

EXECUTIVE SUMMARY

The Alberta Community HIV Fund (ACHF) engaged PRA Inc. to conduct a study to determine Aboriginal preferences for accessing and receiving HIV/AIDS information and services off-reserve. The target population for the consultations included, but was not limited to, Aboriginals living off-reserve who are intravenous drug users, two-spirited, sex trade workers, or HIV positive.

Methodology

In recognition and respect of the culture and traditions of Aboriginal people, the project began with a pipe ceremony in Edmonton. The methodology for the study comprised the following tasks: a group consultation with and an email survey of ACCH members; a document and literature review to summarize what is known about HIV/AIDS in the Aboriginal community; key informant interviews with community-based organizations; and group discussions with Aboriginal people in High Level, Grande Prairie, Edmonton, Red Deer, and Calgary. In total, the group discussions involved 87 participants and an additional group was held with approximately 40 participants. The final report was submitted to the project Advisory Committee and presented to the ACHF Provincial Population Health Consortium. The project concluded with a smudge.

Findings

AIDS Service Organizations (ASOs) provide a wide range of HIV/AIDS information and services to their clients including education and awareness, professional support and counselling, harm reduction services, and referrals. Most, if not all, of these organizations have Aboriginal clients. Some of them provide information and services specifically for Aboriginal people such as posters, brochures, and flyers with pictures of Aboriginal people; brochures referencing Aboriginal culture and traditions; access to Aboriginal units and/or Aboriginal staff members; and access to Elders and cultural facilitators.

Some ASOs have well-established, long standing relationships with Aboriginal organizations and can therefore refer their clients to Aboriginal resources. Other organizations, however, have yet to begin, are in the early stages of, or have had difficulty forming relationships with Aboriginal organizations. Some of the ASOs who have not attempted to form these relationships stated that it is not part of their mandate. Others who are finding it difficult to form relationships either said they do not have an “in” with the reserves, their funding does not allow them to go on-reserve, or they do not have the resources to devote to building the relationship.

It is important for those providing HIV/AIDS information and services to Aboriginal people to recognize that not all Aboriginal people share the same connection with their culture or follow the same teachings and traditions. Some Aboriginal people may actively participate in their culture and others have limited or no knowledge of their culture and

are not interested in pursuing traditional teachings or practices. Additionally, the teachings and traditions of Aboriginal people vary by nation, both within Alberta and across North America. The implication for service organizations is that they cannot generalize about Aboriginal people; the desire for and definition of “culturally appropriate” information and services can vary for each Aboriginal person the service organization encounters.

In most of the group discussions with Aboriginal people, the first comments that participants had about HIV/AIDS are related to the stigma attached to the disease. They said that HIV/AIDS is “not something that is talked about.” Participants explained that because of the stigma attached to HIV/AIDS, many people who are living with HIV/AIDS will not tell their family members or friends they are infected and will isolate themselves.

It is important to note that the stigma associated with HIV/AIDS is not only present within Aboriginal communities, it is also present within cities and the medical community. Several participants experienced discrimination at health-care facilities. They indicated that the discrimination stemmed from several fronts, including being someone who was living with HIV/AIDS, being an Aboriginal person, and being economically disadvantaged.

A lack of awareness and knowledge of HIV/AIDS among Aboriginal people is present in all age groups. Based on the participants in the groups and their comments, elders appear to have the least awareness about what HIV/AIDS is, how you get it, and how it is treated. However, there is also a serious lack of knowledge and awareness among youth. Most of the youth who engage in at-risk activities said the best source of information on HIV/AIDS is correctional facilities.

Participants indicated that it can be difficult for Aboriginal people who communicate in traditional languages to discuss HIV/AIDS. There are hundreds of Aboriginal languages spoken across Canada and few of them, if any, have a word for HIV/AIDS. Many people admitted that they first heard about HIV/AIDS when either they became infected or someone they knew became infected. For them, this was the first time it became important to learn about the disease.

Participants asserted that organizations involved in helping people who are living on the streets, disadvantaged, or dealing with addictions have opportunities to educate individuals about HIV/AIDS. One of the groups involved in the study included people enrolled in a residential addictions treatment facility; few of the participants recalled receiving or seeing any information about HIV/AIDS at the centre. Examples of other organizations that participants believe could be more active in providing information on HIV/AIDS are food banks, needle exchanges, etc.

Individuals who are living with HIV/AIDS said that their disadvantaged socio-economic status complicates their efforts to deal with the disease. People said that once they are

identified as infected, it becomes even more difficult to meet their daily needs. Many of the participants who are living with HIV/AIDS spoke of being evicted from their apartments or losing their jobs once it became apparent that they were positive.

For many participants, meeting their daily needs is their first priority, and protecting themselves from contracting HIV/AIDS is not something they regularly think about. In addition, many of the people who are at risk of contracting HIV/AIDS are involved in mind-altering activities, such as intravenous drug use or alcohol abuse. These activities place them at greater risk of becoming infected because they are not always aware of their actions. Others may knowingly engage in risky behaviour, such as those in the sex trade.

Participants believe that raising awareness of and educating people about HIV/AIDS is important. They offered several general comments about how organizations should provide information and services: facilities should be welcoming and located in areas where the at-risk population is present; clients should be treated respectfully regardless of their race, socio-economic status, and health status; information should be provided in writing and verbally; information should be easily understandable and relatable; and someone with first-hand experience should provide the information, for example, someone who has lived an at-risk lifestyle or someone who is living with HIV/AIDS.

Several participants expressed interest in becoming an advocate for people living with HIV/AIDS and educating people about the disease and prevention and treatment options. Although they believe this is beneficial work and that it is one of the best ways of reaching people, they did not know how to become involved in this type of work. Another barrier to becoming involved in awareness and education building activities is the health of the individual. Many people who are living with HIV/AIDS are also living with other diseases, such as Hepatitis C, and may find it difficult to have the physical strength and intellectual capacity to give presentations.

Participants discussed what makes information and services culturally appropriate. Those who desire culturally-appropriate information and services spoke of the importance of ties to Aboriginal people. This may involve several different approaches such as including pictures of Aboriginal people in brochures, commercials, and other media; providing information and services in Aboriginal languages; and relating information and services to Aboriginal teachings. Many participants indicated that they would prefer to receive information and services from another Aboriginal person.

Recommendations

The following are recommendations for consideration in the development of future initiatives and programs aimed at providing HIV/AIDS information and services to Aboriginal people.

1. Any future activity relating to HIV/AIDS awareness and education should be evidence-based and aimed at all segments of the Aboriginal population.
2. Consultations should be held and an ongoing relationship should be developed with high profile and influential provincial Aboriginal organizations (e.g., the Alberta Native Friendship Centres Association and the Métis Nation of Alberta) and provincial representatives of national Aboriginal organizations (e.g., the Canadian Aboriginal AIDS Network).
3. Aboriginal organizations should receive some guidance on how to meet the funding eligibility requirements.
4. Cultural awareness training should be provided to non-Aboriginal organizations who serve a large number of Aboriginal clients.
5. Non-Aboriginal organizations should continue to use Aboriginal units and/or engage Aboriginal people to deliver information and services to other Aboriginal people where possible.