITIVE CHANGE MAKERS
AN IMPACT EVALUATION OF THE
Ontario AIDS Network
LEADERSHIP DEVELOPMENT PROGRAM
January 6, 2010



Production of this evaluation report has been made possible through a financial contribution from the Public Health Agency of Canada. The views expressed herein do not necessarily represent the views of the Public Health Agency of Canada.

The Ontario AIDS Network gratefully acknowledges the support of the Ontario Trillium Foundation:



Research Team

Research Consultant and Writer
Mary Tangelder
Director, Spire Consulting

Co-principal investigators:
Shelley Cleverly
Director of Community Based Research
Ontario AIDS Network

Thomas Egdorf
Director of PHA Programs
Ontario AIDS Network

Co-investigators:
Brian Costey
Research Assistant
Ontario AIDS Network

Marisol Desbiens
Research Assistant
Ontario AIDS Network

Rick Julien
Research Assistant
Ontario AIDS Network

Claudette Samuels
Research Assistant
Ontario AIDS Network

Table of Contents

A. Introduction	6
Program Structure	7
Background to the Impact Evaluation	7
B. Purpose of the Evaluation	7
C. Research Methodology	8
D. Study Participants	111
E. Results	144
E1. Journey Into Leadership	146
E2. Meaningful Involvement of Persons Living with HIV	177
E.3 Diversity in Application of Leadership Principles	21
E.4 Factors that Facilitate or Inhibit Leadership Development	23
F. Recommendations for Improvement	26
G. Concluding Remarks	27

Executive Summary

The *Leadership Development Program* (now known as the Positive Leadership Development Institute since the commencement of the partnership with the Pacific AIDS Network in 2009) was launched in 2006 with the purpose of supporting people who are HIV positive to realize their leadership potential and increase their capacity to participate meaningfully in community life. The program fosters a collaborative model of leadership—also known as a shared, collective or distributive model—which is grounded in shared values of individuals, the diverse actions of leaders, and their capacity to collectively act upon a shared vision.

In February 2009, The Ontario AIDS Network initiated an evaluation of The Leadership Development Program in order to assess the Program’s impact over the last three years. The purpose of the impact evaluation was to assess and document the impact of the program on the lives of individual participants, their communities, and the HIV/AIDS sector in Ontario. The study was also designed to both examine facilitating and barrier conditions that influence participants’ ability to use their leadership skills to take action, and to identify areas for program development.

This study is grounded in a participatory action research model. The approach included 20 in-depth telephone interviews; an electronic survey that was completed by 65 Leadership Program graduates out of 175 graduates that received the survey (a 37.14% response rate); and an electronic survey that was completed by 31 out of 107 staff (a 28.9% response rate) from 46 AIDS service organizations across Ontario. The use of multiple data sources allowed for examination of paradoxes, contradictions, and similarities among data sets.

The findings from each set of study participants were overwhelmingly positive. On an individual level, results showed that the Leadership Program is having a deep impact on the lives of graduates. The program improved participants’ confidence about disclosing their HIV status. For some, increased confidence to disclose helped them to step into new leadership roles (such as public speaking) and combat feelings of internalized stigma. Many participants also reported that the program led them to pursue other development opportunities.

Eighty percent of graduates reported a greater sense of self-worth as a result of taking the Leadership Program; and 78.6% of ASO respondents reported observing this among graduates. Eight-five percent of graduates reported improved confidence; and 92.9% of staff indicated they had observed improved confidence among graduates. As well, 71.7% of graduates reported improved ability to give feedback, however 32.1% of ASO staff noted they had observed this.

Study participants also reported that the Program has had an impact in the communities in which graduates live and work. The experiences and perspectives shared by Leadership Program graduates and ASO staff indicate that the Leadership Development Program is having a powerful impact among many people living with HIV/AIDS (PHAs) within Ontario, mobilizing graduates to be dynamic and active change agents within their communities. Data showed that graduates expressed diverse leadership styles, and the diversity and breadth of examples of “leadership activities” indicate the many forms leadership can take. Furthermore, data indicate that the number of Leadership Program graduates participating in AIDS Service Organizations (ASOs) is increasing: 75% of ASOs reported having 1-5 graduates participating in their organization, and 11% reported having more than 20 graduates participate. While data indicate that a growing number of Leadership Program graduates are participating in the work of their ASO, perhaps a more significant change is the quality and type of volunteer contributions graduates are making. Inter-

viewees were unanimous in their perception of how the program has influenced the quality of their volunteering. They reported that the program provided them an opportunity to refine their goals, skills, and develop more motivation and confidence to take action in their community.

Another important change is the high percentage of graduates reporting more meaningful involvement in the HIV/AIDS movement: 75% of graduates reported that they felt “a lot” or “moderately” more meaningfully involved in the HIV/AIDS movement. The majority of ASO respondents reported in the open-ended responses that the Leadership Program contributed to more meaningful involvement of PHAs, including volunteering, board work, outreach and education, and even leading to employment.

Study participants reported a number of factors that facilitated their capacity to apply their leadership skills. All graduates indicated that the Leadership Development Program formed a “community of leaders” that enables them to problem-solve, develop ideas, access support and encouragement, gather information, and identify ways to work together to create change. Supportive ASOs also played an important role in facilitating opportunities for the application of leadership skills. Learning how to participate in decision-making structures (specifically board work) was recognized as an important strategy for influencing policy.

When asked to identify potential barriers to application of leadership skills, many study participants identified the lack of volunteer or employment opportunities after graduation and the need for more personal support after graduates have completed the program. Study participants were almost unanimous in their recommendation to expand the Leadership Development Program. While the program has a diversity of participants, many study participants indicated that plans for expansion needed to involve those marginalized groups not yet fully represented.

Data indicated that more work is needed to strengthen links between the Program and ASOs, and more investigation is needed to understand what other barriers are preventing Leadership Program graduates from having access to employment or volunteer opportunities.

Data indicate that a number of programmatic features have led to the Program’s success. The first is the structure of the program itself: all participants indicated that Level I training, with the focus on identifying core values and personal leadership capacities was an important--and for many—transformational and empowering experience. Another important feature of the program is facilitation by PHAs for PHAs. Graduates noted that this structure helped to create an emotionally safe space for participants to share personal experiences and challenges, a greater sense of empowerment, and reduced isolation.

This report marks an important contribution to OAN's understanding of how the Leadership Development Program is impacting individuals and communities across Ontario. While evidence strongly indicates that this program is making a vital contribution to the meaningful involvement of PHAs, there are still gains to be made. It is hoped that the findings presented in this report will generate dialogue about how to further support leadership development across Ontario.

A. Introduction

In 2006, The Ontario AIDS Network (OAN) launched the Leadership Development Program. The aim was to support people living with HIV/AIDS (PHAs) to realize their leadership potential and increase their capacity to participate meaningfully in community life. The impetus for the development of this leadership development program grew from the need to actualize The GIPA Principle (Greater Involvement of People with HIV/AIDS) developed at The Paris Summit (1994). The program also grew from a belief that authoritarian or “top-down” approaches to leadership have little currency in a world that demands innovation, creativity and supportive networks to tackle increasingly complex social and health issues.

The approach to leadership adopted by OAN starts from the belief that “leadership” does not belong to a small group of charismatic individuals, but rather that everyone has the capacity to be a leader in his or her own way. The program fosters a collaborative model of leadership—also known as a shared, collective or distributive model—which is grounded in shared values of individuals, the diverse actions of leaders, and their capacity to collectively act upon a shared vision. A workgroup was formed to further articulate and inform the vision:

Thomas Egdorf - Director of PHA Programs, Ontario AIDS Network

Rick Kennedy - Executive Director, Ontario AIDS Network

Steve Harris – PHA Caucus Co-Chair, Board of Directors, Ontario AIDS Network

Joseph van Veen - PHA Caucus Co-Chair, Board of Directors, Ontario AIDS Network

John Hatchett – PWA, consultant in leadership training, New York, New York.

Yvette Perreault – Director AIDS Bereavement Project of Ontario

Diana Drackley – Consultant in Volunteer Management and Leadership

Thomas Egdorf, Diana Drackley and Ed Argo developed the Ontario AIDS Network’s Leadership Program, in part by drawing on and adapting materials in *The Leadership Challenge* (Kouzes and Posner, 2003).

Program Structure



The program offers participants three levels of leadership development. The first level called “Who am I as Leader” forms is the core component, while the other two levels focus on building practical skills and knowledge to help leaders take action in their communities.

Background to the Impact Evaluation

In February 2009, The Ontario AIDS Network planned an impact evaluation of The Leadership Development Program. The previous program evaluation activities have captured and documented the outcomes of the Program (Weir, 2008), however, still undocumented was the program's impact. Through informal means, the OAN learned about the Program's positive and profound impact in the lives of program participants. For example, many individual participants had casually reported their personal growth and involvement in new activities that were consistent with having greater and more meaningful involvement in the HIV movement. As well, there was a high demand for the Program, and some community agencies reported that graduation from the Leadership Development Program would be considered an asset for paid staff positions. Staff members of the Ontario AIDS Network were also informally aware that some Leadership Program graduates encountered barriers as they tried to apply their new leadership abilities in their communities.

With this information, and having offered the program to nearly 200 graduates since the Program's inception, there was a strong desire to formally assess the Program's impact formally. Staff at the Ontario AIDS Network designed the impact evaluation, hired and trained research staff, and worked closely with the independent research consultant to carry out the impact evaluation. The remaining sections of this document outline the purpose, methodology and results of the impact evaluation.

B. Purpose of the Evaluation

The purpose of the impact evaluation of the PHA Leadership Development Program was to assess and document the impact of the program on the lives of individual participants, their communities, and the HIV/AIDS sector in Ontario. The study was also designed to examine facilitating and barrier conditions that influence participants' ability to use their leadership skills. The final aim was to identify areas for program development.

The objectives of the impact evaluation were to:

- profile 20 graduates of the Leadership Program in a plain language report on the impact evaluation (and offered in coffee-table book format);
- describe socio-demographic characteristics of Program participants;
- document personal-level changes that can be attributed to the Leadership Program (e.g. mental health, sense of self-worth, employment, education, seeking new challenges in life, personal goal setting);
- document community-level changes that can be attributed to the Leadership Program (e.g. at AIDS Service Organizations (ASO) elsewhere in the HIV/AIDS sector; in the community outside the HIV/AIDS sector);
- understand participants' journeys into leadership (e.g. what leads an individual to take the Leadership Program, and what other learning or growth opportunities do participants take on as a result of taking the Leadership Program);
- learn about the facilitating and barrier conditions that influence graduates' capacity to use their skills;

- assess the manner and extent to which the Leadership Program has influenced the greater involvement of people with HIV/AIDS (GIPA), and the meaningful involvement of people with HIV/AIDS (MIPA);
- identify areas for future program development; and
- support skill building of the four co-investigators who worked as research assistants on the project.

C. Research Approach and Methodology

An action research approach was used for this impact evaluation. Action research seeks to:

engage participants in reflection in order to support them to explore, challenge, and respond to the needs within their communities; ensure that the knowledge generated through this study will translate into action; and

The following sections outline key steps of the methodology used for the impact evaluation.

Support and Involvement of Research Assistants

The research assistants received training sessions and ongoing support throughout the various phases of the research. A one-day training event was offered to address the following topics: 1) overview of research methods; 2) research ethics; and 3) interviewing skills. The research assistants participated in the refinement of the interview guide and the consent form, scheduled interviews, managed the consent and confidentiality protocol, and conducted all interviews.

For the electronic surveys, the research assistants were trained to collect and enter survey data collected by telephone when participants didn't have computers, email access, visual ability, or sufficient written English language skills. They also sent reminder messages by email to all potential survey participants to help facilitate participation in the survey.

Data Collection Procedures

This study used a mix of qualitative and quantitative methodologies. Data collection activities included in-depth interviews with a subset of Level II and Level III Program graduates, electronic surveys of all program participants, and electronic surveys of selected staff in all of the OAN's member organizations across Ontario.

In-depth Interviewing of Program Participants

The in-depth telephone interviews were designed to support participants to share their stories and experiences related to the impact of the Leadership Program.

The interview guide was developed to gather rich qualitative data that would reveal detail and texture related to the purpose of the study.

The interviews were designed to last about one hour, though in reality they lasted between 40 to 90 minutes.

In an introductory email, potential participants received information about the study, and a copy of the consent form. They were then approached by telephone to assess their willingness to participate in an interview, and were given an opportunity to ask questions. They were also given an opportunity to discuss the consent form. If they were willing, an interview date was set and they faxed back their signed consent forms. The interviews were conducted by telephone and tape recorder. Care was taken to ensure participants' privacy was maintained.

Electronic Survey of Program Participants and AIDS Service Organization (ASO) Staff

Electronic surveys were developed to gather quantitative information from Leadership Graduates and ASO staff. Qualitative questions were included to validate and/or augment the qualitative data gathered through in-depth interviews.

The electronic surveys were sent out to the appropriate group, along with follow up reminder messages.

Sampling Framework

The following outlines the sampling procedures.

Survey of Leadership Graduates

Leadership Program participants were known to vary considerably in their socio-demographic description, their completion of the various components of the Program, their geographic distribution, and their experience of taking the Leadership Program. As well, since the electronic survey instrument readily supported a high level of participation, it was decided that the sampling frame for the Leadership Program participants would be all 175 Program graduates.

Interviews of Leadership Graduates

In addition to the 175 graduates surveyed, a sampling frame was developed to include 20 graduates of Level II and Level III who reflect the range of socio-demographic qualities held by the larger group of Leadership Program participants. Age, gender, sexual orientation, culture, geographic location in Ontario, and level of education were the criteria used. The interviewees were also sampled in relation to their willingness to be profiled in a separate plain language ‘coffee-table book’ style of impact evaluation report. A sample of twenty interviewees was thought to be sufficient to provide saturation of the data.

Survey of Selected Staff in Ontario’s AIDS Service Organizations

The Ontario AIDS Network has a membership of forty-six AIDS service organizations located in communities all over Ontario. Because program participants live in communities all over Ontario, and since three types of staff were thought to have the greatest knowledge of the impact of the PHA Leadership Program, the sampling frame for the second electronic survey included Executive Directors, Support Workers and Volunteer Coordinators (where these positions exist) in all forty-six-member organizations. The surveys were sent to a total of 107 ASO staff (46 Executive Directors, 33 Support Workers, and 28 Volunteer Coordinators).

- **Quantitative Analysis**

The survey data were collected using online survey software called Survey Monkey. This software automatically analyses data according to a standard approach as well by allowing the user to prescribe terms of analysis. Since the twenty interviewees were invited to participate in the survey, the survey included a question that asked participants to indicate whether they had participated in the interview. This question allowed data analysis options. Specifically, the data could be examined as one large set, or it could be analyzed after separating the interviews from the larger data set (to avoid duplicate information). The quantitative data from the Leadership graduate survey were analyzed as one data set to create a socio-demographic description of all participants and to summarize data on survey questions which were unique to the survey. The analysis of the ASO staff survey data was done automatically by Survey Monkey on the whole group of participants.

- **Qualitative Analysis**

All interview data were transcribed, and transcriptions were coded, analyzed, and organized into themes. Qualitative data from the surveys of Leadership graduates and staff in AIDS Service Organizations were reviewed to support validation of the interview data. The qualitative data from the survey of Leadership graduates was separated out of the larger data set for this part of the analysis (to avoid duplicate information). Since the response rate and the level of detail were low for the qualitative questions in the survey, a full analysis of these data was not conducted.

- **Triangulation and Validation**

The use of multiple data sources allowed for examination of paradoxes, contradictions, and similarities among data sets.

D. Study Participants

There were three sets of study participants. The first set of study participants were 20 Level II or Level III Leadership Graduates who participated in the telephone interviews. These participants reflected a range of socio-demographic characteristics. Of the 20 participants, 12 (60%) identified as male and 8 (40%) identified as female; 12 (60%) identified as homosexual, 8 (40%) identified as heterosexual. Interviewees reflected a range of educational history: one person (5%) reported having “some high school”, three persons (15%) had a high school diploma, nine (45%) had a college diploma, and seven (35%) had a university degree. In regards to ethnicity, two interviewees (11%) identified as Aboriginal, five interviewees (25%) identified as African, two interviewees (10%) identified as Hispanic/Latin American, and 11 interviewees (55%) identified as White/European/Caucasian. Interviewees also reflected the geographic diversity: seven were from Central Ontario, two were from Northern Ontario, five were from Eastern Ontario and six were from Southwestern Ontario.

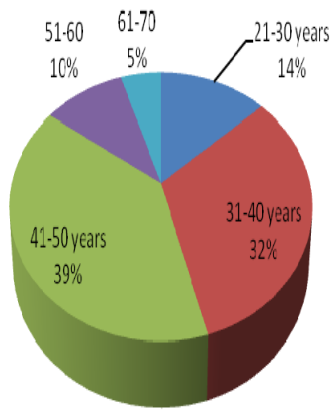
The second set of study participants were Leadership Graduates who participated in an electronic survey. Sixty-five of 175 survey recipients (37.4%) completed the Leadership Graduates survey. Among these were people who also participated in the interviews noted above.

The third set of study participants were staff in AIDS Service Organizations (ASOs) who participated in an online survey. There were 31 responses from 107 survey recipients, a 28.9% response rate.

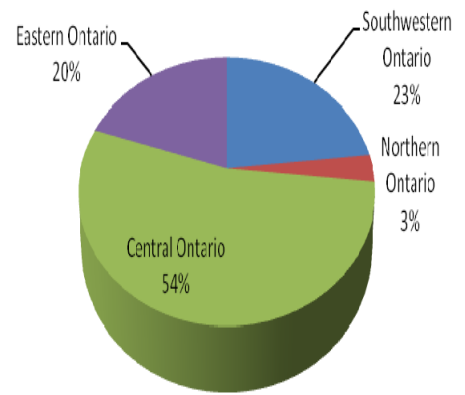
Fourteen ASO staff were from Central Ontario (Toronto), five ASO staff were from Northern Ontario (North Bay, Sudbury, Thunder Bay), five ASO staff were from Eastern Ontario (Oshawa and eastward, also includes Barrie), and seven ASO staff were from Southwestern Ontario (Mississauga and westward).

The following graphs illustrate the socio-demographic characteristics of the Leadership Graduates for the ‘second set’ of research participants noted above.

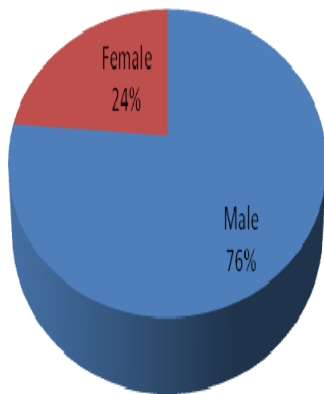
Age of Surveyed Leadership Program Graduates



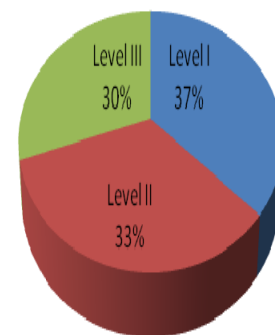
Geographic Distribution of Surveyed Leadership Program Graduates



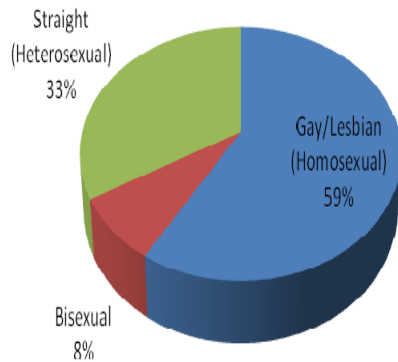
Gender of Surveyed Leadership Program Graduates



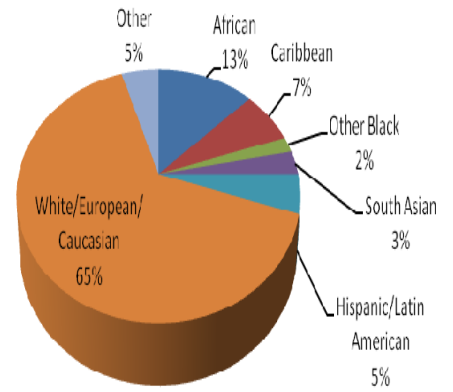
Level of Leadership Training Completed among Survey Leadership Program Graduates



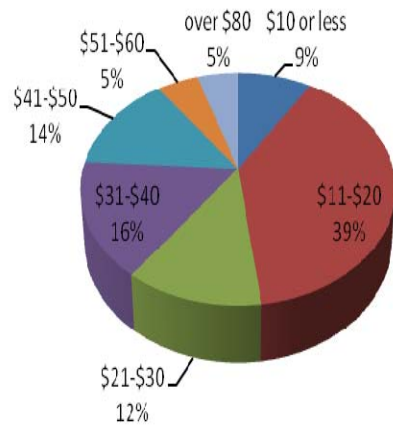
Sexual Orientation of Surveyed Leadership Program Graduates



Ethnicity of Surveyed Leadership Program Graduates



Income Levels of Surveyed Leadership Program Graduates (\$1=\$1000)



E. Results

The survey and interview data described the impact of the program, and yielded insights about how the Program can be further developed. The results, including the quotations, are presented according to the themes that emerged from an analysis of data from all three data sets.

E1. Journey Into Leadership

Interview and survey data generated insight into the different dimensions of individuals' journeys into leadership. These themes are explored in greater detail below.

- **Motivations for Applying to the Leadership Development Program**

"I was really looking for a way that I could develop my own skills, so I could bring more of myself to my volunteering."

- Graduate, Interview

"I came to the Leadership Program as part of learning how to function in a new country. ...and I didn't have that much confidence. I wanted ... to find out how I can go about the whole thing."

-Graduate, Interview

The OAN Leadership Program begins from the principle that everyone can be a leader. Furthermore, being a leader is not about status or identity, but rather about taking action and mobilizing others to also get involved in creating change.

This view of leadership was echoed in participants' motivation to enroll in the program. Leadership Program graduates reported a range of learning opportunities prior to involvement in the program, ranging from completion of grade 10 high school to partaking of professional coaching, personal therapy, workshops, volunteer training, research training or mentorship training. Forty-five percent of Leadership Graduate survey participants indicated that they had participated in three or more such learning opportunities, while 65% of this group reported one to two learning opportunities prior to training.

Regardless of the extent of leadership development opportunities prior to enrolling in the program, study participants reported that they were motivated primarily by the feeling that they could "do more". Participants expressed a strong desire to bring their individual capacities, knowledge, and lived experiences with HIV to their volunteer or professional work in HIV/AIDS activism. Some participants, who were also newcomers to Canada, expressed the desire to learn how to apply the leadership skills they developed in their home country to the Canadian context.

- **Improved Self-Esteem and Confidence**

"People come to us with a confidence level that is not seen in people who have not taken the Leadership Program - both positive and negative serostatus."

-Staff, AIDS Service Organization

“More PHAs have increased self-esteem and self-worth...this has improved mental health. PHAs also have transferable skills they can use elsewhere in their lives.”

-Graduate, Survey

“I know that when I speak with people now about HIV/AIDS, they see the real me, a confident PHA who is able to connect with them. I can now build trust with the audience a lot faster, which leads to a more effective group learning experience.”

-Graduate, Survey

Many Leadership Graduates reported in the interviews that disempowering experiences, such as experiences as client/patient, volunteer, or as a newcomer had led to feelings of apathy, cynicism, and lack of confidence. Interviewees also reported that the Leadership Development Program had a profound impact on their understanding and belief in their own abilities, their self-esteem, and motivation for taking action. All interviewees also reported an improved change in their capacity to speak publicly, share knowledge, and present their opinions.

Interviewees reported that the first program component *Level I: Who am I as a leader?* was a particularly transformative experience, as it provided the opportunity to reflect on and identify personal values, unique capacities and individual strengths. The program deepened their belief and understanding of their own capacity to influence change, and for many, improved confidence and self-esteem, led to improved energy levels and also to greater motivation to take action.

- **New Techniques for Resolving Conflicts**

“I’m able to resolve conflicts better with my partner, with my co-workers; and use active listening skills and just really effectively communicate, whether it’s on a social basis or on a professional basis.”

- Graduate, Interview

In Level I, participants learn how to effectively communicate to resolve conflicts using a technique called “structured feedback”. This technique promotes identifying and sharing positive feedback, using “I statements”, and sharing specific areas for improvement.

All interviewees gave positive responses to learning and using this technique, and many gave detailed examples of how they have used this technique to resolve conflicts in the workplace and at home. Many acknowledged that it takes practice, and identified key steps they took when first utilizing these new ways of communicating and resolving conflicts (such as writing it down first).

- **Increased Comfort with Disclosing HIV Positive Status**

“I don’t step away when people don’t want to talk about it. I remember about a year-and-a-half ago I was out West visiting my family and my sister said “tomorrow if anybody asks what you do, don’t mention where you volunteer - just say that you’re retired and that you’re spending time with your grandchildren”. At that time I hadn’t completed Leadership Program and so the next morning I woke up and I told her I had a migraine and I didn’t think I could go, because I didn’t know how to respond to my sister. Today...if people ask what I do, then I tell them. If my sister has repercussions from it, those are her issues, not mine.”

- Graduate, Interview

“The program has helped me be ‘out’ about my status more confidently. I’ve been ‘out’ pretty much since my diagnosis, but I’ve never felt so much ease in doing so.”

- Graduate, Interview

The decision to publicly disclose one’s HIV status is a highly personal choice that involves weighing potential risks such as termination of employment, social rejection, and other forms of isolation and discrimination, as well as the potential benefits of publicly disclosing one’s health status. Recognizing that disclosure to one’s community is not an option for everyone, interviewees shared that the Program improved their confidence about disclosing their status. For some, increased confidence to disclose helped them to step into different leadership roles (such as public speaking) and combat feelings of internalized stigma.

- **Improved Capacity to Envision the Future and Set Goals**

“I noticed that immediately after I took Level I training, I started working on my communication skills. I started trying...I started taking on new projects, new responsibilities.”

- Graduate, Interview

All the interviewees and the majority of the survey respondents reported that since taking the Leadership Program, they are envisioning new possibilities for their future and beginning to take steps towards accomplishing their goals. Interviewees explained that the capacity to envision a future and to feel excited about new possibilities was a profound change, particularly in light of the life challenges many of them have faced. These challenges included job loss, isolation, stigma and discrimination, depression, poverty, the stress of the immigration process, and the death of loved ones.

For many graduates, a greater sense of hope translated into taking initiative to pursue personal and professional goals. These goals included formal or informal education opportunities, getting back into the workforce, and/or expanding their role as a volunteer. For those who came into the program already highly motivated and with defined personal and professional goals, the program helped them to articulate a clearer plan of action for attaining their goals.

- **Improved Motivation for Volunteering and Ongoing Learning**

Many graduates reported that the program positively impacted their volunteering activities. For some it motivated them to take on additional volunteer responsibilities, and for others, it increased their capacity for meaningful participation in their volunteer activities. For those who couldn't take on new responsibilities due to personal circumstances, the program helped to deepen their commitment to their current roles (e.g. employee, student, or parent).

Many participants also reported that the Program led them to pursue other development opportunities, such as other levels within the Leadership Development Program (if they had not yet completed all three levels), and also facilitating in workshops, giving conference presentations, or joining a speakers' bureau.

Eighty percent of graduates reported a greater sense of self-worth as a result of taking the Leadership Program; and 78.6% of ASO respondents reported observing this among graduates. Eight-five percent of graduates reported improved confidence; and 92.9% of staff indicated they had observed improved confidence among graduates. As well, 71.7% of graduates reported improved ability to give feedback, however 32.1% of ASO staff noted they had observed this.

E2. Meaningful Involvement of Persons Living with HIV

“If it weren't for the Leadership Program, I would still be doing the work that I'm doing, but I wouldn't be able to do it as well. I think that I would be struggling to find my identity, to find my place and where my ideas and my perspectives might actually fit. Now that I've got all those outlets... I'm more effective. I can actually start better conversations. I have access to promote campaigns that I wasn't able to promote before. ... the community definitely benefits because I'm more active.”

-Graduate, Interview

“Things are being decided for you, because 'you don't know any better. When I recommend the Program, I say: “Look, if you're getting tired of being stepped on and pushed down, patted on the head, tapped on the back, go to the Leadership Program. They will give you the skills to say: 'I have a right to say something... I want to be more included in my own life. I should be making decisions...’”

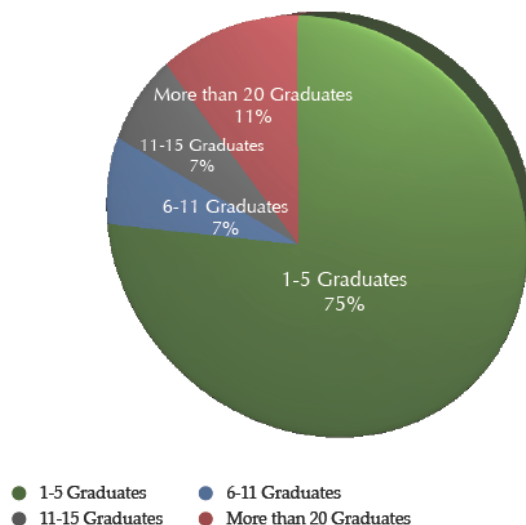
-Graduate, Interview

“They understand the importance of educating those who don't know, or need someone to advocate. They also take much better care of themselves and see themselves as a leader and not someone who has fallen between the cracks.”

-Staff, AIDS Service Organization

Data indicate that the number of Leadership Program graduates participating in AIDS Service Organizations (ASOs) is increasing. The graph below illustrates the percent ASOs along with corresponding level of involvement of Leadership Program graduates.

% of AIDS Service Organizations (ASOs) with Leadership Graduates



When asked if PHAs were more meaningfully involved in their organization as a result of the program, almost all ASO staff indicated that the Leadership Development Program has had a positive influence on the meaningful involvement of PHAs in the HIV sector. Examples of involvement included enriched education programs through graduates’ involvement as facilitators, speakers, and/or involvement on the PHA Advisory Council.

Survey results from ASO staff offered the following:

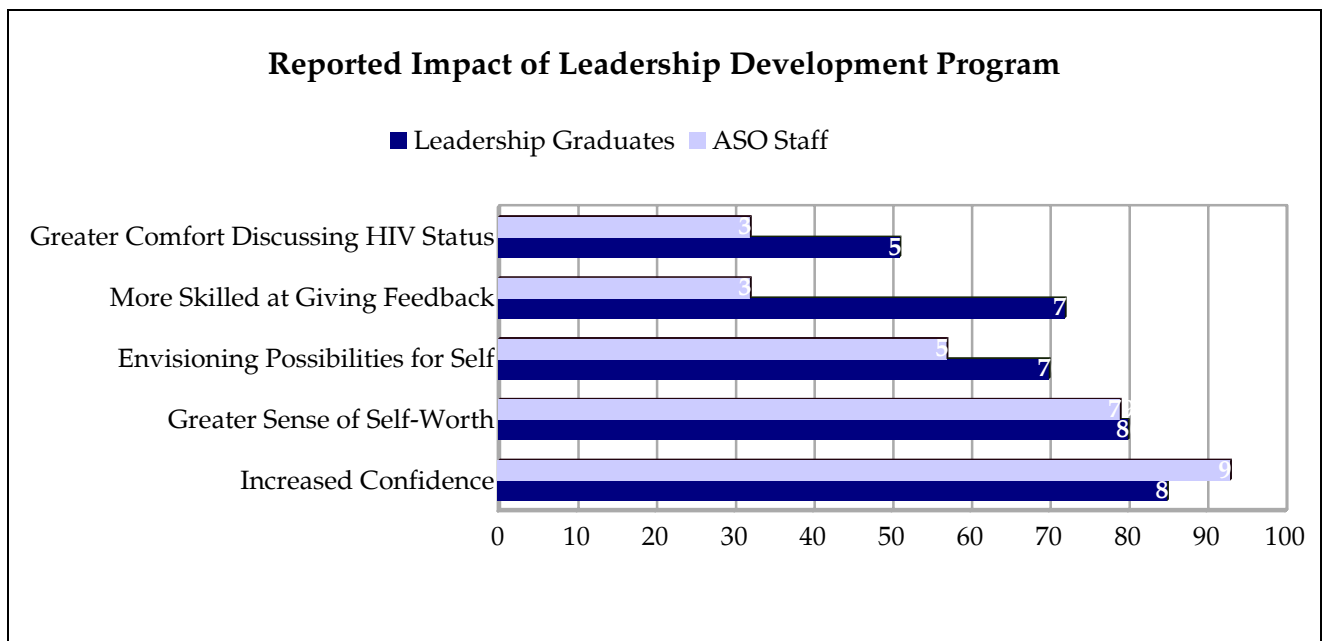
- over two-thirds (69%) of ASO staff reported that PHAs are “more” or “a lot more” meaningfully involved;
- 28% ASO staff reported that PHAs were “a little more” involved, and 3% reported PHAs “not at all” involved.
- one ASO staff person indicated that their negative experience with a leadership graduate has contributed to skepticism about the value of the program itself.

Some ASOs consider the Leadership Program an important part of professional development and give consideration to an applicant’s completion of the Program in their hiring process. However, some ASOs also noted that while this program has had great benefits to the HIV/AIDS community, PHAs have had other types of leadership development experiences outside of the Leadership Development Program, and these experiences should also be considered in the hiring process.

While data indicate that a growing number of Leadership Program graduates are participating in the work of their ASO, perhaps a more significant change is the quality and type of volunteer contributions graduates are making. Interviewees were unanimous in their perception of how the program has influenced the quality of their volunteering. They reported that the program provided them an opportunity to refine their goals, skills, and develop more motivation and confidence to take action in their community.

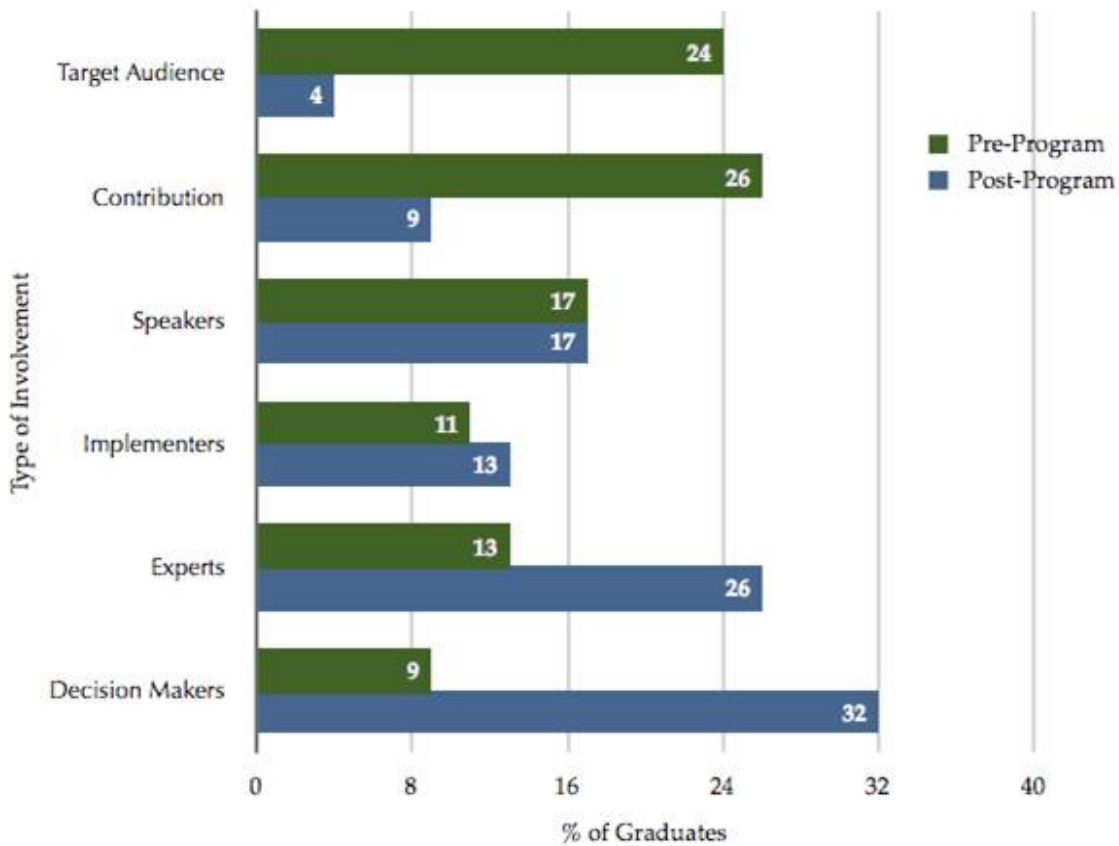
Another important change is the high percentage of graduates reporting more meaningful involvement in the HIV/AIDS movement: 75% of graduates reported that they felt “a lot” or “moderately” more meaningfully involved in the HIV/AIDS movement. The majority of ASO respondents similarly reported in the open-ended responses that the Leadership Program contributed to more meaningful involvement of PHAs, from volunteering, board work, outreach and education, and even leading to employment.

The graph below illustrates how graduates and ASO staff perceive the impact of the program in relation to volunteering and skill development. Both groups reported an increase in volunteering inside and outside of the HIV sector. They also noted an increase in the development of their networks. Sixty percent or more of graduates reported they were taking on new leadership roles and seeking new skills as a result of the Leadership Program.



It should be noted that although some graduates felt that they were not yet as involved as they would like to be, they anticipate becoming more involved in the future. A small number of survey respondents felt that few opportunities existed for them to be more involved than they already were before taking the program. Some interviewees noted that while their own involvement has increased qualitatively or quantitatively, some of their peers may need more support to help them identify how to best apply their skills in their community.

Leadership graduates reported a positive change in their meaningful involvement in the HIV/AIDS movement. The graph below illustrates how survey respondents perceived their involvement prior to and after the Leadership Development Program.



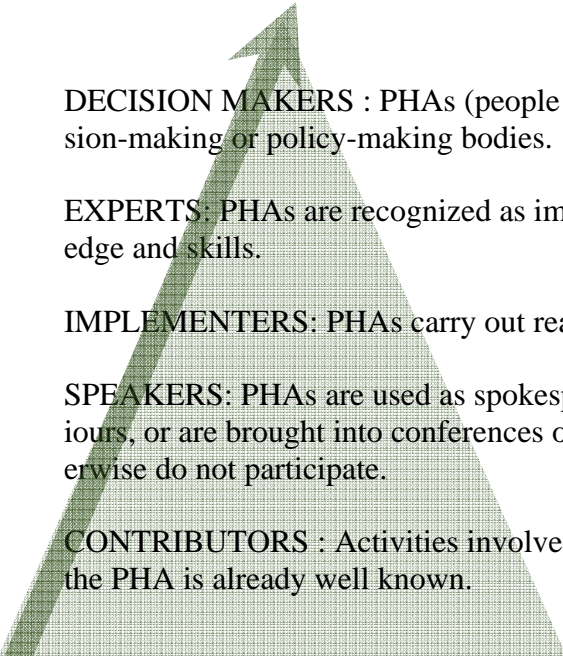
Meaningful Involvement of People Living with HIV/AIDS¹

¹ The UNAIDS (1999) 'key material' From principle to Practice, Greater Involvement of People Living with or Affected by HIV/AIDS (GIPA)

E.3 Diversity in Application of Leadership Principles

“It’s not just me, I see fellow PHAs all around now...out and active...they are coming out of the woodwork. The training’s reputation is strong and others see the difference when we come back to our communities.”

- Graduate, Survey



DECISION MAKERS : PHAs (people with HIV/AIDS) participate in the decision-making or policy-making bodies.

EXPERTS: PHAs are recognized as important sources of information, knowledge and skills.

IMPLEMENTERS: PHAs carry out real but instrumental roles in interventions.

SPEAKERS: PHAs are used as spokespersons in campaigns to change behaviours, or are brought into conferences or meetings to share their views but otherwise do not participate.

CONTRIBUTORS : Activities involve PHAs only marginally generally when the PHA is already well known.

The Leadership Development Program emphasizes that everyone can be a leader and that there are diverse paths to and expressions of leadership. The five leadership practices promoted through the Leadership Development Program are listed below,² and include a summary of the types of activities reported by graduates in the surveys and interviews.

² The Five Practices of Leadership are described in The Leadership Challenge by J.M. Kouzes and B.Z. Posner (2003).

Model the Way means to “find your voice by clarifying your personal values and set the example by aligning actions with shared values.” (Kouzes and Posner, 2003, p. 22). Examples of this practice reported by Leadership Program graduates include the following:

- ✂ Being a role model for others; leading by example
- ✂ Encouraging others to take the leadership program
- ✂ Disclosing HIV status when appropriate and possible
- ✂ Standing up for personal beliefs and opinions

Inspire a Shared Vision means to “envision the future by imagining exciting and ennobling possibilities; and enlisting others in a common vision by appealing to shared aspirations” (ibid). Examples of this practice provided in the data include the following:

- ✂ Tapping into personal resources and resources within the communities, and identifying opportunities to take action.
- ✂ Developing opportunities for self and others to work in prevention, anti-stigma, psychosocial support of PHAs,
- ✂ Sharing knowledge through conferences, research forums communication campaigns, and support groups
- ✂ Supporting ASOs in improving outreach work
- ✂ Advocating for rights of PHAs within their AIDS Service Organization, community, and province
- ✂ Encouraging and supporting others by facilitating workshops and support groups
- ✂ Collaboratively designing workshops; defining shared goals and strategies
- ✂ Creating inspirational messages through art and music

Challenge the Process means to “search for opportunities by seeking innovative ways to change, grow and improve, and experiment and take risks by constantly generating small wins and learning from mistakes” (ibid). Study participants offered the following examples of this practice:

- ✂ Challenging processes and policies
- ✂ Asking questions and seeking clarification when needed
- ✂ Providing evidence of alternative ways of doing things
- ✂ Identifying processes and procedures for taking action
- ✂ Gathering support from one’s peer network to address challenges
- ✂ Using structured feedback to manage conflict and influence positive change
- ✂ Trying not to take things personally when confronted with a challenge

Enable Others to Act means to “Foster collaboration by promoting cooperative goals and building trust and strengthen others by sharing power and discretion” (ibid). Leadership graduates noted the following examples of this practice:

- ✂ Identifying skills/capacities/achievements of others, and encouraging their personal and professional development
- ✂ Facilitating opportunities for others to take a leadership role
- ✂ Encouraging others to take the Leadership Program
- ✂ Enlisting volunteers in new initiatives
- ✂ Encouraging co-facilitation
- ✂ Guiding, instead of directing others through decision-making processes

Encourage the Heart means to “Recognize contributions by showing appreciation for individual excellence and celebrate the values and victories by creating a spirit of community” (ibid). Study participants offered the following examples of this practice:

- ✂ Role model how you want others to act
- ✂ Offer emotional support to others who are facing personal challenges
- ✂ Follow-up with volunteers and workshop participants afterwards to see how they are doing
- ✂ Encourage people to step outside their comfort zone and take on new challenges
- ✂ Remind others that you care about them
- ✂ Trying to practice compassion and empathy

E.4 Factors that Facilitate or Inhibit Leadership Development

In an effort to better understand how to further support leadership among PHAs and to understand the effect of the social environment on the extent of the Program’s impact, all study participants were asked to identify facilitating factors and barrier conditions affecting their capacity as leaders. The following themes emerged related to these factors.

• **Community of Supportive Leaders**

“I just felt this overwhelming feeling of finally, I’m not alone. I really felt like that. I felt there were others out there just like me and I felt so connected to a new network of people.”

- Graduate, Interview

“I’ve been going from small, and with all the support, I’m going big. The program can pull a lot of people out of a period of powerless lethargy, the feeling that there is nothing they can do. Then suddenly---BOOM. Right back in.”

- Graduate, Interview

“[The Program] offers a supportive environment for PHAs to dig deep into themselves and articulate what they would like to be doing in a leadership capacity within or beyond the ASO community. And beyond the digging and articulating, they then learn how to actualize...”

-Staff, AIDS Service Organization

All graduates indicated that the Leadership Development Program formed a strong community that supports their ongoing leadership development. They reported that this “community of leaders” enables them to problem-solve, develop ideas, access support and encouragement, gather information, and identify ways to work together to create change.

An immediate outcome of the program was reduced isolation and a sense of belonging. For many, the program influenced the understanding of “community”, where “community” extended beyond shared experiences and was centred on a shared commitment to taking action and affecting change. This sense of community was cultivated through a number of key activities, including the opportunity to bear witness to each other’s life journeys, celebrate each other’s unique capacities and life paths, and identify and share personal values. Graduates also indicated that the encouragement and supportive, critical feedback given through trainings and events that focused on recognition and celebration of achievements further facilitated a community of support.

- **Supportive Structures**

Graduates reported that their AIDS Service Organizations have played an important role in facilitating opportunities for the application of leadership skills. For study participants, ASO staff demonstrated support through encouraging innovation, being willing to listen to and follow up on new ideas, and recognizing their capacities and contributions. ASO staff also acknowledged the role they can play in supporting leadership development by offering personal support, mentorship, involving leadership graduates in decision-making processes, and simply being willing to listen to new ideas.

- **Identifying Processes for Influencing Change**

Beyond gathering strength, support, and ideas from their community, graduates indicated that it is important to identify processes that will further strengthen their capacity as leaders. Becoming involved in board work was identified as an important strategy for influencing policy. Some participants indicated that at times it is important to self-select out of situations that may be detrimental or even harmful to one’s personal leadership development.

- **Lack of opportunities for volunteering or employment with AIDS Service Organizations**

Many study participants identified that the lack of volunteer or employment opportunities after graduation can be a significant barrier to involvement. ASO staff indicated that there simply are not enough employment opportunities available, and that more support is needed to link graduates to volunteer opportunities. On the other hand, some interviewees suggested that it is important for graduates to take initiative and develop their own volunteer opportunities.

- **Need for more personal support after training**

Responses from both graduates and ASO staff indicate that more personal support is needed for graduates after they have completed the program. Some suggested that a mentorship program, formalized support structure, and training of ASO staff may help to support those who have not been able to find ways to practically apply their leadership skills within their ASO.

- **Lack of acknowledgement for other types of accreditation and experiences**

Some participants, particularly long-term survivors (generally accepted to mean people who tested HIV positive prior to the advent of HAART), indicated that the shift from community activism--where HIV positive people were historically more involved in front-line work—to a social work model or “professionalization” within the HIV/AIDS sector made it difficult for them to find their place in the volunteer sector. Furthermore, newcomers identified some systemic barriers such as lack of acknowledgment of credits or degrees from other countries that made it difficult for them to move into paid positions.

- **Feelings of “Tokenism”**

While many graduates reported that their ASOs have supported their leadership development, some participants reported lack of meaningful involvement in the HIV/AIDS sector. Some ASO staff also acknowledged that more efforts are needed to involve PHAs in other areas of HIV/AIDS work, beyond education and service provision, such as decision-making processes and HIV/AIDS research.

Some graduates reported that lack of meaningful involvement in their ASO contributed to feelings of “tokenism”. Examples of factors that have led to feelings of tokenism centred on an absence of recognition and opportunity: lack of opportunities to influence decision-making, lack of acknowledgements for their contributions, lack of follow-up after offering ideas, or lack of recognition of the knowledge and experiences of long-term survivors. Some participants shared that experiences of tokenism contributed to feelings of helplessness, depression, increased apathy and lack of trust in their AIDS service organization and/or other actors in the HIV/AIDS sector.

- **Need for Improved Access**

While study participants were almost unanimous in their recommendation to expand the Leadership Development Program, many study participants indicated that plans for expansion needed to increase the involvement of marginalized groups among PHAs. Groups identified included Aboriginals, Asians, and long-term survivors.

F. Recommendations for Improvement

The following section presents recommendations for the Leadership Development Program. The recommendations presented here were developed from themes that emerged from the data analysis, as well as from insights gained from working across data sets throughout the course of the study.

The recommendations are the following:

Strengthen links between ASOs and the Leadership Development Program

- Foster understanding of the objectives and content of the Program, and what Leadership Graduates and ASOs can expect after graduation
- Offer individual support to Leadership Graduates after graduation, through mentorship or employment specialists

Program Expansion

- Offer more opportunities within and beyond Ontario for PHAs to take the Leadership Development Program

Extend program content to support ongoing skill development

- Offer additional courses beyond Level III to deepen the understanding of strategies for influencing change
- Suggested topics by study participants: understanding organizational structures that can influence decision-making, communications and advocacy skills for organizing and influencing program and policy.

Identify strategies for involving marginalized populations

- Identify strategies for involving more youth, northern communities, and Aboriginal communities in the program

Develop stronger links between ASOs and Leadership Graduates

- Identify leaders from other agencies to help define roles and responsibilities within ASOs, and create awareness of the capacities of graduates.
- Orient ASO staff about the program, including the approach and course and course content, and strategies for involving Leadership Graduates
- Identify clear links between the staff who supervise and coordinate the Leadership Graduates at ASOs and the Leadership Development Program.

G. Concluding Remarks

Study participants' views about the Leadership Development Program were overwhelmingly positive. The experiences and perspectives shared by Leadership Program graduates and ASO staff indicate that the Leadership Development Program is having a powerful impact among many PHAs within Ontario, mobilizing graduates to be dynamic and active change agents within their communities. That many ASOs acknowledge the positive contributions of graduates indicates that many welcome and benefit from the meaningful involvement of PHAs. However, ASO perspectives also indicate that more work is needed to strengthen links between the Program and ASOs, and more personal support is needed for graduates to identify and pursue volunteer and employment opportunities within and outside their ASO. Furthermore, more work is needed to further understand and address other barriers that are preventing Leadership Program graduates from having access to employment or volunteer opportunities.

The program emphasizes a facilitative model of leadership, whereby leaders identify and draw upon their own strengths and capacities and that of others to take action. This emphasis was echoed in the participants' discussions of the importance of drawing upon a "community of leaders". The breadth and diversity of actions the Program graduates are taking also indicate an understanding that leadership activities can take many forms, such as designing and leading education activities, writing proposals, initiating new activities and programs, participating in ASO boards and advisory committees, and leading support groups, trainings, and workshops. Leadership Program graduates shared the understanding that leadership development is an on-going, life-long process that requires practice and support, and many expressed enthusiasm for moving forward in reaching their personal and professional goals.

The findings indicated that a number of programmatic features have led to the program's success. The first is the structure of the program itself: all participants indicated that Level I training, with the focus on identifying core values and personal leadership capacities was an important--and for many--transformational and empowering experience. This course formed an important foundation to the other two levels of training, which emphasizes developing skills for leaders to take action in their community.

Another important feature of the program is facilitation by PHAs for PHAs. Graduates noted that this structure helped to create an emotionally safe space for participants to share personal experiences and challenges and seek peer support. While many acknowledged that many persons within the HIV/AIDS sector, including ASO staff, would also benefit from the program and may possibly contribute to improved links between the leadership program and ASOs, the "PHA only" policy contributed to greater feelings of empowerment, safety, reduced isolation, and the formation of community.

This report marks an important contribution to OAN's understanding of how the Leadership Development Program is impacting individuals and communities across Ontario. While evidence strongly indicates that this program is making a vital contribution to the meaningful involvement of PHAs, there are still gains to be made. It is hoped that the findings presented in this report will generate dialogue about how to further support leadership development, and contribute to ongoing efforts to meaningfully involve PHAs in the HIV/AIDS movement.