Voices of Two-Spirited Men

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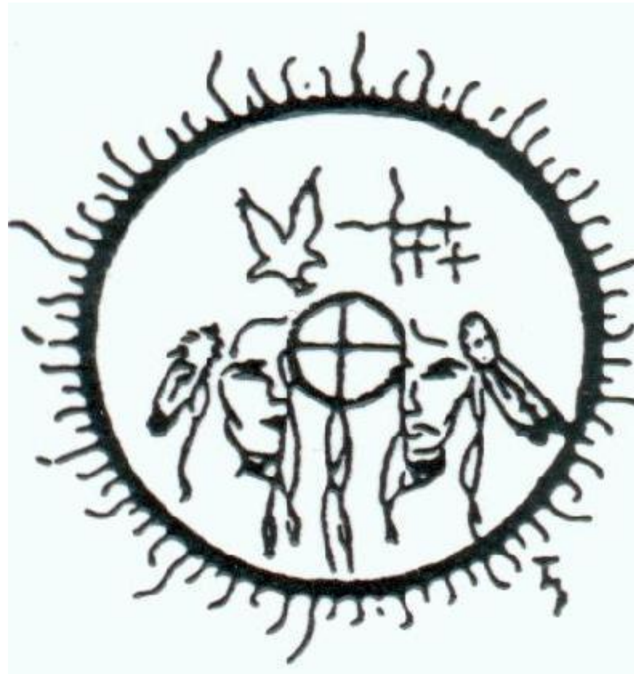

and

Judith Waalen

March 31, 2001

Preface

A Survey of Aboriginal Two-Spirited Men across Canada

This study is about knowledge, attitudes, behaviours and social conditions of Aboriginal, two-spirited men across Canada. It was commissioned by *2-Spirited People of the 1st Nations* in Toronto and was distributed by researchers at the Centre for Quality Service Research, Ryerson University. Aboriginal people representing various communities were involved in the development of the survey questions.

The 12-page survey took about 45 minutes to complete. Once the individual answered the questions, the survey was put in the envelope provided, sealed, and returned to the person who provided it. The sealed envelope was mailed to the Centre for Quality Service Research, Ryerson University (Toronto). Questions or concerns about participation in this study were handled on the cross-Canada toll-free line established for this study.

We gratefully acknowledge the participation of our respondents who gave their time to this project. We also appreciate their candour. They provided us with a great deal of information, insight, and advice on some very sensitive issues. Further, they allowed us to appreciate the circumstances of their lives and the challenges they face. Accurate knowledge about HIV transmission is evident in all our respondents. For those who are HIV+, it was heartening to read about the care they take in protecting others from exposure to HIV. For those who do not have HIV, knowledge about HIV transmission is a very real concern.

These two-spirited men face enormous pressures - racism, homophobia, poor housing. Many have experienced homelessness and unemployment. Yet they are very concerned about the threat of HIV in their communities of origin. They express a great deal of worry for Aboriginal people. Almost half of them are HIV+, yet many of them avoid medical treatment due to fear of discrimination because of their status and lack of information about where to go for services.

To those two-spirited men who responded to this survey, we have heard your voices. Thank you for your input.

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Literature Review (as of October, 1999)

To gather relevant information on this needs assessment, a number of search strategies have been employed. Among them are the use of Internet search engines (such as MetaCrawler and Dogpile), Lexis/Nexis (with specific reference to MEDLINE), library journal holdings, and conference proceedings. The key words used in these searches included: Aboriginal, two-spirited, models of intervention, HIV/AIDS high-risk behaviour, and educational initiatives. In addition, a number of researchers familiar with issues surrounding HIV transmission, educational initiatives, and Aboriginal issues were contacted by phone, email or fax (for example, Marcel Dubois, Ted Myers, Albert McLeod, Diane Aubry, Steve Hill, and Bill Greenwood provided reports, made suggestions, and suggested other contacts).

From these searches and contacts we compiled a number of articles, proceedings, monographs, and government reports. In reviewing these, a number of themes emerged and are summarized in separate sections below. Although many of the articles span more than one topic area, they are organized under specific headings.

Aboriginal HIV/AIDS Issues

Infection Rates

A main problem in the collection of data on the spread of infection of HIV/AIDS disease among Aboriginal people is that data collection on ethnicity was first initiated in 1988 (Ontario Aboriginal HIV/AIDS Strategy, 1996). What we did find was that infection rates were lower for Aboriginals than for the general population but these have now risen higher than the general population (Rekart et al., 1991). Young Aboriginals seem to be especially at risk (Health Canada, 1998) as well as Aboriginal women mainly due to sexual contact possibly infecting infants during pregnancy (Duff et al., 1993). Infection rates may still be underestimated because of underreporting. Given an increase in seroprevalence rates in Aboriginal communities, Thomas et al. (1998) predict that further economic hardship will fall upon already impoverished communities.

There is evidence in one study that some Aboriginals in British Columbia may be carrying the variant HTLV-I of the virus (normally endemic to the Caribbean and South America). This may have implications for the treatment of this population as well as the different rate of infection in this population (Picard et al., 1993).

The literature also focuses on high-risk behaviour (Rekart et al., 1991), lack of access to services and poverty (Canadian HIV/AIDS Legal Network, 1996). These factors mean that infection rates and progression of the disease may

be more rapid in the Aboriginal population (Goldstone et al, 1998). HIV/AIDS is especially a challenge in rural communities (Canadian AIDS News, 1996) because services and basic infrastructures are limited resulting in: increased threat of opportunistic infections; lack of access to appropriate health care; lack of access to proper diet, lack of access to medications, and; lack of supportive housing/long-term care facilities (Ontario Aboriginal HIV/AIDS Strategy, 1996).

Further, Houston and Reese (1996) report that "Canadian Aboriginal people experience high rates of socioeconomic and behavioural risk factors for HIV infection including poverty, incarceration, IDU, STD, and commercial sex".

Infection rates seem to be exhibiting Pattern II trends in the Aboriginal community as opposed to Pattern I in mainstream Canada. The implication is that prevention programs targeting mainstream Canadians will not be effective for Aboriginals and that prevention should be focused on the prevention of sexually transmitted diseases (Wortman, 1990) as well as encouraging condom use.

Nguyen et al. (1996) report that the proportion of reported AIDS cases among Aboriginals has increased from 1.2% (pre1990) to 2.8% (1993-95). The main exposure categories for Canadian Aboriginal Men are men who have sex with men (72.3%), IDUs (6.5%) and heterosexual contact (4.9%). Aboriginals are infected earlier than non-Aboriginals and IDU is the most important mode of transmission among Aboriginal women.

Environmental Circumstances

A consistent theme in the literature is the lack of adequate housing facilities for Aboriginals both in urban and rural environments. A needs assessment prepared by *the 2-Spirited People of the First Nations* in 1995 "found that 70% of the sample community is unemployed, 30% of the community does not have stable housing, 52% of the community lives in unaffordable housing, and that 58% of the homes presently occupied by Aboriginal PHAs [people living with HIV/AIDS] are not suitable for people living with HIV/AIDS" (Deschamps & Thoms, 1995). This study recommended that there is a "urgent need" for a housing facility in Toronto specifically for Aboriginal people living with HIV/AIDS.

The mobility of the Aboriginal population between urban centres and their communities of origin poses the additional problem of facilitating the spread of HIV/AIDS disease to the rural communities by sexual contact or injection drug use where adequate services are not available (Health Canada, 1998; Deschamps, 1998).

Earlier studies seemed to show that the Aboriginal population is at risk because of lack of basic AIDS information (Myers et al., 1993). However, more recent studies show that the knowledge of HIV/AIDS disease is increasing

(DuBois et al., 1996). Increased knowledge of the disease, however, does not seem to be translated into the reduction of engaging in high-risk behaviour.

Other factors that place Aboriginal people at risk are outlined in the Ontario Aboriginal HIV/AIDS Strategy (1996). They include the high rates of sexually transmitted diseases, non-consensual sex (sexual assault, incest, abuse), lack of self-esteem, intravenous and injection drug use (IDU), the abuse of alcohol especially in conjunction with other drugs, and limited safer sex education. "For two-spirit people, and in particular two-spirit youth, whose identity may be repeatedly assaulted by racism and homophobia, the risk for suicide is dangerously high" (Manitoba Aboriginal AIDS Task Force, 1998).

Also, a high level of homophobia, intolerance and discrimination relating to HIV/AIDS (McLeod, 1998; Vanderhoef, 1998; Canadian HIV/AIDS Legal Network, 1996; Manitoba Aboriginal AIDS Task Force, 1998) has been seen in the community possibly as a result of "a history of oppression, racism and colonization" (Matiation & Jurgensz, 1998; Canadian HIV/AIDS Legal Network, 1996). This has produced a move away from traditional culture taking on the homophobic attitudes associated with established religions (Manitoba Aboriginal AIDS Task Force, 1998). The current trend to return to traditional culture and spirituality may reduce intolerance in Aboriginal communities especially rural ones. Also, traditional healing and spirituality may play an important role in treating Aboriginals who are infected with HIV/AIDS (DuBois, 1996; Lambert, 1993; Manitoba Aboriginal AIDS Task Force, 1998).

Although introduced in 1990, the concept of "two spiritedness" may be a way for the Aboriginal gay community to promote and support itself and become accepted once again as part of mainstream Aboriginal society (Manitoba Aboriginal AIDS Task Force, 1998). Two-spirited people sometimes have special roles that are spiritual or ceremonial in certain cultures as counsellors, healers, seers and visionaries (DuBois, 1996; McLeod, 1998; Deschamps, 1998). However, our focus group interviews seem to show that urban Aboriginal gays do not seem to identify themselves as two-spirited but rather as "gay".

Complicating Risk Factors for Aboriginal People

Substance Abuse

Strathdee et al. (1996) report that substance use is associated with high-risk sexual behaviour among young MSM and sexual abuse is independently associated with a two-fold risk of sexual risk-taking.

Injection drug use among Aboriginal peoples is a main concern especially for young people (Mai et al., 1998) with an over-representation of Aboriginal people seen in the injection drug user population specifically in Vancouver and a greater likelihood of HIV transmission in this population (Schechter et al., 1998).

Birkel & Golaszewski (1993) found that younger intravenous drug users (IDUs) were less likely to lower sex risk, and showed lower levels of change overall for both sex and needle risk.

Condom Use

In a survey of 658 Aboriginal men and women (Calzavara, Burchell, Myers, Bullock, Escobar and Cockerill, 1998), of those that had sexual intercourse in the last 12 months (n=400) 61% reported that they never used condoms. However, rates of condom use differed by age and gender. Males, under the age of 30, were most likely to use condoms. Further, condoms were used by for those people who were knowledgeable about HIV/AIDS and had more than one sex partner. Our target population for this study is with young men — the group that is most likely to use condoms.

Encouragement of condom use is an essential strategy in reducing the risk of HIV transmission. "The use of condoms for birth control was the strongest predictor of condom use for STD prevention. This suggests that efforts to increase condom use in this population should address pregnancy concerns and ensure that individuals at risk of STDs or HIV disease do not discontinue using condoms if they switch to another method of birth control" (Calzavara et al., 1996). "In view of the fact that familiarity with the traditional way of life was an important predictor of condom use, a better understanding of the effect of culture on condom use may be useful in developing prevention programs" (Calzavara et al., 1996). "A better understanding of the meanings people ascribe to sex is important to help individuals become more aware of why they choose to participate in particular sexual activities, and will ultimately lead to more culturally sensitive AIDS education strategies" (Bullock et al., 1996).

Street-involved sexual behaviour

In a small study of transsexuals (n=40), half of whom were of Aboriginal ancestry, Rekart et al. (1993) found that this group faced serious social difficulties including homelessness, discrimination, physical abuse, racism and homophobia. HIV risk behaviours were common including unprotected receptive anal intercourse (85%), prostitution (90%), and infection drug use with needle sharing (62%).

HIV-related tuberculosis

In the United States, increases in the numbers of cases of active tuberculosis (TB) are thought to be related to HIV infection (Fitzgerald, 1995). However, this recent increase in Canada is probably not due to HIV infection but it is acknowledged that risk factors, such as HIV, are associated with increased risk of TB. In Canada, the highest rates of TB are seen in Aboriginal people (80/100,000) so it is important for physicians to be aware of this and understand

the management of TB. Unfortunately, one of the common adverse reactions to three of the commonly used first line drugs is hepatitis.

High-risk behaviour

Although the more recent studies show that the knowledge of HIV/AIDS disease is increasing (DuBois et al., 1996) increased knowledge of the disease does not seem to be translated into the reduction of engaging in risk behaviour (Basen, Engquist & Parcel, 1992). As stated earlier, some studies have focused on high risk behaviour (Rekart et al., 1991). In AIDS prevention for the general population, Browne and Barone (1991) suggest certain variables that need to be considered. Specifically, they report that age, gender, and AIDS-related anxiety are significant variables in the AIDS education process. In adults, perceived susceptibility to AIDS is associated with reports of safer behaviour but also more coercive attitudes towards people with AIDS. They also found that improved knowledge is weakly associated with greater tolerance and intention towards safer behaviour. Mill (1997) suggests that HIV risk behaviours such as running away, substance abuse, abusive relationships, are survival techniques for Aboriginal women.

In a study on risk behaviours and HIV prevalence among a cohort of young men who have sex with men in Vancouver, Martindale et al. (1996) found that a sizeable proportion of young men who have sex with men are engaging in unprotected sexual intercourse. Moreover, this study also found that there was a strong association between sexual abuse in childhood and adolescence and subsequent involvement in sex trade. Aboriginal people accounted for 5% of this study.

Education and Prevention Strategies

Effective education and prevention programs seem to focus on the oral traditions of Aboriginal culture (Lennie & Daniels, 1996). The use of storytelling, visual aids (McLeod, 1996; Hill & Gillies, 1996), gatherings (Vanderhoef, 1998) and strategies based on the model of the Medicine Wheel (Weiser & Badger, 1996) seem to be effective in education and promotion. The large number of different nations, languages and cultures means that programs are best targeted to specific groups and implemented with the participation of Aboriginal people with the blessing of the elders (Houston & Reese, 1996; Manitoba Aboriginal AIDS Task Force, 1998). Community-level involvement and planning (Myers et al., 1993; 1999; Manitoba Aboriginal AIDS Task Force, 1998) and confidentiality and participatory models (Haour-Knipe & Aggleton, 1998; Nguyen et al., 1998; Health Canada, 1998) are reported as being most effective. "Drop-in programs and outreach can successfully target high risk groups and provide comprehensive care if they are culturally sensitive and include a harm reduction and strong advocacy approach" (Littlejohn et al., 1998). Also, prevention programs should focus on reducing injection drug use and promoting needle exchange programs

(Mai et al., 1998; Schechter et al., 1998). The lack of evaluation protocols in many programs described in the literature means that their effectiveness may not properly assessed. Future initiatives must include an evaluation component (Nguyen et al., 1998).

The literature has also revealed several differences in prevention and education strategies between the general population and the Aboriginal population. For example, in a study conducted by Haour-Knipe & Aggleton (1998), the poorest and most marginal people experience HIV-related vulnerability factors.

To address the needs of Aboriginal people many culturally sensitive teaching tools have been used in HIV/AIDS prevention strategies. Tools used to counter language and literacy barriers are 101 posters (McLeod & Manitoba Aboriginal AIDS Task Force Inc., 1996), puppetry (Hill & Gillies, 1996). However, posters are seen as ineffective for people who are functionally illiterate, have sensory impairment (IDUsers), or live in poverty (a disproportionate number are Aboriginal) (Egan, 1998).

According to Walter & Vaughan (1993), some predictors of AIDS-related risky behaviours are susceptibility, severity, benefits, barriers, self-efficacy, values, and norms. Also, HIV-related risks vary with level of intimacy/commitment, relationship status/phase, different partners, sexual communication, etc.

Freudenberg and Trinidad (1992) point out possible obstacles in AIDS prevention activities such as lack of available social and health services, drug use, fear of stigmatization, and lack of resources. Crown at al (1993) address obstacles to HIV prevention and techniques used to overcome them. These include: confidentiality & anonymity in small communities, language (i.e. 8 official languages in the NWT and some with no comparable vocabulary for HIV/AIDS concepts), and high turnover of staff (lack of professionally trained people).

Models/Theories in Health Prevention

One model used frequently in the HIV/AIDS prevention literature is the Health Belief Model (HBM) (Petosa & Wessinger, 1989-90; Petosa & Jackson, 1991; Walter & Vaughan, 1993). HBM focuses on failure of people to participate in programs to prevent/detect disease. Factors include perceived susceptibility, perceived benefits of prevention and treatment as elements in decision-making process (Haour-Knipe & Aggleton, 1998). There have been criticisms of this model: It over-emphasizes individual rationality and rational decision making and fails to move beyond the retrospective accounting for health behaviour in order to offer ways to predict and/or to bring about behaviour change (Haour-Knipe & Aggleton, 1998).

Risk Reduction and Harm Reduction Models

Another model frequently cited involves Social Cognitive Theory, which considers both the person and the environment in determining health risk behaviours (Stiffman, & Dore, 1995; Walter & Vaughan, 1993). In the Theory of Reasoned Action (TRA) (Basen, Engquist & Parcel, 1992), there is emphasis on the role of intentions and beliefs in engaging in certain behaviours. Criticisms of the model include an over-emphasizes individual rationality and rational decision making and a failure to move beyond the retrospective accounting for health behaviour in order to offer ways to predict and/or to bring about behaviour change (Haour-Knipe & Aggleton, 1998).

The AIDS risk reduction model (ARRM) (Catania & Kegeles, 1990) consists of:

1) **labeling** of high risk behaviours as problematic,
2) making a **commitment** to changing high risk behaviours,
3) seeking and **enacting** solutions directed at reducing high risk activities.

The goal of this model is to broaden understanding about why people fail to progress over the change process.

Fisher and Fisher (1992) propose that there are 3 fundamental determinants of AIDS-risk reduction: information regarding the means of AIDS transmission and specific methods of preventing infection; motivation to change AIDS-risk behaviour; and behavioural skills. Two things determine motivation: attitudes towards performance of AIDS-preventive acts and perceptions of personal vulnerability to HIV (Fisher et al., 1996).

Other models that have been used in the study of HIV/AIDS prevention and education are: Information-Motivation-Behavioural Skills (IMB) Model (Fisher, Fisher, Misovich, Kimble & Malloy, 1996); Model of Social Influence (Walter & Vaughan, 1993); Transtheoretical Model of Change (Prochaska & Redding, 1994); and Protection Motivation Theory (Haour-Knipe & Aggleton, 1998). Petosa & Jackson (1991) discuss motivational schema which includes perceptions of normative sexual behaviour; interest in adopting adult roles; and needs for peer support and affection.

Findings from the Reviews of Prevention Strategy Effectiveness

Prochaska and Redding (1994) suggest that an important distinction between main sexual partners and casual sexual partners be made.

Janz and Zimmerman (1996) comment that few published descriptions of the process of *implementing* AIDS prevention interventions are available. In their

opinion, the 5 most effective project activities include: small group discussions; outreach to high-risk populations; train peers/volunteers; provide safer-sex kits; and large-group discussions

Stiffman and Dore (1995) argue that preventive programs should focus on personal problems in mental health and environmental problems in parent-child relations, peer behavours, stressful events, and neighbourhood violence and unemployment.

Strathdee et al. (1996) stress the importance of sexual abuse counseling. They recommend this should be a component of HIV prevention efforts.

Erben (1991) recommends providing information at an early age; involving community action groups; building healthy public policy and creating supportive environments (i.e., theatre, "make the healthier choice the easier choice").

Egan (1998), from his experience, suggests that the people he worked with seek other venues of information: informal discussions, broadcast media, and for those with a low level of literacy, use interpersonal verbal interventions.

McLeod & Manitoba Aboriginal AIDS Task Force (1996) using bingo games, support participation rather than focusing only on information exchange.

Moar (1993) reports that establishing trust on the street using a non-judgemental approach was effective in doing prevention education with IDUs.

Birkel & Golaszewski (1993) used indigenous outreach workers as change agents for IDUs (Hispanic subjects). The Outreach worker profile was a recovering IDU; active in 12-step programs; who lived and used drugs in the area; possessed a desire and commitment to "give back to the community"; was a natural leader; role model to members of the target population; had a knowledge of the IDU network and current use patterns; and an ease in approaching IDUs and other drug users on the streets.

Basen-Engquist & Parcel (1992) found that attitudes, norms, and intentions were directly related to the number of sexual partners. Self-efficacy and condom use intentions were directly related to frequency of condom use and knowledge does not determine practice. In addition, there was no difference in knowledge between those who use condoms and those who don't, and social norms are the weakest prediction of intention and behaviour.

Dowsett et al. (1998) outlines 3 concepts as useful framing devices for thinking about young people's sexual interests: **sexual cultures**: systems of sexual behaviour among any group of people; **sexual identities**: provides a psychological place for situating the self in sexual activity; and **sexual meanings**: a way of getting a firmer grip on the significance of sexual activity to young

people; and shift our rethinking from the merely behavioural and descriptive, to the more sociocultural and interactionist.

The mobility of the Aboriginal population between urban centres and their communities of origin poses the additional problem of facilitating the spread of HIV/AIDS disease to the rural communities by sexual contact or injection drug use where adequate services are not available (Health Canada, 1998; Deschamps, 1998; MAATF, 1999). Missing from existing services/ programs for IDUs is: 1-on-1 counselling, elders, methadone program to wean oneself off, programs just for IV (IDU) use, compassion and understanding, follow up programs, and counsellors who have experienced the use of needling (CAAN, p.57). They suggest that programs should provide more specific information about how to link with regional health authorities, acquire needles, establish methadone programs and secure funding for community-based Harm Reduction programs. Also, there should be should be: condom distribution, needle exchange, and methadone maintenance treatment. Attention should not focus on abstinence but should consider cultural and local level needs, be non-judgmental, pragmatic, flexible and allow people to make own informed decisions.

Empowerment Issues

A high level of homophobia, intolerance, and discrimination relating to HIV/AIDS (McLeod, 1998; Vanderhoef, 1998; Canadian HIV/AIDS Legal Network, 1996; Manitoba Aboriginal AIDS Task Force, 1998) has been seen in the community possibly as a result of "a history of oppression, racism and colonization" (Matiation & Jurgensz, 1998; Canadian HIV/AIDS Legal Network, 1996). This has produced a move away from traditional culture taking on the homophobic attitudes associated with established religions (Manitoba Aboriginal AIDS Task Force, 1998). The current trend to return to traditional culture and spirituality may reduce intolerance in Aboriginal communities especially rural ones and also empower those who are perceived as 'different'. However, it is important to empower those that are personally affected by homophobia, intolerance and discrimination (Haour-Knipe & Aggleton, 1998). This can involve the development of participatory programs.

Petosa & Jackson (1991) suggests that educational programs to promote safer sex intentions should focus on health related motivations among younger students. For older adolescents, factors directly relevant to their motivational schema and social environment should be addressed.

Harper et al. (no date) suggest "giving high-risk youth a voice". In their study, young people were invited to join the collaborators in order to incorporate their perspectives in the research. The young people helped by assessing the feasibility and acceptability of certain concepts, translating them into "street youth" language, recruited participants, etc. They also provided access to populations that are typically suspicious of adults, greater ease in tracking

participants, greater acceptability and credibility of the research, the feeling of empowerment in offering feedback

La Fortune (1993) suggests empowering gay, lesbian and bisexual Native persons through historically correct and/or adapted social roles, self-worth and self-preservation. And Rekart (1993) presents a seven step plan for empowering the urban aboriginal community to develop, deliver, manage, and support Aboriginal people themselves. Mill and DesJardins (1996) stress developing culturally-sensitive HIV programs which emphasize empowerment at the individuals and group level but make sure they are congruent with the shift to self-determination by Aboriginal people. Pepper & Henry's Model sets our 4 conditions necessary to the development of self-esteem in Indian children: connectiveness, uniqueness, power, and appropriate role models (Mill, 1997).

Spirituality

Traditional healing and spirituality may also play an important role in treating Aboriginals that are infected with HIV/AIDS (DuBois, 1996; Lambert, 1993; Manitoba Aboriginal AIDS Task Force, 1998). Driedger (1996) found that faith was most commonly expressed through relationships with others rather than through a systematic internalized belief system and that PLWHAs report the need to feel productive and creative, and that they matter to something or someone. Although they generally reject religious institutions, spirituality plays an important role in the lives of PLWHAs, providing a sense of meaning and purpose in life.

Cultural Sensitivity

In research on the Aboriginal Harm Reduction Model, 84% of respondents said they think culture is important when dealing with HIV/AIDS and 80% would find an Elder helpful and 78% would use the services of an Elder. It would seem that effective education and prevention programs should focus on the oral traditions of Aboriginal culture. The use of storytelling, visual aids, gatherings (Vanderhoef, 1998) and strategies based on the model of the Medicine Wheel (Weiser & Badger, 1996) seem to be effective in education and promotion. Other supporters of programs that rely on oral traditions include McLeod and Johnson (1996) who suggest that culturally-appropriate teaching tools are transferable to more than Aboriginal people. They suggest that these types of tools may be appropriate for other hard to reach populations such as prisoners, street-involved people, people with low literacy levels, and non-English speaking populations. Other studies include:

McLeod and Manitoba Aboriginal AIDS Task Force (1996) on HIV/AIDS teaching tools using the medicine wheel to explain how HIV affects all aspects of life and the teaching turtle poster - an animal that is recognized as a spiritual guide

Manitoba Aboriginal AIDS Task Force (1999) on Strategies of Four Doorways Project: which portrays a model for peer education training, outreach and community development through partnerships, research and culture-based services

Lennie and Daniels (1996) use HIV (the Shape Shifter) as a teacher, through the oral and spiritual traditions; hope (Eagle feather) symbol, balance, healing and self-empowerment. Their position is that taking "AIDS 101" for a couple of hours does not work because it only appeals to the mind. Rather, one must examine the causal issues controlling risky behaviour: mind, body, emotions and spirit

La Fortune (1993) suggests disseminating information which incorporates traditional teachings about sexuality, spirituality, and social organization; empowering gay, lesbian and bisexual Native persons through historically correct and/or adapted social roles, self-worth and self-preservation. This allows the broader Native population to access information with more success and less subjectivity

Valverde and Smeja (1993) suggest that increase in self-sufficiency in AIDS education underlines the importance of using a methodology that is *culturally appropriate* and respectful of *traditional customs and ways of learning*.

Adams and Wortman (1990) describe "snapshots" - drama depicting the experiences of a native youth whom discovers he has AIDS. They found this to be effective for AIDS and other sensitive topics to aboriginal audiences where a frank discussion of these issues can be difficult to initiate.

Mill and DesJardins (1996) suggest designing culturally-sensitive HIV programs which emphasize empowerment at the individuals and group level. This is congruent with the shift to self-determination by Aboriginal people. And Crown et al. (1993) described an approach where Band chiefs were informed, and elder support was obtained.

Role of Communities

Community-level involvement and planning (Myers et al., 1993; 1999; Manitoba Aboriginal AIDS Task Force, 1998) and confidentiality and participatory models (Nguyen et al., 1998; Health Canada, 1998) are reported as being most effective. "Drop-in programs and outreach can successfully target high risk groups and provide comprehensive care if they are culturally sensitive and include a harm reduction and strong advocacy approach" (Littlejohn et al., 1998).

Freudenberg and Trinidad (1992) describe the role of community organizations in AIDS prevention in Black and Latino communities. They state that these groups differ from gay communities in important ways: social

resources, income, education, etc. The advantage to this approach is that of community organizations have knowledge of relevant cultural values and beliefs, familiarity of relevant channels of communication, and a commitment to safeguard the well being of their neighbourhoods.

The MAATF (1999) uses a Four Doorways Project that involves the development of a model for peer education training, outreach and community development through partnerships, research and culture-based services. Valverde & Smeja (1993) emphasize training support of Native AIDS educators towards community-based activities and policy development. Wortman (1992) uses a dual approach that involves support of community-based initiatives.

As mentioned earlier, Crown et al. (1993), feel it is important to inform Band chiefs and gain elder support. Also, use door to door campaign and community visits by PLWAs giving the message about healthy lifestyle choices. Further, they suggest that Community Health Representatives (CHRs) play a vital role in health promotion and HIV/AIDS awareness.

Also, prevention programs should focus on reducing injection drug use (Mai et al., 1998) and promoting needle exchange programs. The lack of evaluation protocols in many programs described in the literature means that their effectiveness may not properly assessed. Future initiatives must include an evaluation component (Nguyen et al., 1998).

Myers et al. (1999) have shown that "most prevention initiatives in response to HIV/AIDS have been introduced with a public health paradigm, a paradigm of modern medicine". In addition, concepts about the discussion of sex between partners and following the medical advice of experts with regard to condom use may not coincide with Aboriginal cultural traditions. Therefore, "cultural conflict between traditional ways, knowledge and responses and public health imperatives is a primary issue" (Myers et al., 1999). Using culturally appropriate and specific tools that integrate with or complement the holistic approach to health used in Aboriginal communities will achieve better results while keeping in mind that the Aboriginal community is a complex mix of cultures, languages and traditions: "with differences within and between communities and individuals" (Myers et al., 1999). This is supported by LeMaster & Connell, (1994) who discuss a major barrier to successful interventions: a mistrust of interventions implemented by individuals with a different cultural background; language barriers; and geographic location. Other barriers outlined in the work on the Aboriginal Harm Reduction Model include:

-focus of drug treatment centers on quitting/abstinence
-centers' lack of understanding of IDU addictions
-centers' lack of cross-culturally trained staff
-structural/institutional barriers
-abstinence expectations

-issues of labels and stigma
-internalized shame and personal obstacles
-the attitude of service providers
-lack of cultural awareness among service providers, and
-internal community and cultural barriers confidentiality

Factors that facilitate intervention effectiveness are outlined by Janz and Zimmerman (1996). They include: culturally relevant and language appropriate; AIDS information embedded into broader contexts; creative rewards and enticements; opportunities for program flexibility; promoting integration into and acceptance by the community; repeat essential AIDS prevention messages; create a forum for open discussion; solicit participant involvement. Additionally, Freudenberg and Trinidad (1992) describe characteristics of groups that successfully reached populations at risk of HIV infection. These include: hire staff of similar ethnicity, class, and gender; engage clients in discussions on issues such as drug abuse and sex roles; control and lead by a community resident rather than by professionals who live outside the community; and an established planning mechanisms in which staff and constituents provide ongoing feedback on program to agency directors. Hill and Gillies (1996) recommend promoting community discussion around common values and respect for diversity. Also, they suggest that puppetry can reach audiences who are uncomfortable with traditional methods of learning; bridges language and literacy barriers.

HIV Testing

"Anonymous HIV testing may play a role in the effective HIV prevention in the Canadian Aboriginal population [since] HIV infection could spread quickly through the relatively young Aboriginal population, with potentially devastating consequences" (Tseng, 1996). A survey conducted by Watershed Writing and the 2-Spirited People of the 1st Nations found that "HIV surveillance data should not be collected by Health Canada without personal consent, that chief and councils or Provincial Testing Organizations (PTOs) can not authorize Health Canada to undertake blind HIV testing of an Aboriginal population area, and that individuals and the community are the best persons to authorize this form of HIV surveillance" (2-Spirited People of the 1st Nations, 1996).

In their work on the effects of HIV testing patterns on reactions of HIV+ diagnosis, authors Calzavara, Brabazon, Myers, Millson, Major, Logue, and Rachlis (1998) found that although HIV anti-body testing can be a difficult ordeal, qualitative interviews conducted on individuals who underwent HIV anti-body testing revealed that individuals who were tested and counselled often and repeatedly were able to adapt better and more quickly to the news a positive test result.

In a surveillance of AIDS in Canada, Farley et al (1998) showed that of the reported AIDS cases in Canada there were changing trends in the number of

reported cases and the shifts in the affected risk categories. The number of reported AIDS cases are declining and although men who have sex with men still represent a large proportion of reported cases, current findings indicated new trends in those who are infected. It is speculated that new drug treatments and prevention programs may account for the decline in reported cases. "Recent trends are however showing increases in the heterosexual, women, intravenous drug use and aboriginal [sic] categories."

McGee and Cerre (1996) report that multi-government co-operation and communication facilitated the identification and development of community projects that enhanced collaborative efforts. "The creation of close working relationships between government community ensures productive and effective programs."

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Methodology

The Survey Development Process

A focus group was organized drawing on clients of the *2-Spirited People of the 1st Nations*. The focus group consisted of seven young Aboriginal gay men and was conducted on March 25, 1999 by Dennis Haubrich and Judith Waalen (Centre for Quality Service Research). Two of the participants identified themselves as transgendered and reported that they obtained their income through work in the sex trade and one individual mentioned he was involved in the drug trade. A third participant reported deriving his income by selling drugs and sex trade work. None of the other participants reported employment. The focus group lasted approximately two hours. Each participant was reimbursed with fifty dollars for their participation in the study. The focus group discussion questions are listed below. The staff of the *2-Spirited People of the First Nations* organized this event which was held at Ryerson University.

Focus Group Discussion Questions

1. What does it mean to you to be a two-spirited person?
   Probe: · to your family
   · to your community
   · to your culture

2. What were the circumstances in your life when you came out as a two-spirited person?

3. What were the circumstances in your life at the time you left your community of origin?

4. What were the issues that you had to face when you first came to Toronto? Have these changed? How did these change?

5. What impact has HIV disease/AIDS disease had on your life?

   Probe: · If you are HIV-, is becoming HIV+ a concern for you?
   · Have you been tested for HIV? When? How many times?
   · If you are HIV+, when do you think you were infected?
   · What has changed in your life since you became infected with HIV?
   · What are the ways in which you manage your infection?

6. What is your current relationship with your family and your community of origin?

7. How do you see your future?

Focus Group Themes

The focus group interview was audiotaped and transcribed verbatim. Four members of the research team independently reviewed the transcript in order to identify issues and generate questions for the survey.

There were several themes that emerged from the focus group participants. They were:

self-identification;

the process of coming out;

relationships (with partners, families and friends);

discrimination (race, culture, sexual orientation, welfare and HIV status);

poverty; mobility and changes in residence;

relationship and history with various social services and systems (i.e., education, legal, social services, CAS, child welfare);

abuse (i.e., physical, mental, emotional, sexual, spousal or partner, alcohol and drug);

involvement in activities which could bring them into conflict with the law (i.e., sex and drug trade); and

coping and adaptation skills.

Self Identification

Most of the participants in the focus group did not refer to themselves as two-spirited but as gay men, although one participant mentioned that it would depend on the situation. They further elucidated their identity by describing their coming out process.

Coming out process

For some participants, disclosure of sexual orientation and HIV positive status was a difficult process. Many of the participants expressed an early realization and rejection of the (gay) "party scene." The participants also

described many of the difficulties of coming out on the reserve and within the Aboriginal community.

Family

Most of the participants had several or different notions of family (i.e., adoptive, foster, biological and chosen). Participants described the difficulties of coming out to families and development of relationships with families. The participants' families had varying degrees of acceptance and tolerance. Some were more understanding than others were.

Reservation/community/nations

Perceptions and attitudes of their home communities/nations regarding sexual orientation have changed over time. Participants identified how historically the Berdache or two-spirited people were considered important members of the community. However, the participants also described how present day attitudes, namely the lack of acceptance of gay identified individuals and people living with HIV/AIDS have manifested into ostracizing and discrimination from within the Aboriginal community and even from band leaders and Aboriginal governments. These circumstances have forced some of the participants off of their reserves.

History of "being in care"

A number of participants described their circumstances and involvement with Children's Aid Society, child welfare and other social services. While in care some of them experienced and/or witnessed discrimination and abuse.

Housing

Many of the participants came from and lived in a variety of foster homes, shelters, and rooming houses and/or were involved with Children's Aid Society. They also described their current crisis in lack of housing. Several of the participants have lived on the streets surviving through drug trafficking and/or the sex trade.

Abuse

The participants described how they experienced or witnessed a variety of abuse (i.e., physical, mental, sexual and emotional abuse) from friends and relatives. Some participants also described experiences with spousal abuse.

Survival and adaptation on the streets

Practically all of the participants survived by working in the sex trade and/or the drug trade. One participant described his alleged involvement in other criminal activity such as break and enters.

Discrimination

All participants described experiencing discrimination of some form. One participant described his experiences of racism (within the gay community). Other participants elucidated their experiences of homophobia within their respective families and Aboriginal communities. Moreover, a few of the participants described their experiences of gay bashing. One HIV+ participant described his experiences of discrimination based on his HIV status and negative attitudes in his reserve community. A common assumption or stereotype placed upon them is that all gay people have or will get HIV/AIDS. The participants also described discrimination because of welfare status as a common experience.

Positive Experiences

Despite many of difficulties that the participants described it seems all of them have found some way to cope and survive. Most notably many of the focus group participants used humour to deal with their circumstances. Most of the participants appeared highly independent and one participant described it as "taking care of oneself."

Spirituality

One participant described his belief and practice of traditional Aboriginal medicines. Although, he mentioned that he later switched to Western medical treatment.

Development of Research Strategy

At the end of the focus group discussion, we asked what would be the best way to get information on the topics we asked about from the broader two-spirited community.

1. Individual self-administered surveys were the suggested data collection method. "You would get more truthful answers".

3. Ensure that the survey is confidential and that people could write down their answers without showing it to anyone.

4. Face to face interviews were reported as too invasive for some but others felt the group setting was safe also because of the nature of the questions.

From these themes and suggestions, a number of questions were developed for use in the survey. Questions that arose from the focus group included:

- What is the level of education/literacy?
- If and when did they leave school? Have or did they return to school?
- How does mobility (i.e., moving from city to city) affect their circumstances and life chances?
- How frequently have they moved?
- How do their different notions of family (i.e., adoptive, foster, biological, etc.) and their relationship to those families affect them?
- What are the available supports? How accessible are they?
- What is their level of knowledge with regards to services that are available?
- What is their perception of the services that are available to them?
- Have they had any involvement with the law?
- Have they had any involvement with the psychiatric system?
- How do they perceive and practice their spirituality?
- Are they taking responsibility for safer sex and/or disclosure of HIV status?
- Have they been tested for the HIV anti-body?
- How does HIV/AIDS affect them personally?
- What were the circumstances that were involved in their coming out?
- When did they come out?
- What are the different circumstances that would cause individuals to willingly leave or be forced off of their reserve community?
- How do they deal with their issues (need to specify which issues)?

From our review of the literature, additional survey questions were developed. These include:

Demographic Information (Questions 1-8)

- Age
- How many months have you lived in the city you now live?
- How many other cities have you lived in?
- Aboriginal identification
- Highest level of education
- First language

These questions are generic in nature but questions on Aboriginal identification and highest level of education were adapted from the Primary Source Questionnaire which was part of the Gay and Lesbian of the First Nations (GLFN) Native HIV/AIDS Awareness Project survey (Jamieson, 1991) used in

Toronto. The question on language was taken from the Urban Aboriginal AIDS Awareness Survey (UAAAS) (Dubois, 1996) used in Montreal.

We developed a question with six options to determine the self-identified sexual orientation of the respondent. Specifically, the question reads, "How do you identify yourself presently? Check all that apply to you." "Two-spirited" was one of the choices. Supporting literature for inclusion of two-spirited response comes from McLeod (1998), Deschamps (1998), Manitoba Aboriginal AIDS Task Force (1998), and Parker et al. (1998).

Four remaining demographic questions related to housing, employment and source of income are:

- What is your current housing situation?
- What is your usual occupation?
- What is your primary source of income?
- What is your current weekly income?

Questions on housing and primary source of income were modified from the UAAAS (Dubois, 1996) and the question on occupation was taken from the GLFN Primary Source Questionnaire (Jamieson, 1991). In addition, supporting literature for these four questions comes from Deschamps & Thoms (1995), Deschamps (1998).

<u>Background Information and Relationships (Questions 9-14)</u>

This section consists of seven questions. Among them are:

- Did you ever live in various housing facilities?
- When you arrived in this city, how easy was it to make contact with Aboriginal people, Aboriginal gay men, and non-Aboriginal gay men?
- Have you ever considered moving back to your home community?
- If you wanted to move home, is there anything that would prevent it?

The above questions were modified from the GLFN Primary Resource Questionnaire (Jamieson, 1991). Supporting literature came from Canadian AIDS News (1996), Deschamps (1998), and Thomas et al. (1998).

Another type of question was developed specifically for this survey as a result of the focus group discussion to allow for the development of an importance-satisfaction analysis. Fifteen (15) items were listed (e.g., the amount of control you have over your life, the emotional support you get from others) and the respondent was asked to rate their levels of satisfaction and importance for each item. One set of questions asked how satisfied the respondent is with various elements of his life (i.e., spirituality, relationship with friends) and the second set asked how important these areas of his life are to him. Graphical

representation of the responses on a grid identifies four quadrants representing high and low importance as well as high and low satisfaction on each of the fifteen areas.

Hope (Questions 15-17)

In two open- and one closed-ended questions, we asked for what hopes the respondent has in his life and how likely he feels that he will achieve this.

Health Concerns (Questions 18-22)

The section on "Health Concerns" is comprised of five questions.

- What do you consider to be your health risks with regard to sexually transmitted diseases? Check all that apply (9 options are listed).
- From the following list, what do you consider to be your health risks? Check all that apply (8 options are listed).

Supporting literature for health risks relating to tuberculosis includes Canadian Thoracic Society (1994), Fitzgerald (1995), Blenkusk et al. (1996), Miedzinski et al. (1996), Arvanitakis et al. (1998).

- What do you consider to be your lifestyle risks with regard to injection drug use? Check all that apply (6 options are listed including 'other').
- What to you consider to be your lifestyle risks? Check all that apply (15 options are listed including 'other').

Supporting literature includes Steffani et al. (1996), Deschamps (1998), Farley et al. (1998), Goldsone et al. (1998), Mai et al. (1998), Schechter et al. (1998).

Social Factors (Questions 22-23)

- Have any of the following social factors affected your life? Check all that apply or have applied to you (20 options are listed including 'other').
- Who do you consider to be your family? Check all that apply (6 options are listed including 'other').

Supporting literature includes Freudenberg & Trinidad (1992), Dubois (1994), Deschamps & Thoms (1995), Canadian HIV/AIDS Legal Network (1996), Steffani et al. (1996), Deschamps (1998), Haour-Knipe & Aggleton (1998), Malcolm et al. (1998), Schilder et al. (1998b, 1998c), Stiffman & Dore (1998), Thomas et al. (1998), Vanderhoef (1998), Jinich et al. (1996) and Dubois (1996). In addition, the 'family' question was developed as a result of feedback

from the focus group discussion, which indicated there are various notions for the term "family".

Sexual activity (Question 24)

This question is modified from the UAAAS (Dubois, 1996).

- Do you have one steady sex partner at the moment?

The three follow-up questions (if the respondent answered 'yes') were structured to determine the length of the current steady relationship as well as the number of sex partners of the respondent and his steady partner. Supporting references include Basen-Engquist & Parcel (1992), Prochaska & Redding (1994).

Attitudes about Sexual Activity (Questions 27-39)

Thirteen questions are included in this section.

- According to your community of origin, is it okay for men to have sex with men?
- According to your family, is it okay for men to have sex with men?
- According to you, is it okay for men to have sex with men?
- In the last 12 months, have you received money, gifts or favours in return for sex?
- In the last 12 months, have you been forced into sex with a person against your will?
- In the last 12 months, have you had sex with a person you didn't want to have sex with?

Supporting literature for these questions includes Freudenberg & Trinidad (1992), Deschamps (1998), Steffani et al. (1996), Stiffman & Dore (1998) and Dubois (1996).

Samples of the remaining questions in this section are:

- Do you ever use protection during a "*blow job*" (oral-genital sex) or "*bum fuck*" (anal-genital sex)?
- Have you had sex without a condom in the last 12 months? If yes, are any of the following reasons why you have not used a condom ("rubber" or "safe") on one or more occasions in the past 12 months?

Supporting literature includes Basen-Engquist & Parcel (1992), Bullock et al. (1996), Calzavara et al. (1996), Martindale et al. (1996), Deschamps (1998), Calzavara et al. (1998) and Dubois (1996).

Alcohol Consumption (Questions 40-45)

This section is made up of questions adapted from the UAAAS (Dubois, 1996).

- How often do you usually have drinks containing alcohol?
- If you do drink, where do you normally go to drink?
- Do you usually have sex [with people other than your steady sex partner] when you have been drinking?
- Do you usually have sex when steady sex partner has been drinking?
- Do you think drinking helps you meet people sexually?

Supporting literature includes Steffani et al. (1996), Myers et al. (1997), Deschamps (1998), and Ontario Aboriginal HIV/AIDS Strategy (1996).

Concerns about Access to Services (Questions 46-47)

- Have any of the following reasons kept you from using the health services available to you? Check all that apply (11 options are listed).
- Have any of the following reasons kept you from using the social services available to you? Check all that apply (11 options are listed).

Supporting literature: Canadian HIV/AIDS Legal Network (1996), Deschamps (1998), Schilder et al (1998d, 1998e), Hays (1996). These two questions were modified from the GLFN Primary Resource Questionnaire (Jamieson, 1991).

Knowledge & Attitudes about HIV/AIDS (Questions 48-67)

- Have you personally ever known anyone with HIV/AIDS disease?
- In your opinion, how great is the risk of getting AIDS or the HIV virus from any of the following activities?
- How many times would you say you have discussed AIDS with various people?
- How much of an immediate threat do you think AIDS is to the health of Aboriginal people?
- What are the chances that you yourself might get AIDS?
- How worried are you about getting AIDS?
- Do you think that you need to change any of your behaviours to protect yourself from getting AIDS?
- Have there been situations in which you felt that you should protect yourself from getting AIDS but were not able to?
- If one of your friends were to be diagnosed with AIDS, would you still continue to visit him/her?
- Who do you think should care for a person with AIDS?

- What do you think should be done to make sure that the virus is not passed from one person to another?
- How many times have you been tested for AIDS or HIV?
- If you had or thought you had AIDS, who would you feel most comfortable speaking about it besides your family?
- If you had or thought you had AIDS, would you seek support from any of the following?
- How common do you think AIDS is among First Nations, Native or Inuit people?

The above questions are all taken or adapted from the UAAAS (Dubois, 1996).

- What HIV/AIDS prevention programs do you think are most effective for Aboriginal people? (5 options are listed).
- Do you believe AIDS transmission among Aboriginals is mainly through? (4 options are listed).

These questions were developed as a result of the focus group discussions and additional supporting literature including: Wortman (1990), Rekart et al. (1991), Lambert (1993), Bullock et al. (1996), Canadian HIV/AIDS Legal Network (1996), Dubois (1996), McLeod et al. (1996), Mill & Desjardins (1996), Weiser & Badger (1996), Baker (1998), Calzavara et al. (1998a), Deschamps (1998), Goldstone et al. (1998), Health Canada (1998), Lea & Price (1998), Littlejohn et al. (1998), Schilder et al. (1998a, 1998d, 1998e), Vanderhoef (1998), Myers et al. (1999), and The Canadian Aboriginal AIDS Network (1998).

<u>Aboriginal Identification (Question 68)</u>

- Do you identify yourself as native, native Canadian, First Nations, Indian, Aboriginal, Inuit, Status, Non-Status, Treaty, Non-treaty, C-31, Metis, Mixed Heritage? Check all that apply to you.

At the end of the survey, space was left for respondents to include something that we might have missed or that they would like to tell us. A copy of the survey is located in the Appendix.