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DOING HIV PREVENTION WORK IN ONTARIO'S AIDS SERVICE ORGANIZATIONS

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EXECUTIVE SUMMARY

What Is The Ontario ASO HIV Prevention Study?

This study was undertaken by the provincially-funded Community Linked Evaluation AIDS Resource (CLEAR) unit, examining HIV prevention work in Ontario AIDS Service Organizations (ASOs.). The objectives of the study were to identify the kinds of prevention programs currently in existence in Ontario ASOs, their impact on target groups, and the challenges (and successes) for people doing HIV prevention work. This information will hopefully lead to ideas on how HIV prevention work can be enhanced, and how research can assist ASOs in carrying out their prevention strategies.

What Does It Have To Say About HIV Prevention Work In Ontario?

Thirty-three frontline prevention workers from 11 Ontario ASOs shared their stories so that we may better understand HIV prevention work in Ontario. They provided insights into the complex and challenging nature of HIV prevention work, the passion with which it is carried out, the commitment to excellence on the part of those doing it, and the difficulty in knowing how effective it is.

Prevention work involves more than giving out condoms…

- … it is complex and multi-layered and includes interventions at both the individual and societal levels.
- … it encompasses relationship and trust building, sharing knowledge, helping people cope and providing for everyday needs, reducing harm from behaviours, and changing the way society thinks, feels, and behaves.

Prevention work in Ontario attempts to reach a diversity of people…

- … including people of all ages, genders, ethnicities, and sexual orientations.

Prevention work is both difficult and rewarding…

- … involving often significant challenges and barriers, including the values, fears and attitudes encountered in society, “AIDS boredom”, geography and other access issues, scant resources and the restraints of the system, and changes in the epidemic and clientele.

Prevention workers come from all walks of life…

- … and bring their skills, past experiences, passions, politics, and perseverance to the work.

Prevention work is done collaboratively…

- … with other organizations and institutions, and includes volunteer, staff and peer resources.

Prevention programs are generated through a variety of means…

- … including “in house” by ASO staff, with input from community members, clients, and other ASOs.

Prevention work involves questioning …

- … whether programs have any effect on target groups – frontline workers use a variety of means and cues to gauge their impact.

Prevention workers in Ontario ASOs…

- … love their work and their workplaces, appreciating the room to take risks and work on their own. Most importantly, they see what they do as contributing to social change.

The future of HIV prevention work in Ontario will include …

- … the need for innovation in prevention programs and strategies; the need to adapt to increasing pressures for "evidence-based" programming; the need to work in an even greater number of partnerships; and the need to put risk-taking into a broader social and political perspective.

These themes encapsulate what HIV prevention workers said in their interviews about their work. Please read on – you will find the above themes addressed more fully in the body of the report, illuminated by the words of prevention workers themselves.

DISCUSSION POINTS

The stories that were told by HIV prevention workers led to several areas for further discussion among ASOs, program funders, policy makers and researchers. (See discussion at the end of the report for more complete explanation of these points.)

Discussion Point 1: What are the most appropriate prevention levels (biological factors, individual behaviours, societal and political factors, etc; refer to Appendix 2) for ASOs to be working on? Are these the prevention levels that they are currently involved in, or could they be expanded, reduced or re-focused? How does the prevention work of ASOs fit with the prevention levels that other types of organizations are working on?

Discussion Point 2: Could the strengths of the current methods of program development be improved further by providing information and skills for program developers? Are there ways that more formal types of information, training, and research evidence could be made more available and useful for ASO prevention workers?

Discussion Point 3: What measures of program effectiveness would be most useful to Ontario ASOs? How can currently existing measurement tools be acceptably adapted to suit Ontario's prevention programs? What new measures of effectiveness could be developed to provide ASOs with the information they need to know whether their strategies are working?

Discussion Point 4: Could prevention program funding be improved (increased or re-structured) to be more effective in producing sustainable prevention programs? Are there ways in which sectors other than ASOs could increase efforts to improve access to target groups, decrease societal discrimination, and increase societal awareness of ongoing urgency around HIV/AIDS?

Discussion Point 5: How can the immense strength of the grass-roots history of Ontario ASOs be maintained and utilized effectively? How can this quality continue to inform effective prevention work?

Discussion Point 6: How can research be integrated into the prevention work of Ontario ASOs?

Discussion Point 7: What are the new prevention messages, and how can they best be developed?

Discussion Point 8: What are the most important organizations for ASOs to develop partnerships with, and how can these be facilitated and enhanced?

Discussion Point 9: How can risk-taking be framed in a political and social perspective, and how can this framework be used effectively to enhance HIV prevention efforts?

BACKGROUND

The first reported case of Acquired Immunodeficiency Syndrome (AIDS) in Canada was in 1982, and in the years immediately following, the Human Immunodeficiency Virus (HIV) epidemic primarily affected only men who have sex with men (MSM) and those infected through blood and blood products. In response to this new and poorly understood disease, grass-roots organizations were born with the primary mission of providing support to people who were infected, their friends, and their families. These organizations are now referred to as AIDS Service Organizations (ASOs).

In Ontario, HIV prevention work is carried out by ASOs, as well as other community-based organizations and public health units. It is funded primarily by the provincial and federal governments. There are 74 community-based organizations that are funded by Ontario's Ministry of Health and Long-Term Care to carry out various forms of HIV/AIDS work. This study was concerned only with community-based organizations receiving provincial funding.

The communities affected by HIV have changed over these 20 years and are diverse in terms of age, gender, sexual orientation, ethnicity, income level and educational level. ASOs have also changed over time to respond to the needs surrounding them. The imperative to provide support to people affected by HIV remains a priority, yet working toward the prevention of new HIV infections has also been an increasingly important activity taken on by these organizations.

HIV prevention work was identified by people working in ASOs as a priority area for future research. The Community Linked Evaluation AIDS Resource (CLEAR) unit, funded by the AIDS Bureau of Ontario's Ministry of Health and Long-Term Care, was invited by its stakeholder steering committee to undertake this study. It is the first part in what will become a

series of research projects dealing with HIV prevention work in ASOs. The CLEAR Unit requested that ASOs identify and prioritize the areas of research. Informed by feedback during an annual ASO meeting, teleconference calls, fax survey, and some on-site visits, a research strategy was collaboratively developed with the CLEAR Unit Steering Committee. Along with establishing a standard electronic information system, three research projects emerged as areas of key interest: HIV prevention programs; organizational capacity building; and recruitment, retention and deployment of staff and volunteers.

The information gathered from this study, and any future studies, is meant to provide people working in ASOs with information that will assist them to serve their clients and communities more effectively. These studies are "of ASOs, by ASOs, and for ASOs".

This prevention study was designed with the following objectives:

1. To identify the types of prevention programs that Ontario ASOs are currently conducting.
2. To determine the impact resulting from Ontario ASO prevention programs.
3. To describe the barriers and facilitators of implementing HIV prevention programs/strategies in Ontario ASOs.
4. To highlight the prevention programs that Ontario ASOs identify as organizational successes.

This study received ethical approval from the Hamilton Health Sciences-McMaster University Research Ethics Board.

METHODS

Who Participated In This Study?

An ASO was defined as any Ontario organization that was receiving funding from the AIDS Bureau, Ontario Ministry of Health and Long-Term Care. Forty-nine ASOs were contacted in 2000, by fax and by telephone, to determine whether their staff would be interested in participating in interviews about doing HIV prevention work. Table 1 below, is a summary of the agencies and staff that agreed to participate in the interviews. In total, 33 individuals were interviewed from 11 organizations.

TABLE 1 – Research participants…	
Female	20
Male	13
• Education/Prevention Coordinator	10
Education/Prevention Worker	6
Support Coordinator	2
Executive Director	8
Other Staff	7
o ASO with all population, all service mandate	21
ASO with specific population mandate	10
ASO with specific service mandate	2
Community population >500,000	8
Community population <500,000	25
In-person interview	24
Telephone interview	9

- • Terminology used by workers to describe themselves
- o All population, all service mandate includes ASOs whose work is defined primarily by geographic boundaries; specific population mandate includes ASOs whose target population is a specific demographic group (ethnicity, gender, etc.); specific service mandate includes ASOs with a single activity.

There were four interviews done with people working with First Nations organizations. The results from these interviews are included in this report. However, the people from these organizations also requested that their interviews be analyzed separately. They felt that their communities' needs and organizations were unique compared to other ASOs, and were

concerned that these differences would be erased if their interviews were combined with all of the others. Thus, the First Nations interviews are analyzed and reported separately.

How Was The Information Collected?

This was a "qualitative" study using in-depth interviews that were carried out between January and July 2001. All interviews were conducted in person by the same interviewer. (Where an interview could not be carried out in person, it was done over the telephone). The interview guide is in Appendix 1 for you to look at.

Even though the interviewer used a written guide to ensure that each person was asked similar questions, participants were encouraged to talk freely about any relevant issues. In a sense, each participant was encouraged to tell his or her own story about doing prevention work in an ASO. Because of this, the information gathered from the various participants could be quite different. There were no numbers, no check boxes; just experiences, ideas, opinions and feelings.

The participants were asked for their permission to record the interview on an audiotape. This tape was then used to prepare paper transcripts of the interviews. The tapes and interviews were kept in safe storage so that they would remain confidential.

How Was The Information Analyzed?

The method used to analyze this information is called "grounded theory". There were no statistics. In short, this means that all of the interviews were read by each of 5 different people working with the CLEAR unit. While reading the interviews, the readers each tried to see what issues, or 'themes', were being talked about by the participants…what feelings were underneath

the words, where stories were coming from, and why some issues emerged more than others. The readers got together on several occasions to talk about what they were hearing in the interviews, and the emerging themes. When the reading was finished, a final list of themes was created, and then each interview was read again and representative quotes were labelled and coded to match each of the specific themes.

Following this step, the people reading the interviews organized all of the themes, categorizing in ways that would describe general concepts about prevention work.

In September, 2001, all of the people who were interviewed were invited to attend a workshop where this information was given back to them, to see whether they thought they had been heard accurately, what story THEY could read in all of the information, and what they thought the important messages were.

This report is meant to express 'the common story', the way that ASOs in general express their experiences in doing HIV prevention work. Because it is much smaller than all of the interviews put together, some important information may have been left out. We worked hard to see that this has not happened, or at least rarely.

RESULTS

Here is what people working in ASOs had to say.

Part 1 – How We Work Toward Preventing HIV…

In a nutshell, HIV prevention work is about understanding the complex reasons why people are at risk for HIV and implementing ways to lessen that vulnerability. Sometimes the approaches are focused on individuals, while at other times, they are broader and encompasses community development and change.

"I usually say I do prevention, health prevention and promotion so I make a distinction between health prevention and health promotion. In terms of prevention, what I mean by that is getting specific tools, whether they're tools that affect people's knowledge or tools that affect people's attitudes or their behaviour so that people can help to prevent either themselves or others from getting HIV. In terms of health promotion, I think of that as a broader community-based kind of work in which we're attempting to make a community a safer place, and I say safer in the larger sense of that word, a safer place for people who are in risk categories for HIV."

Most people in this research made the argument *"that it is all related to prevention"*. They highlighted the complexities of HIV work – the need to get beyond focussing solely on sexual behaviour and saying "here wear a condom".

" I think it's a thread that runs through every piece of work that we do, and probably a fairly heavy thread. It's part of conversations on the phone, it's part of support work, prison work, volunteer work. You know it's there all the time. It's always, it's often just to, to emphasize and reiterate information about how people can take responsibility for themselves, how to reduce harm, how to make choices, healthier choices. I think it's there all the time actually. "

HIV prevention work is complex and layered. Social, familial, and personal factors impact people's vulnerability to HIV infection, and prevention work is often focussed on these more fundamental issues.

"I mean it comes down to Maslow's kind of thing and I mean I've always used the analogy of an onion that HIV is sometimes is in the centre of the onion and

how can you deal around issues of HIV when there's other layers that people need to be able to work through before they can even think about HIV prevention or think about how they are going to look after themselves because they're living with HIV."

ASO prevention workers say their work encompasses five interrelated areas:

TABLE 2 – Key aspects of HIV prevention work…
1. Relationship and trust building. 2. Sharing knowledge about HIV. 3. Helping people cope and providing for everyday needs. 4. Reducing harm from behaviours. 5. Changing the way society thinks, feels, and behaves.

1. Prevention work is about…relationship and trust building.

"You have to have community partners. You can't do this alone"

HIV prevention work is a tricky business overlaid with difficult and challenging social conditions including AIDS-related stigma, homophobia and racism. Key to successful HIV prevention work then is increasing the visibility and awareness of prevention work, and developing relationships over time with other community groups, pubic health departments, schools, funders, government, and other institutions:

"So it's developing relationships. So starting from scratch what I would do is get in contact with individuals or organizations who work with the target groups that I'm interested in and start to develop a relationship with that organization. And we do that by offering them whatever services we can. What we want to do is get in there and do an in-service with their staff and their volunteers, and then after that have access to their clients. And sometimes it takes a bit longer for me to ...

whatever is important to them we need to get involved in some way, and then slowly we get our agenda on their agenda. That's how it happens."

" … It's an incredible challenge to try and raise awareness about the work and the services we provide, and just letting people know what the basic facts are so that there is less stigma, less fear, and more acceptance."

Prevention messages and programs are likely to be more successful if target groups trust the people delivering the message. Establishing trust between community organizations and members therefore, is a crucial part of HIV prevention work.

"… we have a good working relationship with that needle exchange programme, and I think if we didn't have that relationship we would not be able to get into the community because that programme has some really, really good staff who are on the streets as well, who know the community I guess from their backgrounds and know these people, and they've built up long-term trusting relationships with users in the community who know that they're safe people to approach and to talk to and will trust."

2. Prevention work is about…sharing knowledge.

" *The only vaccine is education"*

Much of HIV prevention work is about sharing knowledge with people at risk through a variety of methods. Prevention workers feel that the most immediate thing they can provide people with is knowledge about HIV, its transmission, and means to reduce infection.

"Well if one person puts a condom on, you know, that's prevention. I just want one. Knowledge. Knowledge is all we have to offer."

At the same time prevention workers say that while sharing knowledge is a significant part of their work, changing attitudes, and providing people with resources to incorporate new knowledge are equally important.

> *"So we've got knowledge, we've got motivation, and the third one is ability. What is possible for this person in the context of their life? How much control do they have? Can they say yes to sex or can they say no to sex without any consequences? If that's not there, then that's the issue you have to look at first. So working with women in abusive relationships, the first step we have to do is get them out of the abusive relationship. So ability is a big part of it."*

3. Prevention work is about…helping people cope and providing for everyday needs.

> *"Poverty would probably be the biggest problem… I think that many of our service users have, so we need to be involved."*

Prevention work also moves beyond the sharing of knowledge and into the social context or real world in which people live. This can take the forms of assisting clients with life and relationship skills, poverty, illness, and addictions. It can also entail advocating for them in the workplace and with housing and government agencies, and providing practical supports including clean needles, formula, and food vouchers.

> *"The knowledge is out there. It still doesn't change behavior so you have to step back and a lot of it is getting into life skills and relationship skills, and looking at where people are in their life and what actually is available to them."*
>
> *"The Formula Program is actually a direct prevention program, because it is providing formula to HIV positive mothers to keep them from breast-feeding their*

babies so that they don't pass on HIV directly to the infant. So that's pretty, that's pretty direct prevention."

"We help them in a number of ways. We can help them wade through the bureaucracy. Many of our service users are, well we have a fair number of our service users who are injection drug users currently or have previously been in conflict with the law, perhaps don't have much education, are extremely poor and are distrustful of the bureaucracy of any form and do not know how to wade their way through it. So we can help them do that. We can help them understand what they need to do in order to find housing, as well as to work with landlords and property owners, trying to find them appropriate housing."

4. Prevention work is about…reducing harm from behaviours

Prevention work is also about providing resources and information to people to help reduce harmful behaviours. Many HIV prevention workers realize that expecting target group members or clients to completely stop harmful behaviours (e.g., drug use, unprotected sex) is both an unrealistic prevention goal, and something that is value-laden, reflecting a moralistic standpoint. Many speak of the importance, of incorporating the principles of "harm reduction" into their prevention work, where the goal is reducing harmful behaviours (or making them less dangerous as in providing clean needles for injection drug use) rather than eradicating them.

" We operate from a harm reduction model so we don't try to be absolutist in any of the things that we do because we know it doesn't work. So prevention to me is finding ways to help people to reduce the harm they do to themselves. So it's a fairly broad term."

"And I would also say that prevention has to do with giving people supplies to maybe not change a behaviour but to make a behaviour safer. For example, the needle exchange or condom use. Just the whole stuff around harm reduction is also prevention. Maybe not prevention of a behaviour but ... you can certainly introduce information and supplies that can help make that safer."

"The knowledge is out there. It still doesn't change behaviour so you have to step back and a lot of it is getting into life skills and relationship skills, and looking at where people are in their life and what actually is available to them. So actually I take more of a harm reduction approach when it comes to sexual behaviour, than preaching use a condom 100% of the time because people don't and they won't, if you say it they just won't listen to you."

5. Prevention work is about… changing the way society thinks, feels, and behaves

A significant part of prevention work involves advocating for changes at a broader societal level. HIV-related stigma and other kinds of discrimination are barriers to effective HIV prevention work, and challenging them is a significant part of what frontline people do on a daily basis.

"I talk about homophobia instead of HIV/AIDS in schools… and we try to get local queer groups to be stronger as a way of addressing homophobia."

"I mean obviously we're trying to prevent the spread of HIV. We're trying to prevent stigmas and isms from continuing. So we're trying to get to the root of problems such as homophobia, racism – those kinds of things. We're trying to find the ... establish a community that's much more understanding and receptive

to working with or living with people who are different than themselves or different than the norm, as you will."

Part 2 - Who We Are Trying To Reach…

While gay men and other men who have sex with men continue to comprise the majority of people newly infected with HIV in Ontario, ASOs are increasingly doing prevention work with a broader diversity of at-risk or affected communities. In addition, while communities at risk are diverse, funding requirements are such that programs are required to be specific and targeted to certain groups.

"Initially I think it was gay men who started the agency like many others but it sort of, the face of AIDS has changed in this area."

TABLE 3 – Our target groups are…
1. Gay men 2. Men who have sex with men 3. Women 4. Transgender/transsexual people 5. Youth 6. Injection drug users 7. People in custody 8. First Nations 9. People from ethno-specific communities 10. And others…

1. Gay Men

Gay men are still a significant focus of much of the HIV prevention work in Ontario. Many ASOs are rooted in the gay communities of Ontario's cities and continue to focus their prevention efforts on gay men.

"Well, we have been around for a long time. Um, since the 70s. And we are

fairly well advertised in the gay community so there is . . . gay . . . Most of our clients are gay men."

2. Men who have sex with men

Still others have taken on the challenge of prevention work with non gay-identified men who have sex with men. Difficult to reach, this group of men typically does not frequent gay bars, bathhouses, or other venues where HIV prevention work typically occurs. Some communities have found success in reaching these men through outreach programs to public sex environments including parks and public washrooms.

"Ok, we have I would say one, two, three, four main prevention streams. One is our MSM programming, our men who have sex with men programming, and that is very targeted prevention education."

3. Women

Recognizing that women's prevention needs and methods differ from men's, many ASOs have developed targetted programs for at-risk women. Incorporating issues from women's lives is key to successful women's prevention programming. Often this includes focussing on issues in relationships with men such as power, violence, and emotional or physical abuse. At other times, the focus is broader and may include concerns related to childcare, poverty, and sexual abuse.

"Um, in the women's project we also do peer education and we're working with several groups of women at risk."

"Oh, well we just formed a working group and it consisted mainly of women. And

we decided that the languages would be English, French, Spanish, Portuguese and then there would be 4 African languages. We chose those 4 languages based on the Remis report and how women from HIV endemic countries were the ones who were testing positive the most. And so it was really important to be able to reach out to those women. We knew that, you know, it wasn't even close to being enough but it was a starting place. We had to start somewhere."

Frequently, women's HIV prevention programming is carried out in the broader context of women's community development work where prevention workers see themselves as part of a broader network of service providers working with and for women.

"The woman whose been hired has come to the job with lots of connections in the women's community so we've been able to do prevention work in the shelters, with Sexual Assault Crisis Centres in the region showing the link between being at risk of HIV and survivors of sexual assault and abuse. Lacking self-esteem, not having been taught or not having one's boundaries protected as a child can lead one into behaviour that would put them at risk of HIV."

4. Transgender/transsexual people

Little has been written about the HIV prevention needs of transgender and transsexual people, yet some women's HIV prevention workers in Ontario are creating programs for this under-served group of people.

"And then the other part of the women's project we're working in similar methods with the transgendered and transsexual women sex trade workers."

"So we were asked because one of the staff had done quite a bit of work and was

fairly public about her work around transgendered issues and HIV-AIDS, if she would come in and do workshops and educationals on transgendered issues and help to develop some policy around transgendered individuals in the shelter. And so some of it is invitations to do policy, to come in and talk about universal precautions."

5. Youth

Since the early 1990s, there has been increasing concern about the HIV infection rate among young people in Ontario. As a result, many prevention programs targetting youth have been implemented across the province. Prevention workers reveal a sense of optimism about youth, believing that intervening while they are in early stages of development may lead to more sustained and therefore longer-term behaviour change.

"We're certainly dealing young people on the solid belief and understanding and it's certainly been well researched that you educate young people at a very young age actually before a lot of the sexual behaviours start and then when they do, they'll certainly think about using a condom."

"The ones that, the majority I ... sorry ... the ones that I focus on or I keep tending to go back to would be the youth because if you can educate them they'll take it you know with them …"

While the concern has been focussed across all youth, Canadian epidemiological data have particularly drawn our attention to increasing infections among gay youth. As a result, considerable leadership in developing HIV programming for lesbian, gay and bisexual youth has been demonstrated by ASO prevention staff in Ontario. Support groups, campaigns, peer

outreach networks, and drop-ins are commonplace for these youth in many Ontario communities.

> *"And also with the youth coalition. The youth coalition for lesbian-gay-bisexual youth because we know that younger gay men are getting infected. The rates are increasing so this is a way hopefully to do prevention work that way even though these young people are living with HIV, this is an opportunity for them to learn about taking responsibility for themselves and prevention."*

6. Injection Drug Users (IDUs)

As research continues to indicate greater infection levels in the IDU community, more and more ASOs continue to develop targetted programs. Using a variety of prevention methods including needle exchange programs, brochures and poster campaigns, and peer outreach programs, prevention workers are focussing considerable efforts meeting the prevention needs of this population.

> *"Over the years we've tried a number of things but I think that in the last 4, 5 years what we've really moved our focus into is behaviours related to substance use, including injection drug use because that seems to be the areas in which we've been seeing the largest numbers of people becoming infected. So we've had to work on developing strategies that would try to address those issues, and so most of the, I guess, real directed prevention programmes have been both through ACAP projects, the originally the substance use outreach project, and now the targeted prevention initiative which is essentially a peer outreach programme. Actually it has several components to it, and it started out there was a social marketing component which involved the development of a series of*

posters and materials that were placed both as posters and as transit ads put up in the buses that addressed issues of substance use and HIV".

7. People in custody

People in custody continue to be a focus of HIV prevention workers in Ontario. HIV behavioural and seroprevalence research indicates high rates of risky behaviour and HIV in prisons. This is compounded by new challenges such as Hep-C co-infection.

"There had been a study done in 1997 and the HIV prevalence was 1.7% which is still high, and we know that the rate in prison is much higher because of risk behaviours, the hepatitis C rate was something like 33% in that particular institution in … we've always had prisons as part of our community."

8. First Nations

Some HIV prevention workers are focussing their work on First Nations peoples. Dramatic increases in new HIV infections among First Nations peoples exist against a back-drop of poverty, addictions, childhood sexual abuse, enforcement into residential schools, high youth suicide rates, migration to urban centres, and systemic racism.

"The issue around First Nations folk is huge for us in this community."

In addition, there is an increasing realization in the field that working with First Nations peoples commands methods and approaches that are culturally-sensitive and appropriate, and are best delivered by people from those communities.

"And we have peers also that access bars, the aboriginal community specific targeted populations as well. Because those communities can relate more to

those individuals than they can to the staff here at the agency. So we do a coordinating, organizing thing at the staff level here, and then the peers go out there into the community and do the work."

"It's, it's very different for every community. The process of going into the aboriginal community is very different than going in a non-aboriginal community. You know there has to be more of an invitation and because we have an aboriginal worker here that has facilitated that task because she's known in that community so we've been able to make more headroom there."

"… and they just indicated they're getting an aboriginal person to come in and do the work, which is good because that's the culturally appropriate interventions."

9. People from ethno-specific communities

Ontario's diverse population (especially in the larger cities) has led funders and ASOs to implement prevention programming targetted to people in ethno-specific communities. Differing community norms in relation to religion, family, and sexuality, the impact of systemic racism and poverty, and issues related to immigration and settlement, result in a need for cultural sensitivity and appropriate HIV prevention methods and programs.

"The program itself is really culturally sensitive, that's why we have an aboriginal outreach worker, IDU outreach worker, my programme which is fully bilingual. So that yes, there is some cultural sensitivity on all aspects and we take that into consideration. If I'm doing a presentation in a high school versus an adult environment, of course the language changes. I also take into consideration if people are Muslim, Christian, or non-denominational, that changes on how you approach on safer sex issues or birth control issues."

"Well there are a variety of places, the site that we go to – bathhouse, bar, parks, private parties, community events. Now last few years since 1996 we outreach through Internet. We using the Internet to go to the people go through site where most Asian men go, gay Asian men go, such as gay Asian Toronto website personal classified, go to chat room. So those are where we, we go to reach out."

10. And others

Finally, the rapidly changing nature of the epidemic has resulted in prevention workers creatively developing programs for groups not typically targetted with HIV prevention programs.

" ... most of the ASOs, many of the ASOs, their history has been around gay men and now we have this greater population of, women coming in, straight men being impacted, needle users being impacted, and now children. So it's, a real shift for many of the services to be making. To become more family oriented in a way and be able to deal with some of the issues that are coming up for parents around their children. It's not something that we've had a lot of dealings with but it does come up occasionally, and if it comes up occasionally then you have to be ready to deal with it."

Part 3 – What Makes Prevention Work Difficult…

Table 4 below, outlines the challenges to effective HIV prevention work raised by prevention workers during this research.

TABLE 4 – Challenges to effective HIV prevention work….
1. The values, fears and attitudes that we encounter in society. 2. "AIDS boredom". 3. Geography and other access issues. 4. Scant resources and the structure of the system. 5. Changes in the epidemic, changes in the clientele.

1. The values, fears, and attitudes that we encounter in society

There are significant barriers to effective HIV prevention work including AIDS-related stigma, misinformation, denial, fear of people with HIV, and discrimination against those groups perceived to "get it". These issues are at work in the populations that agencies are trying to reach, but they are also directly felt by the people working in the agencies, leading to fatigue and frustration.

> *"The other part of it is that there is a fair amount of AIDS phobia out there and homophobia. I'd say that probably those two working together are really difficult and I think more than anything I find the ongoing homophobia that I have to deal with the most draining probably because it's the most personally felt."*
>
> *"A couple of other things about barriers, sexism and gender relationships, racism, classism. HIV tends to go to marginalized groups. So any of those barriers if we can work to reduce some of those barriers, we can be doing more effective prevention work."*

2. "AIDS boredom"

HIV has been a health concern for almost two decades. Keeping it high-profile and on the agenda of organizations and individuals is an ongoing challenge.

"That's one thing I'm concerned about, that if that happens like I'm finding that especially in the adult population, or in the 19, 20s type thing, a lot of people are hearing more and more and more about HIV-AIDS, safe sex, and it's just getting to a point that you know what, I don't care any more."

3. Geography and other access issues

For some working in HIV prevention, access to hard-to-reach and isolated communities poses a serious challenge. In smaller communities, accessing "out" self-identified gay men with information about HIV is hampered by homophobic attitudes.

"We also have in the past tried to reach the gay community. That's a real challenge and real struggle in this… small city; the outlets for reaching them like the commercial outlets aren't there. There aren't bars, there aren't identifiably gay community areas, there are limited community organizations. So reaching those people is extremely difficult, and that's been a challenge all along."

Other kinds of fears and attitudes pose hurdles to HIV prevention workers trying to do their jobs. Typically schools have been politically-charged environments where getting information out is often very difficult.

"Well this meeting on the 13th of February, we have a meeting with the school to tell us what we can and cannot say."

In other instances, schools are viewed as a domain separate from the mandate of community-based organizations.

"Well, not too much in the schools because apparently we're not allowed to be there. The Public Health is supposed to be there but in fact we do, do some school based work. But we talk to community organizations."

At other times, the issues is not so much attitudes or mandate, but geographical catchment areas that are difficult to cover.

"So in this area we have a city of 65,000… and then we have a population of about 150,000 that's scattered throughout four counties and they're all small towns. And of course then there are lots of kids or people living in rural areas. Well how do you get prevention messages out in a largely rural setting? It's difficult."

At other times, target groups may be less organized in smaller communities compared to big cities.

"However, I think in [our] region, it's much more difficult than in Toronto where you have a larger population and communities that are more organized. So for us to target at risk youth, we can't. There are very few youth-related organizations where we can go and find the youth, find the people who work with youth, we sort of need to cast our net wide in order to do that. And that's particularly true of working with women and marginalized women. Or various ethnic groups and immigrants in particular."

4. Scant resources and the structure of the system

Participants frequently mentioned "out-of-touch" funders, scarce funding, the "professionalization of AIDS", time-limited grants, excessive paperwork, and over-worked staff, as key difficulties in prevention work.

> *"I think what does make this whole field difficult and I'm sure it's the same for other fields like cancer, whatever, is you know we moved away from grassroots organizing into a highly professionalized field. We had to at some point I think. But what that has in turn done has made our work extremely taxing and less about working with people and more about filling out papers."*
>
> *"It's not what the government, for some reason seems to think it is, is AIDS 101. It's not an AIDS 101 world. And if that's what they're funding for, then that's nonsense. It's not what we experience out there."*
>
> *"We have, essentially we have one full-time person doing the education work and that person also does other things in the office as well because he's the, he's the computer expert in this office… So this one person gets some of their time pulled in different directions. And then where there has been some support such as through our federally-funded programmes, those projects have been temporary, part-time, finite, they end. We can't continue with doing messages or programmes. We make a certain amount of headway, for instance, with targeted prevention work into certain population groups, then that will end."*

5. Changes in the epidemic, changes in the clientele

One of the other significant challenges in HIV prevention work is the rapidly changing nature of the epidemic. No longer are gay men the only target group of agencies. Instead, varied groups, who have diverse needs and require innovative programming, have become the norm in most communities.

"One of the issues we deal with are the varying kind of PHAs. We have gays, we have First Nations, we have women, and we have injection drug users. And none of them talk to each other. And if one is in the agency, the other one won't come. We're not successful with our workshops, our seminars, our any things. If we only invited those in the gay community, they'd come. Or if we only invited the IDUs, they'd come. But they won't come together because they don't like each other."

"I think we need more training in terms of multi diagnoses. We're seeing more and more clients – well you're nodding – with Hep C, with mental health issues, that kind of thing. I think more training needs to be provided for ASOs around that."

Part 4 – Who Is Doing Prevention Work…and Why…

People doing HIV prevention work come from all walks of life, religion, and culture and many have been personally affected by HIV. They are men, women, and people from the trans communities. They are lesbians, gay men, bisexuals, and heterosexuals. They are young and they are old. They bring their histories, passions, fears, anger, beliefs and perspectives.

"We're from the communities we're trying to serve."

"I was personally impacted by HIV having had a friend of mine, who's living with HIV, a way back when, who has since died, and so that's part of it. I have always been interested in social justice issues."

"…having a feminist analysis and looking at power dynamics has helped me understand how to do prevention work. So you can't look at HIV outside of its social context. So whatever analysis you have, I'm a feminist and socialist so I apply those and look at issues like poverty and discrimination and equality and base my prevention strategies on that."

The people working in HIV prevention long to learn about the world, about other people, and about themselves. They are people who learn from their mistakes and successes, people who are passionate about what they do.

"Yes I'm a very curious person. I'd put that down. Curiosity. I like a challenge."

" I like making mistakes. I like taking risks and so I don't judge anybody for anything that they do unless it gets to the point where they complain about the situation they're in and don't change it. Because I'm guilty of that too."

"… I feel incredibly privileged to work here. I mean we all know the pay isn't great but there's so much else that feeds one … I could be making twice the money I'm making now… Yea, well it's [the passion], there for all of us I think or we wouldn't be here. And it has to do with the work, but it also has to do with the incredible respect and stability that this organization has, and it's a privilege to be a part of that."

1. The people doing prevention work get their skills from…

Frontline prevention workers possess a diverse array of skills, and come from diverse backgrounds including theatre, counselling, education, addictions, health promotion, nursing, administration, and social welfare. Many say there is no college or university program that prepares them for HIV prevention work, though some have chosen that route. Most learn on the job, through listening to their clients, reading, consulting, and staying up-to-date and current with information.

> *"Certainly not from university, that's for sure. A lot I got from spending 8 years working at a Sexual Assault Crisis Centre at a grassroots level. And then through on-the-job training. You have to stay up-to-date. I've done lots of research, done lots of reading about HIV…"*
>
> *"I read as much as I can. I talk to as many people as I can. I don't like going to conferences particularly. I find them a little too basic most of them for me. It's from doing a job ... So why go to conferences? I tend to be around educators who have been doing this work for a year or 2, and I don't need the basics on HIV. I understand the disease quite thoroughly."*
>
> *"So, I mean, you know, knowledge is amassed over time and experiential ... it's much more experiential. You can read a lot of material on HIV right now but unless you're working in it I think your knowledge isn't as broad as it needs to be. And also, of course, once you work in it you can't help but be impassioned by it."*

2. The people doing prevention work expand their reach through collaboration with other organizations, peer programs, and volunteers…

Given scarce financial and human resources, HIV-stigma, and the potential for isolation, any HIV prevention workers spend considerable energy and time building partnerships, networks, coalitions, and other means of collaborating with others.

> *"The Catholic church has been incredibly supportive of us. We have Sisters who package condoms, and I lecture them because I don't think that they should be doing that. They should be making afghans or something. But they come in here, I mean we have a meeting going on right now of church folks."*
>
> *"There's the Needle Exchange Coalition and the Rainbow Youth Coalition. And those two coalitions are comprised of myself and representatives from other agencies and the target groups, so whether it's youth or injection drug users, and we have monthly meetings and we do planning for workshops, posters, publications, whatever."*

From the beginning of the epidemic, volunteers have been crucial to the development and ongoing survival of ASOs (particularly for smaller ASOs).
In many cases, organizations rely heavily on volunteer support and would be unable to deliver programs without their support.

> *"I mean it's a small office. There are just ... five of us are full-time… and the volunteers are our staff too. I mean they staff, the person who answers the phone is a volunteer. So they're part of the staff as well."*
>
> *"We used to have, and we do actually keep it on an ad hoc basis, an education committee which is a committee of volunteers who he'll pull together when he*

requires their advice or support around programmes or what should be done. Often that's around maybe a specific project that's coming up. We also utilize where possible volunteer speakers. If there's a speak, most primarily have been clients, although I think we've had some volunteers who have gone out and done speaks at organizations that they're familiar with church groups or whatever organizations those volunteer resources we attempt to use."

Part 5 – How We Develop Program Ideas…

TABLE 5 – Program ideas are generated ….
1. "in house" by ASO staff…
2. with input from community members and clients…
3. from needs assessments and other research…
4. from other ASOs.

Prevention workers draw on a variety of sources of information when developing programs. These include other ASOs, frontline staff, clients, other community members and organizations, and research findings.

1. Program ideas are generated 'in house' by ASO staff…

As a direct result of frontline experience, ASO staff possesses intimate knowledge of the complexities of HIV prevention work. They rely on their intuition, what they see around them, and the gaps they observe. Often then, program ideas emerge as a result of being involved at the frontline.

"… about 3 years ago or so I was just reading some new pamphlets that were coming through and read some statistics on transgendered sex trade workers.

And the rates of HIV infection on transgendered sex trade workers are extremely high. Some say as high as 70% are infected with HIV. Which got my mind thinking. We don't ever talk about that issue here. There are no services that are available for transgendered transsexual women … How can you do prevention work or even provide the basic services for a group of people for whom there's nothing… So I started doing some workshops on trans phobia. I then started to work with people who were interested in those areas. I did community-based, at like International Women's Week, did some workshops and then for Gay Pride I did some workshops…"

2. Program ideas are generated with input from community members and clients…

Community input has become an established norm in the development of HIV prevention programs. The establishment of project advisory committees, coalitions, and other networks demonstrates the commitment of frontline workers to ensure they are accountable to the communities they work with.

"It depends on what their target audience was. If the target audience were youth, gay and bisexual youth, I would go to that coalition. If the target audience were gay men, I'd go to the MSM advisory committee. If the target group were injection drug users, I'd go to the needle exchange coalition. If the target group were none of those, so for example, one of the things that I'm thinking about for the near future is some kind of women's programming – ongoing prevention, education – women's-based programming. Well what I would do is, then in fact what we're doing is we're holding a one day workshop and we're bringing people

hopefully people from different women service agencies to get together to learn information and get skills, but part of that is hoping to establish a sort of a committee, a working committee, that wants to look at women's sexual health issues in the area. And then we can build on that, you know, and maybe a year's time be able to develop a proposal for funding for some kind of ongoing education programming. But it's really going to the community that you're trying to serve and getting their buy-in or endorsement or identification of a need first."

"It's very, very driven actually by the clients. Not necessarily the positive clients but if someone phones up, we have a programme, actually it's sitting up on the filing cabinet up there, that's aimed at the developmentally delayed students. And the need came was because we had a developmentally delayed client. Severely developmentally delayed. And when we started doing that work within the schools it was an instant success. We got things we didn't bargain for out of the programme"

3. From needs assessments and other research…

Conducting needs assessments, service provider consultations, and client focus groups are commonplace in HIV prevention work. Ensuring that programs are relevant and responsive to the needs of target groups is a high priority for prevention staff.

"What we generally do in our community to find out what the community needs are, we hold focus groups with the community and we let ... We always, always put the community first and we always ask them what would you like to see, what do you think is in need of change and we go by that."

"So from some data, so outside research reports that we've been able to get, feedback and input again from people in the community, and our own assessment of what we think is required here as well, I think that's how it's done."

4. From other ASOs…

Finally, workers are adept at "not reinventing the wheel". They look to other communities and countries around the globe to see what has been done and what has been successful. Access to the Internet means that HIV prevention programs developed throughout the world can be adapted to local needs.

"Well it depends on the programme. It's an amalgamation. I beg, borrow, and steal from other ASOs"

"I think especially in, in working with HIV/AIDS, there is something that everyone follows because it's proven to work time and time again. No one is going to reinvent the wheel on something that's proven to be effective in the last 10 to 15 years. So if I go and I do an HIV 101, it's going to be very similar to something that they would do up in (name). The information is going to be the same. The way it's delivered might be a little different but the crux of the prevention programme is going to be very similar"

Part 6 – How We Know If What We Do 'Works' …

"And those are three key words I'm learning about – availability, accessibility, and appropriateness. By that I mean do people know about the programme, do they know that it's available, have they heard about it? Secondly, is it accessible

to them? Do they know what time it is? Can they get there? Is the location safe? Is the time a good time? And thirdly, is it appropriate to them? Are the topics that are discussed, is the way the meeting is run, managed, the way conflicts are managed in groups, the way information is delivered, the way questions are taken, the way the facilitators' knowledge and his attitude – are all those appropriate to the target group?"

Increasingly, in an evidence-based milieu, prevention workers ask themselves "how do we know if what we do works?" Many state that they are so busy that "there isn't time to reflect". Others show concern that while "sharing knowledge" comprises the bulk of their work, it is unclear what actual impact it has on behaviour change.

" …we basically don't have a clue about the outcome of what we're doing. We don't know. If our specific narrow goal is preventing transmission say for sex behaviour, harm reduction, injection drug use behaviour, I don't know, usually you're not going to see these people again. You see them once maybe twice if you're lucky. It is hard for us to know whether the education that we're doing is actually accomplishing it. It is impossible to know if it is accomplishing what we want … and also … sexual behaviour and drug use are very irrational behaviours. I mean they're hugely complicated behaviours. So we don't know what is happening and it is difficult anyway".

Table 6 summarizes the means by which prevention workers gauge success, and their subjective indicators of success.

TABLE 6 – How we know if what we do 'works' …	
Tools to gauge success	**Indicators of success**
- program evaluation - focus groups/interviews - client feedback	- ability to engage participants - people call - other organizations seek our input - requests to do presentations - frequency of presentations - calls from the "corporate world" - people request info about us - decreasing infection rates - people are aware of program - programs are accessible to clients - meeting objectives

Despite the difficulty of measuring the effectiveness of HIV prevention interventions, frontline staff shows a persistent curiosity about their successes, and a desire to improve their programs. They assess, evaluate, "ask questions", and "look for clues" of success.

> *"We do an evaluation, for example, the targeted prevention project …there was an evaluation done of it to get a sense of, and part of that was a focus group with peers asking questions about what they thought worked, and you know what were the things that we could change or try to make better. So yes we try and get feedback from people".*

Part 7 – Personal Feelings About Our Work and Our Workplace…

Given the daily stressors faced by HIV prevention workers, supportive workplace environments and co-workers are key to reducing the risk of burnout, and enhancing longevity in this work. Participants in this research spoke glowingly about their jobs, the tasks involved, the workplace structures that surround them, and the players they interact with daily.

TABLE 7 – Personal feelings about our work and our workplace…	
What people say about their work	**What people say about their workplace**
- you feel valued - you feel respected - not a "status quo" type of work - it's really important work - opportunity to take risks - can change history through work - a great deal of autonomy - wealth of resources (e.g., CLEAR, OAN)	- co-workers get along well - people committed to work - people are creative/room for creativity - people work collaboratively - accessible management - best work environment I've been in - room for success and failure - opportunities for healthy conflict resolution - organization is stable and staff remain

Many spoke of the cooperative and collaborative ways in which their coworkers interact, and the significant commitment people have to their work. Others spoke about accessible management, the stability of their organizations, and the external resources that are available.

"I think one of the advantages of our agency has been stability of staff. We've been able to build programmes and stable organization, and even going though having (name) away for a couple of years, we've been able to carry on and function quite well because we have people with continuity and we've been able to do it".

"Things on the provincial level, networking. The AIDS, movement has tremendous resources ... the networking and resources that are offered. There is the organizational development team, there is CLEAR, there is an ED's retreat, there is an ED/chair meeting, the OAN conferences, CAS skills building, there is CAS AGM, and there's time for caucuses for PHAs".

The importance of being autonomous in their work was highlighted. Many appreciate the room allowed to take risks and to be creative.

"We're given space to be creative. There's a very creative group of people here and I think you really need to be really creative in this field of work, and we're

allowed to do it. And if there's a lot of fear that you would be punished for failure, you wouldn't do it. So we all get out there and put ourselves out on the edge."

Prevention workers do not view their work as status quo. Instead, they see it as an opportunity to affect social change.

"I think it is really easy, you know, when you know you do good work and you are part of something really important … it just makes your work so much easier when you are part of this history of …, radical work and amazing people doing amazing things".

Finally, HIV prevention work affords opportunities to be respected, for workers to feel valued and good about themselves.

"You feel very valued. You feel very respected for the work you do. So that is number one."

Part 8 – Possibilities, Future Directions…

In this research, there was considerable excitement and passion about the future of HIV prevention work. Four key themes were identified as requiring significant attention.

TABLE 8 – The future of HIV prevention…
1. The capacity to do research.
2. The need for new prevention messages and programs.
3. The need for increased partnerships.
4. The need to put risk-taking into a social and political perspective.

1. The capacity to do research…

Prevention workers struggle with keeping programs current and relevant. Many spoke of the need for up-to-date information, for needs assessments and other kinds of research that would inform program development and delivery.

> *"… I think it's research we need to do in order to find out where we need to put our prevention efforts*."

In order to enact these wishes, frontline staff in ASOs requires increased capacity to do research. Identifying current research skill sets, gaps, and learning needs, are important steps in the development of research capacity building for ASOs. Further, the development of partnerships with academic researchers will further assist ASOs in reaching this goal.

> *"As far as organization in the development of their prevention programmes, I think one of the biggest things that we're struggling with is, and I believe it's going to be addressed partly, is our ability, our capacity if you want to call it to conduct the research that's required to get the information to help us put together the projects better."*

2. The need for new prevention messages and programs…

Innovation in HIV prevention programming is a key challenge for the future. Many frontline staff fear that prevention messages and methods of delivering them have become stale, and that new strategies are urgently required. The combination of people living longer on HIV anti-virals, and decreased media attention to the disease, has made many anxious that HIV is no longer "on the public agenda" – despite the changing face of the epidemic.

"We're going to need a new method or programme or message or whatever. We've seen that shift in change all along over the years, and we've had to change our messages as the disease progressed from being a predominantly gay disease to a disease that affected women and aboriginal communities and had many more faces, we've had to change our messages."

Prevention workers express a desire to reflect, to take stock, to gather information, and to be innovative with new program ideas and methods of reaching people.

"So what we've been struggling with is, what are the new messages, what's the new way of getting out there into the communities to do our prevention work, and we believe, at least I believe, part of that is about being able to do some sort of ground baseline research in the community where are we at right now; where's the community's perception at with HIV/AIDS; even our organization, how receptive are we, what's their knowledge base awareness now because there was no awareness or knowledge before. Now there's a certain level but what is that level of awareness? Where are the gaps? How receptive are people in different target groups and how are they hearing the messages? So I think it's research we need to do in order to find out where we need to put our prevention efforts."

Others worry that the decreased focus in HIV will lead to complacency, greater vulnerability to infection, and increasing infection rates.

"I think we've done a good job here. But we can't just continue to repeat it so it is time to say where do we go from here. And I don't know what the answer is. I think there's a need on a broader scale for a new prevention front, perhaps on a national provincial level. The province of Ontario did some television

commercials back in '92. There's been nothing since then. The federal government has not done any real national campaigns for years. So the whole issue of HIV and AIDS has kind of faded away, plus with all the death rate going down and the success of some of the combination therapies people are starting to think well it's not an issue anymore, we don't need to worry about it. So it's receded I think in people's consciousness. So I think that if we really, if we let that continue to happen, then I think we're going to start to see that those infection rates rise again because there's still pools of infection and people are getting infected because they're not paying attention to it ".

Frontline staff envision multiple approaches in future HIV prevention work. They note that while the trend toward large-scale social marketing campaigns is a useful one, the more "labour-intensive" and personal peer outreach approach is as crucial. They are concerned, however, that the current conservative funding environment will dictate only a mass-marketing (and therefore less personal) approach to prevention.

"… I think there's going to need to be a combination of macro projects such as national or provincial social marketing campaigns to raise the awareness of the issue on a broader basis, combined with really labour-intensive targeted programmes, and I don't mean targeted to risk groups, more targeted to behaviours, and I say labour-intensive because I think this idea of using peers and doing one-on-one discussions with people is the way to do it. It doesn't do any good to just give people pamphlets or give them information or tell them, here's the information. It needs to be, in order for connections to be made, people need to be able to talk about the issues and think about them in such a way that they

can analyze for themselves, oh well then maybe I do need to make changes here. So I think the prevention work is going to become more ... is more difficult because it's more labour-intensive, and I don't see that there's going to be an increase of resources to be able to do that. So that's a dilemma that I see right now and I don't know what the answer is".

The creation of new prevention programs has to be balanced with the support and maintenance of those already in existence that currently yield many successes and are still important.

"We always talk about creating new programmes, but I think there needs to be more discussion about maintaining the programmes and the services that we already provide. You just don't create them and then they exist by themselves forever. You have to nurture them all the time. Just like AIDS service organizations have a high level of turnover, most social services do, so you are constantly rebuilding or reaffirming the relationships that you have and it's absolutely essential."

3. The need for increased partnerships…

There is excitement and optimism about future increased collaboration in HIV prevention programming. Increased funding cuts, fewer resources, and the potential for staff isolation and burnout necessitates that frontline staff continue to work in partnership initiatives to maximize their effectiveness. Other concerns were expressed in relation to people having the autonomy to choose potential partners before others (e.g., funders) dictate them.

"I think that our community partnerships are going to have to become a lot

stronger. I think that you know, in Toronto, especially there are a lot of agencies fighting for the same dollars. I think we're really going to have work together to provide services … so partnerships are going to become essential".

"I think it would be much better to choose, knowing that partnerships are a thing of the future, to be able to choose the partnerships that you want to engage in rather than being forced into them. So I think that's what's here at the (name) group. We're starting to look at. You know, what would be a good fit for us rather than what somebody tells us would be."

4. The need to put risk taking into a social and political perspective…

The tendency to "individualize" risk, by viewing risky behaviours in isolation of a social context is worrisome. The future potential of developing HIV prevention programs that view risk-taking behaviour within a social context is both exciting and challenging. It may be that the prevention paradigm of telling people to "use a condom every time" is not only unrealistic in the long-term, but that it is also ineffective because intervention is restricted to the level of the individual. Said differently, the strategy runs the risk of seeing the individual as the problem – their risk-taking is viewed as an "unhealthy choice". What remains unchanged as a result of these interventions, however, are the social reasons for HIV risk-taking.

"So I think the more radical community approach to sexual safety has been supplanted by an institutional one that stresses individualization of risk taking behavior and I think that is a problem. I think we need to start thinking in terms of community based and collectivization of risk and when we start doing that, we are cracking things open to become more political. I think we have lost the

political perspective on risk management and I think that the message has been co-opted."

DISCUSSION

The design of this study allows us to draw some important conclusions. However, there are also limits to the kinds of conclusions that can be made, for several reasons. First, there were 11 organizations included in the sample. There are a total of 74 community-based organizations in Ontario that receive provincial funding for HIV/AIDS programming. Therefore, some of the observations from this study are likely to be similar to the issues that all ASOs in Ontario experience. However, this study may have missed some important experiences from workers in ASOs that were not interviewed .

In addition, this study tells a story about the people and organizations doing prevention work. It is useful for understanding the broad concepts about doing prevention work in ASOs in Ontario. We did not collect any 'structured' data using numbers and categories. Thus, it is not possible to report an accurate listing of items such as programs being carried out, target groups being considered, or methods being used for program evaluation.

What Are The Pieces Of HIV Prevention Work?

People working in Ontario ASOs perceive that the factors that ultimately lead to a person being infected with HIV are vast and varied, they are individual and societal, they are about behaviours and about attitudes, about privilege and oppression, about knowledge and about capacity to put knowledge into practice.

This conceptual framework is consistent with the ways that HIV prevention work has been described in the academic literature. As an example, Auerbach and Coates have described the levels of HIV prevention work in the following terms: enhancing access to prevention technologies, providing appropriate prevention counseling and education, changing social norms and policies to promote prevention, and employing medical strategies such as HIV treatment in order to prevent new infections.[1] Other authors have used different terminology, but all are conceptually similar to the ways in which people working in ASOs described their own levels of prevention work. Appendix 2 and appendix 3 show two different models, or ways of thinking about how these different levels of prevention might be related to each other, and to the person at risk.

People working in ASOs see their work happening on many of these different levels. Programs that provide access to condoms, to clean needles, and to infant formula are all improving access to technologies that decrease risk from certain behaviors. Programs that provide knowledge about HIV and its transmission are equipping people with information. These programs appear to be fairly common in ASOs. Programs that provide people with opportunities to learn new skills, such as negotiating sexual interactions, or cleaning injecting equipment were also mentioned by the study participants, although less often. Programs that aim to improve the public understanding of AIDS-phobia, homophobia, racism and other forms of discrimination were also mentioned often; these approaches are almost more a "way of life" for ASO workers than they are specific programs. Participants also spoke of facilitating access to HIV medical care, an important aspect of preventing transmission from someone who knows that they are positive.

It is apparent that there are also some areas in which ASOs do not work on a regular basis. These include the more biomedical areas of prevention, such as vaccines, microbicides, post-exposure prophylaxis and access to medications; facilitating access to HIV testing, except in a few organizations where this was a specific part of their mandate; strategies targeting social norms and policies at higher administrative levels; programs that target multiple aspects of behaviour change at the same time, such as providing condoms, developing peer relationships, and teaching social skills; and, promoting HIV prevention in a global context.

Discussion Point 1: What are the most appropriate prevention levels (biological factors, individual behaviours, societal and political issues, etc) for ASOs to be working on? Are these the prevention levels that they are currently involved in, or could they be expanded, reduced or re-focused? How does the prevention work of ASOs fit with the prevention levels that other types of organizations are working on?

How Are Prevention Strategies Developed?

Participants generally emphasized how prevention programs are firmly grounded in the realities of their specific communities, the experiences of the people they wish to reach, and the wisdom of the people working on the front lines. Prevention strategies were generally described as responsive and "home grown", although they also relied on the experiences of other ASOs in order not to "re-invent the wheel". Occasionally, participants spoke of the value of conferences and workshops on prevention, but some also described a dislike for this type of learning.

There also appeared to be a reluctance on the part of many study participants to make use of published materials on designing HIV prevention programs, or to be involved with more formal types of learning about HIV prevention. There was seldom mention of referring to specific theories of behaviour change when developing prevention programs. Numerous publications have accumulated information on various prevention programs for different target groups, how to implement these programs, and the evidence for their effectiveness in changing behaviours [2-7]. However, these types of resources were not discussed in relation to developing HIV prevention ideas.

Discussion Point 2: Could the strengths of the current methods of program development be improved further by providing information and skills for program developers? Are there ways that more formal types of information, training, and research evidence could be made more available and useful for ASO prevention workers?

How Do ASOs Know If Their Programs "Work"?

Participants generally expressed frustration with not knowing whether their prevention strategies were successful or not. They often conducted surveys or informal inquiries to find out whether people were satisfied with the particular program, and usually had a good idea of whether the program was accessible, appropriate and attracted the desired population. However, there were few participants who felt confident that they knew whether their strategies were bringing about the desired changes in behaviour, and in HIV infection rates. Often, their only feedback on effectiveness of their strategies was through hearing about rises and falls in

provincial HIV infection rates. A continued rise in infections rates was often perceived as a failure.

In general, HIV prevention science has grown to rely upon measures of behaviour (such as sexual practices or needle-use practices), and occasionally on knowledge levels, disease rates such as STDs, and HIV infection rates.[2;8] Other available measures include measures of societal attitudes and stigma, as well as measures of "buy-in" from relevant decision-making persons and organizations. Many different systems for implementing these measures for HIV prevention programs have been developed since the beginning of the epidemic, and can inform prevention workers of the effectiveness of well designed programs. However, these measures do not appear to have been generally adopted by Ontario ASOs.

Discussion Point 3: What measures of program effectiveness would be most useful to Ontario ASOs? How can currently existing measurement tools be acceptably adapted to suite Ontario's prevention programs? What new measures of effectiveness could be developed to provide ASOs with the information they need in order to know whether their strategies are working?

What Are The Barriers To Doing HIV Prevention Work?

Difficulty accessing target groups, societal discrimination, diminishing perception of urgency surrounding HIV/AIDS, increasing complexity of issues facing people at risk of HIV, and funding problems were the most frequently mentioned challenges facing HIV prevention workers. In a previous program review among Ontario ASOs by Ed Jackson, similar challenges were reported.[9]

Discussion Point 4: Could prevention program funding be improved (increase or re-structured) to be more effective in producing sustainable prevention programs? Are there ways in which sectors other than ASOs could increase efforts to improve access to target groups, decrease societal discrimination, and increase societal awareness of ongoing urgency around HIV/AIDS?

What Is The Culture Of AIDS Service Organizations?

People working in ASOs find the complexity of their work challenging, stimulating and meaningful. They enjoy the need for constant creativity. They have come to this work because they believe in helping all kinds of people who are facing all kinds of difficulties. They have come to this work because they long to learn…about themselves, and about other people. They have come to this work because they want to make the world a more just and equitable place. But most of all, they have often come to this work because they feel that HIV is in some way about them, and their response grows out of compassion.

The ASO movement in Ontario is grounded in a history of people affected by HIV reaching out to others at risk for, or infected by, HIV.[9] This history has led to an organizational culture of dedication, responsiveness and accountability to community. There was also some concern expressed by study participants that increased pressure to "professionalize" would compromise the historical strengths of ASOs.

Discussion Point 5: How can the immense strength of the grass-roots history of Ontario ASOs be maintained and utilized effectively? How can this quality continue to inform effective prevention work?

What Suggestions Are There For Improving HIV Prevention Work?

Carrying out prevention research, developing new prevention messages, developing strong partnerships, putting risk taking into a political and social perspective were discussed by participants as ways to improve prevention work in the future. These ideas from Ontario's prevention workers were consistent with the United States' Centers for Disease Control Five Year HIV Prevention Strategic Plan.[10]

Discussion Point 6: How can research be integrated into the prevention work of Ontario ASOs?

Discussion Point 7: What are the new prevention messages, and how can they best be developed?

Discussion Point 8: What are the most important organizations for ASOs to develop partnerships with, and how can these be enhanced?

Discussion Point 9: How can risk-taking be framed in a political and social perspective, and how can this framework be used effectively to enhance HIV prevention efforts?

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APPENDIX A

Interview Guide

INTERVIEW GUIDE

Thank you for agreeing to take part in this interview. As you know, we are trying to find out from people who are actually involved in ASO work what their thoughts and experiences are about their organization's prevention programmes. I have several questions to ask you about this.

1. **What kind of work does your organization do?**
   Probes: How much of your work is related to prevention?
   i) How does your organization decide which prevention programmes to provide?

2. **What kind of prevention work is your organization involved in at the present time?**
   Probes: Who is/are the target group/s?
   i) What are the goals of these prevention activities – short-term / long term?

3. **Regarding your organization's prevention work, can you describe in more detail the activities involved in this work?**
   Probes: Who carries out this work within your organization – staff or volunteers?
   i) To what degree is there dedicated staff for prevention activities?
   ii) What type of training / expertise is necessary for this work?
   iii) Looking at this diagram of the prevention pathway, what level are your
   iv) organization's activities focused on?
   v) Have different strategies been used on different target groups?
   vi) What process do you follow to develop a new prevention initiative?

4. **Do you think that your present prevention programmes are working?**
   Probes: How do you measure the success of prevention projects within your organization?
   i) Are the target groups being reached? How well do you think these groups are receiving the prevention messages?
   ii) What factors have helped in implementing your prevention strategies?
   iii) What factors have hindered the implementation of these strategies?
   iv) Overall, how effective do you think your organization's prevention strategy/strategies have been?
   v) What more, if anything, do you think needs to be done?

5. **When you look into the future, what types of prevention programmes / strategies do you think will be needed?**

   Probes: Within your organization? / Looking at the broader picture (e.g. provincially / federally / internationally)?

   i) What resources do you think will be needed to implement these programmes?

6. **Now I'd like to ask you about prevention activities in a more general way.**

   Probes: What do you think are the key factors in the successful implementation of prevention programmes?

   i) How aware are you of the prevention strategies being employed by other ASOs?

   ii) How do you find out about new prevention strategies?

   iii) How does the work that your organization does fit into the provincial strategy for HIV prevention?

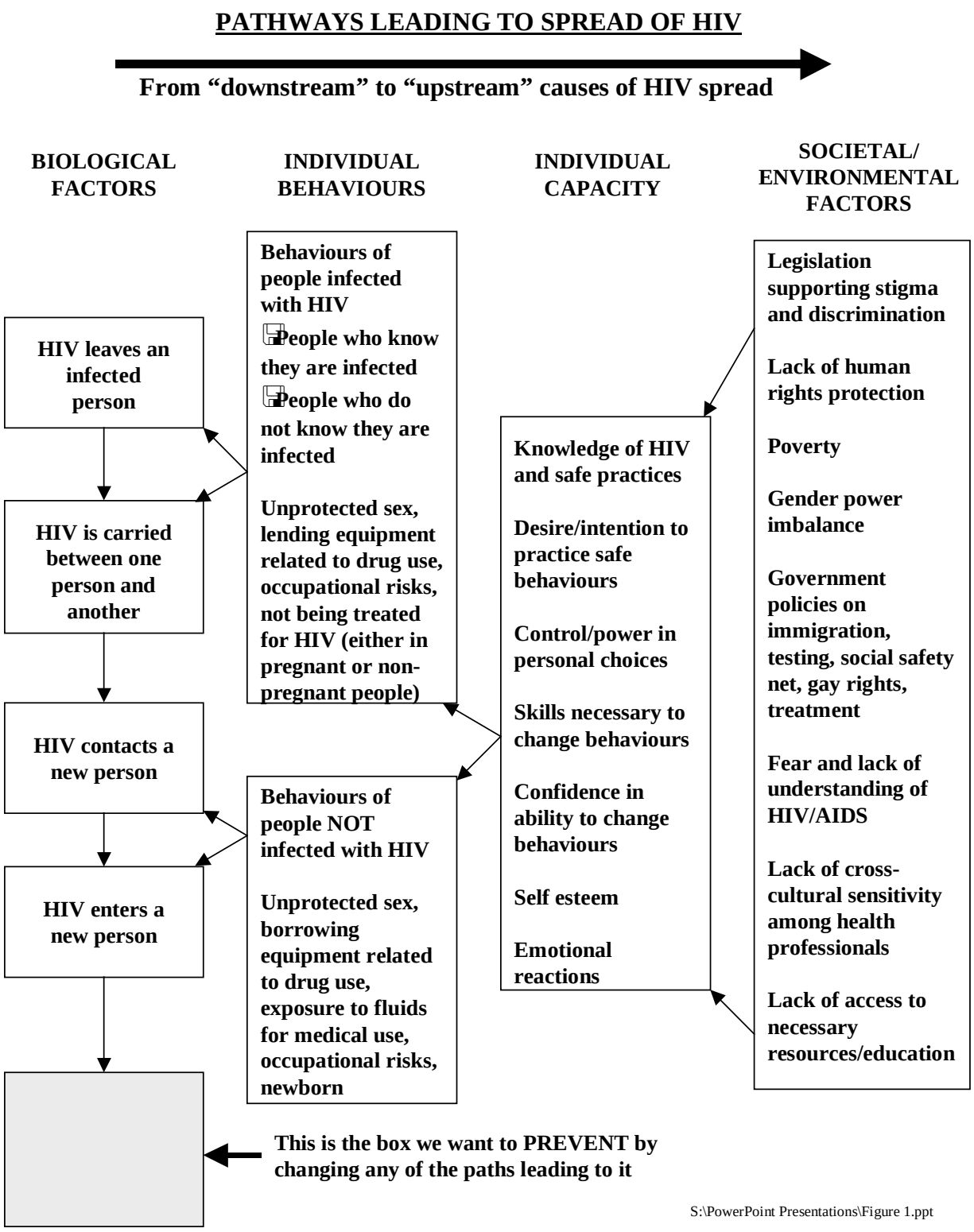
7. **We are going to use the results of these interviews to try to better understand the prevention programmes that ASOs are currently undertaking, as well as which programmes ASOs feel will be needed in the future as the HIV epidemic continues to evolve. Do you have any advice for us?**

8. **Have I missed anything? Is there anything about the area of prevention that we should have talked about but didn't?**

APPENDIX B

Prevention Model 1

PREVENTION MODEL 1



APPENDIX C

Prevention Model 2

PREVENTION MODEL 2