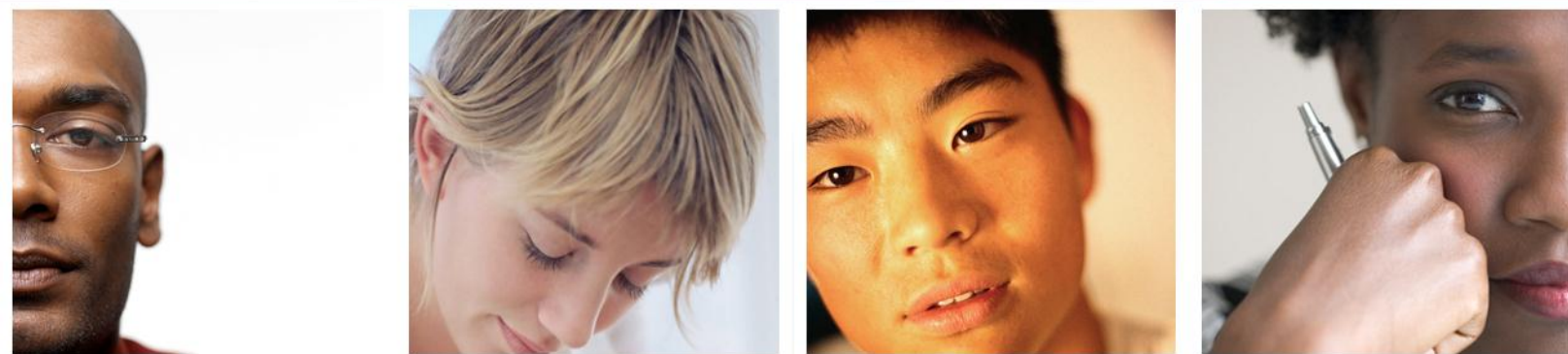


“Everything to Everybody?”

An Environmental Scan of Support Services Provided by AIDS Service Organizations in Ontario

May 2013



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The Environmental Scan Team gratefully acknowledges the guidance and assistance of the advisory committee established by the AIDS Bureau. The committee provided various perspectives of agencies across the province, including suburban and urban areas; north, east and southwest regions; agencies serving different priority populations; agencies with both large and small caseloads; stand-alone agencies; and those linked to other services, such as clinics.

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In Memoriam

This report is dedicated to all the people with HIV who turn to AIDS service organizations for support services, and to the dedicated support workers who continually strive to meet their needs. We would also like to dedicate this report to Patrick Truong, Support Program Coordinator with Asian Community AIDS Services (ACAA) and a member of the Environmental Scan Advisory Committee, who died in February 2012. Patrick, an advocate and caregiver, lived with the challenges of HIV for 26 years. His life and work inspired many.

EXECUTIVE SUMMARY

In 2012, the AIDS Bureau funded an environmental scan of support services provided by 28 AIDS service organizations (ASOs) across the province (see Appendix 1). The scan included a survey and focus groups with support workers, interviews with Executive Directors (EDs) and a survey of HIV outpatient clinics. Here is a summary of the key findings organized under the five objectives of the scan:

1. Understand the scope and range of support services and the challenges and strengths of support services provided at ASOs

ASOs and their support workers are highly committed to the work they do. They are driven by a strong sense of social justice and dedicated to their clients. Most support workers are female, and many are relatively new to their position (62% have been support workers for three years or less). Most have post-secondary education.

Support workers reported providing a range of services; however, the way they defined and delivered those services varied from agency to agency. Despite this variation, a few services consistently emerged as “core services” including practical assistance, referrals, case management, intake and assessment, and individual advocacy. However, these services are not being delivered in a consistent way across the province.

The strengths of the services were their inclusivity and flexibility as well as the strong focus on harm reduction. Workers considered it a strength that their agencies were inclusive and did not turn anyone away, and that they were flexible and willing to adapt programs to meet clients’ diverse needs. Workers also identified the dedication of ASO staff and the blurring of prevention and support services within ASOs as strengths.

In terms of challenges, support workers often felt frustrated and overwhelmed by the increasing demand for services, the continuing stigma, and the difficulty accessing allied services and supports in their communities such as housing and social assistance. Support workers said they struggle to meet complex client needs within available time and resources, and they feel ill-equipped to respond to some particularly challenging problems, such as complex immigration issues, mental health needs and providing services for people within the prison system. In many ASOs, these issues are exacerbated by the fact that there may only be one support worker.

Some workers talked about the dichotomy of balancing their role in providing care and trying to help people meet basic needs versus their role in client empowerment. For example, some identified some clients’ sense of entitlement and expressed concern that the current approach to support services may encourage dependency on the ASO as opposed to being an asset-based or strengths-based approach that helps clients develop the skills to manage their health.

2. Understand the partnerships that ASOs have developed with HIV clinics and identify opportunities to strengthen and expand these partnerships

In general, ASOs and HIV clinics enjoy positive working relationships; however, there is room for improvement. ASOs and clinics would work more effectively together to support clients if there were enhanced communication between the two, including a clear understanding of one another’s roles, mandate and culture, regular meetings to discuss client needs, and a formal partnership agreement that would set out the responsibilities of both partners and improve referrals and communication.

3. Examine the extent to which the GIPA/MIPA (Greater/Meaningful Involvement of People Living with HIV/AIDS) principles and practices are reflected in support services

ASOs are strongly committed to GIPA and MIPA: 36% of the support workers and 48% of EDs who participated in the scan disclosed that they were living with HIV. All agencies reported that they actively recruit people living with HIV to paid and volunteer positions and they routinely engage clients in planning services. Despite the strong commitment to GIPA/MIPA, agencies reported that they struggle to achieve the level of meaningful engagement they would like to see. Reasons include clients not wanting to be actively involved in the agency,

transportation issues, and skill gaps. Even when ASOs are successful in engaging people living with HIV, some reported issues related to boundaries and confidentiality when someone goes from being a client to a peer worker or staff person, and problems accommodating people with HIV who may need more time off work for their health.

4. Identify training priorities for ASO support service providers

In terms of training, support workers wanted to learn more about mental health, de-escalating conflicts and conflict resolution, counselling, case management, immigration and settlement issues, HIV-related legal issues and the co-morbidities that people with HIV experience. Workers in agencies that serve specific ethnic communities wanted more culture-specific counselling and case management training/resources.

5. Examine the turnover of support workers within ASOs and identify strategies to improve staff retention

Staff retention continues to be a concern within ASOs. EDs talked about strategies they use to attract the “right” people to the position who have a mix of training, work experience and lived experience. The main challenges to keeping staff were burnout, boundary issues in the workplace and compensation, which workers said was low compared to comparable positions in other fields. The main strategies to retain staff were strong management and supervision as well as key supports – such as clinical consultation – to help staff manage the stresses of front-line support work. However, only one-quarter of ASOs reported providing regular clinical consultations for staff.

While ASOs should continue to explore effective ways to recruit and retain staff, it is also important for them to be aware of the fact that most support workers see their current position as a step on their career path. Many see themselves working for a few years as support workers and then moving on to other positions in the ASO or in other organizations/fields.

Recommendations

ASOs and their dedicated support workers are committed to providing high-quality services for people living with HIV and to making appropriate referrals to other services in the community. However, many support workers feel overwhelmed by clients’ increasingly complex health and social needs, and by the growing demand for services – particularly in the current fiscal environment, where it would be unrealistic to expect any increase in funding. In the view of the Community Advisory Committee and the representatives of ASOs who guided the environmental scan, many of the challenges identified in the scan – including the variation in how services are defined and delivered, concerns about recruitment and retention, the challenges of operationalizing GIPA and MIPA, and the need to enhance communication between ASOs and clinics (and ASOs and other partners) – may be addressed in the absence of additional funding by clarifying the ASO’s role in providing support, establishing realistic expectations of ASOs and their support workers, and actively sharing and promoting best practices.

The Community Advisory Committee recommends the following strategies:

1. The AIDS Bureau, in partnership with the OHTN Evidence-based Practice Unit (EBPU), should create a Support Services Best Practices Working Group comprised of EDs & support workers to:
 - Develop comprehensive, specific definitions for core support services
 - Identify the minimum core support services that all ASOs are expected and able to provide (with the understanding that ASOs with more resources may provide more than the minimum)
 - Develop minimum provincial standards and guidelines for the core support services that will ensure consistency across the province
 - Develop a manual defining the scope of core support services at ASOs across Ontario and setting the minimum standard that all ASOs are expected and able to provide
 - Create an effective mechanism to share best practices in delivering core services
 - Develop a KTE plan to ensure that staff at all agencies are aware of the manual and have a common understanding of core ASO services (e.g. regional workshops, a KTE day).
2. To ensure effective implementation of GIPA/MIPA across the province, ASOs should:

- Review existing guidelines on how to operationalize GIPA/MIPA (e.g. the OAN's Living and Serving 3) and discuss this issue annually as part of their organizational planning. Implementing GIPA/MIPA is an ongoing process. What works in some regions may not work in others; and incorporating this into a regular planning cycle will ensure ASOs are attending to the ongoing development of GIPA/MIPA.
 - Share the successes they have had in implementing GIPA/MIPA and acknowledge the efforts each has put into involving people living with HIV in their local community.
 - Take advantage of many GIPA/MIPA resources available through the Ontario AIDS Network, the AIDS Bereavement and Resiliency Program of Ontario Turning to One Another Program, or the Ontario Organizational Development Program.
3. To forge stronger relationships between ASOs and HIV outpatient clinics:
 - At the provincial level, the OHTN, in partnership with the AIDS Bureau, should organize a KTE day to highlight the Environmental Scan and provide a forum where clinic coordinators and representatives from ASOs can discuss the needs of people living with HIV and what both clinics and ASOs can and cannot do to address any gaps (e.g. transportation).
 - At the local level, ASOs and clinics should develop formal partnerships, which may include:
 - A written document that describes the responsibilities of both the ASO and the clinic and an agreement to share information between the two organizations
 - Regular face-to-face meetings with clinic coordinators, social workers and ASO support workers to do case consultations for specific clients
 - Identifying effective ways to collaborate to provide services.
 4. To help support staff enhance their skills and manage work-related stress, ASOs should implement some form of clinical supervision for all support staff, such as:
 - Develop formal supervision and mentoring programs where workers can discuss client and organizational issues, workload management, training and support needs, and career goals
 - When supervision or consultation is not available, connect support workers with workers from other agencies with similar titles and work experience for the purposes of support and mentorship
 - Explore cost-effective clinical supervision methods such as peer supervision (i.e. staff-run group sessions)
 - Develop key discussion themes and resources on clinical supervision and supervision in general for EDs at the next ED retreat in cooperation with the OAN Skills Development Program and the Ontario Provincial Resource in Human Resources.
 5. To help address workload issues for support staff, ASOs should:
 - Develop – if feasible – a protocol to actively manage how other agency staff will deal with client emergencies when the support worker is not available due to vacation, sick leave, training days or community development work
 - Encourage balanced work environments - monitor lieu and vacation time regularly to ensure staff are using this time, and support staff are taking this time off as earned.
 6. To ensure that data systems are implemented consistently and are useful for ASOs:
 - The Evidence-based Practice Unit at the OHTN should establish province-wide standards and best practices for record-keeping and conduct a technical review of OCASE to ensure that it is user-friendly
 - EDs should provide leadership in their agencies for consistent data collection and record-keeping, and recognize that record-keeping is an integral part of best practices by planning or mandating time for support workers to enter data and complete other administrative tasks (e.g. no appointments on Friday mornings).

INTRODUCTION

Background

In the early days of the HIV epidemic, community-based activists formed AIDS Service Organizations (ASOs) to provide prevention information to help people – primarily gay men – avoid this new health risk; provide support for the families, partners and friends of people living with HIV (i.e. people affected); and help those infected and, in most cases, dying of AIDS by providing support services such as buddy programs, volunteer drivers, peer counselling, support groups and hospital visits.

In 1996, with the development of highly active antiretroviral therapy (HAART), the support service needs of people living with HIV began to change dramatically. While HIV is still a life-limiting illness, people who receive appropriate treatment can live a near-normal lifespan with the virus. To meet the changing needs of people living long-term with HIV, ASOs now offer a growing array of social support, education, health promotion, practical support, housing, food security, employment, immigration and other programs. The types of services provided vary depending on local needs and the capacity and focus of each individual ASO. In addition, many ASOs have adapted their programming to target populations most at risk of acquiring HIV and to meet the needs of the growing number of people in Ontario with hepatitis C.

Purpose of Environmental Scan

The AIDS Bureau of the Ontario Ministry of Health and Long-Term Care is the core funder of the province's 29 dedicated ASOs. Given the changing demands on ASOs over the past 15-plus years, the AIDS Bureau wanted to understand and describe the scope and range of support services being delivered by ASOs today. ASOs report semi-annually on the support services they provide through the Ontario Community HIV and AIDS Reporting Tool (OCHART). The OCHART report tells us the number of clients served, and the number and type of services provided. Through the Ontario Community-based AIDS Services and Evaluation (OCASE) tool, ASOs are now collecting more detailed information on the type and mix of services that each client receives. However, in the process of collecting and reporting these data, both ASOs and the AIDS Bureau have realized that each ASO provides a different range of support services and describes and defines these services in different ways. Although there are some universal definitions for support services in OCHART, these definitions are open to interpretation and there is no clear understanding of which services are common or core across all ASOs.

To help Ontario ASOs continue to improve the quality and consistency of their support services, the AIDS Bureau funded an environmental scan that will help the field:

1. Understand the scope and range of support services and the challenges and strengths of support services provided at ASOs
2. Understand the partnerships that ASOs have developed with HIV clinics and identify opportunities to strengthen and expand those partnerships
3. Examine the extent to which the GIPA/MIPA (Greater/Meaningful Involvement of People Living with HIV/AIDS) principles and practices are reflected in support services
4. Identify training priorities for ASO support service providers
5. Examine the turnover of support workers within ASOs and identify strategies to improve staff retention.

Based on the results of the environmental scan, the team – in collaboration with the Community Advisory Committee – will identify a common set of core support services across all ASOs in Ontario and develop guidelines for the delivery of these services.

Methods

The team used a mixed-methods approach, which included online surveys, focus groups and key informant interviews to gather data for the environmental scan. Each participant was asked to read and sign a consent form, which included information on the purpose of the project, potential harms, risks or discomforts, benefits of participation, confidentiality and the participant's right to withdrawal. The consent forms, surveys and focus group guide were approved by the McMaster University Research Ethics Board prior to use. All participant recruitment strategies, such as email invitations, were also approved by the McMaster University Research Ethics Board. Participants were informed that their participation would be on a voluntary and confidential basis.

1. Background Surveys of Support Workers

Prior to participating in a focus group, support workers were asked to complete an online survey for the purpose of collecting background information. Collecting this information in advance allowed for the focus group guide to be shorter, and provided more time for support workers to discuss the issues important to them. SelectSurvey.NET, a web-based survey tool, was used. The background survey included questions on agency size, position title, highest level of education, the changing nature of support services, HIV clinic relationships and OCASE administrative procedures. Support workers who agreed to participate in a focus group received the survey through a URL link in an email one week prior to the date of the focus group.

2. Focus Groups with Support Workers

Focus groups were designed to provide a confidential space for support workers to discuss the delivery of support services, including the nature and scope of support services, relationships with HIV clinics, GIPA/MIPA practices, and staffing and career issues (see Appendix B for the guide). The focus group discussion guide was pilot-tested with the first focus group, then reviewed and revised based on the facilitators' notes and the transcript of the focus group. Future focus groups then used this updated guide, making minor changes along the way based on feedback from each focus group.

To recruit support workers, the team sent a generic email invitation to the EDs of all 29 ASOs, asking them to personalize it and forward it to their support workers. Workers interested in participating were asked to contact the OHTN research coordinators (focus group facilitators) directly. Each focus group was an hour-and-a-half to two hours long, and the audio of the discussions was recorded for transcription purposes. Only the focus group facilitators and the environmental scan team lead (Dr. Roy Cain) read the transcripts.

3. Interviews with Executive Directors

EDs were interviewed over the phone. The interview guide covered topics such as the changing nature of support services, pressures faced by agencies in providing support, the relationship between support and prevention services, human resources, HIV clinic relationships, GIPA/MIPA practices and administration practices. EDs were sent an email invitation to participate in these interviews, and those who were interested were asked to provide their availability using an online scheduling tool (Doodle). The interviewers (OHTN research coordinators) would then contact them with a time slot. These interviews took approximately one hour to complete and were recorded using a private teleconference line.

4. Surveys of HIV Clinics

To help understand and assess the relationship between ASOs and the province's HIV clinics, the team created a short online survey for HIV clinic staff. This survey was also created using SelectSurvey.NET. HIV clinic staff were made aware of the survey through their coordinators, who are part of the Outpatient Clinic Network. Clinic coordinators were then sent an email invitation with a URL link from the Manager of Human Resources and Training at the OHTN. They were asked to forward this invitation to other staff who have a direct relationship with a local ASO, such as clinic social workers.

Analysis

After all qualitative responses from online surveys and focus group transcripts were collected, they were compiled and coded in Nvivo 9 software, which categorized participants' responses according to themes. The themes were developed based on the research team's initial questions and the emerging analysis from our findings. Quantitative data collected from the online surveys was compiled using the SelectSurvey.NET's built-in analysis tools, producing bar graphs and detailing percentages.

OUR SAMPLE

1. Support Workers

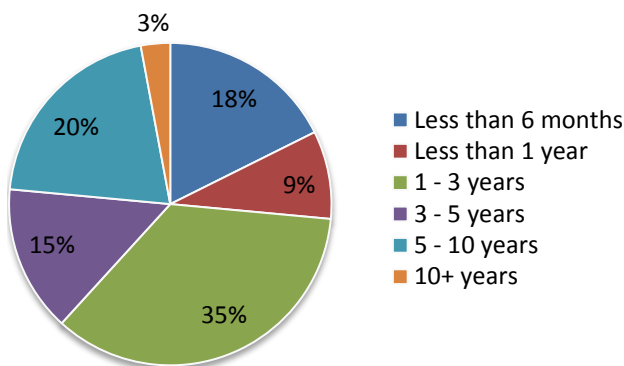
Out of a pool of approximately 200¹ support workers across the province, 45 (23%) expressed an interest in participating in a focus group. Of these 45, 42 participated in the online background survey sent out before each focus group.

The majority (62%) of support workers had worked in their current support services position for three years or less

Of the 42 support workers that participated in the online survey, 34 voluntarily gave information about their employment history. The results indicated that most did not have extensive experience providing support services within an ASO. Although 50% had worked for at least five years in the ASO sector, only 38% had worked in support services for more than three years and only one person had been in their current position for more than 10 years (see Figure 1):

- 26% (N=9) had been in their current position for less than a year
- 35% (N=12) had been in their current position for three years or less
- 15% (N = 5) had been in their current position for three to five years
- 21% (N=7) had been in their current position for five to ten years
- 36% (N = 12) had worked in the ASO sector for three years or less
- 32% (N=11) had worked in the ASO sector for five to ten years
- 18% (N=6) had worked in the ASO sector for more than ten years.

Figure 1: Length of employment in their current position as “support worker”



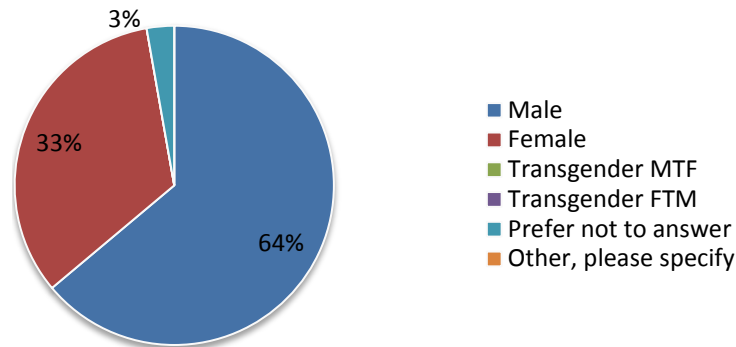
¹ This number is an approximation and fluctuates based on available funding, illness, leave of absences, staff turnover, etc.

Most respondents were female

Thirty-six of the 42 workers who completed the online survey answered questions about gender. Of those:

- 64% (N=23) were female
- 33% (N=12) were male
- 3% (N=1) preferred not to answer.

Figure 2: Gender of the support workers who participated in the focus groups



A significant proportion of respondents had post-secondary education/training

All 34 respondents who provided information about their education reported having at least a high school diploma, and 79% had post-secondary training:

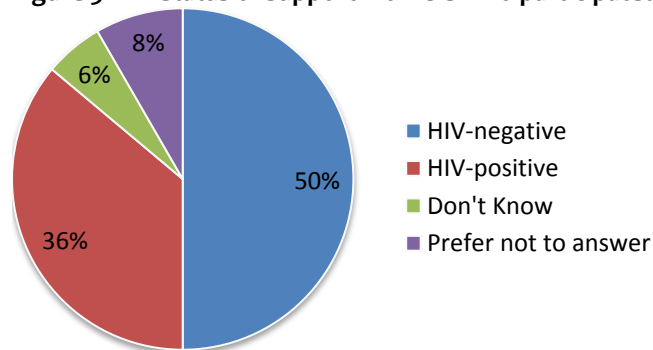
- 29% (N=10) reported having a college diploma
- 35% (N=12) reported having a Bachelor's degree
- 15% (N=5) reported having a graduate degree.

A significant proportion of respondents were living with HIV

Thirty-six respondents also provided information about their HIV status. Of those:

- 36% (N=13) reported being HIV-positive
- 50% (N=18) reported being HIV-negative
- 6% (N=2) reported not knowing their status
- 8% (N=3) preferred not to answer.

Figure 3: HIV status of support workers who participated in the online survey



Focus group participants represented all regions of the province

Thirty-eight of the 42 support workers participated in one of six focus groups while four were unable to attend a group due to work-related emergencies. Participants represented 26 of Ontario's 29 ASOs. Table 1 lists the number of workers attending each focus group, the regions involved and the location of each group. The selected locations were always central meeting points for workers in a given region while one focus group was conducted by teleconference due to scheduling conflicts.

Table 1: Number of support workers participating in the focus group by region

Focus Group #	Focus Group Region	Location	Number of Support Workers
1	Toronto	Toronto	7
2	Toronto & GTA	Toronto	7
3	North	Sudbury	5
4	Central Southwest	Hamilton	9
5	East	Teleconference	6
6	Toronto & GTA	Toronto	4
	TOTAL		38

2. Executive Directors

Twenty-one of the 29 EDs participated in a phone interview, which took approximately one to one-and-a-half hours to complete. There was strong representation of EDs from across the province (actual numbers have been omitted to maintain participants' confidentiality) including:

- 100% of EDs from Northern Ontario
- 80% of EDs from Eastern Ontario
- 71% of EDs from Central Southwest Ontario
- 64% of EDs from Toronto & the GTA.

Most EDs were male

Thirteen EDs (62%) were male and 8 (38%) were female.

A significant proportion of EDs self-disclosed that they were living with HIV

While we did not ask EDs to reveal their HIV status, approximately one-half of our sample disclosed that they were HIV-positive:

- 48% (N=10) identified as being HIV-positive
- 52% (N=11) did not explicitly disclose their HIV status.

More than one-third of EDs had held their current position for seven years or more

The number of years that EDs had been in their positions ranged from one to 11 years, with many having worked in their current role for eight to nine years. The EDs acquired their positions via three main routes: previous experience working at the same ASO as a volunteer or staff member; previous experience working at different ASOs in different capacities; or previous experience from other positions in the social service sector.

Of the 21 EDs interviewed:

- 19% (N=4) had held their current position for one to three years
- 29% (N=6) had held their current position for four to six years
- 38% (N=8) had held their current position for seven years or more
- 14% (N=3) of interviews skipped this question due to time constraints.

3. HIV Clinics

Thirty-four clinic staff members, representing 15 of the 18 HIV Outpatient Clinics in Ontario, completed the HIV clinic survey. Most responses were from a single individual in a clinic (e.g. social worker, nurse, physician); however, in one case, the response represented the aggregate view of four nurses from one clinic.

Seventeen of the 34 survey participants (50%) skipped the questions about the clinic's relationship with ASOs, presumably because they did not work with them on a consistent basis.

SUPPORT SERVICES

As the list of support services in the OCHART report (see below) illustrates, Ontario ASOs offer a large variety of support services. However, to date, there has not been any consensus about which ones should be considered “core services.” For the purposes of this report, the term “core services” refers to services that are the most commonly accessed and are offered at all agencies across the province.

Below is a list of the range of possible services offered by ASOs:

- Case Management
- Practical Assistance
- Food Programs
- Counselling
- Complementary Therapies (e.g. massage, nutrition, counselling)
- Health Promotion/Treatment information
- Referrals
- Individual Advocacy
- Scheduled Drop-in Program
- Supportive Housing
- Employment Services
- Settlement Services
- Workshops/training/skills development
- Intake and/or Assessment
- Home and hospital visits/Care teams
- Housing Assistance
- Support Groups
- Bereavement Services
- Interpretation and Translation
- Buddy Program
- Financial Counselling
- Retreats
- Other.

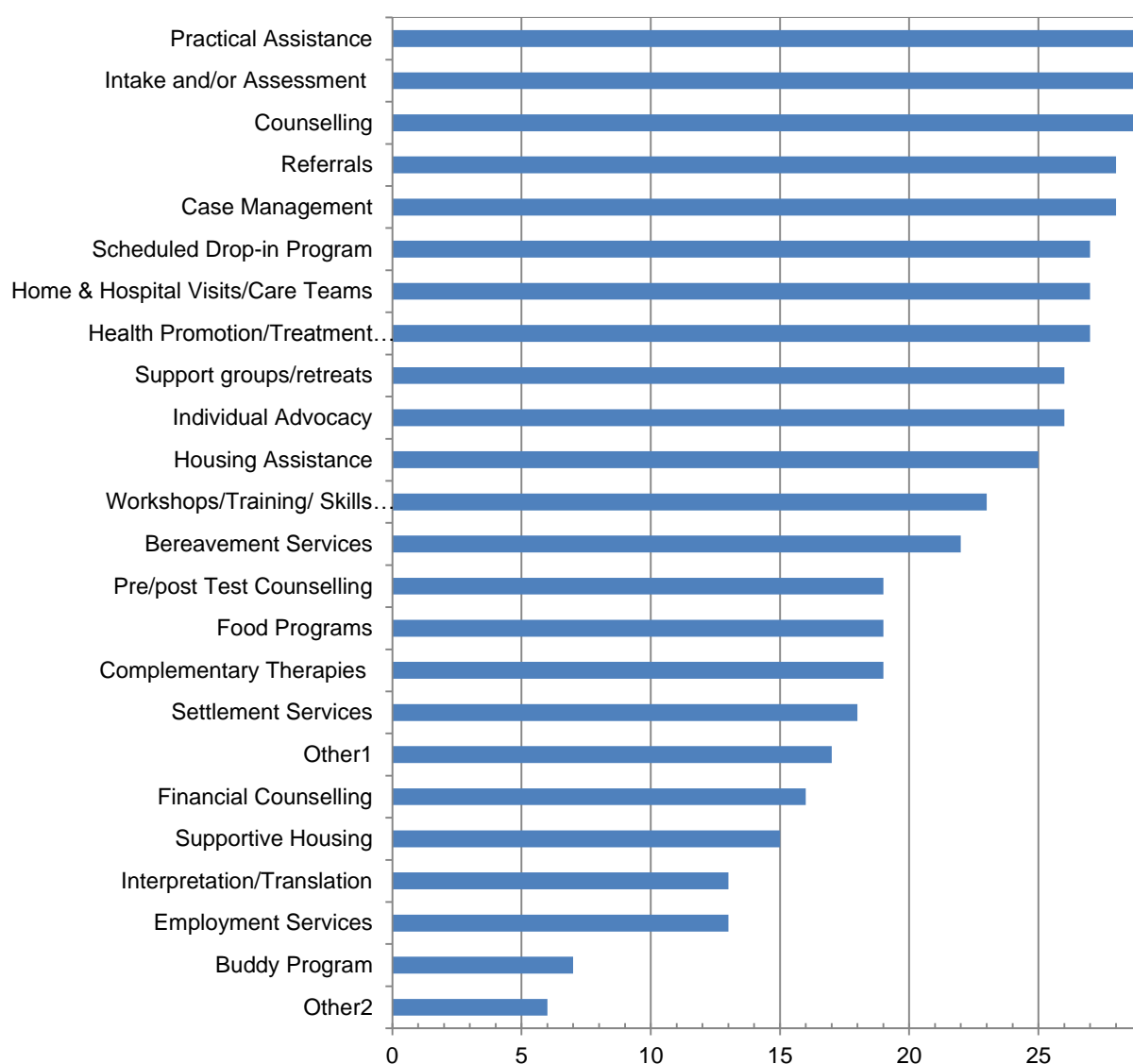
Key Findings

1. The range of support services varies across the province

- All 29 ASOs provide practical assistance, intake and/or assessment and counselling
- Although many services are offered, some services are provided more often than others
- There are regional differences in the volume and type of support services provided.

The following figure of OCHART data shows the number of ASOs that provide each support service. The most commonly provided support services are practical assistance, intake and/or assessment and counselling. This is closely followed by referrals and case management, provided by all but one of the 29 ASOs.

Figure 4. The number of ASOs in Ontario that provide each support service



Although all 29 ASOs reported that they provide certain services shown in Figure 4, in practice, it appears some services are provided more often than others. The following four graphs, based on OCHART data, display the number of sessions of each support service provided in different regions of Ontario. The most frequently provided services in most regions were case management and practical assistance while counselling ranked among the top-four all across Ontario, with the exception of Northern Ontario, where it ranked fifth. Supportive housing ranked fourth in both Central and Southwest Ontario and in Eastern Ontario, and food programming was second and third in the North and Toronto, respectively. Some services were only available in certain regions.

Figure 5. Number of sessions of each support service provided in Central & Southwest Ontario

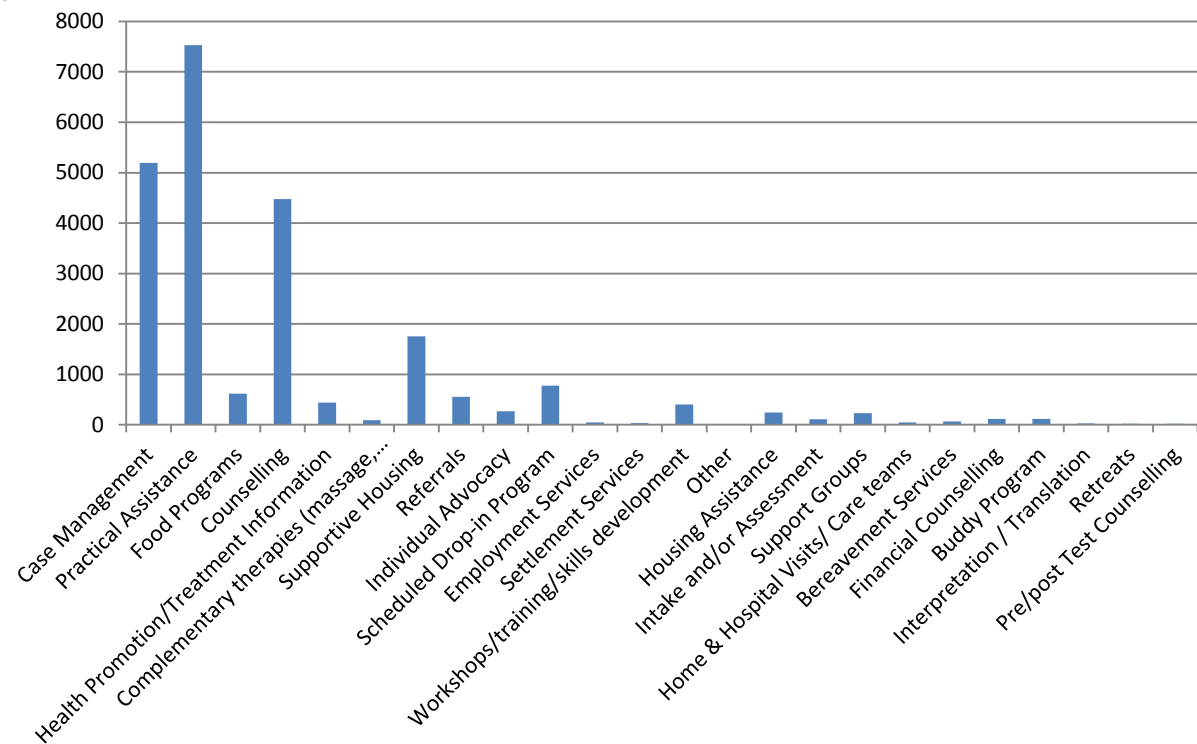


Figure 6. Number of sessions of each support service provided in Northern Ontario

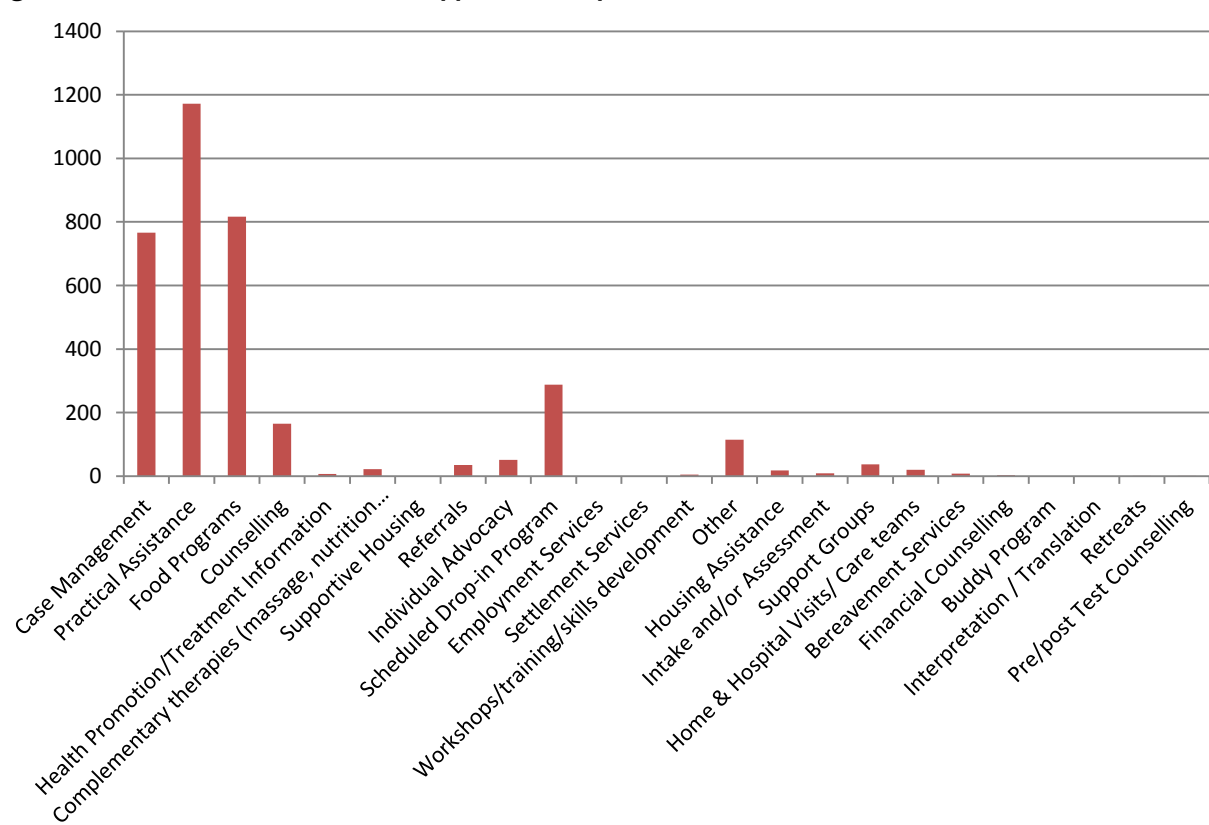


Figure 7. Number of sessions of each support service provided in Eastern Ontario

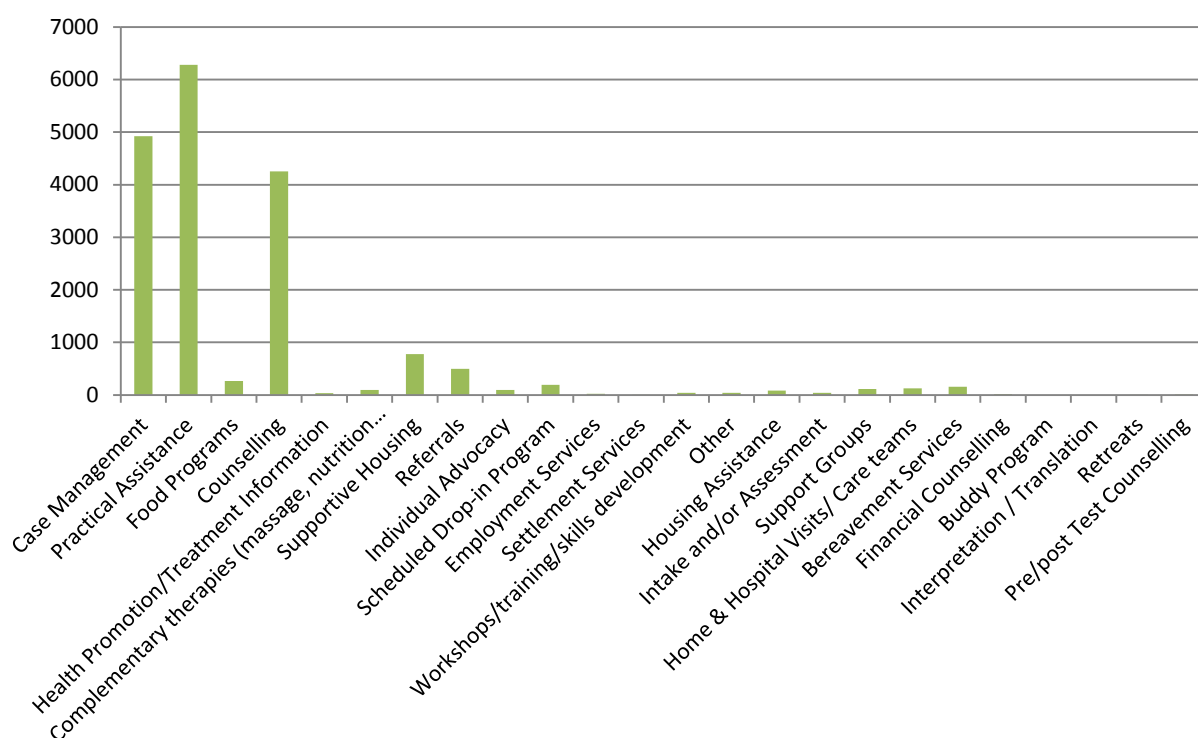
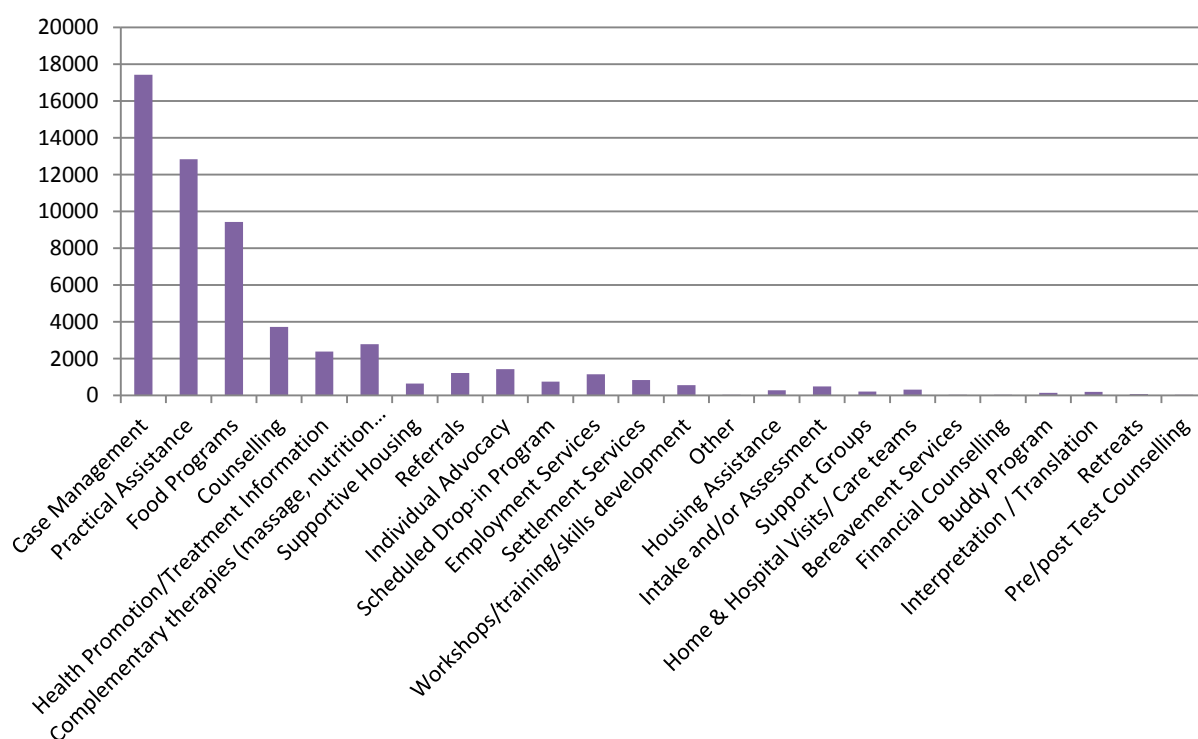


Figure 8. Number of sessions of each support service provided in Toronto & the GTA



The background survey asked support workers to indicate all the services on the OCHART list provided by their agency, giving the workers an opportunity to think about the services provided on a daily basis. The top five

responses were intake and assessment, case management, health promotion/treatment information, referrals, and individual advocacy. However, the data does not necessarily tell us whether these are “core services.” In the focus group discussions, we asked support workers a simple question: “What are the core support services offered at your agency?” We did not define the term “core services” but simply posed questions such as “Which support services make up the majority of your work?” and “Which services does your agency provide the most of?” Support workers may have identified certain services as “core” in the focus groups but their responses may be a more accurate reflection of local community needs than the formally established programs at their agency. For example, in the Central/Southwest focus group, workers identified “settlement services” as a core service because of the significant newcomer populations in these regions. But they also disclosed that they are stretching current resources to meet the needs of these clients as there is no formal settlement services program.

Overall, when asked about their agency’s core services, the most common participant responses were: case management, referrals, advocacy, practical assistance, accompaniments and counselling.

2. Service definitions vary

Comparing the three sources of data (see Table 2) – OCHART reports, the online survey and focus group transcripts – there is some variation in what could be considered “core services.”

Based on the interviews with support workers, this is due to:

- The overlap in delivery of some support services
- The absence of comprehensive and specific definitions of each support service.

Although OCHART provides definitions for these services (see Appendix C), they are general and leave room for interpretation. Consequently, when support workers enter data into OCHART or when they describe services in the focus groups, they may be defining the same service differently. For example, there is a lack of clarity in the definitions of case management and counselling. As one support worker explained:

“You might call a counselling session something different than I call a counselling session so maybe I’ve got way more counselling sessions than you do but it’s because you call it a case management session right? And it’s never been clarified. And I know that if somebody comes into the office and sits down and says hi and leaves some people put in as case management ... whereas I don’t.”

As a result, when asked to define case management, participants gave a variety of answers. Some explained that case management varied for each client and depended on each client’s unique needs. Others believed that the process of case management occurs in conjunction with the delivery of other core services, such as referrals, advocacy and practical assistance. This type of overlap can occur with other services as well. For example, individual advocacy can take place during an accompaniment, and health and treatment information can be provided during a counselling session. Moreover, some services may be difficult for workers to record or quantify because they happen in conjunction with the delivery of other services.

Table 2. Comparison of “core services” reported in OCHART, online survey and focus groups

Core Services	Source of Reporting		
	OCHART	Background Survey	Focus Groups
Accompaniments			✓
Advocacy			✓
Case Management		✓	✓
Counselling	✓		✓
Health Promotion & Treatment Information		✓	
Individual Advocacy		✓	
Intake & Assessment	✓	✓	
Practical Assistance	✓	✓	✓
Referrals	✓	✓	✓

Despite the variation in how the different data sources captured information, a few services consistently emerged as “core services” (see Table 2): practical assistance, referrals, case management, intake and assessment, and individual advocacy.

3. Strengths of support services at ASOs

When support workers were asked, “What do you see as particular strengths of the support services offered by your agency?” their responses varied based on their resources and the focus of their work (i.e. some ASOs focus on a specific service such as housing or a specific population such as prisoners or ethnic communities). Still, focus group discussions highlighted general strengths of support services that seemed to cut across agencies, such as inclusivity, flexibility, blurring of prevention/support services, a harm reduction orientation, and a dedicated ASO staff.

a) Inclusivity

One of the most commonly cited strengths of support services was that ASOs **do not turn anyone away** from their agency. It should be noted that support services are not limited to people living with HIV but are also offered to people at risk or affected (e.g. clients’ partners and families). As one support worker explained:

“When we say we have 120 clients, we actually have 300 and that includes families and live-in partners and people who count as sort of their friends. We don’t label. We just let people say these are my family members. They can access everything except practical assistance.”

Workers described this strength as being a client-centred approach, recognizing that clients do not live in a bubble. To deliver effective support services, workers must take into account all aspects of their clients’ lives.

b) Flexibility

Another strength reported by support workers was their agency’s **willingness to adapt programming to meet their clients’ diverse needs**. Each agency serves clients with different backgrounds and complex needs, including gay men, people who inject drugs, newcomers, prisoners and youth. The individuals in each of these populations have unique histories and service needs:

“We try and provide a broad spectrum of supports and we have a fair amount of flexibility because we don’t have cookie cutter clients ... we tailor our services to people rather than have the people tailor to our supports, so that’s one of our strengths.”

c) Blurring the lines between prevention and support services

The willingness of ASO staff and EDs to blur the lines between support and prevention services was seen as another strength. Traditionally, ASOs have separated education/prevention from support services. Prevention workers typically provide services to the general public and HIV-negative individuals seeking information and resources while support workers provide services to people infected and affected by HIV. However, in recent years, agencies have begun to recognize that these boundaries are not distinct. As people living with HIV age,

they may require education and prevention resources in order to lead healthier lives. At the same time, many people who are at risk can benefit from support services, such as counselling and practical assistance. As client needs have evolved, there has been more **overlap between support and prevention services**. Although each staff member has a defined role (e.g. support worker, education worker, outreach worker), they occasionally adjust their roles to meet clients' needs. Support workers believe there is great value in blurring the lines between support and prevention services:

"I think there needs to be really healthy boundaries between the programs and then there needs to be places where there are permeable boundaries so that we can have some fluidity."

The blurring of services occurs in a number of ways. For example, all ASO staff are encouraged to be knowledgeable about "positive prevention" services – including strategies to reduce the risk of HIV transmission between people living with HIV and their HIV-negative partners – and to be prepared to answer any questions clients may have. While some agencies have a designated positive prevention worker, many support workers reported that positive prevention comes up naturally in one-on-one conversations with clients. If the support worker is unable to answer specific questions, he/she may call in a prevention worker to join the session, and answer any questions in detail.

d) Harm reduction lens

Another strength is that staff are required to deliver services through the lens of harm reduction (i.e. focus on reducing risks related to sex and drug use). As one worker said:

"In general, the way that we look at clients is like evaluating harm and seeing where that harm can be reduced, be it from systems or from relationships or from behaviours or whatever."

All participants stressed that the philosophy of harm reduction is at the heart of all programs and services delivered by ASOs. Support workers said they work hard to make clients feel welcome and know that they are in a safe and **non-judgmental** environment. Their role is to **meet clients "where they are,"** and work with them to achieve their goals. Aside from the overarching philosophy of harm reduction, many ASOs also offer harm reduction services such as needle exchange programs, which brings us to the next example of the blurring of support and prevention services. Participants described harm reduction services as both prevention and support. Promoting the use of new injecting equipment, or not sharing equipment, prevents the spread of infection and the workers who deliver these services also support clients in other ways. This support could come in the form of simply "lending an ear" to clients. One participant gave an example of how the combined delivery of prevention and support is a great strength for certain clients:

"The folks that go out and do outreach end up doing support assistance as well. An example would be someone who is an injection drug user who is really bound to her house because she's got so many physical issues such as her back and the abscess issues on her feet. Through our outreach, we were able to get her to go to the hospital to get assistance. I would call that both support and also prevention because you're helping someone who is in a situation where she would very likely be using dirty needles, to continue to use clean needles and to do all the kind of self care stuff that needs to be done right."

In some agencies, all support workers are required to do one outreach shift on the street or in the needle exchange program. They described this as very useful for meeting potential clients and **building relationships**, as well as trust, so that clients are comfortable coming into the office to access support services. When clients make a connection with, for example, a prevention worker, they are more likely to access support services at the agency if they can work with that same person with whom they have already built a relationship.

The above example highlights another strength, which is the **portability of support services**. As mentioned earlier, support workers across the province spend much of their time doing accompaniments, home visits, and hospital visits. Workers said that clients value these services, especially when they are sick and not able to go the agency themselves. Some workers felt like they often act like a "second family" for clients.

e) Dedicated ASO Staff

The fact that some clients indicated that ASO workers felt like a second family speaks to the hard work and care they provide. One ED explained that support workers often **serve clients with their “whole heart.”** ASO staff are dedicated to accommodating clients and it is their unique skill-set and experience that contribute to the quality of support services. Support workers attributed the unique combination of lived experience, education and work experience as the reason for their ability to connect with clients.

Many participants who were HIV-positive spoke of the hopelessness and helplessness they felt when they were first diagnosed, but expressed that having support in various forms helped them take charge of their health. The support services provided at ASOs across the province were effective for support workers and EDs as well, some of whom were former clients at the agencies where they now work:

“I think that one of the benefits of having an emphasis on one-on-one in terms of relationship is that you provide people with the ability to take control over their own health and to give them the access that they need to things to support that health.” – ED

Finally, staff from two ASOs mentioned that their biggest strength is that they have a **one-stop-shop model of service delivery**. At both agencies, there is an on-site HIV clinic, making it easy for clients to see their doctor as well as their support worker/case manager and pick up a bag of food. Support workers believe this is a strength because clients are more likely to come in and access services if they know they can get more than one thing done. This is especially true for clients who do not have access to transportation or who prefer not to make appointments.

KEY CHALLENGES IN SERVICE DELIVERY

Two questions were posed to support workers and EDs: “Which services present particular challenges?” and “What are the key challenges your agency faces in providing support needed by your clients?” The responses we received can be categorized into three groups: resource issues, client-related issues and systemic issues.

Key Findings

1. Workers face a number of resource issues

a) Lack of Time

Workers reported a lack of time to successfully:

- Deliver productive and effective support services to every client
- Engage in capacity building opportunities such as training, program planning and community networking.

Not having enough time was the most common challenge identified by EDs and support workers. The time constraints reported by support workers stem from both a shortage of human resources and an increased number of intakes across many ASOs. In fact, many agencies outside of Toronto only have one support worker on staff. The caseload per worker varies by agency and we did not ask support workers about their caseload numbers but, among those who discussed their caseload burden, the number of clients per worker ranged from 45 to 250. However, the number of clients per worker may not necessarily be the best indicator of time pressures because, as support workers described, some clients have more needs than others. For example, in a caseload of 45, all 45 may be active clients with high needs while a caseload of 250 may only have 38 active clients with the rest rarely coming into the ASO for services.

Regardless of caseload, workers unanimously reported that they were overworked, strapped for time and spent the majority of their time responding to requests for referrals and practical assistance. Time pressures had a number of direct impacts on the delivery of support services. Workers often only had enough time to work with clients who were in a crisis situation, saying that once one client comes out of a crisis, they have to move quickly to focus on another. One worker described how quickly an individual can re-enter crisis mode. As another worker put it:

“I only have time to focus on the one client or two clients who are high intense and the other clients get a band-aid solution.”

Workers said that effective support services should involve some follow-up with clients after a crisis situation has been resolved to avoid other crises in the future and to get to a place where they can set goals and achieve them.

Ideally, workers would like counselling situations to last at least one hour and, in agencies with only one worker, this isn't possible for every client. Scheduling enough time for each client is made even more difficult because, in many ASOs, clients do not make appointments and prefer to access services on a drop-in basis. If a client visits an ASO and the support worker is in a meeting, then the client cannot have his or her needs addressed right away. In some cases, clients can become very upset when this occurs. A similar situation occurs when support workers accompany clients to medical visits or visit them at home or in the hospital. When that worker leaves the office, it means that other clients have to wait.

Time pressures also affect support workers' ability to take advantage of training and professional development opportunities or to participate in activities that build relationships with staff from other agencies. While there are training opportunities available and EDs are generally supportive of workers attending training, many support workers feel there is a lack of infrastructure in place to allow them to leave the office. For example, because most agencies have few staff, when a support worker attends a training session, his or her work falls

to other staff who may not be able to address a certain client's support needs. When the worker returns to the office, he or she often faces an overwhelming number of client issues and requests which have accumulated in his or her absence.

Some of the same issues arise when support workers are asked to engage in program planning discussions or when they devote time to building relationships with staff from other organizations. Although the need for community networking is increasing with the growing number of intakes and requests for referrals, support workers struggle to find the time to devote to building and maintaining these networks.

b) Lack of Funding

Workers and EDs reported a lack of funding to:

- Build and maintain core programming
- Hire needed staff
- Respond to practical assistance requests.

Both support workers and EDs reported that one of their major challenges was funding. Current budgets have not kept pace with increasing demands. As a result, many agencies are involved in fundraising activities to support their services.

Many EDs expressed frustration with the lack of consistent funding for core programming (e.g. volunteer services, administration, support positions). They reported that it is difficult to plan or provide meaningful support without a guarantee of funding for different service components. This finding was somewhat surprising as the AIDS Bureau provides core funding for many of these positions and its funding has either remained stable or increased in recent years. EDs may have been referring to programs or services supported by other funders.

Support workers also reported receiving a lot of requests from clients for financial assistance with transportation costs (e.g. tokens or tickets) and emergency financial assistance; however, many agencies do not have enough funds to allocate for this type of support. As one worker said:

"It's one thing for me to work with a client and come up with these goals and action steps. But if my client doesn't have a token to get on the subway to go to these appointments, it's a big problem because then there won't be any follow through which means the work that we're doing really doesn't actually end up happening. Although we have some limited funding for that, it's not even close."

To mitigate this challenge, some agencies are trying to come up with creative strategies to meet the needs of clients. Here is one example:

"The single biggest change we have seen in support services is the need for practical support. A lot of people are accessing our wellness fund ... so we took a look at what people were requesting for and we are trying to make this money go further. We saw how much we were spending on vitamins and so now we no longer cover vitamins because we've started a vitamin bank. We are also seeing a lot of people with bone density problems and a lot of people losing teeth, because of meds, so we are now looking for ways to connect with dentists in the area."

2. Workers identified a number of client-related challenges

a) Stigma continues to be a key challenge

Support workers reported that it can be difficult to engage clients because of stigma and geographic barriers. ASOs across Ontario reported that it remains difficult to get existing clients as well as new clients to access their services. The reluctance among potential clients to use ASO support services is mainly due to stigma – both internalized stigma and stigma within clients' communities. Workers discussed clients who took 10 to 12 years to come into the agency – mainly because of fear and inadequate information about HIV/AIDS in different communities. While internalized stigma is not limited to clients who are newcomers to Canada, it was especially pronounced for this group. One person described it as:

"The fear of being seen in our office by another PHA from their country of origin."

One worker described a situation where clients from a specific ethno-racial community refused to come in on days when a receptionist from the same community was working in the office. Getting clients to use services was particularly difficult in rural areas, where there are few social services and even less knowledge of issues relating to HIV/AIDS. The large geographic areas served, coupled with community stigma, makes it particularly challenging to engage new or existing clients. Support workers reported using strategies to reduce stigma and/or people's fears such as letting people out of the back door or scheduling appointments so that certain clients will not see one another. One agency has tried to address this challenge by booking an office space, located an hour north of their main office, once a month in order to see clients who live far away. Another agency has partnered with a food bank to share a space and have a satellite office.

b) There is an increased demand for a wide range of support services

ASOs serving urban areas and mixed urban-rural areas reported an increase in demand for services. This increase is likely due to the fact that people with HIV are living longer and developing different service needs. In addition to the increasing number of new intakes, existing clients are continuing to access services on a regular basis. At the beginning of the AIDS epidemic, clients turned to ASOs mainly for support groups and treatment information and exchange. Today, clients' issues may be related more to practical needs rather than their HIV status. As a result, many support workers and EDs reported that they feel they are “being everything to everybody.”

These days, clients need more long-term case management, referrals to a range of different services, and practical assistance. Support workers noted that once clients felt safe and built a trust with them, they were more likely to turn to the agency for support with a whole range of issues which may or may not be related to HIV.

c) Workers do not feel equipped to address the need for settlement services

Support workers from ASOs in urban areas reported a significant increase in demand for settlement services. They noted that clients often come with multiple complex needs and the support workers do not always feel equipped to address them. One person gave this example:

“This person is going to be deported tomorrow, can you help them?”

Some agencies refer their clients to HALCO for assistance with these issues but support workers are well aware that HALCO staff are overworked as well. It is clear from these findings that ASOs and their clients would benefit greatly from more training and resources on settlement and immigration issues or better links to immigration and settlement services. In addition to a need for more training and resources, many clients requiring support with these issues do not have English as their first language, which can be challenging when ASOs do not have a worker or interpreter who is able to translate. One agency has partnered with a local multicultural community social service agency to create an HIV-specific curriculum for interpreters to be able to understand the terminology and work with clients in an effective way.

d) Some clients have a “sense of entitlement” when they come to the agency

Focus group participants said that both clients and support workers have reported that some clients approach the agency with a “sense of entitlement.” As one worker described it:

“We have some rogue cases who, you know, are finding their voice and feeling good about that and are running over other PHAs and over staff, calling them up and saying ‘I am the boss, you’ve got to listen’ that sort of thing so that can be really, really hard and it makes staff, other volunteers, and other PHAs really resentful.”

Clients who feel a sense of ownership over the agency can become very verbal about their dissatisfaction with its services or policies. EDs described how clients can become upset if there is a change in policy or procedure at the ASO, if boundaries are enforced, or if they are not given a service they have requested such as financial assistance or transportation. Some clients have said that funded resources should go directly to them in the form of financial assistance instead of to programming.

Support workers reported experiencing verbal abuse from some clients when they didn't immediately get what they wanted, indicating a discrepancy between the support worker's perception of their role and client expectations. This pressure is sometimes more pronounced from clients who don't often come into the ASO. As a result, they come in with the expectation that they will receive everything they need simultaneously and immediately.

"We're sometimes like a door to everything ... or they try to make us the door to every service."

Finally, some workers believe that long-term clients feel that they have more of a right to services than newer clients. Some EDs in urban settings described how some clients who have been accessing services for more than 20 years sometimes alienate clients from other communities. These clients have made comments such as "We let them in," in reference to newcomers, youth and injection drug users.

e) The culture of support service provision may create client dependency rather than empowering clients

Both support workers and EDs discussed whether the culture of service provision was causing clients to become dependent on the agency rather than empowering them to manage their own lives and access other services in the community. It is sometimes difficult to get long-term clients to "move on" from accessing the agency's services, or to get them to follow through on action steps and goals. As one ED put it:

"We need to get better at getting our clients to move on. At any given time, we have 600 clients for only 14 staff."

Support workers and EDs agreed that one of the reasons why long-term clients continually return is because they feel a sense of belonging and community at the agency. Support workers have no desire to push clients away but because of limited ASO time and resources, they feel they should be devoting more time to newer clients who may have more urgent needs. Some workers also expressed frustration about clients not following through on their case management goals. As one person said:

"You should never be working harder than the person you're trying to help."

The inability on the part of clients to follow through on care plans sometimes has ramifications for the agency. For example, when a support worker makes referrals and the client doesn't show up for the appointments, it can affect the ASO's relationship with other services in the community. Some EDs were concerned that the current culture of service provision may be encouraging clients to remain dependent on the agency, rather than empowering them to meet their own goals and move on once they receive the support they need. Some suggested that support workers may have been trained to meet their clients' every need rather than walking them through the steps to have their needs met. As one support worker said:

"You're eager to help and you know, given all the problems they already have in their life, you try to minimize the impact of HIV in their lives and then sometimes end up not empowering them and by doing stuff for them, that creates a dependence."

At the same time, it is important to note that each client has different capabilities and some may need more support than others. For example, workers described how clients who are newcomers are often not familiar with the health and social service systems and may need the worker to do more things for them. There is a delicate balance between empowering clients and at the same time, not denying anyone the services they need.

3. ASOs struggle to build a strong referral network

ASOs work with many other community agencies to ensure clients have access to the range of services they require. As one support worker noted, having a strong referral network allows agencies to provide comprehensive care to their clients without additional cost to either agency. However, navigating these health and social services networks is not easy for first-time users, and clients often need the ASO to help them access services from other agencies. Support workers and EDs identified key factors in creating successful community partnerships including: establishing strong "worker-to-worker" relationships; dedicating resources to assist

clients in navigating social services; using public health unit services for low-income clients; and assisting with the administrative burden (e.g. paperwork) for the agency taking on a client.

"We have 4 ADA [alcohol and drug assessment] trained workers, so we can try and get [clients] into a rehab facility or through the methadone program if they wanted to do that ... It's not just giving out kits ... it's making a connection ... so we can look at some of the underlying problems that they're really dealing with." – Focus group participant

Support workers and EDs identified several challenges to building community partnerships, which ranged from the time and effort required to create partnerships to the challenges of maintaining relationships with each agency. For some ASOs, a key challenge is finding organizations that are willing to work with them.

a) Lack of formal partnership agreements

Most support workers spoke of referrals done on a "worker-to-worker" basis rather than agencies having formal partnership agreements. Without formal agreements, there is no clear understanding of the obligations of each agency and the relationship between the agencies is more fragile. Partnerships based on worker relationships require constant monitoring and evaluation, which can be time-consuming for support workers to manage, especially when difficulties arise. Furthermore, such partnerships – which often depend on the personalities of the workers and the length of employment of either person – can be fragile. If one worker leaves, his or her successor may not maintain the relationship. An organizational agreement could solve this problem, by setting clear boundaries and outlining worker responsibilities, creating secure communication channels for sharing information and safeguarding the partnership against future staff turnover. A lack of clearly defined expectations makes it harder to address challenges that can arise when ASOs and external agencies conflict on how services should be delivered.

b) HIV stigma

Most support workers and EDs spoke of the lack of an anti-racist and anti-oppressive (ARAO) framework in the work of other social service agencies. Some agencies are willing to work with the ASOs and seek information on the issue of HIV stigma. However, this requires support workers to serve as an informal educator for the other agency's staff, or the ASO outreach department to organize a workshop, which places an additional burden on the organization.

"Often we have to support people through this process. We do a lot of work educating workers in other agencies, as well as coaching our clients who sometimes do not trust the system ... be there with them through appointments and do more training with other workers from different agencies. It's hard because we are trying to get clients to take responsibility for their own wellness and health and also having to do this with other services providers." – ED

As a consequence of experiencing HIV stigma, most clients prefer to not have their HIV status revealed when they are referred to other social services. ASOs are well known for the work they do and the clients they serve so when an ASO support worker refers a client, the receiving agency often automatically assumes the client is HIV-positive. If an ASO is also known for serving a specific population (e.g. intravenous drug users), other agencies may resist accepting referrals or even refer clients to the ASO. As a result, ASO support workers often have to make the case with the other service worker that the client's main issue falls under the other agency's – and not the ASO's – mandate.

"Another challenge would also be that people would just say well, I don't want you to leave condoms in our venues because we don't see people like that. So, it ties along with all the stigmas and the stereotypes. It's not actually just the smaller towns, it's really still in Toronto as long as you step outside of Yonge and Bloor." – Focus group participant

c) Developing and maintaining effective working relationships

Working with other agencies to support clients with complex needs can be challenging. Support workers spoke of some social service agencies refusing to accept or assist with a client who faced issues ranging from bed bug infestations to immigration and mental health issues. Some issues are only handled on a case-by-case basis, or when certain workers are on duty the day the request is made. One support worker spoke of clients

who were about to be deported showing up at the ASO unannounced, saying another agency had sent them there for assistance.

Support workers described the challenges they face getting some clients to attend appointments with another agency. Partnerships with other agencies can be negatively affected when a client fails to show up for an appointment. If this occurs repeatedly, the support worker may be forced to start the referral process all over. As one worker noted, the ASO reputation becomes tarnished, making it harder to refer other clients to that agency.

d) Lack of resources

A lack of resources is one of the biggest challenges in working with other agencies, especially for ASOs located in suburban and rural areas. ASOs in the northern part of the province face financial hurdles in referring clients to another city to obtain the help they need. Some ASOs have attempted to overcome these barriers by arranging for telemedicine sessions via Skype, but this can be logistically challenging, as doctors cannot bill OHIP unless specific software and equipment is used. Some professionals have offered to provide free care but the logistics of doing this often presents its own set of challenges (i.e. additional paperwork, client no-shows, technological difficulties).

4. Workers identified a range of systemic issues

Workers and EDs identified a number of broader systemic issues that affect the delivery of ASO support services. As one person said:

"We can't look at support services without looking at the systems that we're working within and that people living with HIV are living within."

a) Lack of affordable housing

There is a severe shortage of affordable housing across Ontario and the majority of clients served by ASOs are living on a low income that is often below the poverty line. As a result, requests for housing assistance and referrals are quite high. Workers reported that finding housing for clients that is both affordable and in suitable condition (i.e. free from mould, safe neighbourhood, good plumbing) is challenging.

b) Complex social assistance system

Many clients are either on ODSP, trying to get on it, or trying to get off it. In each case, they must go through a complex process involving extensive forms which create a burden for both clients and workers. Some workers described instances where one item on a form is missing or incorrect and the whole thing is mailed back, further delaying the application process. According to support workers, ODSP staff are not always helpful or informed about clients' issues or concerns:

"I was there with a client to try and get a cheque and the ODSP worker was like, 'Your rent is \$630, you should try and find a place that's less expensive.' And I am sitting there and I'm like ... he's in a mould infested one bedroom apartment! He's lucky he got that!"

In some cases, workers say the ODSP program is so complicated to navigate that even ODSP workers are sometimes unaware of what the program actually offers and support workers have to educate them on what is available for clients.

c) Lack of mental health resources

Respondents reported having few providers or organizations to refer clients to for help with mental health issues and most specialists have long waiting lists. There are even fewer places for people with severe mental health issues such as borderline personality disorder, schizophrenia and vicarious trauma.

d) Limited communication between ASOs who serve the same clients

In Toronto, where there are nine ASOs, the same clients sometimes access different services at different agencies. Although there is some communication among these ASOs, it is limited. Some EDs and staff

advocated for better communication to avoid duplication of services and to ensure that ASOs support clients in the most productive way possible. As one person noted:

“The challenge sometimes is getting ASOs to talk about those systemic pieces. How do you truly support someone? Who takes the lead in case management? How do you move towards a good health outcome for clients? Frankly, we all share the same clients but we get encumbered by confidentiality and consent which are important but we can’t use those as barriers to deliver good services. We need to work together more in a meaningful way, in a consistent manner and have an understanding of what we mean by support.”

e) Stigma within the community

As mentioned earlier, stigma in the community continues to be a challenge in the delivery of support services. This stigma, which extends to some medical professionals and social services agencies outside of the HIV/AIDS sector, creates barriers for ASOs trying to create partnerships and refer clients. The stigma that clients and ASOs experience is not limited to HIV but includes stigma related to homophobic attitudes and racism. Both support workers and EDs identified a need for more advocacy and education in the community in order to break down these stigma-related barriers and ensure more continuity of care for clients accessing services outside the HIV sector.

5. Workers identified region-specific systemic issues

Workers in the Northern region identified a number of concerns that were particularly pronounced for them:

- Lack of affordable housing
- Food insecurity is more pronounced; food prices are higher than in other regions
- Large geographic distances make it difficult for clients to access services.

The prices of groceries are especially high in the north and, because many clients are living on low incomes, food insecurity is common. To meet their clients’ food security needs, ASOs in the north focus a significant portion of their programming on food banks and vouchers.

ASOs that serve the north or have large catchment areas in the south, such as those in Kingston, London, HARS, Hamilton and Peterborough, serve a number of clients who live far distances from the ASO. This distance makes it difficult for clients who do not have a car or who cannot afford public transit to participate in ASO activities. This inability to easily travel to their ASOs has resulted in further isolation for these clients. One support worker mentioned that one of his clients was unable to ever come to the agency, so all counselling sessions had to be done over the phone. Although some ASOs have had transportation programs in the past, most ASOs are unable to provide a shuttle program on a consistent basis due to a lack of money and volunteers.

6. Workers identified challenges serving prisoner populations

Given the significant number of correctional facilities in Central, Eastern and Northern Ontario, ASOs in these areas serve a significant proportion of clients who are prisoners or ex-prisoners. Agencies struggle to meet these clients’ needs because:

- Many have significant behavioural and mental health issues
- It is difficult to connect them with other community agencies because of the stigma against prisoners
- Working with correctional facilities is difficult.

Workers have explained that they do not feel equipped to support clients with severe mental health and behavioural issues. Some have described organizations coming forward who are interested in learning how to work with prisoners but there is much education and work still to be done to eliminate the stigma towards them. As one ED put it:

“Access is always a challenge for our clients, whether it be while still in prison or when they get out. Access to other services other than us...there are huge barriers because of who they are. Sometimes people take a look at them and see that they look “dirty” and they don’t want to deal with them. This could even be at a hospital ... and our clients are more likely to go to emerg than to go to a doctor. This is problematic.”

In addition to stigma against prisoners, support workers from ASOs have challenges dealing with correctional facilities. Pre-release planning, which involves finding the client a doctor, a place to live and identification, can be challenging when different institutions have different rules. One worker explained it like this:

"Sometimes each prison is run like their own little system, regardless of whether its federal or provincial, and so the rules at one may not be the same as the rules at the other or their application or how they're implemented."

GREATER INVOLVEMENT OF PEOPLE LIVING WITH AIDS (GIPA)

MEANINGFUL INVOLVEMENT OF PEOPLE LIVING WITH AIDS (MIPA)

The principle of Greater Involvement of People Living with HIV/AIDS and the Meaningful Involvement of People with HIV/AIDS (GIPA/MIPA) recognizes, among other things, that people living with HIV have the right to make decisions about their own health care and to participate in the policies and programs that affect their lives. First coined as “The Denver Principles” in 1983, GIPA/MIPA was ratified by 42 countries at the 1994 AIDS Summit in Paris, France. By 2006, the number of countries signed on to GIPA had quintupled to 192².

Key Findings

1. Agencies are committed to GIPA/MIPA

From the interviews with EDs, and focus group discussions with support workers, it was clear that all ASOs support the GIPA/MIPA principle. They demonstrate their commitment to GIPA/MIPA in many ways including:

- Hiring staff who are HIV-positive
- Designating positions on the Board for people living with HIV
- Asking clients for input into program and strategic planning
- Supporting clients to take on leadership roles, such as serving on the Board, facilitating support groups and becoming a peer research assistant on HIV health studies.

As noted earlier, 36% of support workers and 48% of EDs who participated in focus groups and interviews self-disclosed that they were living with HIV – a strong indicator of the commitment to implement GIPA/MIPA.

Approximately 10% of the EDs interviewed reported that their organization had adopted the Ontario Accord (a statement of solidarity with GIPA/MIPA) while others planned on adopting it within the next year.³ An even greater proportion of EDs highlighted the usefulness of the Ontario AIDS Network’s (OAN) *Living and Serving* framework in guiding their work.

One ED noted that, in addition to providing formal input on agency programs, clients are a valuable source of information about changes in sexual and drug-related behaviours in their communities. The ASO can use this knowledge and expertise to identify and address emerging trends as they occur.

2. GIPA/MIPA enhances ASO effectiveness and capacity, and provides positive role models

Both support workers and EDs (primarily in the GTA) spoke of the benefits of integrating GIPA/MIPA into the agency’s work. Benefits include being able to address clients’ needs more effectively, and increasing the capacity of the agency (e.g. board members, advocacy work and volunteers for agency-related events). Support workers identified numerous benefits of enacting GIPA/MIPA for clients, including providing them with

² http://data.unaids.org/pub/BriefingNote/2007/jc1299_policy_brief_gipa.pdf

³ (Definition of the Ontario Accord)

role models, creating safe spaces, and allowing clients to give back to the agencies and communities that support them. When asked about what GIPA/MIPA meant to them, one support worker summed it up as:

"It's very simple, being a PHA myself; it's being a good role model to the clients." – Support worker living with HIV

From the perspective of support workers who are living with HIV, it's important that clients know that they are HIV-positive so that they can see "being positive in a positive light." Support workers hope that, by being a positive role model, they will inspire clients to not limit themselves based on their HIV status:

"They're just seeing that yes being HIV-positive does not mean I can't have a job [for clients who are unemployed]. I can do anything I want to ... Or I can be positive for 20 years and you wouldn't recognize me on the streets as somebody who's positive. That's very important to a lot of people ... It's like having a role model." – Support worker

Clients who volunteer can also be important role models for their peers. As one support worker explained, having clients lead support groups accomplishes two things: it presents someone living with HIV as a leader, and it ensures that clients feel safer talking about their experience being HIV-positive:

"Also during the groups, it's always better to have like a peer support person who will help you do your group because in that way people are more comfortable because they know 'okay the person is a PHA like me.' It's going to give me more the opportunity to interact with the rest of the group instead of shutting down." – Focus group participant

In addition to a strong commitment to implement GIPA/MIPA from agencies, support workers spoke of a desire among clients to give back to the agency that has served them.

3. Putting GIPA/MIPA into action can be challenging

While all ASOs support GIPA/MIPA, many acknowledged that it can be challenging to implement. These challenges include:

a) Clients not able to participate

According to support workers and EDs, for numerous reasons, many clients do not want to be involved in ASO activities. These include having other challenges in their lives (e.g. newcomer/immigration issues, other co-morbidities, family responsibilities), a preference for privacy and a desire not to disclose their HIV status and/or because they want a break from HIV, needing to disconnect from activities that remind them of their HIV status.

"That [clients] have so many things to deal with. It's usually because they have kids ... immigration is a huge issue right now too. I have a lot of clients dealing with immigration, and so there are not just, it's not just being HIV positive [Um hmm], it's everything around that." – Focus group participant

Support workers reported that most clients do not have the desire to be an activist or role model for others living with HIV. People living with HIV who do become actively involved in the sector are not immune to "burn out" or fatigue, even if they are highly motivated. One support worker who is living with HIV planned to leave the job in the near future, saying, "I just want to stop living HIV 24/7."

Clients may have other priorities in their lives that supersede volunteering at an ASO or engaging in ongoing activities, such as attending board meetings.

The stigma and discrimination still associated with HIV also makes some people less willing to participate in ASO activities. As one ED noted, some clients do not want to take on any role that may publicly disclose their HIV status, such as being a board member or representing the ASO on an external committee.

b) Geographic/transportation barriers

For ASOs in rural and suburban areas, or for clients in urban centres who cannot afford public transit on a regular basis, transportation is a barrier to participating in GIPA/MIPA-related activities.

c) Skill Training

ASOs try to hire people living with HIV, but some applicants do not have the skills – without additional training – to fulfil the responsibilities of paid positions. In these cases, ASOs have to assess whether they have the resources to provide the necessary training and support to ensure their standards are not compromised:

“So if there is an applicant and they’re negative but they are stronger and there is a positive applicant and they are close and you have the capacity to develop them and all other things considered ... then great, GIPA/MIPA comes into play. But if they are unqualified to the point where you do not have the infrastructure to support them, then that is not the right choice. It’s not fair to clients or to the peer.” – ED

In particular, EDs discussed the fact that people with lived experience who have been out of the workforce or on ODSP for an extended period of time may need “back-to-work training” or skill-specific training so they can make a contribution. When applicants with HIV do not have the skills required, they are often placed in positions that may not be meaningful to them (e.g. packaging resources rather than counselling peers). When ASOs do hire people with lived experience who require training, the responsibility for providing that training and support often falls to support workers, adding to their workload.

One ED suggested that conflict between support workers and peers may occur most often when clients do not have the necessary interpersonal skills or leadership experience. As a result, they may come across as abusive or disrespectful to staff. These issues can often be resolved by providing leadership training, and encouraging these leaders to assert themselves in a respectful manner. EDs and support workers discussed experiences with clients who they felt had inappropriately dictated or scolded staff members, or misinformed clients about how the ASO operates.

d) Favouritism

Support workers often get along better with some clients than others. At the same time, some clients have more skills and experience and so are invited to participate more regularly than others. All of this can lead to the perception of favouritism when certain clients are asked to take on volunteer or paid activities. As a result, some clients may feel left out while others may feel overburdened by ASO requests. This appeared to be more of an issue in small ASOs rather than in larger ones.

“I am frustrated with the picking and choosing. [Long pause] This is confidential right? I’ve got a committee and going through the list of names of people and picking the ones that maybe do best or the most desired job on that committee to have it turn out the way the committee leader wants it to turn out. Does that make sense? Rather than including everyone ... It’s very political ... which can be burdensome for the favourite volunteers who always get called on.” – Focus group participant

e) Boundary issues

When a client makes the transition to a paid position or formal volunteer role with an ASO, there may be boundary issues with other clients. For example, when clients with strong personalities volunteer, they may not know how to facilitate discussions or create opportunities for others to speak. As a result, some clients may be withdrawn because they feel they won’t have an opportunity to contribute and that others will dominate the conversation.

“We actually had quite a few clients that were really active but they kind of burned some bridges within our agency, we kind of had to bar some people from the agency, based on some of the activities [they engaged in]. But since some of these more aggressive characters have kind of quieted down we’ve had like a huge flourishing of other people who had been silent for quite a while.” – Focus group participant

f) Confidentiality concerns

The issue of confidentiality can be complicated when clients become involved in delivering services. Regardless of the level of supervision, agencies reported issues with breaches of confidentiality when clients were hired into volunteer or paid positions at the ASO. More often than not, these incidents are not deliberate but reflect the person’s lack of understanding of their responsibilities in their new role. For example, the person working

near the desk of the support worker may have access to another person's private information, or they may come to know the HIV status of the support worker and disclose it to others without that person's permission. In some cases, the mere presence of a client can create concerns about confidentiality. One support worker recalled a sharp decrease in the number of clients using ASO services when an established member of the community was staffing the reception desk for the week.

"Because we have volunteers on our reception desk so you would think 'Oh that would be great to have clients sit there' but it isn't always you know. This client knows this person but they don't know their status and they come walking in there and then they're like 'Oh what the heck are you doing here, you're [a PHA]?!'" – Focus group participant

g) Loss of peer support

People living with HIV who move into volunteer or staff roles at an ASO may lose their sense of peer support. Because of the ASO's policies on boundaries, they may no longer be able to turn to people who are now their clients for support, as they had in the past. This loss of peer support can cause them to feel more isolated, giving them fewer options to meet their own support needs:

"Okay, when I start working ... I had to sacrifice some of my support within my agency ... stuff like I used to go out with my friend, I cannot go out anymore with my friend, I cannot drive my own friend because [of the boundaries with the] people that I serve you know ... I cannot access the food banks, all kind of stuff you know? Even with my co-worker it has been, it took a long time to be considered as a co-worker instead to a participant all the time." – Focus group participant

h) The personal costs of being "the PHA" on staff

Some support workers who are living with HIV had the sense that, as part of their ASO's effort to demonstrate their commitment to GIPA/MIPA, they are called upon too often for public events or speaking engagements, often without adequate notice.

For some support workers, the additional responsibility of being the agency's representative of people living with HIV can become a burden. They reported feeling that they often sacrifice their own self-care in order to meet these demands which, given their compromised immune systems, can have grave consequences:

"As one of two PHAs who work in the agency, if ... one of our client speakers isn't available then I am like the default PHA ... 'Can you tell your story in 5 minutes?' ... I don't feel the pressure but it's funny you know? What if there weren't any PHAs working in the agency? ... Yeah I'm like the default PHA: DPHA." – Focus group participant

Other participants identified additional work pressures that resulted from disclosing – or not disclosing – their HIV status:

"I would just add that there is a challenge with expectations either clients or colleagues to disclose your status and to identify whether you were a PHA who's now working in the agency or not ... I think we are really protective of the clients and the people that we provide services to. We're very protective of their status and understand disclosure when it comes to that but it's much harder to understand that when it comes to service providers ... So, there's almost an added pressure or expectation that your status should be disclosed to either become a guest speaker or become some ... living inspiration kind of thing. And that is a challenge in itself because some people might just not want their status disclosed sometimes if you're dealing with clients who at times openly ask and challenges your status that is very challenging." – Focus group participant

i) Lack of accommodation for staff who are living with HIV

Many ASO staff members who are living with HIV felt that their agencies did not provide adequate support or accommodation, given the nature of HIV infection. For example, staff members who are living with HIV do not receive additional sick days beyond the number allotted to all staff.

"You know in the good old days ... say I had a bad cold, well I don't come in ... You'd stay home and get well because you're going to spread that disease. Now, you have this many sick days and if you surpass that then you're going to lose pay and you're not going to be able to carry over ... and you can't do that ... not on this type of agency. You have to allow us to be able to say I really am sick and I really need to stay home for the sake of clients, not just for me. It's not just a 'Benylin day'" – Focus group participant

This lack of accommodation compounds the tendency of staff who are HIV-positive to push themselves to work past their own healthy limits in order to ensure the agency is not short-staffed. As a result, they reported that they missed more work than they would have had they taken the time they needed to stay healthy.

j) Resource limitations

One of the challenges in implementing GIPA/MIPA can be financial. For example, ASOs want to provide comprehensive benefits for staff, including health insurance that supplements OHIP coverage, drug plans and short and long-term disability. ASOs that are not part of a larger employer insurance pool often find it difficult to afford insurance premiums when they employ staff who are living with HIV or other catastrophic illnesses.

"I've had to deal with this and most of us as service organizations ... don't have a lot of money, and what happens when we hire employees who are HIV positive and they are a drain on our benefits plan? Our insurance companies penalize us by increasing our rates therefore, forcing us to increase our budget and, and or decrease our services. ... my fear is and I am not saying that it happens but my fear is that if you are in charge of the budget and if you do have your benefits supplier giving you a hard time because your staff are using their services which you're paying for, I find it can sometimes be distracting to the hiring process and actually fully implementing GIPA/MIPA without any sort of prejudice or any barriers." – Support worker

SUPPORT SERVICE PARTNERSHIPS WITH HIV CLINICS

ASOs do not work in isolation. They are part of a broader network of health and social services that can help meet the comprehensive needs of people living with or at risk of HIV. A key set of partners in this network are the 18 HIV outpatient clinics located across Ontario. To best serve their clients, ASO support programs must build strong partnerships with the clinics and create effective referral networks. This section of the report looks at the relationship between ASO support services and the HIV outpatient clinic(s) in their region.

In our scan, we looked specifically at the working relationships between the ASOs and the 18 ministry-funded HIV clinics, which provide specialized medical care and, in some cases, primary care services for people living with HIV. As the following map illustrates, geography is a factor in ASOs' ability to build partnerships with clinics. For example, ASOs located in the Greater Toronto Area (GTA) have access to seven different clinics and therefore have the opportunity to build relationships with more than one. On the other hand, other ASOs across the province generally have only one clinic in their region.

Thirty-one of the 42 ASO support workers who completed the online survey responded to questions about their work with clinics. Of those respondents, 16 indicated that their ASO partners with more than two HIV clinics, seven partnered with one, and eight reported not partnering with any.

- ▶ [Map of AIDS Service Organizations and HIV Clinics in Ontario \(Appendix D\)](#)
- ▶ [Map of AIDS Service Organizations and HIV Clinics in Ontario \(Interactive\)](#)

Key Findings

1. Most view the relationship between ASO support services and HIV clinics positively

Most ASOs reported having a good working relationship with the HIV clinic(s) that serve their areas. Most support workers (N=19, 73%) rated their partnerships as 'Good' or 'Excellent,' while six (23%) rated the partnership as either 'Fair' or 'Poor' (23%). Most EDs also responded positively when asked about their ASO's relationship with the HIV clinics.

Respondents from HIV clinics also generally described their relationship with ASOs in positive terms. We received survey responses from 15 of the 18 HIV clinics but only about 50% of clinic respondents (N=17) answered the questions related to working with ASOs. Of those who did, most have had positive experiences with the ASOs, and understood the work demands placed on ASO support staff. About 82% (N=14) of clinic respondents rated their relationship with ASOs as either 'Good' or 'Excellent,' while 18% (N=3) rated it as 'Fair' or 'Poor.' When asked about the quality of the services provided by the ASOs, 76% of respondents (N=13) rated the services as either 'Good' or 'Excellent,' while 12% (N=2) rated them as either 'Fair' or 'Poor.'

Respondents from HIV clinics generally recognized and appreciated the work of the ASO support staff. When asked about the benefits of their relationship with ASOs, they discussed ASO support services and how they help patients. These ASO services are especially important for clinics that have no social workers on their staff and for those who require assistance providing culturally-sensitive support. One clinic staff member commented on the benefits that clients enjoy as a result of this process:

"We are all focused on linking clients with services and helping them cope with the stigma of HIV. We have a good mix of long-term and newer staff who share common goals, are client-focused, aware of the broader issues of HIV care, and share the future goal of clients managing their own treatment." – HIV clinic staff response

The flexibility of support workers in attending the clinic with clients is valued by clinic staff, and ASO staff spoke of feeling appreciated when this was acknowledged. It was evident that most HIV clinics recognized the value and appreciated the work of the ASO support staff.

"I think what's also really great that I've seen is the appreciation for the work that we do by the medical staff in those environments. So like they do make referrals and they do understand the services that we offer and they value them as a compliment to actual clinical care." – Focus group participant

As one clinic staff stated in the online survey:

"We know everything about each other. I can't imagine providing holistic care without them [ASOs]." – HIV clinic staff member

2. Communication is seen as key to effective ASO-clinic partnerships

ASO staff that have positive relationships with HIV clinics discussed certain factors that make the partnerships work well – most of which highlight the importance of communication:

- Maintaining open communication channels (meeting together, holding regular meetings between staff, sitting on the other's committee, greater face-to-face interaction, feeling valued and respected)
- Understanding each other's services (having realistic expectations)
- Being flexible (ASOs being able to attend client visits to the clinic and advocate on a client's behalf)
- Sharing office space.

Several support workers and EDs described how good communication with the staff at the HIV clinics helped maintain the quality of their relationship. Communication is particularly important when a client is using the services of both the ASO and the clinic, and when staff from both are collaborating on a client's case management. It is key that both the ASO and the clinic be aware of any new services being offered or existing services being discontinued so they can give their clients accurate information. This type of communication and collaboration helps ensure that expectations are realistic and that clients' needs are met using existing ASO and clinic services.

"For example [staff member of HIV clinic] will call and say 'I have this case, this person lives in your region and this is the issue,' and we consult about how best to deal with it and ... we decide who is best to provide the service ... then the case management piece comes in about who will be doing what in terms of helping this person negotiate the system. They may need help through Trillium [drug program] so maybe I would be the person who helps to fill that person's form out because they don't have that many appointments with their HIV specialists." – Focus group participant

Good communication with the clinics is also important when ASOs must advocate on behalf of a client. For example, when clients have a medical concern or difficulty navigating the medical system, support workers may attend clinic appointments with them and, in some situations, act as their representative or advocate. They may also intervene on the client's behalf if they have been barred from clinic services, because of their behaviour, for instance.

"We are used to building relationships with people whose philosophy is different than ours ... When it comes to the HIV clinics, we find this pretty easy compared to what we have to deal with [other service sector]. We can say 'We hear this client got kicked out, is there anything we can do to facilitate this client coming back to your service? What happened?' We talk about it. We appreciate that our clients are difficult." – ED

3. Regular meetings strengthen ASO-clinic partnerships

ASOs that have developed strong partnerships and open communication with clinics reported that regular interaction and meetings between the two is helpful. Several support workers described how their agency's relationship with HIV clinic staff, especially the reception desk, improved after they had toured the clinic or attended an appointment with a client. EDs and support workers who work for ASOs with good to excellent relationships with the clinics also noted that they have made an effort to invite clinic staff to ASO committees and events. And some organize a twice-yearly lunch for ASO and clinic staff. As one support worker said:

“When I first came I took the time to sit down with the docs and have lunch and we were all really like-minded ... all not territorial, not grabby-grabby with clients and we were just trying to work together and stopped having ownership issues.” – Support worker

Clinic staff also spoke about the importance of meeting regularly. Some clinic staff described meeting quarterly or semi-annually with ASO support workers to discuss, for example: trends or common needs among clients and how to create solutions to address them; their roles within the relationship; service plans; and community issues or gaps in service that will impact the clinic’s or ASO’s ability to provide adequate service to their clients. A few clinic staff members reported meeting regularly with ASO support staff specifically to discuss individual client cases and develop the appropriate case management plan.

4. Suggested strategies to improve relationships between ASOs and clinics

Although most working relationships between ASOs and clinics are positive, there is still room for improvement – and most of those improvements involve more effective communication.

a) Improved client-related communication

Some support workers discussed a lack of two-way communication with clinics about clients’ progress. They felt that clinics do not communicate with the ASOs on a consistent basis about a client’s care because of confidentiality policies in their hospitals. For example, some hospitals do not allow their clinic staff to communicate client information by fax, email or phone. Some ASO staff also noted that despite the fact that clinics are located in hospitals, clinic staff may be unaware when clients are hospitalized. In turn, ASO staff sometimes interpreted this as the HIV clinic staff being disconnected from their clients’ needs – leading to trust issues with the clinics.

“They are very medical based ... A lot of times I will find out that one of our mutual clients is in the hospital, or has passed away before [the clinic staff] do ... when in the long run all that stuff is taking place in the hospital [where the clinic is based].” – Focus group participant

Communication problems work both ways. Clinic staff reported that ASO staff do not always inform the clinic when they have followed up with a client. One clinic staff spoke to the importance of better communication with ASO support staff:

“Often we are not certain if an ASO followed up with a client. We are out of the loop at our end of the city, and often downtown HIV services have ways to make referrals to each other. Being more familiar with the ASOs makes for increased trust in relationships. Some agencies do not always respond in a timely manner to telephone messages, so changing this would also help.” – HIV clinic staff

b) Improved client referrals

Although most support workers spoke positively about how clinic staff members coordinated referrals to the ASOs and clinic staff reported working with ASO staff to coordinate comprehensive client care, some support workers – particularly those whose agencies had more strained relationships with HIV clinics – complained that HIV clinic staff did not refer patients to their services. For example, several support workers in urban and suburban regions reported that the clinics in their respective areas rarely referred clients to them. And one support worker reported feeling “invisible” to the HIV clinics.

For their part, some HIV clinic staff members do not believe ASOs are able to adequately provide the services that patients need. One clinic staff member noted that they often assess the capabilities of an ASO before they refer their patients there, looking specifically at the ASO’s ability to support people living with HIV. When ASOs do not demonstrate that capacity, clinics will not refer their clients to them. Some clinic staff members recognized that ASO staff and volunteers are overwhelmed with demands:

“60 hours a week is not volunteer work.” – HIV clinic staff

Most HIV clinic workers reported that ASOs are quite responsive to their requests but a few noted some poor responses from ASOs when requests were made.

c) Clear understanding of mandates, roles and organizational cultures

Many of the tensions reported by both ASOs and clinics can be traced to a lack of unrealistic expectations about the other's roles and responsibilities and differences in approaches to care, particularly harm reduction and the need to set formal appointments. Moreover, clinics that do not work closely with ASOs tend to have misperceptions about what ASOs do. For example, they expect them to provide clients with transportation to clinic appointments but are not aware of the range of other support services the ASOs provide that would be negatively affected as a result.

In terms of culture and values, some clinics that serve people who inject drugs do not endorse the harm reduction approach taken by ASOs. For example, some doctors have a strict policy about not prescribing anti-retroviral medications to patients who inject drugs unless they start methadone treatment. Because supplies of methadone are distributed weekly, this requirement can be a challenge for clients in rural areas where transportation is an issue. One ED reported that physicians in his region were stricter about patients using medicinal marijuana than doctors he knew in urban areas. Another ED noted that some doctors do not prescribe Oxycontin to clients in chronic pain, regardless of their previous prescription history.

Another difference in organizational culture has to do with the need for formal appointments. Many people who seek services at ASOs have mental health and/or addiction issues. These individuals lead relatively chaotic lives and may not be good at managing appointments. Support workers often commented on the relaxed nature of client appointments at ASOs, including the tendency to establish drop-in times to accommodate clients who have trouble keeping appointments. On the other hand, HIV clinics are seen to be more rigid in their approach to appointments, with doctors being harsh with clients who repeatedly miss them.

d) Formal partnership agreements may strengthen clinic-ASO collaboration

Although ASOs and clinics generally collaborate to serve clients, it is rare for them to have a formal memorandum of understanding or partnership agreement. While some ASOs view these agreements as unnecessary because the relationships were already working well, the lack of formal agreements between ASOs and HIV clinics means that the quality and consistency of working relationships often depend on individual staff connections. For example, one ASO support worker may build a relationship with one staff person in the clinic or vice versa – as opposed to the ED and clinic coordinator meeting regularly and establishing an agency-wide commitment to working together.

By spelling out the process for referring clients to each other, a formal agreement between ASOs and clinics could result in more consistent referrals. These agreements can also help clarify what services each provides to the other, and under what conditions. For example, in some ASOs in suburban and rural areas, support workers may drive clients to their clinic appointments as a courtesy but most ASOs do not have the resources to provide this service on a consistent basis. Misunderstandings about what ASOs can provide to clinics and vice versa can create negative perceptions – the sense that one partner is “failing” the other and this can damage the working relationship.

“ASO staff are supposed to drive clients to appointments, but they do not show up.” – HIV clinic staff

Support workers sometimes felt that HIV clinic staff members had unrealistic or inaccurate information about the services they provide:

“One [HIV clinic worker] called for a client that needed a ride somewhere [one hour's drive from the ASO] ... I am not blaming the social workers [at the HIV clinic] because that's what we do, we handle crises... and part of it is the responsibility on the clients to communicate with us. But I sometimes feel like requests are coming our way [from the HIV clinic] that are unrealistic in terms of what we can do.” – Focus group participant

A formal agreement that outlines their respective roles and responsibilities may also help minimize the likelihood that workers compete for clients. A small number of ASO support workers and clinic staff discussed the issue of territoriality, where ASO or clinic workers feel they are primarily responsible for or “own” the

client. While these attitudes are borne out of concern for the client, they may have a negative impact on the person's care.

"We should use the circle of care idea, rather than your client or mine." – HIV clinic staff

A formal partnership agreement could outline a process for identifying and responding to unmet client needs.

STAFFING ISSUES

In their OCHART reports, agencies have identified a number of staffing issues, including problems recruiting and retaining support workers, and high turnover rates in the field. The environmental scan explored staffing issues with EDs and support workers.

Key Findings

1. Agencies try to recruit people who will be a good fit for the job as well as the agency

When we asked EDs about the qualifications they look for when hiring support workers, their criteria consisted of:

- Work experience
- Lived experience
- Education (e.g. BSW or MSW).

NOTE: Agencies defined lived experience in different ways, including the experience of living with HIV, the experience of being part of an ethno-specific community or the experience of a mental health problem or addiction.

Agencies considered social work experience, either within the ASO sector or in a community agency that serves marginalized populations, an asset. If the support worker's personal experience can help them relate to clients, then that is also considered a strength.

In general, ASOs try to hire people who understand how the determinants of health influence HIV transmission and who understand the impact of HIV-related stigma. A couple of support workers described two rare situations where newly hired employees' lack of understanding about disclosure and confidentiality issues related to HIV were detrimental to their work. In their view, these employees had the right education but lacked knowledge and sensitivity to HIV-related issues.

Agencies reported that recruitment can be a challenge, with some mentioning that they have a hard time finding qualified support workers. Sometimes, they have clients or volunteers who are interested in employment opportunities, but who have no training or education. As one person said:

"Being a PHA alone doesn't mean you are qualified to do the work ... you have to know what you are doing. Big heart and well-meaning attitude doesn't replace this fact."

In other cases, agencies have had many applicants with the right education and training but none with the lived experience that would enhance their capacity to do the job. For example, some agencies that serve an ethno-specific community (e.g. Aboriginal or First Nations people, African, Caribbean or Black communities, South Asian communities) prefer to hire workers from that same community. Some EDs reported that it was hard to find individuals, including people living with HIV, from these communities who are qualified and who want to become more involved in the sector.

EDs also discussed the importance of hiring individuals whose philosophy or approach to work is compatible with that of the agency (e.g. sex-positive, non-judgmental).

2. Open communication is key to effective supervision

When EDs were asked to describe the supervision and support available to their support workers at their ASO, they described three different types of supervision:

- Hierarchical supervision: support workers report to a manager, and then managers report to the ED
- Direct supervision: support workers report to the ED
- A combination of both: support workers deal mainly with the manager and also meet regularly with the ED.

Most ASOs have an “open-door policy” where workers can approach their managers or EDs as issues arise. Support workers in particular value this aspect of supervision. As one person said:

“What I really like about my organization is that I do have a really good channel, open channel of communication with the ED as well as the coordinator. So ... I’ve gotten a lot of support. I feel that if anything were to get out of hand I have people that I can go to.”

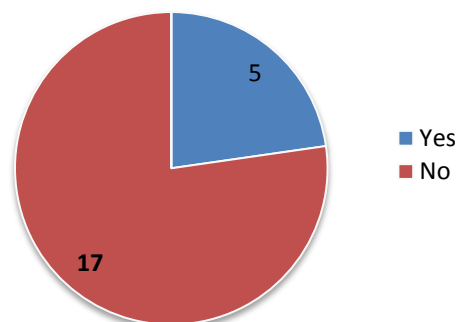
In addition to these informal discussions, workers also receive regular supervision in the form of bi-weekly or monthly meetings. According to EDs, the purpose of supervision is to discuss program-related challenges and successes, as well as to discuss and give advice on client-related issues. Supervision meetings are also a place where workers can discuss professional development and training opportunities. Only two of the agencies involved in the scan did not have a formal supervision process. In both cases, the agencies had a severe staff shortage and the ED was not able to provide supervision. And, in both cases, there was a strong need for supervision. As one worker said:

“I would prefer to have the money in there to have a supervisor to be able to sit down with and talk about all the issues that we face in our own community on a monthly basis.”

3. Only about one-quarter of agencies provide clinical consultations for staff

Agencies were asked whether they provide clinical consultations for staff – that is, clinical sessions with an external professional with no direct accountability between the support worker and the professional providing the service. The clinical sessions give workers an opportunity to debrief about any work-related issues, identify stressors and develop strategies to prevent burnout. Of the 22 EDs we interviewed, only five said they provide their workers with clinical consultations.

Do you provide your workers with access to clinical consultations?



Of these five agencies, three partnered with a local mental health provider to provide the consultations. In these cases, a local professional visits once a month to do a one-on-one session with each support worker and may also do a group clinical session with the whole staff team. The other two agencies used an internal staff person with clinical training (e.g. an on-site psychiatrist) to provide clinical consultations either every two weeks or once a month.

To at least temporarily provide clinical consultations, one ED paired ASO support workers with colleagues in similar positions in other organizations. The paired workers met on an as-needed basis and the consultations provided a space for workers to debrief openly about any issues. In some other agencies, staff reported taking it upon themselves to come together and support each other either informally or through formal, monthly “peer supervision” meetings. However, for agencies with only one support worker, this strategy is not feasible.

4. Support workers want more training related to clients' mental health issues

When EDs and support workers were asked about the training workers need to be more effective, the most common request among workers was training on mental health issues such as trauma and vicarious trauma, suicide, addictions, counselling and group counselling.

Workers across Ontario discussed clients coming in with complex issues such as a history of sexual abuse, the experience of being a child soldier, and trauma from correctional facilities. In addition to these issues, many clients have other serious mental health problems such as borderline personality disorder, schizophrenia, bipolar disorder or concurrent disorders. Many workers did not feel equipped to recognize or address any of these issues. As one worker said:

"We had a client who kept coming back saying, 'I really want to talk to you about this and this happened to me,' and we would say we can't do that, we don't have training for that kind of work."

Because of a shortage of mental health services in many communities, "hard to serve" clients with multiple issues often end up coming to the ASO for help. Workers wanted additional training and resources on how to recognize mental illness as well as strategies for serving clients while staying within the scope of what an ASO is able to provide.

In an attempt to meet this need, one agency arranged for staff to receive the Hincks-Dellcrest Centre "Trauma and Resiliency" training program, which is very useful but costly to provide regularly.

5. Workers want more opportunities for advanced training

Support workers expressed the need for more advanced training. While the training offered by the Toronto Hostel Training Centre and the Ontario AIDS Network is useful for new workers, there are few training options for more experienced workers. In particular, workers would like advanced training related to:

- De-escalating conflict
- Conflict resolution and mediation
- Counselling
- Case management
- Immigration and settlement issues
- HIV-related legal issues
- Co-morbidities for people living with HIV
- More ethno-specific resources on counselling and case management for workers in agencies with a mandate to serve specific ethnic communities.

Many of these unmet training needs highlight the case management role that support workers now play, including their responsibility to link their clients to appropriate services and support.

6. Many support workers see their role as one step on their career path

In each focus group, we asked support workers, "Do you see yourself doing this work 5 years from now?" Most said no – not because they did not like the work or wanted to leave the sector, but because they wanted to move away from front line work in order to advance their careers. Workers' career goals include:

- Moving into a leadership role within the agency (e.g. manager of support services)
- Going back to school to obtain a master's degree in social work or in a health-related field (including having the option to complete a degree while continuing to work part-time in their current position)
- Working more as activists in the field
- Being more involved in policy-related work
- Pursuing a career in mental health/obtaining clinical training to be able to serve clients suffering from trauma.

As one worker said:

"I'd really like to focus on psychotherapy in HIV ... the thing that for me is a downer is that I don't get to spend more time with people, because people's needs are so complex."

Of the workers who saw themselves doing the same work five years from now, most were driven by a personal connection to the work and the people they serve or by the feeling that they still have more to contribute to their community:

"I have seniority coming out the yin yang and I love my job more importantly. I got into this work in the early days and it's my passion. So, I'm totally committed to the work. That's one of the reasons I'm still here."

7. Burnout is the greatest threat to staff retention

When we asked workers what would make them leave their job, we received three main responses:

a) Burnout

Although support workers generally love their work and its diverse challenges, many of them worry about sustainability:

"If I stay for another 20 years ... I worry like I might like develop some chronic illness, really, in my body."

"It will be 5 and I will have realized I haven't eaten or gone to the bathroom because I have been so busy."

As noted earlier, many support workers feel overworked. Many do not have a structured nine-to-five work day that can help set boundaries, with numerous workers reporting working late nights and weekends because that is what the work requires. This is especially true when workers are serving many clients in crisis situations. Because their time away from work is so limited, workers reported struggling to manage their personal lives effectively.

Clients' multiple, complex issues can be emotionally draining for support workers. They described how stressful it is for them when clients come in with the same issues (such as mental health) for years and years, and they are not able to help them make the necessary changes. These situations create a constant feeling of helplessness for workers. For some, one of the main causes of burnout is "taking work stress home." Workers who do not have a space to de-brief (through clinical consultations or peer support groups) or who do not have other strategies for managing stress, reported that they cannot stop thinking about work when they get home.

b) Boundary issues

Some workers discussed the stresses related to boundary issues with clients. For example, clients may make suggestive comments that some workers consider sexual harassment, such as:

"I will actually disengage my services as a client if I could go to bed with you."

Workers reported that some clients make these kinds of comments on a regular basis. While workers suspect that these incidents occur because clients feel isolated or are not getting their needs met, they still find these situations stressful and difficult to handle. Some workers described situations where clients made physical threats by phone or email. Support workers who are living with HIV also face boundary issues with clients who want to know their status or try different ways to extract information about their personal lives.

Workers generally receive good support from their managers or EDs when these incidents do occur:

"Immediately our Executive Director called me at home right away and then my boss too. I got a huge amount of support from the agency and it just took the sting out completely because I felt completely supported."

However, some workers said that these types of issues are not discussed openly among staff and there is no consistent agency-wide approach to help workers address boundary issues.

c) Compensation

Another reason why support workers may leave their position is dissatisfaction with their salaries and benefits. According to workers, salaries are relatively low given the demands of the job with some agencies not offering

pension plans or health benefits. Some workers reported that the only reason they are able to continue in this type of work is because their partners have health benefits plans or because they are young and do not yet have families and other responsibilities. However, they expect their needs will change as they get older and they may need to look for positions that provide benefits.

8. Effective management is key to keeping support workers

When asked what would help them stay in their jobs, support workers said a “supportive executive director” and “management which encourages self-care.” As one worker said:

“I feel like, it’s not only our job to always be monitoring our own mental health. Leadership needs to be aware that burnout is a potential thing that can happen and needs to make policies about how to prevent staff from crashing and burning.”

In addition to building a supportive relationship with support workers, there are several structural strategies that managers and EDs can use to make workers feel valued. For example, workers talked about the importance of management:

- **Being accessible/providing regular support and supervision.** Workers are more likely to stay when management is accessible, understands their work stress and allows them to voice their concerns. Regular supervision and guidance also helps support workers’ satisfaction with their jobs.
- **Keeping track of workers’ vacation and lieu time and encouraging them to take it.** Often, workers felt that they could not be away from their jobs because they feared that there would be serious consequences for the agency or for clients. In many agencies, there is no system or infrastructure to cover for workers when they are away. This is less of a problem in agencies with some job-sharing between support workers and other staff. In these cases, workers can take time off feeling confident that clients will continue to receive the services they need.
- **Reinforcing healthy work practices.** Of all the workers we spoke to, there was only one agency that had instituted a mandatory lunch break for staff to ensure that they took a break during the day.
- **Organizing team building exercises.** Some workers also requested more **team building exercises** to strengthen relationships between staff so that they can support each other better.
- **Encouraging self-care.** One person described a situation where an agency organized a staff development day where the office was closed and all staff met at a hotel where they had professionals come in and offer complementary therapies such as massages. In other agencies, staff meet informally and de-brief with one another as a method of self-care and this has proved to be very helpful. One worker also described the monthly clinic done by the AIDS Bereavement and Resiliency Project of Ontario to assess work and stress load, which has also been very helpful.

“The commitment ABRPO and all the support that they give our ASOs ... we’ve been really, really blessed to have them come up and do a lot of work with our team ... I don’t think we could do it without [ABRPO team member] and I have not seen that in any other sector that I have worked in ... That sort of commitment to health and wellbeing of [ASO staff] doing this work; around bereavement and stress ... I’ve just never seen that in any kind of service sector... in corrections you were totally on your own ... mental health and addictions not too far behind that.” – Focus group participant

As noted above, only five of the agencies surveyed had made arrangements for support staff to have formal clinical consultations. Workers indicated that these sessions are important to help them de-brief and learn how to deal with difficult situations. Being able to talk to someone outside the agency is important because of the confidentiality issues that arise when workers talk to other staff or management. Workers reinforced that it isn’t just access to an outside person, it’s also the time to be able to leave the office to attend the session. To be effective, these sessions have to be built into the worker’s schedule.

RECORD-KEEPING

All ASOs are expected to keep records on the support services they provide to clients. As part of their responsibilities, support service workers are expected to document client contacts and the services they use as well as maintain case notes. All the agencies included in this environmental scan are expected to use OCASE, a case management tool provided by the AIDS Bureau and managed/administered by the OHTN to collect and maintain client data. Support workers are also expected to provide information for OCHART, the activity reporting tool that agencies use to submit their data twice-yearly to the AIDS Bureau.

Key Findings

1. Processes for entering data vary widely across agencies

Support workers appear to be using OCASE as a case management tool to record case notes and other information such as appointments and services provided (e.g. counselling, food vouchers, transit tickets, use of food bank). However, the processes and practices that support workers use to collect and record data vary both within and between agencies.

"Each support worker has their own practice. Some of [us] use jmccjmca paper tally sheet ... others input daily, weekly, monthly or every three months."

For example, different approaches include: entering data at certain regular intervals (e.g. daily, weekly, monthly); writing up case notes either immediately following an appointment or no later than one week after; using Excel sheets and transferring the information to OCASE; keeping a statistic sheet in each client's file that coincides with the OCASE fields and updating OCASE when there is time; having individual workers enter the data or having one person (sometimes a supervisor) enter the data; and keeping a checklist for activities like the food bank and food vouchers, completed by the staff person responsible for walk-ins; and having one worker enter that data for the entire department once a month ("It takes about an hour to do this") while individual workers are responsible for maintaining their own client case notes"

"We enter many [client transactions] on the spot into OCHART as the transaction is taking place. In the case of therapeutic and social programming, client attendance is collected every day and then ideally stats are entered weekly."

The frequency in which workers record data in OCASE ranges from every day to every three months – with the most common response being once or twice a week. Although, as one worker noted, the timeliness of data entry is important:

"We have to do it as the events happen ... as soon as the clients come, they do it after the appointment so we do not have a backlog."

Expectations of EDs for record-keeping also vary, and they recognize the gap between what is ideal record-keeping and what is workable for staff:

"This is how it's supposed to work. Support staff are supposed to enter their activities on a daily basis as they happen. It becomes a little bit more difficult for the second support worker because their office is offsite. So they can't log in to OCHART. They record their activities on a sheet and then when they come to our main office, then they can enter it. But I know that in the perfect world that would be great but that doesn't always happen."

From the responses, it was also clear that there is some confusion between OCHART and OCASE, which should be resolved to ensure more effective and consistent use of these data systems.

2. Some workers reported challenges using OCASE

a) System-related issues

Some workers described challenges using OCASE, mainly related to problems inputting data, which included:

- OCASE fields too narrow to capture all their services
- Too many drop-down menus
- Too many fields that aren't relevant to all agencies
- Data cannot be entered from offsite (because of security issues)
- Process is time consuming so they don't enter a lot of information: "If we had one person to enter all that data, you would probably capture a lot more of what we are doing"
- Frequent changes to the software itself and the learning curve involved: "It's time consuming and it takes away from support work."
- Problems with the system crashing.

Some of the challenges that workers experienced were related to their comfort level working with technology and their personal preferences. Some workers preferred using paper record systems while others were more comfortable using the computer-based tool. One person noted that if OCASE could also be a scheduling tool, it would assist with record-keeping.

b) Privacy concerns

In some organizations, record-keeping is affected by concerns about privacy and confidentiality, particularly related to criminalization of non-disclosure of HIV status. As one worker said:

"Workers were told in the past to keep as little information as possible in case of subpoena, in a case of criminalization. In a criminal case, the prosecution may request documentation. The previous ED was a lawyer, and didn't want the information used against us."

Some agencies have developed record-keeping policies to ensure confidentiality, which are signed by clients and staff. Only those who have direct contact with client services have access to the client files.

c) Perceptions of importance of record-keeping

Some workers see the time spent recording data as "taking away from time for support work." They do not necessarily consider data collection part of support work or recognize the potential value of the data.

"If we were all using it and I knew that people would be looking at the notes ... then it would be useful but I think we're also as an agency very weary of data collection. There's an aversion to having notes on people in general."

When asked if support staff are too overworked to enter data, one ED said:

"I used to be in support and I was able to do that and I was overworked as well. I think it's really about a practice and making yourself do it and taking the time. I don't overwork anyone that much where they can't just close their door, enter some data and then continue on. I really think it's about being more disciplined."

3. Service definitions vary within and across agencies

Agencies tend to use OCHART/OCASE terms to describe their services – such as case management, assessment and counselling – but the way in which these terms are defined and used varies. For example:

"Within an agency, you'll have one staff entering something as case management and someone else puts it in as counselling. ... when I look back at my predecessor ... and I saw that person's stats, I felt so insecure because they had like 300 counselling [sessions] and I only had way lower than that. It turned out that they had counted everything as counselling ... like for example if someone drops by for five minutes and says 'hey can we chat for a few minutes,' that was put down as counselling."

In general, support staff said there should be more training or some clear criteria on how to record their activities to ensure the data they are collecting represents an effective way to measure the intensity, impact or success of their services.

"The thing that actually alarms me ... is unless every single one of us across the province uses [OCASE] exactly the same way ... we'll gather stats ... that are completely skewed and they don't mean anything."

4. Leadership and policies can improve data collection

Practices and procedures within the office as well as leadership from the ED can support better record-keeping. EDs that actively encouraged OCASE use and organizations that made a commitment to using the system by, for example, establishing cross-agency user groups, reported that the system is more accepted and more useful. For example:

"I encourage [support workers] to keep OCASE open all day and then enter the information as they go ... if it is face-to-face or offsite then they do it after the meeting as soon as possible. Also Friday mornings are administration time. There are no bookings and they spend that time making sure their notes are up to date." ED

Workers/agencies that incorporated data collection into their work, who entered data more frequently (e.g. daily as part of their work) and who used their data, appeared to be more satisfied with OCASE and OCHART.

"When I run the reports, I look at it on a monthly basis. I compare it against what our outcomes are supposed to be ... and I check where we are in the numbers. I also look at what are the needs, where are the demands – have we had any sharp spikes in certain areas? – and of course overlaps areas."

5. Agencies are developing an evaluation culture

Despite some of the challenges that agencies experienced using OCASE, there appears to be a growing culture of evaluation and continuous quality improvement within ASOs. Support workers and EDs reported using a variety of tools to evaluate client satisfaction with their services as well as service impact/effectiveness including: client satisfaction surveys, focus groups, participant evaluation forms (for people who participate in specific programs), client feedback sheets, one-on-one interviews/meetings with clients and third party evaluations.

Within support programs themselves, ASOs reported using a number of strategies to evaluate the quality of their support services including: supervision, assessing client progress against their care goals, logic models, having staff do presentations on what they are doing, and reviewing data together to identify the number of service users and high-intensity service users.

While many agencies are using evaluation tools, there does not appear to be any consistency across organizations.

SUMMARY AND RECOMMENDATIONS

ASOs and their dedicated support workers are committed to providing high-quality services for people living with HIV and to making appropriate referrals to other services in the community. However, many support workers are feeling overwhelmed by clients' increasingly complex health and social needs, and by the growing demand for services. In the view of the Community Advisory Committee for this environmental scan, many of the challenges identified in the scan – including the variation in how services are defined and delivered, concerns about recruitment and retention, the challenges of operationalizing GIPA and MIPA, and the lack of communication between ASOs and clinics (and ASOs and other partners) – can be addressed by clarifying the ASO role in providing support, establishing realistic expectations of ASOs and their support workers, and actively sharing and promoting best practices.

The Community Advisory Committee recommends the following strategies:

1. The AIDS Bureau, in partnership with the OHTN Evidence-based Practice Unit (EBPU), should create a Support Services Best Practices Working Group comprised of EDs & support workers to:
 - Develop comprehensive, specific definitions for core support services
 - Identify the minimum core support services that all ASOs are expected and able to provide (with the understanding that ASOs with more resources may provide more than the minimum)
 - Develop minimum provincial standards and guidelines for the core support services that will ensure consistency across the province
 - Develop a manual defining the scope of core support services at ASOs across Ontario and setting the minimum standard that all ASOs are expected and able to provide (
 - Create an effective mechanism to share best practices in delivering core services
 - Develop a KTE plan to ensure that staff at all agencies are aware of the manual and have a common understanding of core ASO services (e.g. regional workshops, a KTE day).
2. To ensure effective implementation of GIPA/MIPA across the province, ASOs should:
 - Review existing guidelines on how to operationalize GIPA/MIPA (e.g. the OAN's Living and Serving 3) and discuss this issue annually as part of their organizational planning. Implementing GIPA/MIPA is an ongoing process. What works in some regions may not work in others; and incorporating this into a regular planning cycle will ensure ASOs are attending to the ongoing development of GIPA/MIPA
 - Share the successes they have had in implementing GIPA/MIPA and acknowledge the efforts each has put into involving people living with HIV in their local community
 - Take advantage of many GIPA/MIPA resources available through the Ontario AIDS Network, the AIDS Bereavement and Resiliency Program of Ontario Turning to One Another Program, or the Ontario Organizational Development Program.
3. To forge stronger relationships between ASOs and HIV outpatient clinics:
 - At the provincial level, the OHTN, in partnership with the AIDS Bureau, should organize a KTE day to highlight the Environmental Scan and provide a forum where clinic coordinators and representatives from ASOs can discuss the needs of people living with HIV and what both clinics and ASOs can and cannot do to address any gaps (e.g. transportation)
 - At the local level, ASOs and clinics should develop formal partnerships, which may include:
 - A written document that describes the responsibilities of both the ASO and the clinic and an agreement to share information between the two organizations
 - Regular face-to-face meetings with clinic coordinators, social workers and ASO support workers to do case consultations for specific clients
 - Identifying effective ways to collaborate to provide services.
4. To help support staff enhance their skills and manage work-related stress, ASOs should implement some form of clinical supervision for all support staff, such as:
 - Develop formal supervision and mentoring programs where workers can discuss client and organizational issues, workload management, training and support needs, and career goals

- When supervision or consultation is not available, connect support workers with workers from other agencies with similar titles and work experience for the purposes of support and mentorship
 - Explore cost-effective clinical supervision methods such as peer supervision (i.e. staff-run group sessions)
 - Develop key discussion themes and resources on clinical supervision and supervision in general for EDs at the next ED retreat in cooperation with the OAN Skills Development Program and the Ontario Provincial Resource in Human Resources.
5. To help address workload issues for support staff, ASOs should:
- Develop – if feasible – a protocol to actively manage how other agency staff will deal with client emergencies when the support worker is not available due to vacation, sick leave, training days or community development work
 - Encourage balanced work environments - monitor lieu and vacation time regularly to ensure staff are using this time, and support staff are taking this time off as earned.
6. To ensure that data systems are implemented consistently and are useful for ASOs:
- The Evidence-based Practice Unit at the OHTN should establish province-wide standards and best practices for record-keeping and conduct a technical review of OCASE to ensure that it is user-friendly
 - EDs should provide leadership in their agencies for consistent data collection and record-keeping, and recognize that record-keeping is an integral part of best practices by planning or mandating time for support workers to enter data and complete other administrative tasks (e.g. no appointments on Friday mornings).

APPENDIX A: ASOS INVOLVED IN THE SCAN

TORONTO

2-Spirited Peoples of the First Nations
105-145 Front Street East, Toronto, ON
M5A 1E3

AIDS Committee of Toronto
399 Church Toronto, ON M5B 2J6

Asian Community Services
260 Spadina Ave, Suite 410, Toronto, ON, M5T 2E4

Fife House Foundation
490 Sherbourne, Toronto, ON M4X 1K2

Teresa Group
124 Merton Toronto, ON M4S 2Z2

Africans in Partnership Against AIDS
314 Jarvis Toronto, ON M5B 2C5

Alliance for South Asian AIDS Prevention
120 Carlton St #315 Toronto, ON M5A 4K3

Black Coalition for AIDS Prevention
110 Spadina Ave Toronto, ON M5V 2K4

Ontario Aboriginal HIV/AIDS Strategy
7 Hayden Street, Suite 101
Toronto, ON M4Y 2P2

Toronto People with AIDS Foundation
200 Gerrard E, Toronto, ON M5A 2E6

GTA

AIDS Committee of Durham
22 King Street West, Suite 202
Oshawa, ON L1H 1A3

Peel HIV/AIDS Network
1-160 Traders Blvd E Mississauga, ON L4Z 3K7

AIDS Committee of York Region
194 Eagle Street East
Newmarket ON L3Y 1J6

EAST

Bruce House
251 Bank Ottawa, ON K2P 1X2

AIDS Committee of Ottawa
700-251 Bank St, Ottawa, ON K2P 1X3

HIV/AIDS Regional Services
844A Princess St Kingston, ON K7L 1G5

Peterborough AIDS Resource Network
302-159 King St Peterborough, ON K9J 2R8

CENTRAL SOUTHWEST

Hamilton AIDS Network
101 140 King E Hamilton, ON L8N 1B2

AIDS Committee of Guelph & Wellington County
89 Dawson, Guelph, ON N1H 1B1

AIDS Committee of Windsor
511 Pelissier Windsor, ON N9A 4L2

AIDS Niagara
120 Queenston Street, St. Catharines, Ontario L2R 2Z3

AIDS Committee of Cambridge, Kitchener, Waterloo and Area
2B – 625 King Street East, Kitchener, ON N2G 4V4

NORTH

AIDS Committee of North Bay and Area
269 Main St W #201 North Bay, ON P1B 2T8

Regional HIV/AIDS Connection
Suite 30, 186 King St #30, London, ON N6A 1C7

AIDS Committee of Simcoe County
80 Bradford St Barrie, ON L4N 6S7

AIDS Thunder Bay
574 Memorial Ave Thunder Bay, ON P7B 3Z2

Reseau Access Network
111 Elm Street, Suite 203, Sudbury ON P3C 1T3

OTHER

Prisoners with HIV/AIDS Support Action Network
314 Jarvis St. #100, Toronto, ON M5B 2C5

APPENDIX B: DATA COLLECTION TOOLS AND RECRUITMENT

1. Tools used for Support Workers

A) Email Recruitment Script Created for Executive Directors to Send to Support Workers

Dear (Support Worker),

The AIDS Bureau has commissioned an environmental scan that will look at the nature and scope of support services offered at the 29 ASOs across the province. The Ontario HIV Treatment Network (OHTN) has undertaken this work, and the research team conducting this scan has asked me to forward the following message to you.

Your participation in this environmental scan is completely voluntary and confidential, and if you choose to participate, you may do so during working hours. Please be assured that your participation in the scan and the views that you share in the focus group will have no impact on your employment at this agency. The research team will not reveal who participated in the study or what was said.

If you are interested in participating in a focus group, please contact the research team at the email addresses provided below. Thank you for taking the time to consider this matter.

(signed, Executive Director)

An Environmental Scan of Support Services Provided by ASOs in Ontario

E-mail Subject line: Invitation to participate in an Environmental Scan of Support Services provided by ASOs in Ontario

Community-based support services for people with or at risk of HIV in Ontario have evolved organically over time, driven mainly by client needs and by other factors, such as the mix of other services/service providers in each community or region. Organizations that in the 1980s focused on buddy services for people who were dying now offer a growing array of social support, education, health promotion, practical support, housing, food security, employment, immigration and other programs to meet the needs of increasingly diverse client groups. The types of services provided vary depending on local needs and the capacity and focus of each AIDS service organization (ASO). To better understand their nature and scope, the AIDS Bureau is funding an environmental scan of support services provided by AIDS service organizations in Ontario.

You are invited to participate in a regional focus group discussion that is being held as part of this scan. Focus groups will last approximately 2 hours.

This environmental scan is being conducted by a research team comprised of Jean Bacon and Sergio Rueda (Ontario HIV Treatment Network), Roy Cain (School of Social Work, McMaster University), Evan Collins (OHTN) and Joanne Lush (AIDS Bureau). The projects coordinators are Shani Roberson and Alekhya Mascarenhas.

The environmental scan aims to:

1. Understand the scope and range of support services provided at ASOs

2. Understand the partnerships that ASOs have developed with HIV clinics and identify opportunities for meaningful partnerships with HIV clinics in Ontario
3. Examine the extent to which GIPA/MIPA (Greater/Meaningful Involvement of People Living with HIV/AIDS) principles and practices are reflected in support services
4. Identify training priorities for ASO support service providers
5. Examine turnover of support workers within ASOs and identify strategies to improve staff retention
6. Identify a common set of core support services across all ASOs in Ontario and develop guidelines for those services. Identify best practices in core support services that can be shared among ASOs.

This study has been reviewed by and received ethics clearance from the McMaster Research Ethics Board. For your information, we have attached the Letter of Information/Consent Form for this study. Your participation is entirely voluntary and any information you provide will be kept confidential. Your Executive Director will not be told whether or not you participated in the Focus Group. No identifying information will be used in any report that we write, and no identifying information about you or your agency will be communicated to the Ministry of Health and Long-term Care. To ensure that we collect an accurate record of what is discussed, we plan to audiotape Focus Group discussions, and consent to record the discussion will be sought at the start of the focus group. If you do not consent to the discussion being recorded, you will unfortunately not be able to participate in the discussion. If you have any questions or concerns about the study, please feel free to contact Jean Bacon at the OHTN at 416-642-6486, ex.2233.

Please reply to Shani (srobertson@ohntn.on.ca) or Alekhya (amascarenhas@ohntn.on.ca) by (month, day, 2011) to join one of our focus groups.

B) Consent Form for Focus Groups Participants



LETTER OF INFORMATION / CONSENT

An Environmental Scan of Support Services provided by AIDS Service Organizations across Ontario

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Purpose of the Study

Community-based support services for people with or affected by HIV in Ontario have evolved organically over time, driven mainly by client needs and by other factors, such as the mix of other services/service providers in each community or region. Organizations that in the 1980s focused on buddy services for people who were dying now offer a growing array of social support, education, health promotion, practical support, housing, food security, employment, immigration and other programs to meet the needs of increasingly diverse client groups. The types of services provided vary depending on local needs and the capacity and focus of each ASO.

To better understand the scope and range of support services that are being delivered by AIDS Service Organizations (ASOs) in Ontario, the AIDS Bureau of the Ontario Ministry of Health and Long-term Care is funding an environmental scan of support services offered by 29 ASOs. You are invited to take part in this scan by participating in a focus group of support workers in your region.

The scan aims to:

1. Understand the scope and range of support services provided at ASOs
2. Understand the partnerships that ASOs have developed with HIV clinics and identify opportunities for meaningful partnerships with HIV clinics in Ontario
3. Examine the extent to which GIPA/MIPA (Greater/Meaningful Involvement of People Living with HIV/AIDS) principles and practices are reflected in support services
4. Identify training priorities for ASO support service providers
5. Examine turnover of support workers within ASOs and identify strategies to improve staff retention
6. Identify a common set of core support services across all ASOs in Ontario and develop best-practice guidelines for those services.

Procedures involved in the Research

In the focus group, you will be asked to discuss the following topics:

1. The nature and scope of support services offered at your ASO
2. The nature of your organization's relationship with local HIV clinics
3. The administration of these support services
4. The implementation of GIPA and MIPA principles at your ASO
5. Career issues.

With your permission, the focus group discussion will be tape recorded and should take no longer than 90 minutes. You will also be asked to complete a short questionnaire concerning the kinds of support services offered at your ASO, your job title, length serving in this position and your career plans.

Potential Harms, Risks or Discomforts:

The risks involved in participating in this study are minimal. We will be asking questions about the support services offered by your agency, and your career plans. It is possible that you may feel uncomfortable with some of the questions being asked. You do not need to answer questions that you do not want to answer or that make you feel uncomfortable. And you can withdraw from the focus group at any time and you may also skip questions you do not want to answer.

You may also worry that what you say in the focus group will be released out into the community or to your workplace. We will treat the information you provide in confidence. In the final report will not contain information that can be used to identify you or your agency. The recorded focus group discussion will be transcribed and transcripts will have any identifying information changed or deleted. Bear in mind that you might be identifiable by what you say, so you might want to exercise care in what you share in the focus group. As well, we cannot guarantee confidentiality in a group setting. All members of the focus group will be asked to sign a confidentiality agreement which asked that they promise not to share this information outside the focus group.

Joanne Lush, from the AIDS Bureau, is a member of the research team and is funding this scan. Her dual role as researcher and funder may make some people feel pressure to participate in the scan, and others may worry that what they say in the focus group will be communicated to the AIDS Bureau. To ensure that your participation is voluntary and to protect your privacy, Joanne will not know who participates in focus group discussions, and she will not have access to transcripts of focus group discussions until identifying information has been removed.

Potential Benefits

The results of this scan will help us understand the nature and scope of support services, as well as some of the challenges they face. We expect that this will help improve support services to people living with HIV, and to better support ASOs workers. The scan may also identify a common set of support services across ASOs in Ontario and develop guidelines for these services.

Reimbursement

If you are required to travel to a location outside of your workplace, you will be reimbursed for your travel expenses.

Confidentiality

You are participating in this study confidentially. Every effort will be made to protect your privacy, and we will not use your name or any information that would allow you to be identified. We will not record your name in the transcript of the focus group discussion; instead, you will be identified by a numerical code. We will not tell anyone whether you participated in the focus group. However, we are sometimes identifiable through the stories we tell. We ask that you keep this in mind when sharing your responses.

The information you provide will be kept in a locked cabinet where only the research team will have access to it. Information kept on a computer will be protected by a password. Once the study has been completed, the original recordings, individual responses to questionnaires and transcripts will be shredded and deleted.

Participation and Withdrawal

Your participation in this focus group is voluntary. If you decide to be part of the study, you can decide to stop at any time, even after signing the consent form or part-way through the focus group. If you decide to withdraw, there will be no consequences to you, and we will still reimburse you for your travel costs. In cases of withdrawal, any data you have provided will NOT be destroyed due, as removal of any responses would change the context and render other participants' responses incomprehensible. If you do not want to answer some of the questions you do not have to, but you can still be in the focus group.

Information about the Study Results

We aim to have this study completed by the end of March 2012. A full report of the results will be disseminated to all ASOs. If you would like to receive the summary personally, please let us know how you would like us to send it to you.

Questions about the Study

If you have questions or need more information about this study itself, please contact Shani (srobertson@ohtn.on.ca) or Alekhya (amascarenhas@ohtn.on.ca).

Telephone: 416-642-6486, Shani ex.2205; Alekhya ex. 2256

This study has been reviewed by the McMaster University Research Ethics Board and received ethics clearance. If you have concerns or questions about your rights as a participant or about the way the study is conducted, please contact:

McMaster Research Ethics Secretariat
Telephone: (905) 525-9140 ext. 23142
c/o Research Office for Administrative Development and Support
E-mail: ethicsoffice@mcmaster.ca

I have read the information presented in the information letter about the environmental scan of ASO support services.

I have had the opportunity to ask questions about my involvement in this focus group and to receive additional details I requested.

I understand that if I agree to participate in this study, I may withdraw from the focus group at any time. I have been given a copy of this form.

I agree to participate in the focus group.

Yes	No
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>

I agree that the interview can be audio recorded.

Yes, I would like to receive a summary of the results

Please send them to this email address: _____

OR this mailing address:

Signature: _____

Name of Participant (Printed) _____

C) Confidentiality Agreement for Focus Group Participants



Confidentiality Agreement

I understand that as a focus group participant for an environmental scan being conducted by the Ontario HIV Treatment Network, the AIDS Bureau of the Ministry of Health and Long Term Care, and Roy Cain from McMaster University, confidential information will be made known to me.

I agree to keep all responses from focus group participants confidential and will not reveal by speaking, communicating or transmitting this information in written, electronic (disks, tapes, transcripts, email) or in any other way to anyone after the focus group is finished.

Name: _____ Signature: _____
(Please Print)

Date: _____

Witness Name: _____ Witness Signature: _____

D) Online Background Survey for Prospective Focus Group Participants

Purpose of Environmental Scan

Twice each year, ASOs report on the support services they provide through the Ontario Community-based AIDS Reporting Tool (OCHART). The OCHART report tells us the number of clients served, and the number and type of services provided. Through the Ontario Community-based AIDS Service Evaluation (OCASE) tool, ASOs are now collecting more detailed information on the type and mix of services that each client receives. In the process of collecting and reporting their data, it has become clear to the ASOs that many are providing a different range of support services and that they describe and define those services in different ways. The aim of this scan is to better understand the scope and range of support services that are being delivered at Ontario ASOs.

Purpose of the this Survey

This survey is the first component of getting your input, which will be followed up with a focus group interview. All information you provide in the survey will be held in strictest confidence. Findings from the surveys will be presented in aggregate form, and will improve our understanding of the practice and pressures of support services in Ontario's ASOs. Please remember to not include your name anywhere on this survey, and please be as comprehensive as possible.

Note: Please take the time to answer this survey with as much detail as possible. It will likely take about 30 minutes to complete. If you have any questions, please don't hesitate to contact Jean Bacon, Director of Knowledge Transfer and Exchange at the Ontario HIV Treatment Network.

Phone: 416 642 6486 ext. 2233 Email: jbacon@ohtn.on.ca

Background Information

Before we get started, please tell us a little background about your agency and yourself:

1. How is the size of your agency? (Please check one)
 - ☐ Small = less than 5 full time staff
 - ☐ Medium = 5-12 full time staff
 - ☐ Large = 13+ full time staff
2. What geographical area does your agency serve (Please check one):
 - ☐ Urban
 - ☐ Small Urban/Rural
 - ☐ Rural
3. Is the size/nature of the population you serve affected by?:
 - Aboriginal (First Nation, Inuit, Metis) Communities
 - Migrant workers
 - Proximity to a border
 - Tourism/seasonal population
 - College or university in region
 - Prisoners/ex-prisoners/proximity to correctional institutions
 - Refugees/immigrants
 - Other
4. Number of support staff in your agency:
5. What is your position title?
6. How long have you been employed in this role?
7. How long have you worked in HIV/AIDS services?
8. Please indicate education level completed:
 - High School Diploma
 - Community College diploma
 - University Degree
 - Graduate Degree

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Description of Support Services at your agency

9. Which of the following **support services** does your ASO offer? We have taken these categories from OCHART. (please check all that apply. See options f.-w. on pages 2 and 3)
- a. ☐ Intake and/or assessment
 - b. ☐ Case management
 - c. ☐ Health promotion/treatment information
 - d. ☐ Scheduled drop-in programs
 - e. ☐ Practical assistance
 - ☐ Financial assistance
 - ☐ Bus tickets
 - ☐ Legal advice
 - ☐ Insurance/tax information
 - ☐ Help with transportation
 - ☐ Help in accessing financial assistance programs
 - f. ☐ Home & hospital visits/care teams
 - g. ☐ Support groups/retreats
 - h. ☐ Buddy program
 - i. ☐ Employment services
 - ☐ Resume building
 - ☐ Employment preparation
 - ☐ Vocational counseling
 - ☐ Skills
 - ☐ Interest and abilities assessments
 - ☐ Job placement
 - ☐ Retention services
 - j. ☐ Financial counseling
 - k. ☐ Pre/post test counseling
 - l. ☐ Other counseling/support
 - m. ☐ Bereavement services
 - n. ☐ Referrals
 - o. ☐ Workshops/Training/Skills Development
 - p. ☐ Housing Assistance
 - ☐ Rent-geared-to-income units
 - ☐ Residential programs
 - ☐ Shelters
 - ☐ Supportive housing
 - ☐ Assisting with housing applications
 - ☐ Assisting with apartment searches
 - q. ☐ Individual Advocacy
 - r. ☐ Supportive Housing Provision
 - s. ☐ Settlement Services
 - ☐ Mental health related
 - ☐ Housing related
 - ☐ Legal issues
 - ☐ Employment
 - ☐ ESL
 - ☐ Childcare
 - ☐ Assisting clients with immigration system
 - t. ☐ Interpretation/Translation
 - u. ☐ Food Vouchers
 - v. ☐ Food Bank Program
 - w. ☐ Complementary Therapies
 - ☐ Acupuncture
 - ☐ Chiropractic
 - ☐ Naturopathy
 - ☐ Massage
 - ☐ Homeopathy
 - ☐ Meditation
 - ☐ Art

- ☐ Dance
 - ☐ Yoga
 - ☐ Nutrition counseling
 - ☐ Other Support Services not listed here:
10. We know that support services at your agency have changed over time. Which services, if any, has your agency stopped providing?
 - a. Which new services have been introduced in recent years? How long ago?
 11. Which other support services do you think should be provided at your agency?
 - a. What would you need to be able to provide those services?
 12. In addition to support workers, do any other staff members perform support service-related work (e.g., counseling a client)?
 - a. How often does this occur?
 - b. What services do they provide?

Partnership with HIV Clinics

How would you rate your agency's partnership with the HIV clinic in your area?

(Please check one)

- ☐ Poor
- ☐ Fair
- ☐ Good
- ☐ Excellent
- c. Please describe the nature of the partnership with your HIV clinic?
- d. Please describe the process by which you get referrals from the HIV clinic:
- e. Please describe how you make referrals to the HIV clinic?
- f. What other activities are involved in your partnership with HIV clinics? (e.g., advertisement for ASO services at the clinic or vice versa)
- g. What have been the challenges of working together with HIV clinics?
- h. What have been the barriers to a strong relationship with HIV clinics?
- i. What are the reasons would you cite for your successful relationship with HIV clinics?

Administrative tools for support services

13. What processes/procedures do you use to record information that is reported on OCHART – for example, do you use daily statistics sheets to document your work?
14. What information is not currently reported by OCHART that should be reported?
15. What information is **not** necessary to report?
16. How could OCHART be improved to be of greater benefit to you and the work you do?
17. To what extent do you find OCASE useful to your work on the front line?
 - a. To the agency more generally?
18. Aside from OCHART, OCASE or other funder reporting tools, how do you evaluate your support services? (If a client survey tool used, request a copy)

Career-Related Questions

19. What led you to become a support worker?
20. Describe the ways your agency supports you as an employee (ex. supervision, training, personal development, employee assistance plans, supportive policies etc.)
21. How do you care for yourself given the demands of the job?
22. What support is available to you outside of your agency? Do you access support from outside of your agency?
23. Do you feel you have the skills and resources to match the demands of your job? If not, what unaddressed training needs would you identify?
24. What are your future career plans? (Are they to remain in the HIV/AIDS sector? Advance in this ASO? Shift focus to more policy-related work?)
25. What would help you stay in a position related to HIV support work?

E) Focus Group Discussion Guide

Intro: What is your name/alias name? Why did you want to be a part of this focus group? (30s or less)

Nature and Scope of Services

1. As part of the background questionnaire, we have asked each you to give us an exhaustive list of all support services offered at each of your agencies. Now we would like for each of you to, if you can, name 1 or 2 of services which you would describe as the CORE support services offered at your agency. Who would like to begin?
2. What do you see as particular strengths of the support services offered by your agency?
3. Which services present particular challenges (such as delivery, consistency, intermittent funding etc.)?
4. What other challenges would you identify (e.g., difficulties in acquiring needed resources, like housing, for your clients)?
5. Are there other support services you think should be provided at your agency? What would you need to be able to provide those services?
6. What would you identify as core support services that you think should be offered by all ASOs in the province?

Support Services/Prevention Services:

We are going to move on to the next set of questions. It has become clear to us that the lines between support services and prevention services are kind of blurry. The main goal of this whole project is to try and define what we mean when we are talking about “support services”. So the next set of questions is meant to tease out what support workers at different agencies mean when they say “support services”.

7. Is the boundary between support and prevention shifting at your agency?
8. So, we’ve had this discussion about boundaries between support and prevention...so where would you say “harm reduction services” fit into this?
9. In addition to support workers, do any other staff members at your agency perform support service-related work? (i.e. counseling a client). What services do they provide? How often?
10. Apart from HIV, which are the most common presenting issues you have observed in your clients, such as addictions, mental health issues, Hepatitis C, etc?
 - a. What are some opportunities your agency currently engages in with regards to addressing these issues?
 - b. What are some gaps you have observed when trying to address these issues?
11. Describe the process of referring clients to other agencies which specifically address these issues. What have been the challenges you’ve experienced in making such referrals?

Partnering with HIV Clinics

12. What do you see as the strengths of your relationship to your HIV clinic?
13. What have been the challenges of working together with HIV clinics?
14. What would help you improve your relationship with your HIV clinic?

GIPA/MIPA

15. How is the GIPA/MIPA principle reflected in the support services at your agency?
16. What are the benefits of your agency’s commitment to GIPA to the support services it offers?
17. What challenges does your agency face in enacting GIPA?
18. In your view, how adequate is your agency’s commitment to GIPA?

Staffing/Career Issues

19. In the background questionnaire, we asked a few questions about self-care and training/support needs. We would like to explore this a little more and ask, do you see yourself doing this work in five years?
20. What might lead you to change jobs?
21. What would help you stay in support work?

2. Tools used for Executive Directors

A) Email Recruitment Script for Executive Director Telephone Interviews

Invitation to Participate in an Environmental Scan of

Support Services Provided by ASOs in Ontario _____

E-mail Subject line: Invitation to participate in an Environmental Scan of Support Services provided by ASOs in Ontario

Community-based support services for people with or at risk of HIV in Ontario have evolved organically over time, driven mainly by client needs and by other factors, such as the mix of other services/service providers in each community or region. Organizations that in the 1980s focused on buddy services for people who were dying now offer a growing array of social support, education, health promotion, practical support, housing, food security, employment, immigration and other programs to meet the needs of increasingly diverse client groups. The types of services provided vary depending on local needs and the capacity and focus of each AIDS service organization (ASO).

As you are likely aware, the AIDS Bureau is funding an environmental scan of support services provided by AIDS service organizations in Ontario. This environmental scan is being conducted by a research team comprised of Jean Bacon and Sergio Ruede (Ontario HIV Treatment Network), Roy Cain (School of Social Work, McMaster University), Evan Collins (OHTN) and Joanne Lush (AIDS Bureau). The projects coordinators are Shani Roberson and Alekhya Mascarenhas. The environmental scan aims to:

1. Understand the scope and range of support services provided at ASOs
2. Understand the partnerships that ASOs have developed with HIV clinics and identify opportunities for meaningful partnerships with HIV clinics in Ontario
3. Examine the extent to which GIPA/MIPA (Greater/Meaningful Involvement of People Living with HIV/AIDS) principles and practices are reflected in support services
4. Identify training priorities for ASO support service providers
5. Examine turnover of support workers within ASOs and identify strategies to improve staff retention
6. Identify a common set of core support services across all ASOs in Ontario and develop guidelines for those services
7. Identify best practices in core support services that can be shared among ASO.

You are invited to participate in one of the one-hour telephone interviews with Executive Directors that are being held as part of this scan. For your information, we are attaching a copy of the consent form for the study, as well as our interview guide.

Given some of our questions, you may choose to invite your Director of Support Services (or your equivalent position) to join you in the interview.

This study has been reviewed by and received ethics clearance from the McMaster Research Ethics Board. Your participation is entirely voluntary and any information you provide will be kept confidential. No identifying information will be used in any report that we write, and no identifying information about you or your agency will be communicated to the Ministry of Health and Long-term Care. If you have any questions about the study, please feel free to contact Jean Bacon at the OHTN at 416-642-6486, ex.2233.

Please reply to Shani (srobertson@ohtn.on.ca) or Alekhya (amascarenhas@ohtn.on.ca) to schedule a convenient time for an interview.

B) Consent Form for Executive Directors



DATE: _____

LETTER OF INFORMATION / CONSENT

An Environmental Scan of Support Services provided by AIDS Service Organizations across Ontario

Research Team:

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E-mail: joanne.lush@ontario.ca

Dr. Evan Collins
The Ontario HIV Treatment Network
Toronto, Ontario, Canada
(416) 642-6486
E-mail: ecollins@interlog.com

Purpose of the Study

Community-based support services for people with or affected by HIV in Ontario have evolved organically over time, driven mainly by client needs and by other factors, such as the mix of other services/service providers in each community or region. Organizations that in the 1980s focused on buddy services for people who were dying now offer a growing array of social support, education, health promotion, practical support, housing, food security, employment, immigration and other programs to meet the needs of increasingly diverse client groups. The types of services provided vary depending on local needs and the capacity and focus of each ASO.

To better understand the scope and range of support services that are being delivered by AIDS Service Organizations (ASOs) in Ontario, the AIDS Bureau of the Ontario Ministry of Health and Long-term Care is funding an environmental scan of support services offered by 29 ASOs.

You are invited to take part in this scan by participating in an individual telephone interview that is being held as part of this scan.

The scan aims to:

1. Understand the scope and range of support services provided at ASOs
2. Understand the partnerships that ASOs have developed with HIV clinics and identify opportunities for meaningful partnerships with HIV clinics in Ontario
3. Examine the extent to which GIPA/MIPA (Greater/Meaningful Involvement of People Living with HIV/AIDS) principles and practices are reflected in support services
4. Identify training priorities for ASO support service providers
5. Examine turnover of support workers within ASOs and identify strategies to improve staff retention

6. Identify a common set of core support services across all ASOs in Ontario and develop best-practice guidelines for those services.

Procedures involved in the Research

In the interview, you will be asked to discuss the following topics:

1. The nature and scope of support services offered at your ASO
2. The nature of your organization's relationship with local HIV clinics
3. The administration and supervision of these support services
4. The implementation of GIPA and MIPA principles at your ASO
5. Career issues.

With your permission, the interview will be recorded and it should take no longer than 60 minutes.

Potential Harms, Risks or Discomforts:

The risks involved in participating in this study are minimal. We will be asking questions about the support services offered by your agency. It is possible that you may feel uncomfortable with some of the questions being asked. You do not need to answer questions that you do not want to answer or that make you feel uncomfortable. And you can withdraw from the focus group at any time and you may also skip questions you do not want to answer.

You may also worry that what you say in the interview will be released out into the community or to your workplace. We will treat the information you provide in confidence. In the final report will not contain information that can be used to identify you or your agency. The recorded interview will be transcribed and transcripts will have any identifying information changed or deleted. Bear in mind that you might be identifiable by what you say, so you might want to exercise care in what you share in the interview.

Joanne Lush, from the AIDS Bureau, is a member of the research team and is funding this scan. Her dual role as researcher and funder may make some people feel pressure to participate in the scan, and others may worry that what they say will be communicated to the AIDS Bureau. To ensure that your participation is voluntary and to protect your privacy, Joanne will not know who participates in interviews, and she will not have access to transcripts until all identifying information has been removed.

Potential Benefits

The results of this scan will help us understand the nature and scope of support services, as well as some of the challenges they face. We expect that this will help improve support services to people living with HIV, and to better support ASOs workers. The scan may also identify a common set of support services across ASOs in Ontario and develop guidelines for these services.

Confidentiality

You are participating in this study confidentially. Every effort will be made to protect your privacy, and we will not use your name or any information that would allow you to be identified. We will not record your name in the interview transcript; instead, you will be identified by a numerical code. We will not tell anyone whether you participated in scan.

The information you provide will be kept in a locked cabinet where only the research team will have access to it. Information kept on a computer will be protected by a password. Once the study has been completed, the data will be shredded and deleted.

Participation and Withdrawal

Your participation in this environmental scan is voluntary. If you decide to be part of the study, you can decide to stop at any time, even after signing the consent form or part-way through the interview. If you decide to withdraw, there will be no consequences to you or your agency. In cases of withdrawal, any data you have provided will be destroyed unless you indicate otherwise. If you do not want to answer some of the questions you do not have to, but you can still continue with your interview.

Information about the Study Results

We aim to have this study completed by the end of March 2012. A full report of the results will be disseminated to all ASOs.

Questions about the Study

If you have questions or need more information about this study itself, please contact Jean Bacon at:
Ontario HIV Treatment Network

3600 Yonge Street
Toronto, ON

Email: jeanbacon@me.com
Telephone: 416-642-6486, ex.2233

This study has been reviewed by the McMaster University Research Ethics Board and received ethics clearance. If you have concerns or questions about your rights as a participant or about the way the study is conducted, please contact:

McMaster Research Ethics Secretariat
Telephone: (905) 525-9140 ext. 23142
c/o Research Office for Administrative Development and Support
E-mail: ethicsoffice@mcmaster.ca

C) CONSENT FORM FOR INTERVIEW PARTICIPANTS

I have read the information presented in the information letter about the environmental scan of ASO support services.

I have had the opportunity to ask questions about my involvement in an individual telephone interview and to receive additional details I requested.

I understand that if I agree to participate in this study, I may withdraw from the interview at any time. I have been given a copy of this form.

I agree to participate in an individual telephone interview.

I agree that the interview can be audio recorded.

I would like to receive a summary of the results

Please send them to this email address: _____

OR this mailing address:

Yes No

☐ ☐

☐ ☐

☐ ☐

Signature: _____

Name of Participant (Printed) _____

D) Telephone Interview Guide for Executive Directors

Introductory Questions

1. How long have you worked as Executive Director at this ASO?
2. How long have you worked in the field of HIV/AIDS?
 - a. What other positions did you hold in the HIV-field, prior to becoming ED? In other related fields (e.g., housing, mental health, addictions)?

Changing nature of support services

3. We know that support services have changed over time (for example, buddy programs). We are interested in finding out about the changes at your agency. For example,
 - o Which new services have been introduced in the past 5 years?
 - o Which services, if any, have you stopped providing?
4. Which other support services do you think should be provided at your agency?
 - a. Aside from additional funding, what would you need to be able to provide those services?

Pressures faced by agencies in providing support

5. Which are the key challenges your agency faces in providing the support needed by your clients (such as delivery, consistency, intermittent funding etc.)?
6. What are the most common health/social issues you have observed in your clients? (such as addictions, mental health issues, immigration, criminalization, Hepatitis C, housing, etc.)? (*probe: how often does this occur?*)
7. How well equipped is your agency to address these issues you have observed in your clients?
 - a. For those issues you don't feel well equipped, are you able to refer clients to other agencies which specifically address these issues?
 - o What is the process for doing these type of referrals?
 - o What are the barriers or challenges you face in making referrals? (*Probe: so, what do you do for the client in that case?*)
8. Are there core support services which you think should be offered by all ASOs in the province?

Relationship between Prevention and Support Services

As you know we have already conducted focus groups with support workers from different ASOs. One topic that came up often is that the lines between support services and prevention services can be blurry and vary agency by agency. I'd like to get a sense of how you define & deliver support or prevention services at your agency.

9. Can you talk about the boundary between support and prevention services at your agency?
 - a. Has the boundary between support and prevention services changed over time?
10. Given this discussion about the boundaries between support and prevention, where would "harm reduction services" fit into this?

Now let's focus the discussion to the human resources. In the focus groups one of the themes which came up was 'support for support workers'. Let's talk about this.

Human resources, Hiring and Supervision

11. Can you describe the supervision & support which is available to support workers at your ASO?
 - a. How often do you provide supervision? (*Probe: what issues get discussed in supervision*)
 - b. Do you provide access to clinical sessions for your workers?
 - i. How often?
12. What are the other ways your agency supports its support workers? (*Probe: training, professional development, employee assistance plans, supportive policies etc.*)
13. What additional resources would your support staff need in order to effectively do their job?
 - a. What training needs would you identify that would further aid your support staff in their work?
14. Are there any other staff or volunteers that perform support-related activities (*Probe: such as running a support group, counseling a client after hours etc.*)

- a. Do you think these individuals are getting the support or training they require to deliver these services adequately?
15. What qualifications do you look for when hiring support staff? (*Probe: previous work experience, lived experience, education, etc.*) (*Probe: do you have a hard time finding qualified support workers?*)

One topic that has been discussed in the focus groups is the GIPA/MIPA principle. So let's talk about GIPA/MIPA at your agency.

GIPA/MIPA

16. How is the GIPA/MIPA principle reflected in the support services at your agency?
17. What are the benefits of your agency's commitment to GIPA/MIPA to the support services it offers?
18. What challenges does your agency face in enacting GIPA/MIPA?
19. In your view, how adequate is your agency's commitment to GIPA/MIPA?

Shifting topics again, I'm interested in the nature of the relationship between your agency and the HIV clinics in your area.

Partnerships with HIV Clinics

20. Could you describe the nature of your relationship with HIV clinics in your area?
 - a. What is the process for referring clients to the clinics?
 - b. What is the process for receiving referrals from the clinics?
 - c. Aside from referrals for individual clients, what other activities are involved in your working relationship with HIV clinics?
21. So, overall how would you describe the quality of your relationship with HIV clinics in your area, on a scale ranging from poor to excellent?
☐ Poor ☐ Fair ☐ Good ☐ Excellent
22. What have been the challenges of working together with the HIV clinics in your area?
 - a. Are there any barriers to this relationship?
 - b. What are the reasons for your successful relationship with HIV clinics?
23. How could your relationship with HIV clinics improve?

Finally, we are interested in finding out about the procedures your agency uses for recording program statistics, as well as the use of the use program statistics for program planning.

Practice for administration of support services—i.e. file maintenance, file content, etc.

24. What procedures do your staff use to record program statistics?
Probe: For example, do they enter information into OCASE on a daily basis? Use daily statistics sheets to document your work? Etc.
Do you use any other client information systems at your agency?
25. Are there policies and/or protocols for record keeping at your ASO?
Probe: Could you tell me about the general rules that guide support staff in their work?
26. Do you have a sense for how well OCASE is working for your support staff?
Probe: Tell me about the challenges or advantages they experience when using the software.
27. Aside from OCHART or OCASE are there other ways you collect data to evaluate support services as an agency?
28. Do you use the data you provide in OCASE (OCHART reports) to inform program planning discussions?
Probe: If yes, how do you use this data?
Probe: If no, what data do you use to support this process? Or what other process do you use to develop new programs?
Probe: Who has access to the OCHART report? Do support workers have access?

3. Tools used for HIV Clinics

A) Email Recruitment Script for HIV Clinics

Invitation to Participate in an Online Survey for an Environmental Scan of

Support Services Provided by ASOs in Ontario

E-mail Subject line: Invitation to participate in an online survey for an Environmental Scan of Support Services provided by ASOs in Ontario

Community-based support services for people with or at risk of HIV in Ontario have evolved organically over time, driven mainly by client needs and by other factors, such as the mix of other services/service providers in each community or region.

Organizations that in the 1980s focused on buddy services for people who were dying now offer a growing array of social support, education, health promotion, practical support, housing, food security, employment, immigration and other programs to meet the needs of increasingly diverse client groups. The types of services provided vary depending on local needs and the capacity and focus of each AIDS service organization (ASO).

As you are likely aware, the AIDS Bureau is funding an environmental scan of support services provided by AIDS service organizations in Ontario. This environmental scan is being conducted by a research team comprised of Jean Bacon and Sergio Ruede (Ontario HIV Treatment Network), Roy Cain (School of Social Work, McMaster University), Evan Collins (OHTN) and Joanne Lush (AIDS Bureau). The projects coordinators are Shani Roberson and Alekhya Mascarenhas. The environmental scan aims to:

1. Understand the scope and range of support services provided at ASOs
2. **Understand the partnerships that ASOs have developed with HIV clinics and identify opportunities for meaningful partnerships with HIV clinics in Ontario**
3. Examine the extent to which GIPA/MIPA (Greater/Meaningful Involvement of People Living with HIV/AIDS) principles and practices are reflected in support services
4. Identify training priorities for ASO support service providers
5. Examine turnover of support workers within ASOs and identify strategies to improve staff retention
6. Identify a common set of core support services across all ASOs in Ontario and develop guidelines for those services. Identify best practices in core support services that can be shared among ASO.

You are invited to participate in an on-line survey on the relationship between ASO support workers and HIV clinics that is being held as part of this scan. The survey should take about 30 minutes to complete. For your information, we are attaching a copy of Letter of Information for the study which provides details of the study.

This study has been reviewed by and received ethics clearance from the McMaster Research Ethics Board. Your participation is entirely voluntary and any information you provide will be kept confidential. No identifying information will be used in any report that we write, and no identifying information about you or your agency will be communicated to the Ministry of Health and Long-term Care. If you have any questions about the study, please feel free to contact Shani Robertson (srobertson@ohntn.on.ca) or Alekhya Mascarenhas (amascarenhas@ohntn.on.ca) with any questions about the survey.

B) Letter of Information for HIV Clinics



DATE: _____

LETTER OF INFORMATION

An Environmental Scan of Support Services provided by AIDS Service Organizations across Ontario

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Purpose of the Study

Community-based support services for people with or affected by HIV in Ontario have evolved organically over time, driven mainly by client needs and by other factors, such as the mix of other services/service providers in each community or region. Organizations that in the 1980s focused on buddy services for people who were dying now offer a growing array of social support, education, health promotion, practical support, housing, food security, employment, immigration and other programs to meet the needs of increasingly diverse client groups. The types of services provided vary depending on local needs and the capacity and focus of each ASO.

To better understand the scope and range of support services that are being delivered by AIDS Service Organizations (ASOs) in Ontario, the AIDS Bureau of the Ontario Ministry of Health and Long-term Care is funding an environmental scan of support services offered by 29 ASOs.

You are invited to take part in this scan by completing an on-line survey about your clinic's relationship with AIDS service organizations.

The scan aims to:

1. Understand the scope and range of support services provided at ASOs
2. Understand the partnerships that ASOs have developed with HIV clinics and identify opportunities for meaningful partnerships with HIV clinics in Ontario
3. Examine the extent to which GIPA/MIPA (Greater/Meaningful Involvement of People Living with HIV/AIDS) principles and practices are reflected in support services
4. Identify training priorities for ASO support service providers
5. Examine turnover of support workers within ASOs and identify strategies to improve staff retention

6. Identify a common set of core support services across all ASOs in Ontario and develop best-practice guidelines for those services.

Procedures involved in the Research

In the survey, you will be asked to discuss the following topics:

1. Your position in the clinic.
2. The nature of your clinic's relationship with ASOs with which you work.
3. How has this relationship changed?
4. The strengths and challenges of your relationship with ASOs.
5. The gaps in available services to people living with HIV in your area.

The survey should take about 30 minutes to complete.

Potential Harms, Risks or Discomforts:

The risks involved in participating in this study are minimal. We will be asking questions about your clinic's relationship to the ASOs with which you work. While unlikely, it is possible that you may feel uncomfortable with some of the questions being asked. You do not need to answer questions that you do not want to answer or that make you feel uncomfortable. And you can withdraw from the scan at any time.

You may also worry that what you say on the survey will be released to the community. We will treat the information you provide in confidence. In the final report will not contain information that can be used to identify you or your agency, and we will not identify any ASOs in our report. Any identifying information will be changed or deleted. Bear in mind that you might be identifiable by what you say, so you may want to exercise care in what you share in responding to our questions.

Joanne Lush, from the AIDS Bureau, is a member of the research team and is funding this scan. Her dual role as researcher and funder may make some people feel pressure to participate in the scan, and others may worry that what they say will be communicated to the AIDS Bureau. To ensure that your participation is voluntary and to protect your privacy, Joanne will not know who completes a survey, and she will only have access to a summary of survey responses.

Potential Benefits

The results of this scan will help us understand the nature and scope of support services, as well as some of the challenges they face. We expect that this will help improve support services to people living with HIV, and to better support ASOs workers. We also expect that the survey will help strengthen the relationships between ASOs and HIV clinics.

Confidentiality

You are participating in this study confidentially. Every effort will be made to protect your privacy, and we will not use your name or any information that would allow you to be identified. We will not record your name; instead, you will be identified by a numerical code. We will not tell anyone whether you participated in scan.

The information you provide will be kept in a locked cabinet where only the research team will have access to it. Information kept on a computer will be protected by a password. Once the study has been completed, the data will be shredded and deleted.

Participation and Withdrawal

Your participation in this environmental scan is voluntary. If you decide to be part of the study, you can decide to withdraw at any time, even after signing the consent form or part-way through the survey. If after starting the survey you wish to withdraw from the study, simply close your computer's browser. We will delete any information that you have provided to that point. If you decide to withdraw, there will be no consequences to you or your agency. If you do not want to answer some of the questions you do not have to, but you can still continue with the survey.

Information about the Study Results

We aim to have this study completed by the end of May 2012. A full report of the results will be disseminated to all ASOs and HIV clinics.

Questions about the Study

If you have questions or need more information about this study itself, please contact Jean Bacon at:

Ontario HIV Treatment Network
3600 Yonge Street

Toronto, ON

Email: jeanbacon@me.com

Telephone: 416-642-6486, ex.2233

This study has been reviewed by the McMaster University Research Ethics Board and received ethics clearance. If you have concerns or questions about your rights as a participant or about the way the study is conducted, please contact:

McMaster Research Ethics Secretariat

Telephone: (905) 525-9140 ext. 23142

c/o Research Office for Administrative Development and Support

E-mail: ethicsoffice@mcmaster.ca

How to Complete the Survey

If you have no questions on any of the above and agree to participate in the study, you may click **[HERE](#)** to begin the survey.

The survey will be open until **March 23, 2012 at 5PM.**

Thank you for your time.

C) Online Survey for HIV Clinics

We are doing an environmental scan of the support services provided by AIDS service organizations in Ontario. The goal is to improve the consistency and quality of support services available to people with or at risk of HIV in Ontario.

We are interested in knowing more about the relationship between ASOs and HIV clinics and the nature of services available to people living with HIV.

We appreciate that you may work with more than one ASO. If so, please provide separate answers for each ASO, if there are differences between them.

The information you provide will be treated confidentially. We will not identify which clinics participated in the study. We will remove any information that can be used to identify specific clinics and ASOs.

Please do not provide your name anywhere on the survey.

The questionnaire is completely voluntary, and you should feel free to skip any questions you would prefer not to answer. If after starting the survey you wish to withdraw from the study, simply close your browser. We will delete any information that you have provided to that point.

You may view a PDF of the complete Letter of Information [HERE](#).

By selecting "NEXT," I am indicating that I have read the study's Letter of Information" and am consenting to participate in the study.

Background Questions:

1. How would you describe the area served by your clinic: Rural/urban/mixed
2. What region does your clinic serve? (provide list)
3. What is your position in the clinic: _____
4. How many years have you worked in this position: _____

Relating to ASOs

1. In the past year, which AIDS service organizations have you worked with?
2. Could you describe the nature of your relationship with ASO support services in your area? (e.g., do you refer clients to each ASO? Do the ASOs refer clients to or seek information from the clinic?)
3. What are the most common ASO support services that you refer clients to?
4. Aside from referrals for individual clients, are you are involved in any other activities with ASOs? If so, please describe these activities.
5. Have there ever been events, such as an information session between your clinic and local ASOs to get to know each other and the services you offer? Please describe these events and whether you think they were helpful.
6. Overall how would you describe the quality of your relationship with each ASO support services in your area, on a scale ranging from poor to excellent? Please explain.
a. ☐ Poor ☐ Fair ☐ Good ☐ Excellent
7. Overall how would you describe the quality and consistency of the support services each ASO provides for clients, on a scale ranging from poor to excellent? Please explain.
a. ☐ Poor ☐ Fair ☐ Good ☐ Excellent
8. How do you think the relationship between your clinic and each ASO could be improved?
9. What would you identify as the strengths in your clinic's working relationship with each ASO?
10. What would you identify as challenges in your working relationship with each ASO?
11. Have there been any changes in your working relationship with each ASO in the past five years? For example, has the ASO or your clinic changed the services they provide? Please describe the changes.
12. Please describe any changes you would like to see in your working relationships with ASOs to improve support services for clients.
13. To which other community support services do you refer clients?
14. What, if any, service gaps would you identify in your community?
15. What needed services are ASO support workers unable to provide?

APPENDIX C: OCHART SUPPORT SERVICES DEFINITIONS

Definitions for OCHART section 11.2.1

Intake and/or Assessment

Gathering demographic/medical/social/other information about the client to help identify client needs. Intake and assessment procedures are specific to each ASO and may depend on program offerings and requirements.

Case Management

Meetings or phone calls to discuss client issues, on-going assessment of client needs, on-going service planning, implementation, and coordination, monitoring and follow-up. (e.g., a support worker has a conversation with a physician)

Health Promotion/Treatment Information

Information on treatment, addiction issues, safe sex information. Health promotion includes all except for complementary therapies.

Scheduled Drop-In Program

Geared to members of certain groups and provide a wide range of support, resources and access to services. This may also include social activities such as Summer Picnic, Holiday Dinner & Show.

Practical Assistance

Includes financial assistance, bus tickets, legal advice (including wills), insurance/tax information, help with transportation: e.g. moving/driving client, and help in accessing financial assistance programs (e.g. filling out forms, making phone calls) including Trillium Drug Fund. (Other examples: income support, haircuts, "Holiday Bag", Theatre Access, Wonderland.)

Food Programs

Includes food vouchers, food banks, food hampers, community kitchen, hot meal programs (a walk-in location where clients access hot nutritious meals), meal replacement supplements (like Ensure and Vitamins), cooking classes

Home & Hospital Visits/Care teams

Includes any home and hospital visit to provide support to the client, partner or family and friends.

Support Groups/Retreats

Support groups meet periodically to share information and experiences on different topics and to offer support to one another. (Examples: pre-determined time-limited structured group or ongoing support group; GLBTQ Youth Group.)

Retreats may take a variety of forms and provide an opportunity for participants to get together in a social environment for relaxation, workshops and community.

Buddy Program

A Buddy Program is a program that matches volunteers with people living with HIV/AIDS to offer them a range of support, emotional, practical and spiritual. Buddies can conduct regular visits or accompany individuals to appointments or on errands.

Employment Services

Counselling is designed to assist individuals with employment barriers to achieve paid employment. This may include services such as resume building, employment preparation, vocational counselling, skills, interest and abilities assessments, job placement and retention services.

Financial Counselling

Counselling that is provided to help individuals manage their finances through budgeting, assistance programs and other means.

Pre/post Test Counselling

Counselling that is provided to individuals who are considering HIV testing or have taken the test.

Other Counselling/Support

Includes one-on-one session with a client to talk about anything not covered in another section. This may happen in person or over the phone.

Bereavement Services

Services are provided on a wide range of grief issues including counselling and assistance with memorial/funeral arrangements. Bereavement counseling may be an on-going service for some clients.

Referrals

Connecting individuals with appropriate agencies and services.

Workshops/Training/Skills Development

Skill development programs or workshop sessions which focus on enhancing the knowledge level and skill sets of individuals.

Housing Assistance

Information, advocacy and referrals for housing-related issues including [rent-geared-to-income \(RGI\) units](#), [residential programs](#), [shelters](#), [supportive housing](#), as well as [assisting with housing applications](#), or [apartment searches](#).

Individual Advocacy

Programs may advocate and intervene on behalf of our clients to make sure they get the services and entitlements they need. Others may focus on the empowerment of clients, through training and support, to act as advocates for themselves and others.

Supportive Housing Provision

Applicable only to organizations that provide supportive housing directly to clients.

Settlement Services

Often targeted towards new immigrants of specific ethnic heritage. Services may be provided in the areas of [health](#), [mental health](#), [housing](#), [legal](#), [employment](#), [ESL](#), [childcare](#), [assisting clients with the immigration system](#), etc.

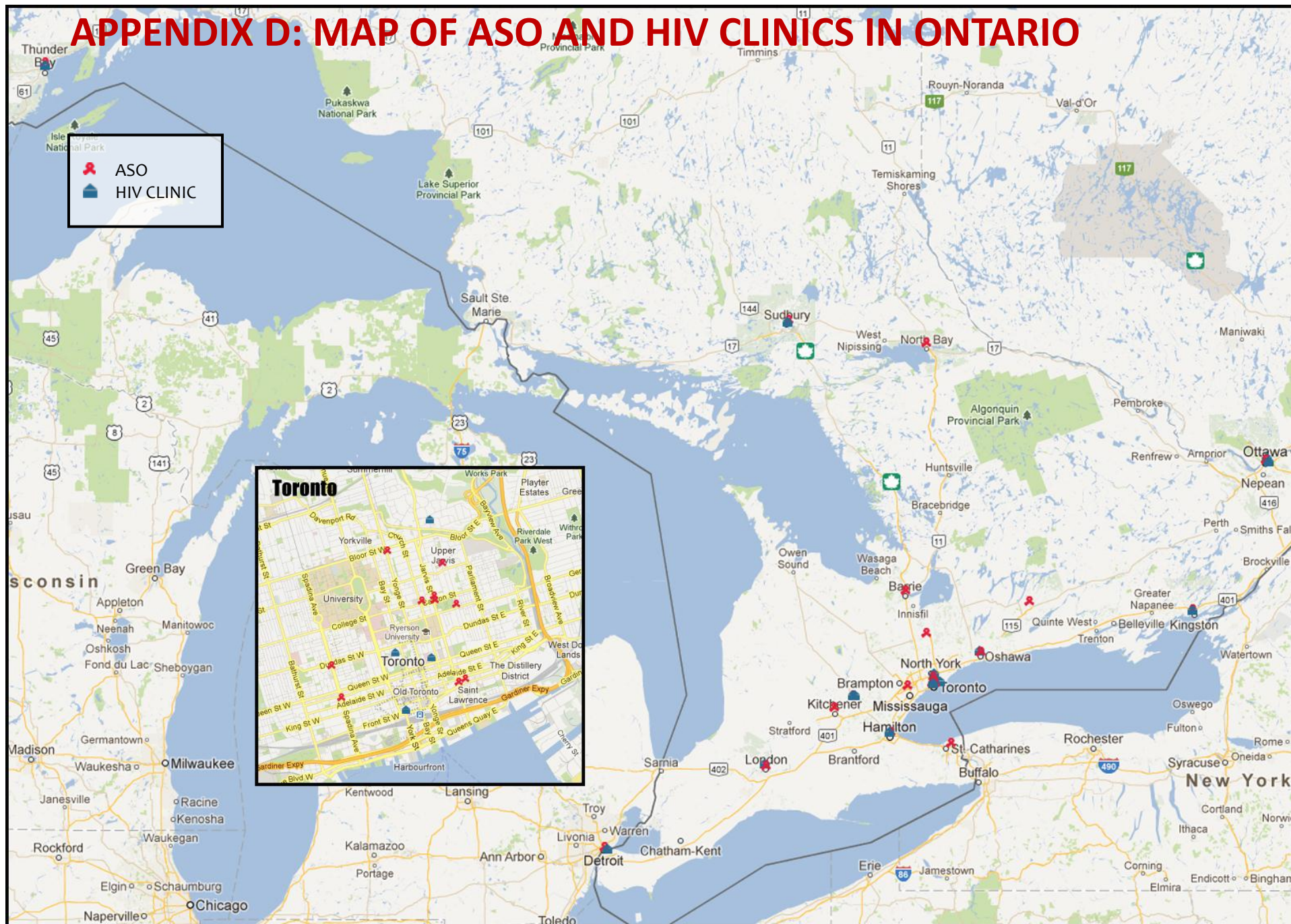
Interpretation/Translation

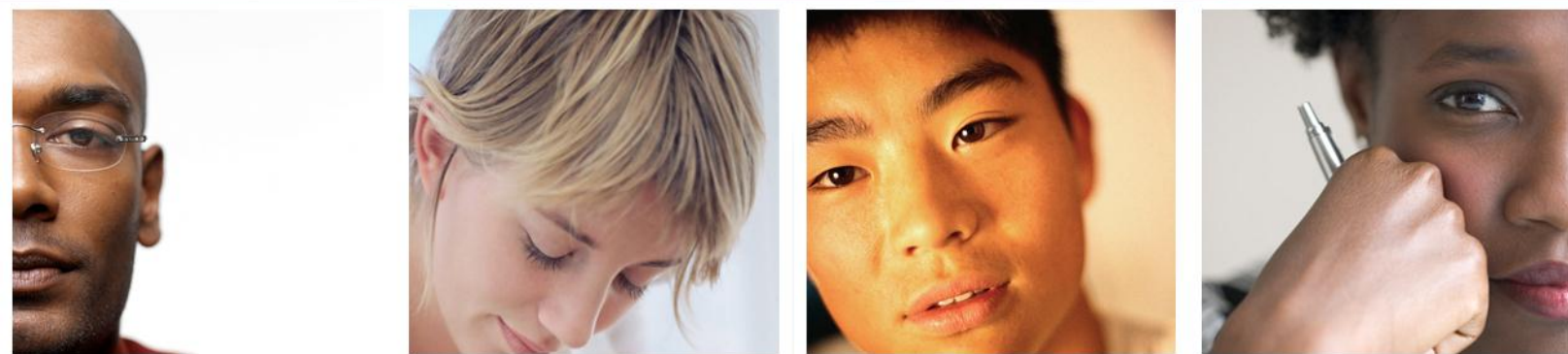
Both written and spoken services provided in the client's mother tongue.

Complementary Therapies

Treatments that have not been considered part of Western Medicine such as [acupuncture](#), [chiropractic](#), [naturopathy](#), [homeopathy](#), [massage](#), [meditation](#), [art](#), [dance](#), [yoga and/or nutrition](#), which may reduce stress, boost the immune system, or have other beneficial effects.

APPENDIX D: MAP OF ASO AND HIV CLINICS IN ONTARIO





If you have questions or would like to reprint this report contact:
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